With Every Breath: A Lung Cancer Guidebook

Tina M. St. John, M.D.

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Important Note to All Readers

I hope you find a great deal of useful information in *With Every Breath: A Lung Cancer Guidebook*. However, *With Every Breath: A Lung Cancer Guidebook* is for informational purposes only.

The information in this book is not a substitute for professional medical advice and care. It is not intended to be nor should it be used as a substitute for individual medical care from a trained medical professional.

All readers are strongly urged and advised to consult a trained medical professional before acting on any of the information in this book. Lung cancer treatment is a complicated and highly specialized field. Treatment plans must be individualized on a case-by-case basis, taking into account the latest developments in the field of lung cancer.

The fact that a particular treatment, supplement, product, or practice is discussed in this book does not mean it is recommended for any individual. Each person seeking to use any of the treatments, supplements, products, or practices in the book should first consult with a trained medical professional.

Similarly, the fact that an organization, Internet site, book, videotape, DVD, or other product is mentioned in this book should not be interpreted as an implication that the author endorses the products, information, services, or information.
With Every Breath: A Lung Cancer Guidebook is dedicated to all the courageous people who face the challenges of lung cancer – past, present, and future.

This book is also lovingly dedicated to all those who have died of lung cancer – our mothers, fathers, husbands, wives, aunts, uncles, cousins, grandmothers, grandfathers, friends, and neighbors. Their presence and spirit remain in the hearts of their loved ones, and of all people who work as lung cancer advocates.
There are times in life when one questions whether there is any order or justice in the world. For me, this happened when my 40-year old, healthy, vibrant husband was diagnosed with stage IV non-small cell lung cancer. We were happily married and had just celebrated our daughter Hope’s second birthday. Everything seemed ‘right’ with the world, except for one seemingly minor problem – my husband had a cough that wouldn’t go away. After several weeks, I suggested a chest x-ray. I remember distinctly that I was setting the table for dinner when he came home on the last day B.C. (before cancer). I set down a plate and glanced up while greeting him, completely unprepared for what was about to happen. When I looked up, I saw something in his eyes I had never seen before. And in that instant, I knew our lives had changed forever.

The next 15 months were filled with many challenges. There were many tears, but also much laughter. There was sadness, but also great joy. There was pain, but also abundant happiness. There were treatments and procedures and appointments. There were birthday parties and anniversary cakes and Christmas presents. In the end, my husband and my daughter’s Daddy died – but not before having lived many happy, joyful days between his diagnosis and his death.

For a time after my husband’s death, it seemed all order had disappeared from the lives of my daughter and me. That was five years ago, and much has happened since those days. We have found our way back to celebrating life – but now, we do so with a deeper sense of gratitude for each day. The joy my family shared during the last 15 months of my husband’s life provided us with many delightful memories that live in our hearts and continue to bring my daughter and me much happiness.

One of the most difficult and yet changeable circumstances of dealing with lung cancer is a lack of knowledge. It can be very intimidating to be faced with potentially life-changing decisions while feeling you do not have the information you need to choose wisely. Filling that gap by providing you with medical and practical information is what this book is all about. In writing this book and deciding what to include, I have relied not only on my professional background, but also on my personal experiences, my husband’s experiences, and the experiences of many friends I have met over the years who have also faced the challenges of lung cancer. *With Every Breath: A Lung Cancer Guidebook* is written for people who have recently been diagnosed with lung cancer and their loved ones. Living with lung cancer is a family matter. The person with the disease and all his or her loved ones are affected by the disease in one way or another.

I am genuinely honored to have an opportunity to try to do something useful for the lung cancer community. Writing this book allowed me to turn the experiences of my family and other families that have been affected by lung cancer into something that will hopefully benefit others. Writing this book has been a labor of love. It is my sincere hope that the information provided in these pages will bring you not only factual knowledge, but also peace of mind. If you find just one thing in this book that contributes to your well-being, the goal of writing this book will have been accomplished.
To Andrew L. St. John, thank you for teaching me what it means to truly live each and every day to its fullest. Thank you for showing me the precious joy of a single moment. And thank you for all the gentle lessons about what it means to truly love someone. Your love and laughter live on – always.

To my beloved daughter, Hope, you are my greatest teacher. You are both my Hope and my hope.

To you, dear reader, I wish you and your loved ones strength for your journey, hope to light your path, peace to fill your soul, and love to warm your heart.

*Tina M. St. John, M.D.*
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It is a truly humbling experience to sit and think of all the people I must thank for making With Every Breath: A Lung Cancer Guidebook possible. So please bear with me — there are many people to whom I need to express my gratitude.

I am profoundly thankful to all the people living with lung cancer and their loved ones who contributed to With Every Breath: A Lung Cancer Guidebook by sharing their thoughts, experiences, and wisdom. Your voices and thoughts enrich this book immeasurably. You have given these pages heart. Thank you for your generosity, candor, and kindness. You are truly an inspiration to me as I am sure you are to many others.

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To my loved ones, all family in my heart (and you know who you are), thank you for your steadfast love, support, and confidence in me. You are part of this effort, too, for without you, I’m not sure I would have come to a place to be able to put words like these down on paper. Thank you for all you are, and for sharing that so generously with Hope and me.

To my daughter, Hope, you are the best, Honey Girl. Thank you for being so patient when Mom was working on the book. But more importantly, thank you for being such a wonderful you. I want to be just like you when I grow up!

I am also deeply grateful to the people listed below for thoughtfully and carefully reviewing With Every Breath: A Lung Cancer Guidebook, in whole or in part. Your input and comments have been invaluable. Thank you for sharing your time and expertise for the benefit of all those facing the challenges of living with lung cancer.

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Introduction

*With Every Breath: A Lung Cancer Guidebook* is for you. This book was written to provide you with information to help you live as well as possible with lung cancer. Regardless of your prognosis, you can choose your attitudes and responses to your disease.

Learning about lung cancer and its treatments will help you and your loved ones make informed decisions about your care and your life. As an informed health care consumer, you will be in the best possible position to find quality care. You will be prepared to plan for the future. You will be empowered to have the best quality of life possible. Information can help you find your own way of living with lung cancer and making treatment decisions that suit your personality and preferences.

There are many medical terms included in this book. While medical terminology can be intimidating because it is unfamiliar, learning medical terms will help you better communicate with your health care providers. To make the process of becoming familiar with medical terms easier, they appear in *italics* the first time they are used in a chapter. Definitions of these words appear in the text and also in the *Glossary* at the end of the book.

A unique feature of this book is the personal comments from people with lung cancer and their loved ones that occur throughout the text. Their comments reflect their personal thoughts and experiences. I am deeply indebted to all those who have shared their unique experiences and perspectives for your benefit.

One of the goals of this book is to help you find the assistance you need to fulfill your health care and personal needs. Numerous references are included throughout the text that are intended to help you find the information and resources you need. There is also a *Resource Directory* section at the end of the book to supplement the information provided in the text.

I hope you find a great deal of useful information in *With Every Breath: A Lung Cancer Guidebook*. However, the information in this book is not a substitute for professional medical advice and care. Lung cancer treatment is a complicated and highly specialized field. Treatment plans must be individualized on a case-by-case basis, taking into account the unique manifestations of the disease in each person and his or her other medical problems. I urge you to seek advice from your personal doctor and cancer care professionals. You have the right to seek the advice of as many professionals as you wish.

As you read *With Every Breath: A Lung Cancer Guidebook*, I hope you feel a sense of support from all the people who contributed their time and expertise to this book. The people who worked on this book did so because they are committed to helping people faced with the challenge of lung cancer.

I sincerely hope the information in this book contributes to your health, well-being, and peace of mind. I wish you healing and wellness.
CHAPTER 1: THE LUNGS AND RESPIRATORY SYSTEM

INTRODUCTION

Lung cancer affects a life-sustaining system of the body, the respiratory system. The respiratory system is responsible for one of the essential functions of life, breathing. Breathing enables us to take in oxygen and expel carbon dioxide. Every cell in the body depends on oxygen to function. If the supply of oxygen is impaired in any way, the entire body is affected.

An understanding of how the lungs and respiratory system work will help you understand how lung cancer affects the body. It may also be helpful as you talk with your health care providers, gather information about your illness, and communicate with your family and friends.

THE RESPIRATORY SYSTEM

Breathing
The respiratory system has one vital function, breathing. When you breathe in or inhale, your body receives oxygen. Oxygen is a gas in the air that is needed to sustain life. The human body cannot survive without oxygen for more than a few minutes. When you breathe out or exhale, you rid the body of carbon dioxide, a gas produced by normal body functions. Getting rid of carbon dioxide is necessary because excessive amounts of carbon dioxide are toxic. The lungs are the place in the body where essential oxygen is taken in, and toxic carbon dioxide is released. When the lungs have difficulty doing their job, other organs in the body have difficulty doing their jobs. Therefore, the health of the lungs has direct and immediate effects on the overall health of the body.
The respiratory system is made up of those body parts that help us take in air and expel carbon dioxide. Take a breath in and you will quickly become aware of some of the body parts of the respiratory system. Air comes in through either the nose or the mouth. It passes to the throat (pharynx), and is pulled into the windpipe (trachea). The trachea splits in two between the lungs sending one branch to each lung (see Figure 1). These branches are called the right and left main bronchus. Before we discuss the path of air once it enters the lungs, let us first consider how we manage the act of breathing.

Air moves in and out of the body by the action of muscles. The diaphragm is a large muscle that sits below the lungs. It separates the lungs and other organs in the chest from the organs of the abdomen. When the diaphragm contracts or tenses, it moves down causing the lungs to expand and pull in air. When the diaphragm relaxes, it moves up, pushing against the lungs and causing them to expel air. There are also muscles between the ribs that help in this cycle of expanding and contracting the lungs, forcing air in and out. Put your hands on your chest and take a breath in. You will feel your chest expand. As you breathe out, you will feel your chest move inward. This movement is the result of the diaphragm and other muscles of the chest automatically contracting and relaxing with each breath in and out.
The lungs take up most of the space in the chest cavity, which extends from the collarbones to the diaphragm (see Figure 2). The organs of the chest are protected by the ribs. The area between the lungs in the middle of the chest is called the **mediastinum**. It contains the heart, windpipe (trachea), food pipe (**esophagus**), blood vessels, and many lymph nodes. Examination of the lymph nodes in the mediastinum is an important part of the lung cancer staging process and is discussed in *Chapter 4: Lung Cancer Diagnosis and Staging*.

![Figure 2: Organs of the Chest*](image)

**The Lungs**

You have two lungs, one on each side of the chest. The top, cone shaped part of the lung that fits under the collarbone is called the *apex*. The broad, bottom part of the lung that rests on the diaphragm is called the *base*. Unlike some other paired organs in the body, the two lungs are not identical (see Figure 2). The right lung is normally larger than the left. It is divided into three sections or *lobes*, the upper (also called superior), middle, and lower (also called inferior). The left lung has two lobes, the upper and lower. The left lung has an indentation called the cardiac notch to make room for the heart. Each lung lobe is divided into segments. Healthcare providers often use the names of lung segments to describe specific locations in the lungs.

The lungs contain elastic fibers that allow the lungs to expand and contract. Healthy lungs have a smooth, shiny surface because they are encased in a thin, moist covering called the **visceral pleura**. There is also a pleural covering called the **parietal pleura** that lines the inner surface of the chest cavity. The visceral and parietal pleura are normally slippery and glide easily against each other as you breathe.

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The right and left main bronchi carry air in and out of the lungs. They are the beginning of a system of airways called the **bronchial tree.** The point at which the main bronchus enters the lung is called the **hilum.** The bronchial airway system is called a ‘tree’ for a very practical reason. The airways branch approximately 20 times in the lungs. At each branch point, the airways become smaller and more numerous much like the branches of trees (see Figure 3). The main bronchi branch into **lobar bronchi,** one for each lobe of the lung. From here, the airways divide into **segmental bronchi,** one for each lung segment. Segmental bronchi branch several times into smaller airways called **bronchioles.** The final branches of the bronchial tree are called **atria.** The atria end in tiny, microscopic air sacs called **alveoli.** Alveoli resemble clusters of grapes under the microscope. Each lung contains about 300 million alveoli. The walls of the alveoli are extremely thin, which makes them fragile and susceptible to damage. Damage to the alveoli is irreversible.

Alveoli are surrounded by tiny blood vessels called **capillaries.** There are about one billion capillaries in the lungs, more than three for each air sac. The blood in the capillaries is separated from the air in the alveoli only by the extremely thin alveolar and capillary walls. This close proximity allows gases to be exchanged between the blood and the lungs in a process called **respiration.** Inhaled oxygen enters the blood from the alveoli. Carbon dioxide leaves the blood and enters the alveoli to be exhaled. The close relationship between the circulatory and respiratory systems will be discussed in the following section, *The Link Between the Respiratory and Circulatory Systems.*

*Figure 3: The Bronchial Tree*
The lungs are traversed by another important system of vessels called the lymphatics. Each lung contains a network of lymphatic vessels that carry a mixture of fluid and proteins called lymph. Lymph is carried from the lung tissues through a series of lymph nodes to filter the fluid before it is returned to the bloodstream. This network of lymph vessels and lymph nodes are an important part of the body’s immune system. The work of the immune system and its role in lung cancer is discussed in Chapter 2: Understanding Cancer.

THE LINK BETWEEN THE RESPIRATORY AND CIRCULATORY SYSTEMS

The Respiratory Cycle
The respiratory and circulatory systems have closely related jobs. The work of these two systems is sometimes referred to together as the cardiorespiratory system. The respiratory system is responsible for taking in oxygen and expelling carbon dioxide. However, it is dependent on the circulatory system to distribute the oxygen that has been taken in by the lungs to the body tissues. Similarly, the circulatory system picks up carbon dioxide from the tissues and delivers it to the lungs where it is exhaled. Every cell of the body requires oxygen to perform its jobs. Carbon dioxide is released as these jobs are performed and must be eliminated to prevent excess amounts from accumulating in the tissues. Continuous removal of carbon dioxide from the body is just as important for health as is a constant supply of oxygen.

In the respiratory cycle, oxygen is picked up by the capillaries surrounding the alveoli (see Figure 4). The oxygen-rich blood is carried to the heart, which pumps the blood into arteries that carry it to the tissues of the body. In the tissues, capillaries release oxygen and pick up carbon dioxide. This carbon dioxide-rich blood is carried by veins back to the heart, which

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pumps it to the lungs. Carbon dioxide is released from the blood into the alveoli and new oxygen is picked up, beginning the cycle again. A more detailed discussion of the circulatory system is presented in the next section, *The Circulatory System.*

The success of the respiratory cycle is dependent on the very thin walls of the alveoli. These walls normally allow for a quick and easy exchange of oxygen and carbon dioxide. Lung diseases like emphysema and cancer can damage the delicate alveoli and interfere with the vital exchange of gases resulting in abnormal levels of oxygen and carbon dioxide in the blood.

The **Circulatory System**

Similar to the bronchial tree, the circulatory system is a branching network of blood vessels. The heart is at the center of the circulatory system. Its pumping action moves blood through the body. The heart has four compartments called chambers, two on the right and two on the left. The two chambers on the right work together as do the two chambers on the left. The top chambers of the heart are called the **right atrium** and **left atrium.** The bottom chambers are called the **right ventricle** and **left ventricle** (see Figure 5).

Carbon dioxide-rich, oxygen-poor blood is delivered from the tissues of the body by the veins to the right atrium of the heart. Blood flows from the right atrium to the right ventricle, and then leaves the heart through the **pulmonary artery** (PA). Before reaching the lungs, the PA divides into a right and left branch, one for each lung. Once in the lungs, the PA branches several times into smaller blood vessels called **arterioles.** These arterioles run in the walls of the airway system’s bronchioles. The arterioles continue to branch and become

*Figure 5: Chambers of the Heart*

Arrows show the direction of blood flow through the heart.

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progressively smaller until they reach the level of the alveoli. At the alveoli, the blood vessels have become the tiny, microscopic capillaries that are capable of gas exchange.

Blood passes through the alveolar capillaries releasing carbon dioxide and picking up oxygen. The oxygen-rich blood is delivered to the left atrium by the pulmonary veins (see Figure 6). Blood passes from the left atrium into the left ventricle, and is pumped out through the aorta to be distributed by a branching system of arteries, arterioles, and capillaries throughout the body.

Lung diseases, including lung cancers, can affect the function of the right side of the heart since blood is pumped from the right side of the heart to the lungs. Although right heart abnormalities are not a common complication of lung cancer, they can occur. The left side of the heart is usually not affected by diseases of the lung. However, if the blood pressure in the lungs becomes very high, the left side of the heart can be affected.

**RESPIRATION AND MAINTAINING CHEMICAL BALANCE**

Respiration is one of the body’s stabilizing or *homeostatic mechanisms*. The respiratory system helps maintain a constant internal environment that keeps all of the body cells functioning effectively. It does this by supplying adequate oxygen and removing excess carbon dioxide. Slight changes in the oxygen and/or carbon dioxide levels in the blood trigger processes that
attempt to bring these levels back to normal. For example, if you exert yourself by running or climbing stairs, your heart rate and breathing will automatically increase. This is your body’s response to an increased need for oxygen and an excess of carbon dioxide that must be eliminated. The harder your muscles work, the more oxygen they need and the more carbon dioxide they produce. By breathing faster, you increase your intake of oxygen and expel more carbon dioxide. A faster heart rate increases the speed of delivery of oxygen and the clearance of carbon dioxide. In other words, when you exert yourself, you breathe more quickly and your heart beats faster because the body is attempting to bring your oxygen and carbon dioxide levels back to normal.

Survival depends on the body’s ability to respond to continuous changes in its environment. The body’s ability to respond to changes in its internal and external environments requires constant communication and interaction between the various organ systems of the body. Changes in the body trigger complex responses. Various body systems often work together to return the internal environment to a normal state.

The kidneys help maintain normal levels of many substances in the body. In the preceding example, we discussed how a short-term increase in carbon dioxide from exercising causes rapid increases in heart and breathing rates. However, if the carbon dioxide level is increased over a longer period and the increased efforts of the cardiac and respiratory systems are unable to clear it quickly enough, the accumulation of carbon dioxide can cause the internal body environment to become more acidic (the blood pH decreases). The pH of the blood is an indicator of the acidity or alkalinity of the body. The kidneys respond to a drop in blood pH. They attempt to assist the cardiac and respiratory systems by ridding the body of its excess acid through the urine. This demonstrates how different organ systems work together to try to keep the body in normal balance.

In addition to responding to the pH of the body, the kidneys also respond to prolonged decreases in body oxygen levels by increasing production of a hormone called erythropoietin. Increased erythropoietin leads to an increase in the production of red blood cells, the cells of the blood that carry oxygen. In this way, the kidneys try to help the body meet its oxygen needs by increasing the oxygen-carrying capability of the blood. Anemia is the condition of
having an abnormally low number of red blood cells. There are many causes of anemia, and cancer is one of these causes. Anemia is also a common side effect of some forms of cancer therapy. The symptoms of anemia include feeling abnormally tired, shortness of breath, dizziness, and becoming easily fatigued (tiring quickly). Anemia associated with cancer or its treatment can overwhelm the body’s homeostatic mechanisms. Therefore, if you have the symptoms of anemia, be sure to discuss them with your health care provider. He or she may be able to give you medications or treatments that will correct the problem and eliminate the symptoms.

Damage to lung tissues can reduce the respiratory system’s ability to respond adequately to changes in oxygen and carbon dioxide levels in the body. This impaired capacity can lead to shortness of breath, dyspnea (uncomfortably difficult breathing), fatigue, dizziness, and other symptoms. Although these symptoms have other possible causes, they are common problems for people living with lung cancer. Breathing methods that are designed to help maximize the ability of the lungs to carry out the effective exchange of oxygen and carbon dioxide are described in Chapter 10: Supportive Care for Symptoms of Lung Cancer and Its Treatment.

SUMMARY

The lungs are vital organs; they are necessary to sustain life. The lungs take in needed oxygen and rid the body of excess carbon dioxide. The respiratory and circulatory systems work together to maintain normal oxygen and carbon dioxide levels in all the tissues of the body. When lung tissue is damaged or removed, the lungs become less effective at the vital exchange of these gases. The effects of this decreased function can be experienced throughout the body and cause a variety of symptoms.
CHAPTER 2: UNDERSTANDING CANCER

INTRODUCTION

We are witnessing an era of great discovery in the field of cancer research. New insights into the causes and development of cancer are emerging. These discoveries have brought a sense of optimism to scientists, health care providers, and people affected by cancer. There is hope that we will soon be able to more effectively prevent and treat cancer.

Learning about cancer will help you better understand the disease and how it is treated. Becoming familiar with cancer-related terms can help you communicate more effectively with your health care team. This knowledge can also help you keep abreast of new discoveries and promising new therapies.

WHAT IS CANCER?

Cancer is a condition caused by the uncontrolled growth of cells. Different kinds of cancer are named according to the type of cell that is growing in an uncontrolled way. Cancer can arise from nearly any part of the body. There are more than 125 different types of cancer.

Normal cells grow, divide, and die in a controlled way and with a predictable lifespan. In adults, most cells divide only to replace old cells or to repair damage. Cancer cells have been damaged in such a way that they have lost their normal control mechanisms. They grow and divide at a rapid rate, and outlive their normal lifespan.

Most types of cancer lead to the formation of tumors, abnormal clusters of cells. However, not all tumors are cancerous. Tumors that cannot invade neighboring tissues or spread to other parts of the body are called benign tumors. With rare exceptions, benign tumors do not cause serious disease and are not life threatening. Malignant tumors are cancerous tumors.
Malignant tumors can invade and destroy neighboring tissues and organs, and spread to other parts of the body. This spread of cancer cells from one part of the body to another distant site is called metastasis. In short, malignant tumors are capable of invasion and metastasis, but benign tumors do not have these capabilities.

HOW COMMON IS CANCER?

The National Cancer Institute estimates that approximately 8.9 million Americans alive today have been diagnosed with cancer at some time in their lives. According to the 2003 Cancer Facts & Figures report issued by the American Cancer Society, men in the United States have approximately a one in two chance of developing cancer in their lifetime. For women, the lifetime risk of developing cancer is just over one in three. In 2003, approximately 1,285,000 people in the United States were newly diagnosed with non-skin cancers. Cancer is the second leading cause of death in the United States killing over half a million people each year. Approximately 16 million new cancer cases have been diagnosed since 1990.

WHAT CAUSES CANCER?

Cancer cells are abnormal because they contain damaged genetic material. The genetic material of human cells is contained in 23 pairs of chromosomes (see Figure 1). Chromosomes are tiny structures inside cells that are made up of a substance called deoxyribonucleic acid or DNA. The DNA inside each cell of your body contains your unique genetic blueprint. Every cell of a person’s body contains an identical copy of his or her unique DNA.

Specific segments of DNA are called genes. Every chromosome contains thousands of genes, each containing the message or genetic code for a specific feature or function of the body.

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Genes control every aspect of the body’s structure and function. They control physical features such as height, hair color, eye color, and bone structure. Characteristics such as natural athletic or musical capability, tolerance for pain, and susceptibility to certain diseases are also controlled by genes. Cellular functions such as the ability to repair damage, divide when new cells are needed, and even to die in a specific timeframe are all genetically controlled.

Throughout our lifetime, we are exposed to many things that can damage our DNA. Chemicals in the environment such as asbestos, tobacco smoke, radon, air pollution, radiation from the sun and other sources, viruses, and even chemicals from our own bodies can cause genetic damage. Our bodies have mechanisms to repair genetic damage. Cancer occurs when genetic damage either overwhelms or slips past the body’s normal repair mechanisms. Generally, it takes several different genetic flaws accumulated over a long period of time for a cell to become cancerous.

The abnormalities that lead to cancer are in the genes that control a cell’s life cycle. These genes control when a cell divides and dies. Normally, a cell divides only when it gets a genetic message triggering it to do so. Similarly, cells normally die according to a genetically programmed timeframe. When the genes that control cell division and death are damaged, cells divide uncontrollably and do not die in the normal timeframe. As a result, cancerous cells accumulate in the body forming tumors that eventually crowd out normal cells. Cancer cells do not perform the necessary jobs that normal cells do. Therefore, as cancer cells crowd out normal cells, body functions begin to fail.

**Oncogenes and Tumor Suppressor Genes**

Scientists have identified two major categories of genes that are damaged in cancer cells, *tumor suppressor genes* and *oncogenes*. Cancer cells usually have mutations or changes in several of these genes. The damage in these genes leads to the uncontrolled cell growth (also known as *cell proliferation*) that distinguishes cancer cells from normal cells. Tumor suppressor genes and oncogenes have opposite functions. In normal cells, these genes work together to control cell proliferation.
Proto-oncogenes are the normal predecessors of oncogenes. All normal cells have proto-oncogenes. They trigger controlled cell growth and division in normal cells. When proto-oncogenes are damaged, they become oncogenes and promote uncontrolled cell proliferation. Therefore, oncogenes are abnormal genes that promote the development of cancers. Some examples of oncogenes common in lung cancer include \textit{ras}, \textit{myc}, \textit{bcl-2}, and \textit{c-erbB-2}.

Unlike oncogenes, tumor suppressor genes help prevent cancer by keeping cell growth under control. Everyone has tumor suppressor genes. The products of these genes act like brakes on a car, stopping the cell growth and division cycle. Because tumor suppressor genes have the opposite effect of oncogenes, they are sometimes called antioncogenes. If normal tumor suppressor genes are damaged or even lost as is sometimes the case with severe genetic damage, cell growth may become uncontrolled resulting in cancer. Tumor suppressor genes can be damaged by exposure to chemicals or radiation. It is also possible to inherit abnormal tumor suppressor genes, which increases the risk of developing cancer. \textit{RB} (the retinoblastoma gene) and \textit{p53} are two common examples of tumor suppressor genes. \textit{P53} mutations are seen in more than 50\% of non-small cell lung cancers (NSCLC) and over 80\% of small cell lung cancers (SCLC).\textsuperscript{1,3} \textit{P53} acts to regulate cell proliferation and has a role in programmed cell death, which is known as \textit{apoptosis}.

Researchers are working to develop new therapies and drugs that target the genetic damage present in cancer cells. However, it can take years to perform the work needed to find therapies that are safe and effective for patients. \textit{Chapters 6 and 7} review current and potential new therapies for lung cancer.

\textbf{WHAT IS CELL DIFFERENTIATION?}

You may have heard the term \textit{cell differentiation} in discussions about cancer. When a cell grows and develops normally, it undergoes a maturation process in which it becomes specialized to perform specific functions. This maturation process is called cell
differentiation. Differentiation causes cells to take on specific characteristics that reflect the function of the tissue the cell came from through cell division. Therefore, a new, differentiated lung cell looks and functions like all other lung cells. As cells become more differentiated, they become more restricted in what they can do. Differentiation is the reason a kidney cell cannot behave as a muscle cell, and a lung cell cannot function as a brain cell.

Abnormal cell proliferation can begin at any point during a cell’s differentiation process. When a single cell divides, it results in two daughter cells. The daughter cells typically have the same cellular characteristics of their parent cell. If an immature or undifferentiated cell begins proliferating, all the cells produced from the original cell will also be undifferentiated. Differentiation is a process. Therefore, cells that begin proliferating abnormally can reflect varying degrees of differentiation.

As cancer cells rapidly grow and divide, the new cells being produced tend to become progressively less differentiated. As cells become less differentiated, they lose their capability to perform the functions of the tissue where they originated. Highly undifferentiated cells are often incapable of performing any tissue-specific functions. Undifferentiated cells do not have the same appearance as mature cells (see Figure 2).

Their size, shape, and internal characteristic differ from that of normal cells. Highly undifferentiated cells may have such an abnormal appearance that it is difficult to determine from what type of tissue the cells came.

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The term differentiation is also used to describe how the cells of a tumor appear compared to normal cells from the tissue in which the tumor arose. Tumors classified as well differentiated contain cells that bear some degree of resemblance to the normal cells of the original tissue. Undifferentiated tumors have cells that no longer look like normal cells. Some researchers have found an association between poor cell differentiation and decreased survival among patients with NSCLC, especially those with stage I tumors.\[46\]

**HOW DOES CANCER SPREAD?**

One of the defining characteristics of cancer cells is their ability to invade neighboring tissues and to metastasize or spread to sites of the body distant from the tissue of origin. Metastasis occurs when cancer cells break away from the original tumor. The cells travel through the body via the blood or lymphatic system to another part of the body where they grow and proliferate forming a new tumor (see Figure 3).

**Figure 3: The Metastatic Process**

Cancers are named according to the tissue from which they originate. When cancer cells metastasize and a new tumor grows in a different tissue, it is still the same cancer. For example, lung cancer often metastasizes and causes tumors in the brain, bones, and liver. Therefore, someone with lung cancer may have tumors in several different places, but all of the tumors are the result of the lung cancer, which has metastasized to other locations.
SUMMARY

All cancer cells share the same fundamental characteristics of uncontrolled growth and the ability to invade neighboring tissues and/or spread to distant sites. The transformation of normal cells into cancer cells is the result of genetic damage. Environmental chemicals, radiation, and a person’s genetic makeup can all contribute to the genetic damage that leads to the development of cancer. Tumor suppressor genes and oncogenes are the two major categories of genes involved in development of cancer.

Approximately nine million Americans alive today have been diagnosed with cancer at some point in their lives. Cancer is the second leading cause of death in the United States. Currently, one out of every four Americans dies of cancer.
CHAPTER 3: LUNG CANCER OVERVIEW

INTRODUCTION

Learning about lung cancer is an important part of preparing for the decisions you will be making about your treatment and aftercare. The more you know about lung cancer, the better position you will be in to make informed decisions and advocate for your own interests. This chapter provides an overview of lung cancer topics including: lung cancer risk factors, how lung cancer develops, grows, and spreads, and types of lung cancers. The information will help you understand other chapters in this book, and your health care providers’ recommendations for your care.

WHAT IS LUNG CANCER?

Lung cancer develops when normal lung cells sustain genetic damage that eventually leads to uncontrolled cell proliferation. Like all cancers, lung cancer cells have the ability to invade neighboring tissues and spread or metastasize to distant parts of the body. Left untreated, lung cancer eventually causes death.

Lung cancer is sometimes referred to as bronchiogenic cancer or bronchiogenic carcinoma. The word bronchiogenic means originating from the bronchi, the airways of the lungs. Most lung cancers begin in the cells lining the bronchi of the lungs. There are two main types of lung cancer, and they are treated differently. Learning about your particular type of lung cancer can help you talk with your health care providers about your treatment choices. The more informed you are, the better prepared you will be to ask questions that will help you make the treatment choices that are best for you.

HOW COMMON IS LUNG CANCER?

Lung cancer is the number one cancer killer in the United States of men and women of all ethnicities. Lung cancer kills more people in the United States every year than breast, colon, and prostate cancer combined. The American Cancer Society estimates there will be 172,570
new cases of lung cancer in the United States in 2005, and 163,510 lung cancer deaths. This means that every day of the year in this country, approximately 470 people are diagnosed with lung cancer and 450 people die of the disease.

Lung cancer is the leading cause of cancer deaths not only in the United States, but worldwide. The World Health Organization (WHO) reports that over 1.1 million people die of lung cancer each year. This number increases every year. As a result, WHO has identified lung cancer as one of the major problems facing the world in this new century.¹

Lung Cancer Trends

Lung cancer is a relatively new problem for human beings. In the early 1900's, lung cancer was extremely rare. Although people have used tobacco for centuries, until the early 1900's, it was most often smoked with a pipe, in a cigar form, or chewed. The machines to mass-produce cigarettes were invented in the 1880's, but it was not until after World War I that cigarette smoking became prevalent in the United States. During the war, American soldiers were given free cigarettes donated by tobacco companies to the U.S. military. Many soldiers left the military with a lifelong addiction to the nicotine in tobacco products. At that time, the medical community did not realize the long-term impact of cigarette smoking on health.

There is usually a 20-30 year lag time between the onset of smoking and the development of lung cancer. In the 1930's, doctors started to note a dramatic rise in the incidence of lung cancer. By 1950, several studies reported the apparent link between rising lung cancer incidence and the new wave of cigarette smoking.²⁶ In 1964, Dr. Luther L. Terry released the first Surgeon General’s Report on Smoking and Health that definitively established the role of smoking as a contributing factor in the development of lung cancer and several other diseases.

Until recently, lung cancer was viewed primarily as a man’s disease. When lung cancer incidence first began to skyrocket, most cases were observed in men. This was because when cigarette smoking first became prevalent in this country, it was primarily among men. Over time, advertising campaigns aimed at women and other factors led to cigarette smoking eventually becoming almost as common in women as in men. The result of this unfortunate
trend has been an ever-increasing incidence of lung cancer among women. Death rates from lung cancer in women increased an astonishing 550% between 1962 and 1992. In 1987, deaths from lung cancer among women surpassed breast cancer deaths. Today, for every three women that die of breast cancer, five women die of lung cancer.7 Clearly, lung cancer is no longer a man’s disease.

RISK FACTORS FOR DEVELOPING LUNG CANCER

Lung cancer develops when the cells that line the lungs sustain genetic damage. Scientists have identified several different chemicals and environmental factors that are capable of causing the kind of genetic damage that can lead to lung cancer. Substances capable of producing cancerous changes in cells are called carcinogens.

The majority of lung cancers occur in people who are either current or former smokers. While the relationship between smoking and lung cancer is well-established, other factors also come into play. We know this because only about one out of every ten smokers develops lung cancer. Further, approximately one out of every six people who develops lung cancer never smoked. These statistics tell us that lung cancer development is a multifactorial process, meaning many different factors contribute to developing the disease. Known lung cancer risk factors are reviewed briefly in this section.

Smoking

More than 85% of all lung cancer cases occur among people who are either current or former tobacco smokers.8 The relationship between smoking and lung cancer is caused by the carcinogens present in tobacco smoke. The risk of developing lung cancer from smoking is influenced by many factors including the age at which a person began smoking. The younger a person was at the time he or she started smoking, the greater the risk of lung cancer. The effects of carcinogens accumulate over time. Therefore, a person’s total lifetime exposure to cigarette smoke is considered when trying to determine his or her risk of lung cancer. Total lifetime exposure is usually expressed in pack-years. See Figure 1 for how pack-years are calculated. Recent studies suggest that women are more susceptible to the
carcinogenic effects of tobacco smoke than men are. This means that if a man and a woman have the same pack-year history of smoking, the woman is at greater risk for lung cancer than the man is.

\[
\text{Packs per day smoked} \times \text{Years of smoking} = \text{Pack-years}
\]

- 2 packs/day \times 10 \text{ years} = 20 \text{ pack-years}
- 1 pack/day \times 20 \text{ years} = 20 \text{ pack-years}
- \frac{1}{2} \text{ pack/day} \times 40 \text{ years} = 20 \text{ pack-years}

*Figure 1: Calculating Pack-Year Exposure to Tobacco Smoke*

Tobacco smoke is not the only type of smoke that contains carcinogens. Scientists have shown that the smoke from marijuana and crack-cocaine contain numerous carcinogens. Therefore, smoking marijuana and crack-cocaine increase a person’s risk of lung cancer.

The good news is that a smoker’s risk of developing lung cancer can be greatly reduced by quitting. Lung cancer risk does not immediately drop after smoking cessation because most lung cancers are present for several years before they become symptomatic. However, ten years after quitting, lung cancer risk drops to a level that is only 20-50% of the risk experienced by those who continue to smoke. Lung cancer risk continues to decline gradually over time. Nonetheless, a former smoker’s risk of lung cancer never drops to the same level as someone who has never smoked. A former smoker’s risk always remains higher than that of a never-smoker.

Even if you have already been diagnosed with lung cancer, there are still benefits to quitting smoking. For example, research has shown that former smokers suffer fewer complications when undergoing chest surgery than do current smokers.\textsuperscript{10, 11} Another study found that people who have undergone successful therapy for small cell lung cancer and quit smoking had a much lower risk of developing another cancerous lung tumor than those who continued to smoke.\textsuperscript{12} A study from China found that ongoing smoking significantly reduced the chance of long-term survival from lung cancer.\textsuperscript{13} Other benefits of stopping smoking include: slowed progress of other lung disorders such as chronic obstructive pulmonary...
disease and emphysema, reduced risk of heart disease, and reduced risk for other smoking-related cancers such as mouth, stomach, and bladder cancer.

Smoking is not simply a bad habit. Smoking is a physical and psychological addiction to the nicotine in tobacco. Nicotine meets all the criteria of an addictive drug. Two recent reports stated nicotine is at least as addictive as heroin, and in some ways, is even more addictive than heroin or cocaine. A report issued by the Tobacco Advisory Group of Britain’s Royal College of Physicians concluded, “Most smokers do not smoke out of choice, but because they are addicted to nicotine.” Stopping smoking requires overcoming nicotine addiction, which is a very challenging task. Studies have conclusively shown that nicotine replacement therapy with nicotine patches, gums, or inhalers double the rates of successful smoking cessation in the first 6-12 months. Counseling and support are also helpful aids if you are trying to stop smoking. If you are currently smoking, talk with your health care providers about getting the help you need to stop smoking.

Second-Hand Smoke
The health risks of tobacco smoke are not limited to smokers. The lungs of anyone who breathes in air that contains tobacco smoke are exposed to its carcinogens. Therefore, exposure to smoky air in the home, workplace, or in public can increases a person’s risk of lung cancer. This kind of exposure is called second-hand smoke, side-stream smoke, environmental tobacco smoke, or passive smoke. The federal Environmental Protection Agency (EPA) estimates that 3,000 people in the United States die of lung cancer each year because of exposure to second-hand smoke. Children are particularly vulnerable to the health risks associated with second-hand smoke.

Environmental Carcinogens
Environmental carcinogens are substances in the environment capable of producing genetic damage that could contribute to the development of cancer. Following is a brief review of some of the most common, known lung carcinogens.
**Asbestos**

Asbestos is a fibrous mineral that has been widely used in manufacturing, construction, and industry over many years. People exposed to high amounts of asbestos are at increased risk for lung cancer and malignant pleural mesothelioma, a rare form of cancer that involves the covering of the lungs.\(^{17,18}\) Although everyone has some low-level exposure to asbestos, it is usually only people who have had work-related exposure to asbestos that are at increased risk for cancer.

**Radon**

Radon is a naturally occurring, radioactive gas. It is odorless and tasteless. It is formed from the radioactive decay of uranium that normally takes place in the soil and deep in the earth. Exposure to high levels of radon is associated with an increased risk of lung cancer. The EPA estimates that radon causes approximately 14,000 lung cancer deaths each year in the United States.

The amount on radon in the soil varies from one location to another. Underground miners may be exposed to high levels of radon if the mine is located in a uranium-rich area. Similarly, if a home is in an area with high soil levels of uranium and radon, cracks in the basement or foundation may cause high levels of indoor radon. Testing kits to measure indoor radon levels are commercially available. Your local public health department may also have informational materials about radon levels in your area.

**Arsenic**

Arsenic is a naturally occurring element in the earth’s crust. Arsenic occurs in an inorganic and an organic form. The inorganic form of arsenic is a carcinogen and has been associated with increased risk for lung and other cancers. Inorganic arsenic is used in insecticides, weed killers, rat poison, fungicides, and wood preservatives. Inorganic arsenic is also used in some paints and in hide preservation in the leather industry. Workers involved in mining, copper smelting, and pesticide formulation or application are at risk for inorganic arsenic exposure.
Chromium

Chromium is a naturally occurring element found in rocks, animals, plants, and soil. Chromium is odorless and tasteless. Chromium exists in several forms. Only chromium (VI) or hexavalent chromium is carcinogenic. Studies have shown that exposure to hexavalent chromium increases risk for developing lung cancer. Chrome plating, stainless steel welding, and chromium-nickel foundry work are occupations that may put one at risk for chromium (VI) exposure.

Nickel

Nickel is a hard, silvery-white metal used to make stainless steel and other metal alloys. Workers who breathe large amounts of nickel compounds are at increased risk for lung and nasal sinus cancers. Many occupations could potentially expose a person to unsafe amounts of nickel. A partial list of these occupations includes metalworking, nickel mining and smelting, sand blasting, stainless steel manufacturing, paint and varnish manufacturing, and welding.

Polycyclic Aromatic Hydrocarbons (PAHs)

Polycyclic aromatic hydrocarbons are a group of over 100 different chemicals that are formed during the incomplete burning of coal, oil, gas, garbage, or other organic substances such as tobacco or charbroiled meat. Diesel fuel exhaust is a prevalent source of PAHs. PAHs are potent carcinogens. Tobacco smoke, wood smoke, vehicle exhausts, asphalt roads, and agricultural burn smoke all contain high levels of PAHs. PAHs are also found in coal tar, crude oil, creosote, and roofing tar. Some PAHs are used to make medicines, dyes, plastics, and pesticides.

In addition to tobacco smoke, sources of exposure to PAHs include work with coke ovens, coal gasification, petroleum refineries, creosote-soaked wood, asphalt and pavement work, roofing, aluminum production, foundry work, and others.

Other Environmental Lung Carcinogens

Known lung carcinogens not already mentioned include bis(chloromethyl)ether, chloromethyl methyl ether, ionizing radiation (x-rays), gamma radiation, mustard gas,
soots, tars, mineral oils, and vinyl chloride. Suspected lung carcinogens include acrylonitrile, cadmium, beryllium, lead, and ferric oxide dust. Many other known, suspected, and potential carcinogens could contribute to the development of lung cancer.

Genetic Factors
The transformation of normal cells into cancer cells is a complex, multi-step process. Everyone is exposed to lung carcinogens. While we know that the total amount of exposure is one factor that governs whether someone develops lung cancer, we also know it is not the only factor. Most lifelong smokers never develop lung cancer, and a significant number of people with no known personal or environmental risk factors develop lung cancer. These facts make it obvious that it is not only what we are exposed to, but also how our bodies handle the exposures that determine whether lung cancer develops.

Genes control how a person’s body handles carcinogens, how susceptible it is to genetic damage, and how capable it is of repairing damage that occurs. Genes also control how well the immune system detects and destroys cancer cells. Therefore, an individual’s unique genetic make-up contributes to his or her susceptibility or resistance to lung carcinogens. For example, people whose parents or siblings have had lung cancer may be at increased risk of developing lung cancer. Other people seem to be resistant to the effects of carcinogens and therefore may be less susceptible to developing cancer than most people are. Genetic susceptibility and resistance to cancer is an area of active research.

One of the most striking features of lung cancer cells is the large number of genetic changes present in them. Often 10-20 genetic mutations are found, indicating a genetic instability in lung cancer cells.

Age
Age itself may contribute to a person’s risk of lung cancer. Genetic damage tends to accumulate over time. Scientists currently believe that cells accumulate multiple genetic defects before becoming cancerous. Therefore, as we age, the probability of accumulating enough genetic damage to lead to cancer increases. In addition, the immune system works
less effectively as we age. This increases the likelihood that cancer cells will slip through our natural cancer surveillance system.

Lung cancer is rare among people less than 40 years of age. The vast majority of lung cancers are diagnosed in people over the age of 50. The average age of newly diagnosed lung cancer patients is around 60 years of age.

**LUNG CANCER GROWTH**

Most lung cancers are relatively slow growing. Researchers have estimated that by the time a lung tumor grows to 1 centimeter in diameter (approximately 3/8 inch), it has been present for an average of 8-15 years. However, significant variability in lung cancer growth has been reported by several researchers. Although most lung cancers are slow growing, they have the ability to metastasize or spread to other parts of the body early in their growth. This process is called *early micrometastasis*, metastasis that is not detectable by ordinary means. The high blood flow through the lungs may facilitate the metastatic process.

During the years when lung cancer is developing but is not yet detectable by x-rays or scans, microscopic and molecular changes are occurring in the cells of the bronchi. Scientists are actively researching new diagnostic techniques for earlier detection of lung cancer. Some of these techniques are discussed in *Chapter 4: Lung Cancer Diagnosis and Staging*.

**LUNG CANCER SPREAD**

The lungs are highly vascularized organs, meaning they have many blood vessels running through them. This vascularization is needed for the quick exchange of oxygen and carbon dioxide that takes place with each breath. Among people with lung cancer, these blood vessels provide many convenient routes for lung cancer cells to travel to other parts of the body. Most cancer cells that enter the bloodstream die. However, if lung cancer cells survive and begin to grow in a site distant from the lungs, they produce metastatic tumors.
The lungs also have a rich supply of **lymphatic vessels**. Lymphatic vessels are part of the immune system. They form a network of vessels similar to the blood vessels of the circulatory system. Lymphatic vessels contain fluid called **lymph** that is made up of immune cells and excess tissue fluid and proteins. Lymph is passed through a network of **lymph nodes** before being returned to the blood circulation. Lymph nodes are compact collections of immune cells. As lymph passes through lymph nodes, foreign particles, bacteria, and viruses are filtered out and processed by the immune system. Cancer cells can also be filtered out into lymph nodes. Cancer cells trapped in a lymph node may begin to multiply causing the node to enlarge. For this reason, a careful examination of the lymph nodes in the chest is an important part of determining whether lung cancer has spread beyond the original tumor. Cancer cells in lymph fluid that escape the lymph nodes may travel to other areas of the body and cause metastatic tumors.

The process of determining whether lung cancer has spread beyond the original tumor is called **staging**. Staging is necessary because the extent of spread of the disease is one of the key pieces of information that determines your treatment options. Three factors determine stage: the size and characteristics of the original or **primary tumor**, spread of the cancer to **regional lymph nodes**, and the presence or absence of distant metastases. In lung cancer, the term regional lymph nodes refers to lymph nodes that receive lymph fluid from the lungs. Examination of these lymph nodes is crucial because involvement of these lymph nodes indicates possible spread to more distant areas of the body. *Chapter 4: Lung Cancer Diagnosis and Staging* provides more information about lung cancer staging.

**TYPES OF LUNG CANCER**

Lung cancer arises from abnormal **epithelial cells** in the airways of the lungs. Epithelial cells form the covering over free surfaces in the body such as the airways. Lung cancer is divided into two main types based on how it looks under the microscope: small cell lung cancer (SCLC) and non-small cell lung cancer (NSCLC). In the United States, approximately 80% of lung cancers are NSCLC and 20% are SCLC. SCLC and NSCLC have different patterns of growth and spread. They are also treated differently.
In 1999, the World Health Organization and the International Association for the Study of Lung Cancer (IASLC) updated their classification system for lung tumors. The information presented here uses the terminology of the 1999 WHO/IASLC classification system. Be aware that some people and reference materials may use other terminology based on other classification systems. If you have questions about the terminology used to describe your lung cancer, ask your health care provider to explain it to you.

**Small Cell Lung Cancer**

As the name implies, the cancerous epithelial cells of SCLC are abnormally small. Their appearance led to the term *oat cell carcinoma* to describe SCLC because the cells resemble oat grains. SCLC is also sometimes called small cell undifferentiated carcinoma. *Carcinoma* is a generic term referring to any malignant tumor that comes from epithelial cells. SCLC cells are sometimes spindle-shaped or polygonal (multisided).

Some characteristics of SCLC are:

- There is a strong relationship between SCLC and tobacco smoking. Only about 1% of SCLC occurs in people who have never smoked.
- SCLC typically grows more quickly than NSCLC does. It tends to spread to lymph nodes and metastasize to other organs early in the disease process.
- SCLC tends to be initially responsive to chemotherapy and radiation therapy.
- SCLC often occurs in one of the larger airways. Therefore, SCLC tumors are often located near the center of the lung.
- Most people with SCLC have metastases at the time of diagnosis.
- Combined small cell carcinoma is a variant of SCLC.

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Non-Small Cell Lung Cancer

There are three major types of NSCLC: adenocarcinoma, squamous cell carcinoma, and large cell carcinoma. NSCLCs are grouped together because they have similar growth patterns and are treated similarly. Each of the three major types of NSCLC has variants or subtypes. The names of the variants describe certain patterns of growth that are visible under the microscope. Following is a brief summary of some characteristic features of the three types of NSCLC.

*Figure 3: Microscopic Views of the Three Types of Non-Small Cell Lung Cancer*

**Adenocarcinoma**

Adenocarcinoma cells have a glandular appearance. Most of these tumors produce a thick fluid called *mucin*. The incidence of adenocarcinoma has increased over the past three decades. Scientists are not certain why this has occurred, but some influences may include changes in smoking habits, dietary patterns, environmental factors, and occupational factors. Some characteristics of adenocarcinoma are listed below.

- Adenocarcinoma accounts for approximately 40% of all lung cancers in the United States, and approximately 55% of NSCLCs.
- Variants of adenocarcinoma include acinar adenocarcinoma, papillary adenocarcinoma, bronchioloalveolar adenocarcinoma, and other mixed subtypes.
Adenocarcinoma is the most common form of lung cancer in women and people who have never smoked. This form of lung cancer is also the most common type seen in people less than age 50.

- Tumors are most often in the outer regions of the lungs.
- Adenocarcinomas are the most common form of lung cancer associated with scarring of the lung tissue.
- A subtype of adenocarcinoma called bronchioloalveolar adenocarcinoma (BAC) arises in the alveoli. BAC tends to be slow growing and seems less likely to metastasize than other forms of NSCLC. For this reason, BAC has a more favorable prognosis than other forms of NSCLC.

### Squamous Cell Carcinoma

Squamous cell carcinoma (SCC) is also known as *epidermoid carcinoma*. This form of NSCLC has decreased in frequency over the past three decades, but is still the most common form of lung cancer among men who are current or former smokers. Squamous cells are large, flat cells. These tumors often produce a substance called *keratin*, which can be seen under the microscope. Some features of SCC are listed below.

- SCC accounts for approximately 25-30% of lung cancer in the United States.
- Variants of SCC include papillary SCC, clear cell SCC, small cell SCC, and basaloid SCC.
- SCC occurs most frequently in men and in people over age 65 of both sexes.
- SCC usually starts in one of the larger airways. Therefore, these tumors tend to be located in the central area of the lung.
- There is a tendency for SCC to metastasize somewhat later than other forms of NSCLC.
- SCC tumors often invade neighboring structures.
- SCC is strongly associated with tobacco smoking.

### Large Cell Carcinoma

The cells of large cell carcinoma (LCC) are the largest of the various types of NSCLC. The cells are generally highly undifferentiated or immature in appearance.
Some experts believe these tumors represent adenocarcinomas or squamous cell carcinomas that are so undifferentiated as to be unrecognizable. Some characteristics of large cell carcinoma are:

- LCC accounts for 10-15% of lung cancers in the United States.
- There are several variants of large cell carcinoma including clear cell LCC, basaloid LCC, lymphoepithelioma-like carcinoma, and large cell neuroendocrine carcinoma.
- This form of NSCLC can occur in any part of the lung.
- The prognosis for large cell carcinoma is generally less favorable than for other forms of NSCLC.

OTHER CANCERS IN THE LUNGS

There are other types of non-epithelial cancers that arise in the lungs. They are all relatively uncommon compared to SCLC and NSCLC. Examples of these cancers include carcinoid tumors, malignant pleural mesotheliomas, fibrosarcomas, and leiomyosarcomas. The lungs are also a frequent location for metastatic tumors from other locations in the body. Carcinoid tumors and malignant pleural mesothelioma are briefly reviewed because they are the most common forms of these rare cancers.

Carcinoid Tumors

Carcinoid tumors are cancers that arise from neuroendocrine cells. Neuroendocrine cells are specialized nerve cells that produce hormones. They are found in many locations throughout the body. The hormones from neuroendocrine cells are released into the bloodstream and travel to target cells throughout the body. The hormones may stimulate, inhibit, or maintain the function of their target cells. Although it is uncommon, carcinoid tumors can secrete high levels of hormones, which can lead to symptoms such as bouts of diarrhea and flushing. Carcinoid tumors are divided into typical and atypical variants. Some characteristics of carcinoid tumors are:

- Carcinoids account for 1-5% of all lung tumors.
• Carcinoid tumors typically occur in people under 40 years of age. They are equally common in men and women.

• There is no known relationship between tobacco smoking and carcinoid tumors.

• The lung is the fourth most common site for primary carcinoid tumors.

• Typical carcinoid tumors tend to have a relatively benign course. They do not metastasize to distant sites for long periods, although they often spread to local lymph nodes. These tumors can often be cured by surgical removal.

• Atypical carcinoid tumors are a more aggressive variant with a greater tendency for distant metastasis and recurrence than typical carcinoid tumors.

Malignant Pleural Mesothelioma

Malignant pleural mesothelioma (MPM) is cancer arising from the covering of the lung and chest wall, not the lung itself. The covering on the surface of the lungs is called the visceral pleura. The covering on the inside of the chest wall is called the parietal pleura. There are other pleural surfaces in the body, but about 75% of malignant mesotheliomas occur in the pleura of the lungs. Malignant mesothelioma is a rare form of primary cancer. The pleura are much more commonly a site of metastatic cancer than of primary cancer. There are approximately 2,000-3,000 new cases of malignant mesothelioma each year in the United States.

There are three types of malignant mesotheliomas. About 50-70% of mesotheliomas are the epithelioid type; this type has the best prognosis. The other two types are sarcomatoid and mixed/biphasic mesotheliomas. Treatment options are the same for all three variants.

Asbestos is the predominant cause of MPM. The period between exposure to high levels of asbestos and the development of MPM is typically 25-45 years. There seems to be no increased risk of MPM among asbestos workers who smoke versus non-smokers. MPM is more frequently diagnosed in men than women because of the occupational link to asbestos.

Surgery is the mainstay of treatment for localized MPM. When the disease has spread, surgery, radiation therapy, and/or chemotherapy are possible treatment options.
SUMMARY

Lung cancer is the leading cancer killer of men and women in the United States and worldwide. More than 157,000 people in the United States and over 1.1 million people worldwide die of lung cancer each year. Lung cancer is a major global health concern and will remain so for many years to come.

There are two major forms of lung cancer, small cell lung cancer and non-small cell lung cancer. Both of these cancers arise from the epithelial cells that line the airways of the lungs. The vast majority of lung cancers are non-small cell lung cancers. Small cell and non-small cell lung cancer have different growth patterns and treatments. Other rare forms of cancer also occur in the lungs including carcinoid tumors and malignant pleural mesotheliomas.

Knowledge of the type of lung cancer you have will help you better understand your disease and its treatment options.
CHAPTER 4: LUNG CANCER DIAGNOSIS AND STAGING

INTRODUCTION

The lungs are vital organs. Working with the heart and circulatory system, they provide life-sustaining oxygen and rid the body of carbon dioxide. Normal lungs have a great reserve capacity to meet the body’s need for oxygen across a wide variety of circumstances. The same is true of the heart and circulatory system. This reserve capacity permits cancerous lung tumors to grow for years without compromising lung function. Furthermore, the lungs do not have many nerves to transmit pain messages. Therefore, a cancerous lung tumor can grow for many years without causing any symptoms. Unfortunately, this means that most people are not diagnosed with lung cancer until late in the disease process. Even more unfortunate is the fact that this long period of silent growth gives the cancer time to spread before it is diagnosed. Lung cancer that has spread beyond the original tumor is difficult to cure.

Eventually, people with lung cancer do develop symptoms. Approximately 95% of people diagnosed with lung cancer have symptoms related to the disease. However, they occur late in the cancerous process. The long silent growth period of lung cancer has led to great interest in lung cancer screening, especially in recent years.

This chapter reviews how lung cancer is diagnosed, and once diagnosed, how the extent of the disease is determined. The processes involved in determining whether the cancer has spread and to what extent is called staging.

The information in this chapter will help familiarize you with some of the procedures you may undergo and the medical terminology you are likely to hear. The chapter begins with a discussion of lung cancer screening and early detection. Although no official screening program currently exists, it is placed at the beginning of the chapter for a reason. Currently, 95% of lung cancer patients are diagnosed because they develop symptoms, a late
occurrence in the disease process. As a result, 85% of people newly diagnosed with lung cancer already have advanced disease. Many lung cancer experts and patient advocates believe that if lung cancer screening and early detection programs were instituted, this pattern of late-stage diagnosis would change. Therefore, lung cancer screening has been placed before symptomatic lung cancer presentation.

**LUNG CANCER SCREENING AND EARLY DETECTION**

No discussion of lung cancer diagnosis would be complete without touching on the topic of lung cancer screening. Cancer screening is testing performed on apparently healthy people to detect unrecognized cancer. The purpose of cancer screening is to identify people with the disease so that measures can be taken to improve their prognosis. There are several familiar cancer screening programs in the United States.

- breast cancer – mammograms and monthly self-breast exams
- cervical cancer – Pap smears
- colon cancer – sigmoidoscopy and occult blood tests
- prostate cancer – prostate specific antigen (PSA) tests and physical examinations

It is notable that there are screening programs for both of the second most common causes of cancer death in the U.S. – breast cancer in women and prostate cancer in men. There are also screening guidelines for the number three cancer killer of men and women, colorectal cancer. Yet, we do not screen for the number one cancer killer of both men and women – lung cancer. Lung cancer kills more Americans every year than breast, prostate, and colon cancer combined. Why isn’t there a screening program for lung cancer?

The reasons are complex and controversial. The most commonly cited reason is based on the conclusions drawn from a lung cancer screening study performed in the 1970’s. Many learned scientists, researchers, and doctors have debated the validity of the trial design and its conclusions. Nonetheless, based on the controversial conclusions drawn from this trial,
lung cancer screening programs are not currently supported or recommended by any official cancer or health agencies.

Despite the lack of support from public health agencies and national cancer organizations for lung cancer screening, many lung cancer advocates urge people who may be at risk for lung cancer to talk with their health care providers. People at increased risk for lung cancer due to smoking history, occupation, or family history should inform their health care providers about their risk factors and discuss appropriate testing.

The *International Conference on the Prevention and Early Diagnosis of Lung Cancer* held in Varese, Italy in December 1998 brought together lung cancer experts from around the world to discuss lung cancer screening and early detection. A consensus statement was issued by the meeting participants. Excerpts from that statement follow.

*For those who develop lung cancer, outcome is dramatically better when the disease is detected at an early stage and surgically treated.... Available clinical data demonstrate that the vast majority of curable lung cancers are currently detected by chest x-rays and CT scans, although there is no proven strategy to assure early detection....*

*The Conference encourages national governments and public health organizations involved in cancer prevention and control to more aggressively address tobacco control and to urgently consider the issues surrounding the early detection of lung cancer....*

**A Program Model**

We know that most lung cancers are present for many years before symptoms of the disease appear. We also know that currently, in the absence of lung cancer screening and early detection, most people with lung cancer cannot be cured because the disease is already too advanced at the time of diagnosis. Given these two known facts, it is at least theoretically possible that lung cancer screening and early detection would improve survival rates.

Proponents of lung cancer screening and early detection suggest such a program should have the following components.

- An educational component to inform the general public of lung cancer risk factors, and to be certain that those at risk understand their risk
• An assessment of risk such as a questionnaire or interview to gather information about lung cancer risk factors such as smoking history (tobacco, marijuana, crack cocaine), exposure to lung carcinogens, and family history of lung and other epithelial cancers

• A testing program which could have several components:
  — imaging studies of the lungs and other early detection test; possible tests that might be used include standard chest x-rays, digital chest x-rays, helical/spiral CT scans, tumor markers, sputum-based tests, or other tests that are currently being developed
  — tests to determine genetic susceptibility to cancer; although we do not yet have such a test, this is an active area of research; such testing could identify people at risk who may need close monitoring

• Smoking cessation counseling and treatment to help those addicted to nicotine overcome their habit

There is a great deal of work to be done to develop a widely accepted, valid, and cost-effective lung cancer screening and early detection program. Many lung cancer experts believe early detection is the key to improving lung cancer survival. Recent technological advances and the call for change being voiced by lung cancer advocates worldwide have led to renewed interest in lung cancer screening policies. In September 2002, the National Cancer Institute launched the National Lung Screening Trial (NLST). Researchers intend to enroll 50,000 current and former smokers. The study will compare spiral CT scans to chest x-rays for lung cancer screening. The trial is expected to last eight years.

The hope of advocates who support lung cancer screening programs is a simple one – to diagnose people with lung cancer earlier in the disease process when there is a greater chance for cure.

**LUNG CANCER PRESENTATION**

In medicine, the term *presentation* refers to the signs and symptoms a person is experiencing that cause him or her to seek medical care and eventually lead to the diagnosis of a specific
condition. Lung cancer usually grows for many years without causing signs or symptoms. However, eventually nearly all people with lung cancer develop symptoms associated with the disease. Only 5% of people newly diagnosed with lung cancer do not have symptoms of the disease.\(^2\)

The symptoms associated with lung cancer are often non-specific. Lung cancer is frequently a masquerader, meaning it can cause signs and symptoms that on the surface seem to have nothing to do with lung cancer. This lack of specificity of signs and symptoms can lead to delays in making the correct diagnosis as other more common causes of symptoms are often investigated before the diagnosis of lung cancer is considered.

The presentation of lung cancer is highly variable. Factors such as the location of the tumor, involvement of different lymph nodes in various locations, and involvement of a variety of distant organs can influence lung cancer presentation. Some of the possible presenting symptoms of lung cancer are reviewed in this section. For simplicity, the symptoms are grouped as local symptoms, locally advanced symptoms, and metastatic symptoms. However, there is quite a bit of overlap between these groups. For example, it is entirely possible for someone with metastatic lung cancer to have symptoms from all three categories or to have only local symptoms.

**Symptoms of Localized Lung Cancer**

Cough is the most common presenting symptom of lung cancer. Over 50% of people with lung cancer have a cough at the time of diagnosis. In non-smokers and long-term former smokers, the cough is usually new and persistent. In people who already have lung disease such as chronic obstructive pulmonary disease (COPD) or emphysema, it is often a change in their usual cough that heralds a diagnosis of lung cancer. Therefore, a change in a pre-existing cough should never be ignored.

I had a cough in January. Since I have had previous lung problems I went in for a chest x-ray. When nothing showed up on the x-ray, I dismissed it. Then one morning in April, I woke up and said to myself, “You idiot! You work for the American Cancer Society. You're in charge of an educational program. You have a persistent cough, which is a sign of lung cancer!” (That's actually the censored version of what I said.) I immediately went and got another chest x-ray. They found a nodule in my lung.

− Sandra, diagnosed with stage II NSCLC in 1998 at age 53
Some people with lung cancer cough up blood. The medical term for this symptom is *hemoptysis*. The amount of blood can range from small streaks to coughing up what appears to be pure blood, which can be a medical emergency. Although there are causes of hemoptysis other than lung cancer, anyone who coughs up blood must see a doctor to determine the cause.

Unintentional weight loss is another common symptom of lung cancer, regardless of whether it has spread beyond the original tumor. Difficult and/or painful breathing (also known as *dyspnea*), chest pain, and wheezing are also common complaints.

**Symptoms of Locally Advanced Disease**

The symptoms associated with locally advanced disease are due to invasion of structures in or near the lungs, or from cancerous spread to *regional lymph nodes*. New onset hoarseness that does not improve or go away can be caused by a cancerous lung tumor that involves one of the nerves controlling the vocal cords. Difficulty swallowing or *dysphagia* can be caused by regional lymph node enlargement or a lung tumor pressing against the *esophagus*, which carries food from the mouth to the stomach.

Shoulder pain, with or without arm and hand numbness and weakness, can be the presenting symptom of lung cancer in the uppermost part of the lung, the *apex*. Facial swelling and prominence of the neck and chest veins can indicate a lung cancer compressing a large vein leading to the right side of the heart. Although these symptoms are not present in most people with regionally advanced lung cancer, their presence should lead to a suspicion of lung cancer.

> What [prompted me to go] to the doctor was a pain just below my rib cage that they initially thought was inflammation of the cartilage. But it turned out to be caused by a tumor in my lung.

—Ann, diagnosed with stage IIIB NSCLC in 2002 at age 54

**Symptoms of Distant Lung Cancer Metastases**

Lung cancer can spread to virtually any organ of the body. The most common sites of metastasis are the brain, liver, bones, and adrenal glands (see Figure 1). Early metastatic tumors may not cause symptoms because of their small size. However, as these *secondary tumors* grow they can cause a wide variety of symptoms depending on their location and size. Some of the more common symptoms associated with secondary tumors in the brain, liver,
bones, and adrenal glands will be reviewed, but there are many other possible symptoms of lung cancer metastases.

**Symptoms of Brain Metastases**

The symptoms of lung cancer that has spread to the brain vary depending on the size, location, and number of tumors present. Severe headaches, uncontrollable vomiting, and seizures are symptoms associated with increased pressure in the brain that can be caused by a growing tumor and/or brain swelling. Weakness or paralysis that is limited to a specific area of the body may indicate a tumor in the area of the brain that controls the affected part of the body. Changes in vision, difficulty speaking or swallowing, loss of balance or coordination, and confusion are all possible symptoms associated with metastatic brain disease.

My first clue my cancer had spread was when one Sunday afternoon, a police officer drove into my driveway. I thought he was soliciting donations. However, that was not the case. He started by asking me all sorts of questions about where I had been earlier that day. Then he said, “Ma’am, you hit a car.” I said, “No I didn’t!” He asked my husband to leave us alone for a moment. I guess the officer thought I was afraid to tell the truth in front of my husband. So, I stepped outside and the officer proceeded to tell me that I did hit a car. I was almost in tears because he wouldn’t believe me that I did no such thing. Then my husband came outside and calmed the police officer and me down. It turned out, my husband knew the officer. To make a long story short it turned out that I had indeed hit this poor woman’s car.

I had an appointment with the oncologist three days later. I was so embarrassed about the [accident], I just kind of mentioned it to the doctor at the end of the appointment as he was leaving. As soon as he about it, he came back in, checked me over again, and sent me for more tests. During this time, I had also noticed my peripheral vision was deteriorating. I had told that NSCLC does not metastasize to the brain, that only small cell lung cancer does that.* So, I hadn’t really been all that worried [about my vision]. But as it turned out, I had a brain metastasis the size of a baseball. – Sue, diagnosed with stage III NSCLC at age 48

*IMPORTANT: This information Sue was told is incorrect. Both SCLC and NSCLC frequently metastasize to the brain.

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Symptoms of Bone Metastases

Pain is the most common symptom associated with bone metastases from lung cancer. The pain can range from mild to severe. Any bone in the body can be involved in lung cancer spread. Bone pain that is not associated with a recent injury or fall is particularly suggestive of possible metastatic disease. Some people are diagnosed with lung cancer after experiencing a pathological bone fracture. A pathological fracture is a bone break that occurs because a tumor has eroded away the involved bone. These fractures typically occur without any history of a fall or an impact, or are associated with a minor impact that would not normally cause a bone to break.

Symptoms of Liver Metastases

The liver is enclosed in a capsule that has little capacity to expand. Therefore, tumors in the liver that stretch this capsule cause pain. The pain is typically located on the right side of the body in the area below the ribs. If the tumors interfere with the function of the liver, there can be many other symptoms associated with liver metastases from primary lung cancer.

Symptoms of Adrenal Metastases

The adrenal glands are small organs that sit on top of the kidneys. The adrenal glands produce hormones that have effects throughout the body. Adrenal metastases from primary lung cancer are often silent, meaning they do not produce symptoms. The most common symptom associated with adrenal metastases is pain caused by tumor growth or sudden bleeding into the gland. The pain is typically located in the back, around waist-level, to the right or left of the spine depending upon the location of the tumor.

Other Symptoms Associated With Lung Cancer

Approximately 10-20% of people with lung cancer have paraneoplastic syndromes. These are signs and symptoms of the disease that are not caused by the tumors themselves, but by substances produced by the tumors. These syndromes can affect several organs of the body,
and cause a wide variety of signs and symptoms. A list of some of the many symptoms that can occur in paraneoplastic syndromes includes:

- loss of appetite and weight loss
- altered sense of taste
- fever
- fatigue
- muscle weakness with or without tenderness
- itchy skin or rashes
- constipation or diarrhea
- edema (swelling caused by fluid accumulation especially in the feet and ankles)

**DIAGNOSING LUNG CANCER**

Lung cancer diagnosis is a variable process. The tests used and the order in which they are done depends on numerous factors including such things as your medical history, your presenting complaints, and the findings on your physical examination. For some people, the diagnosis of lung cancer is straightforward. For other people, the process is more complex. The outcome of each step in the diagnostic process influences what the next step in the process will be.

Approximately 5% of people who are diagnosed with lung cancer have no symptoms. They are usually diagnosed because of an unexpected finding during a physical examination, an abnormality on a routine chest x-ray, or some other incidental finding. However, the vast majority of people diagnosed with lung cancer seek medical attention because they are experiencing symptoms. For the sake of simplicity, we will assume that the diagnostic process is beginning at the point of experiencing symptoms. When a person goes to the doctor, he or she always begins the investigation into the source of the problem with a medical history and a physical examination.
Medical History

Your medical history gives your doctor important information that helps him or her think through possible causes of your symptoms. Pieces of information from your medical history your doctor will probably consider include:

- your personal smoking history and exposure to second-hand smoke,
- any problems you’ve had with your lungs in the past,
- when your current symptoms started, and how they have changed over time,
- your job history and/or exposure to potential lung carcinogens, and
- a family history of lung cancer or other epithelial cell cancers.

Depending on your presenting symptoms, your doctor may ask other questions about your medical history. Try to be as accurate and truthful as possible when reporting your medical history.

Physical Examination

The physical examination is a crucial part of the diagnostic process for any medical problem. Important physical findings in someone who may have lung cancer include:

- fever
- abnormal breath sounds in the lungs
- swollen lymph nodes
- tenderness and/or enlargement of the liver
- tenderness in the flank area (over the kidney)
- swelling in the hands, feet, face, or ankles
- tenderness over any bones
- generalized or regional muscle weakness
- skin changes such as rashes, dark areas, or a blue tint of the lips and nails
- any findings that might indicate a primary tumor in a body organ other than the lungs

There are many other possible physical findings your doctor will consider in deciding how best to proceed.
Laboratory Testing
Laboratory testing is usually included in the diagnostic work-up of someone who may have lung cancer. The specific tests your doctor orders will depend on your medical history, presenting symptoms, and physical findings.

Sputum Cytology
A sputum cytology test may be performed when lung cancer is suspected (see Figure 2). A sample of sputum is collected first thing in the morning. Sputum is the thick, slippery fluid secreted by the airways; many people call sputum phlegm. The sample must come from deep in the lungs, so it must be produced by a deep cough. The sputum is placed on slides and stained in the laboratory. The slides are then examined under a microscope. The technologist examining the slides looks for cancer cells that may be contained in the sputum. Bacteria and other abnormal cells may also be seen. Your doctor may have you collect sputum samples on three consecutive days to increase the chances of finding cancer cells.

When cancer cells are seen in a sputum cytology specimen, it is almost certain there is cancer in the lungs. However, if cancer cells are not detected, this does not rule out the possibility of lung cancer because sputum cytology is positive in only 5-20% of people with lung cancer.

Tumor Markers
Tumor markers are substances in the blood that are found only when cancer is present, or are present in highly elevated amounts when cancer is present. Carcinoembryonic antigen (CEA) is a tumor marker that is sometimes measured when lung cancer is suspected. However, CEA is elevated in several cancers, not just lung cancer. Therefore, an elevated CEA does not necessarily mean lung cancer is
present. The interpretation of an elevated CEA level is further complicated by the fact that smokers often have abnormally high CEA levels.

Scientists are working hard to find tumor markers for lung cancer that are both sensitive to the presence of lung cancer and are specific for lung cancer. Sensitivity is the ability of a test to detect an abnormality if one is present. Specificity is a measure of how likely it is that a test abnormality indicates a particular disease. A sensitive and specific lung cancer tumor marker could potentially be used as diagnostic tool and as a screening test for people who are at risk but have no symptoms.

**Imaging Tests: Is There a Lung Tumor?**

Imaging tests are performed to determine if a lung tumor is present. Some imaging studies can provide information that can help determine if a lung tumor is likely to be benign or malignant. The final determination as to whether a tumor is cancerous can only be made by examining a tissue sample under a microscope. Imaging tests are useful to look for enlargement of regional lymph nodes, which could indicate cancerous spread.

**Chest X-Rays**

Although studies have proven that chest x-rays miss a significant number of lung tumors, a chest x-ray is often the first imaging study performed when primary or metastatic lung cancer is suspected. A lung tumor can be missed on chest x-ray if it is small or hidden behind a rib, collar bone, or the breastbone. Chest x-rays can be useful for detecting abnormalities other than tumors that may be related to lung cancer. For example, chest x-rays can detect an accumulation of fluid around the lung, a condition known as pleural effusion. A chest x-ray may also show enlarged lymph nodes, pneumonia, or blocked airways that are preventing air from reaching part of the lung.

Even if the diagnosis of lung cancer is already clear, your doctor may want to take a chest x-ray to compare with previous and future chest x-rays. Following chest x-rays over time can help your doctors monitor the course of your disease.
Within the last few years, a new type of chest x-ray called the digital chest x-ray has been introduced. The digital chest x-ray collects the image of the chest with a computerized detector instead of on a piece of film as is done with a conventional chest x-ray. The use of the detector instead of film allows for sharper, clearer images. Researchers are also testing the use of computers to aid the reading of chest x-rays in an effort to pick up more lung tumors. This technology is called computer-assisted diagnosis (CAD). Early research indicates the combination of digital chest x-rays and CAD has the potential to greatly improve the efficiency and accuracy of chest x-rays in detecting lung tumors.8,9

CT Scans

CT scans (computerized tomographic scans) are x-ray imaging tests that may be used in the diagnostic work-up of suspected lung cancer. CT scans are able to detect smaller tumors than chest x-rays. They are also better able to determine the size, shape, and exact location of a tumor because they collect information in three dimensions instead of two. For the same reasons, CT scans are better able to detect enlarged regional lymph nodes. When CT scanners were first introduced, the machines took individual x-rays of the body, which were then put together by a computer to form three-dimensional images. The scanning procedure took 15-30 minutes, and the images were affected by small movements during the study. In the early 1990’s, a new type of scanner was introduced, the spiral or helical CT scanner. This scanner is able to x-ray the entire chest in 20-30 seconds while the patient holds his or her breath. The continuous nature of data collection by the computer and the reduced effects of movement make CT scans performed with helical/spiral machines clearer and better able to

*Figure 3: CT Scan of the Chest Showing a Lung Tumor*
detect small tumors. In most instances, the higher quality of helical/spiral CT scans make them more desirable than CT scans performed with older scanning machines.

**MRI Scans**

*MRI scans* (magnetic resonance imaging scans) use a large magnet instead of x-rays to produce three-dimensional images. MRI is not often used in the routine work-up of suspected lung cancer. In special circumstances, MRI may be used to study a particular area that may be difficult to interpret on a CT scan such as the diaphragm or the uppermost part of the lung. However, in most instances, CT is superior to MRI for imaging the structures in the chest.

**PET Scans**

PET (positron emission tomography) scanning is a relatively new technology. Sugar molecules that have a radioactive component are injected into the body and then a scan is taken. The amount of radiation used for these scans is very low. Cancer cells take up more sugar than normal cells because they are growing and dividing rapidly. Therefore, areas of the body with cancer cells show up brighter on the scan than normal tissues. Primary tumors, lymph nodes containing cancer cells, and metastatic tumors all appear as bright spots on a PET scan. Substances other than radiolabeled sugar are sometimes used for PET scans, but the theory behind the scans is the same.

PET scans are not generally used as first-line diagnostic tests for lung cancer. They are sometimes used after chest x-rays or CT scans to differentiate between benign and cancerous tumors. PET scans are particular useful for finding cancerous spread to regional lymph nodes and detecting distant metastatic tumors. However, there are conditions other than cancer that cause positive findings on PET scans. PET scan findings should be interpreted cautiously and correlated with other test results.

**Tissue Diagnosis**

The only way to make a certain diagnosis of lung cancer and determine the type of lung cancer present is to examine a sample of the tumor under the microscope. The process of
obtaining a tissue sample is called a *biopsy*. The method used to obtain a biopsy depends on the size and location of the tumor or lymph node being tested. Different biopsy techniques are reviewed in this section.

**Bronchoscopy**

*Bronchoscopy* is the most common technique used to biopsy a suspected lung cancer. Bronchoscopy involves putting a small, flexible tube called a bronchoscope into the larger airways of the lungs. The bronchoscope allows the doctor to see inside the airways and take tissue samples. Bronchoscopy is particularly useful for obtaining tissue samples from tumors growing in the larger airways of the *bronchial tree*, usually in the central part of the lung. Tissue samples from lymph nodes in and around the lungs can also be obtained with a bronchoscope. Bronchoscopy is generally performed as an outpatient procedure.

Autofluorescence bronchoscopy is a modified bronchoscopy procedure that uses fluorescent light to detect potentially cancerous areas of the airways. Tumors and other abnormal cells naturally glow when exposed to specific types of fluorescent light. This technique helps the doctor identify suspicious areas in the airways to sample. Autofluorescence bronchoscopy is particularly useful for people whose sputum cytology test showed cancer cells, but imaging studies failed to show a lung tumor. Autofluorescence bronchoscopy is also better than standard bronchoscopy for detecting lesions that may be progressing to lung cancer.

**Mediastinoscopy**

*Mediastinoscopy* is a surgical procedure in which a rigid instrument called an *endoscope* is inserted through a small incision at the base of the neck or near the breastbone into the central area of the chest called the *mediastinum*. The mediastinum contains the heart, the large blood vessels entering and leaving the heart, the *trachea*, the esophagus, and several lymph nodes that drain *lymph* fluid from the lungs. Mediastinoscopy is often used for both diagnosis and staging because sampling the lymph nodes of the mediastinum is an important part of determining lung cancer stage. Mediastinoscopy is usually performed as a diagnostic test in people who have
centrally located lung tumors that can be reached from the mediastinum. Biopsies of the primary tumor and mediastinal lymph nodes are taken during the procedure. Mediastinoscopy is performed under general anesthesia and usually requires an overnight stay in the hospital.

**Transthoracic Needle Biopsy**

*Transthoracic needle biopsies* are usually reserved for people who have tumors near the surface of the lung that would be difficult to reach by bronchoscopy. Transthoracic needle biopsy is sometimes called *fine needle aspiration (FNA) biopsy*. In this procedure, a needle is inserted through the chest wall into the lung tumor. Small tissue samples are collected through the needle. This procedure is performed using either computerized tomography (CT) or fluoroscopy (another x-ray technique) to help the doctor direct the needle into the precise location of the tumor. Local anesthesia is used to numb the skin where the needle is inserted, and a mild sedative is used to relax the patient. The procedure is usually performed on an outpatient basis.

**Thoracoscopy**

*Thoracoscopy* is another surgical procedure in which an endoscope is inserted into the chest space. Thoracoscopy has limited use in lung cancer diagnosis, but is sometimes used to biopsy a suspicious tumor and regional lymph nodes. Thoracoscopy has the advantages of allowing the surface of the lung to be examined and permitting sampling of any pleural effusion that may be present.

Video-assisted thoracoscopy (VATS) is technique in which a tiny video camera is inserted into the chest by a small incision separate from the incision used for the thoracoscope. Pictures of the chest cavity are projected onto a screen during the procedure to give the surgeon a better view of the area. VATS and routine thoracoscopy procedures are performed under general anesthesia and usually require an overnight stay in the hospital.
Thoracotomy
In rare instances, doctors are unable to biopsy a suspicious lung tumor using the already mentioned techniques. In these situations, a *thoracotomy* may be performed. A thoracotomy is major surgery performed under general anesthesia. The chest is opened and the rib cage is separated to expose the lungs. A biopsy of the tumor is performed and the tissue is examined under the microscope while the patient is still in the operating room. If cancer is found, the surgeon will sample regional lymph nodes to determine if a surgical cure is possible. Again, the lymph nodes are examined while the patient is still in the operating room. If surgical cure is possible, a potentially curative operation will be performed. Diagnosis and treatment are performed at the same time in this unusual situation. The hospital stay after a thoracotomy is usually a week or longer.

THE LUNG CANCER STAGING PROCESS

Lung cancer staging is the process of classifying the extent of spread of the cancer from the original tumor to other parts of the body according to standard criteria. Staging is important for two reasons. It helps your doctors determine which treatments are likely to be most effective for you. It also helps determine what the course of your illness (*prognosis*) is likely to be. Lung cancer stage is the primary factor influencing the prognosis of the disease.

Lung cancer stages range from I through IV. Stages are typically expressed using Roman numerals where I = one, II = two, III = three, and IV = four. In general, the lower the stage, the less the cancer has spread. The higher the stage, the more extensive is the spread of the disease. The general trend in terms of prognosis is the lower the stage, the better the prognosis.

Three factors are used to determine lung cancer stage. These factors are expressed using the *TNM classification system*. The three factors of the TNM system are as follows.

- **T**: tumor characteristics including size, location, and local invasion
- **N**: regional lymph node involvement
- **M**: metastasis status
Lung cancer staging can include numerous tests and surgical procedures. Generally, health care providers try to establish the M factor (a person’s metastasis status) as early as possible in the staging process. The reason for this is that any distant metastasis automatically moves a person to stage IV. The presence of distant metastasis is usually established with imaging tests, which are much less invasive than procedures such as bronchoscopy and mediastinoscopy that are used to establish lymph node involvement and tumor characteristics. If distant metastasis is present and a person’s stage has been established as IV, no further staging procedures are needed. Therefore, determining a person’s M-status is undertaken early in the staging process to spare people who are stage IV unnecessary procedures.

**Determining Metastatic Status**

The state of metastasis (M) is defined as follows.

- **M0**: No distant metastasis found.
- **M1**: Distant metastasis is present.

Physical findings and presenting symptoms may raise suspicion of metastatic disease in a specific organ or area of the body. Under such circumstances, scans will be focused on that specific area. However, metastatic disease is often asymptomatic at the time of diagnosis, which necessitates a thorough search for distant, asymptomatic metastatic tumors. Imaging tests commonly used to screen for metastatic disease are listed below.

- CT scans - *abdomen*, *pelvis*, and brain
- MRI scans - brain
- PET scans - whole body
- *ultrasonography* – abdomen and liver
- *bone scans* – whole body

CT, MRI, and PET scans were discussed in the previous section under *Imaging Tests*. Ultrasonography uses special frequency sound waves to visualize internal organs. Bone scans are similar to PET scans. A radioactively labeled substance that is taken up by actively growing and dividing cells is injected into the body. A scan is later taken of the entire body...
to look for ‘hot spots’ in the skeleton. Hot spots are areas in the skeleton with high uptake of the radiolabeled chemical that may indicate metastatic disease.

Determining Regional Lymph Node Status

The regional lymph nodes of the chest are divided into three major areas, the hilar lymph nodes, the mediastinal lymph nodes, and the supraclavicular lymph nodes (see Figure 4). The trachea splits into the right and left main bronchus in the mediastinum. The main bronchus enters the lung at the hilum. The lymph nodes in this area are called the hilar lymph nodes; these lymph nodes are located within the lung. The mediastinal lymph nodes are located in the middle of the chest, in and around the trachea and the esophagus. The mediastinal lymph nodes are located outside of the lungs. The supraclavicular lymph nodes are those just above the collarbones. Cancer in lymph nodes beyond the hilar, mediastinal, and supraclavicular lymph nodes is considered evidence of distant metastasis.

Two additional terms are important to understand the staging of regional lymph node involvement. Ipsilateral refers to lymph nodes on the same side of the chest as the primary tumor. Contralateral refers to lymph nodes on the opposite side of the chest as the primary tumor.

Regional lymph node status is divided into the following categories.

- **N0**: No evidence of cancer in the regional lymph nodes
- **N1**: Cancer in the ipsilateral hilar lymph nodes
- **N2**: Cancer in the ipsilateral mediastinal lymph nodes
- **N3**: Cancer in the contralateral lymph nodes or in the supraclavicular area
Regional lymph nodes can be sampled and staged with the following procedures.

- bronchoscopy
- mediastinoscopy
- thoracoscopy and VATS
- thoracotomy

As imaging technologies advance, researchers continue to study the correlation between regional lymph node staging as determined by imaging studies compared to tissue sampling. Although tissue sampling remains the standard for staging, especially among people who are potential candidates for surgery, imaging techniques may have a more significant role in lung cancer staging in the future.\textsuperscript{14,15} One particularly promising technology is the combined use of CT and PET scanning known as in-line CT-PET scanning. Preliminary results indicate that combining the strengths of these two imaging techniques yields better results than either technique used alone.\textsuperscript{16-18}

**Determining Tumor Characteristics**

The categories for lung cancer tumor classification take into account the size, location, and local invasiveness of the primary tumor. Tumor characteristics are determined using the same methods used for diagnosis and evaluation of the regional lymph nodes. The specific tests used vary from one person to another depending on his or her unique history, symptoms, and physical findings. The tumor categories and their descriptors are:

- **T0**: No evidence of primary tumor
- **Tis**: Carcinoma in situ
- **T1**: Tumor that is less than 3 cm (1½ inches) in size and is completely surrounded by lung tissue
- **T2**: Tumor that is larger than 3 cm (1½ inches) but is still surrounded by lung tissue and is not invading the chest wall or any of the structures in the mediastinum
- **T3**: Tumor of any size that invades the chest wall, diaphragm, or the pleura of the mediastinum or heart; a T3 cancer is potentially respectable (surgically removable)
- **T4**: A tumor of any size that invades the structures of the mediastinum or a vertebral body (a backbone)
The area where the trachea divides into the right and left main bronchus is called the carina. If a tumor is close to the carina, it may not be operable if the remaining airways cannot be sewn together. Therefore, tumors involving the carina are T4 tumors. Tumors associated with a malignant pleural (around the lung) or a pericardial (around the heart) effusion are also T4 tumors, as are separate tumor nodules in the same lung lobe. T4 tumors are generally inoperable.

NON-SMALL CELL LUNG CANCER STAGES

Using the TNM classification system, non-small cell lung cancer is divided into four stages. Your doctor must know the stage of your disease in order to recommend treatment options. A general summary of the stages is reviewed in this section.

Stage I
Stage I NSCLC is characterized by a cancerous tumor that has not spread. There is no evidence of cancer in any lymph nodes. The difference between stage IA and stage IB disease is the size of the primary tumor. With stage IA disease, the tumor is 3 cm (1½ inches) or less in size. With stage IB disease, the tumor is larger than 3 cm (1½ inches) in size. Stage I NSCLC is local disease and is potentially curable with surgery.

The stage I TNM designations are:
Stage IA: T1N0M0
Stage IB: T2N0M0

Stage II
Stage II NSCLC is characterized by a primary tumor that has spread to the hilar lymph nodes (the N1 area) on the same side as the tumor. With stage IIA, the tumor is a T1 (3 cm or less). With stage IIB, the tumor is a T2 (greater than 3 cm).
A tumor involving the chest wall without hilar lymph node involvement (T3, N0) is also considered stage IIB disease. Stage II NSCLC is potentially curable with surgery, although the chance of recurrence is higher than for people with Stage I disease.

The stage II TNM designations are:

- Stage IIA: T1N1M0
- Stage IIB: T2N1M0 or T3N0M0

**Stage III**

Stage III is the most complex of the stages, and there are significant differences in the treatment of stage IIIA versus stage IIIB disease. Stage IIIA disease includes a tumor that has invaded the chest wall, diaphragm, or the pleura of the mediastinum or heart, and has ipsilateral hilar or mediastinal lymph node involvement (T3N1M0 or T3N2M0). Smaller tumors that involve the ipsilateral mediastinal lymph nodes are also stage IIIA (T1N2M0 or T2N2M0). Stage IIIA is potentially operable. Preoperative treatment is used for some people and is currently under evaluation in many clinical trials.

Stage IIIB disease includes any size tumor that has invaded any of the vital structures of the mediastinum, the carina, or a vertebral body (T4 tumors), with or without regional lymph node involvement (T4N0M0, T4N1M0, T4N3M0). Lesser tumors (T1-3) that are associated with contralateral lymph node involvement or any supraclavicular lymph node involvement are also stage IIIB. People with stage IIIB disease are generally not considered candidates for surgical cure because it is often physically impossible to remove all the cancerous tissue with this degree of spread.

The stage III TNM designations are:

- Stage IIIA: T3N1M0, T3N2M0
  - T1N2M0 or T2N2M0
- Stage IIIB: T4N0M0, T4N1M0, T4N2M0
  - T1N3M0, T2N3M0, T3N3M0, T4N3M0
**Stage IV**

Stage IV NSCLC is assigned whenever there is distant metastasis, that is, spread of the disease beyond the regional lymph nodes. The TNM designation for stage IV NSCLC is any T, any N, and M1.

**Special Cases**

Stage 0 (zero) represents carcinoma *in situ*. This unique situation refers to the presence of an identifiable area of cancer cells that are confined to a local area and have not grown through the top lining of the lung. Carcinoma *in situ* is curable and incapable of spreading. The TNM designation for carcinoma in situ is Tis. Since there is currently no organized screening program for lung cancer, the percentage of people newly diagnosed with lung cancer who have stage 0 disease is very low.

Occult lung cancer is another uncommon situation in which tumor cells are found in the sputum or *bronchial washings* (rinse solution obtained during bronchoscopy), but no primary tumor can be seen on imaging studies or on direct examination with a bronchoscope. The TNM designation for occult lung cancer is Tx.

Table 1 gives the lung cancer TNM descriptors according to the International System for Staging Lung Cancer.

<table>
<thead>
<tr>
<th>PRIMARY TUMOR (T)</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tx</td>
<td>Primary tumor cannot be assessed OR Tumor proven by the presence of malignant cell in sputum or bronchial washings but not visualized by imaging or bronchoscopy</td>
</tr>
<tr>
<td>T0</td>
<td>No evidence of primary tumor</td>
</tr>
<tr>
<td>Tis</td>
<td>Carcinoma <em>in situ</em></td>
</tr>
<tr>
<td>T1</td>
<td>Tumor less than or equal to 3 cm in its greatest dimension, surrounded by lung or visceral pleura without bronchoscopic evidence of invasion more proximal than the lobar bronchus (that is, not in the main bronchus) The uncommon superficial tumor of any size with its invasive component limited to the bronchial wall, which may extend proximal to the main bronchus, is also classified as T1</td>
</tr>
<tr>
<td>T2</td>
<td>Tumor with any of the following features of size or extent: • greater than 3 cm in its greatest dimension • may extend into the main bronchus if it remains more than 2 cm from the carina • may invade the visceral pleura • may be associated with atelectasis or obstructive pneumonitis that extends to the hilar region but does not involve the entire lung</td>
</tr>
</tbody>
</table>
### TNM Descriptors, Continued

| T3       | Tumor of any size that directly invades any of the following:  
|          | • chest wall (including superior sulcus tumors)  
|          | • diaphragm  
|          | • mediastinal pleura  
|          | • parietal pericardium  
|          | **OR**  
|          | Tumor in the main bronchus less than 2 cm from the carina but without involving the carina  
|          | • may be associated with atelectasis or obstructive pneumonitis of the entire lung  

| T4       | Tumor of any size that invades any of the following:  
|          | • mediastinum  
|          | • heart or great vessels  
|          | • trachea  
|          | • esophagus  
|          | • vertebral body  
|          | • carina  
|          | **OR**  
|          | Tumor with a malignant pleural or pericardial effusion  
|          | **OR**  
|          | Tumor with a satellite tumor nodule(s) within the same lobe as the primary tumor  

### REGIONAL LYMPH NODES (N)

| Nx       | Regional lymph nodes cannot be assessed  

| N0       | No regional lymph node metastasis  

| N1       | Metastasis to the ipsilateral peribronchial and/or ipsilateral hilar lymph nodes  
|          | **OR**  
|          | Direct extension of the primary tumor into intrapulmonary nodes  

| N2       | Metastasis to the ipsilateral mediastinal and/or subcarinal nodes  

| N3       | Metastasis to any of the following nodes:  
|          | • contralateral mediastinal  
|          | • contralateral hilar  
|          | • ipsilateral or contralateral scalene  
|          | • supraclavicular  


### SMALL CELL LUNG CANCER STAGES

The TNM classification and staging system is applicable to both SCLC and NSCLC. While the TNM system is used for SCLC in some research settings, most health care providers more commonly categorize SCLC as either limited or extensive stage disease. This classification system was created by the Veterans Administration Lung Cancer Study Group after it became clear that relatively small differences in the extent of tumor and/or lymph node involvement had little impact on response to therapy or prognosis among people with...
SCLC. Most doctors believe the reason for this finding is that most SCLCs undergo early and widespread metastasis.

People with SCLC are staged with limited or extensive disease based on the extent of the disease in the chest. People whose disease is confined to one lung, the mediastinum, and regional lymph nodes are categorized with limited stage SCLC. Limited stage disease can be enclosed in a single radiation therapy field. Approximately 30% of people with SCLC have limited stage disease at diagnosis. Limited stage corresponds to stages I through IIIB of the TNM staging system.

Extensive stage SCLC has spread to the contralateral lung, is associated with a malignant pleural effusion, or is accompanied by distant metastasis. Approximately 70% of people with SCLC have extensive stage disease at the time of diagnosis. Extensive stage corresponds to stage IIIB with pleural effusion and stage IV of the TNM staging system.

SUMMARY

Medicine is both an art and a science. The science of lung cancer diagnosis and staging involves many different procedures and technologies. The art of lung cancer diagnosis and staging involves matching the unique history, physical findings, and symptoms of each person suspected of having lung cancer with the appropriate tests.

The processes of diagnosis and staging often overlap. The ultimate goal of both processes is to determine the type and extent of the lung cancer. Accurate diagnosis and staging are important so your health care providers can direct you toward the most effective treatments for your unique circumstances.
CHAPTER 5: LUNG CANCER TREATMENT OVERVIEW

INTRODUCTION

Lung cancer is currently treated with three forms of therapy: chemotherapy, radiation therapy, and surgery. They are used alone or in combination depending on the type of lung cancer and the stage of the disease. This chapter discusses basic concepts about each of these forms of therapy and their uses in the treatment of lung cancer. Chapters 6 and 7 review specific treatments for small cell and non-small cell lung cancer.

Health care providers use specific language when discussing cancer treatment options. The beginning of this chapter explains many of the terms used. Familiarity with these medical terms will help you better understand your treatment options and make discussions with your health care providers easier. Many of the definitions presented in this section are derived from the National Cancer Institute’s online dictionary at www.nci.nih.gov/dictionary. This is a good resource for understandable definitions of medical terms. If one of your providers uses a term you are not familiar with, ask him or her to explain it. Remember, there is no such thing as a silly question, especially when you are discussing something as important as your health.

TALKING ABOUT TREATMENT OPTIONS: LEARNING THE LANGUAGE

Response to Therapy

Doctors define your response to therapy in different ways. A complete response is the disappearance of all signs of cancer. This does not always mean the cancer has been cured because there can be residual cancer that is undetectable. For this reason, your doctors may use the phrase ‘apparently cancer-free’ if you have a complete response to treatment. A complete response is also called a complete remission.
A partial response or partial remission is a decrease in the size of a tumor or the extent of cancer in the body, or halting disease progression. In clinical trials, researchers usually specify what qualifies as a partial response by setting a threshold percentage of tumor shrinkage that must occur. When your doctor says you are responding to therapy, it is important to understand that a response to therapy is not necessarily the same thing as a cure. Your cancer may respond to treatment but not be eliminated from your body. Only when cancer is completely eliminated from the body is it considered cured.

Progressive disease means the cancer is growing and/or spreading. If you are on treatment and have disease progression, that particular treatment should be stopped because it is not working for you.

Treatment Descriptors

First line treatment is the first therapy used to treat your cancer.

People who have not had any previous treatment for their cancer are treatment naïve.

People who have not had previous chemotherapy for their cancer are chemonaïve.

Curative intent refers to cancer therapy used to try to cure the disease.

Multimodality therapy or combined modality therapy includes two or more forms of cancer treatment used together or in succession.

Adjuvant therapy is treatment given after the primary treatment to increase the chance of a cure. Lung cancer adjuvant therapy may include chemotherapy, radiation therapy, or both.

Neoadjuvant therapy is treatment given before the primary treatment to increase the chance of a cure. Examples of neoadjuvant therapy used to treat lung cancer include chemotherapy, radiation therapy, or both. Another term for neoadjuvant therapy is induction therapy.

Second line treatment is any form of therapy used after first line cancer therapy. Second line treatment may be used if the cancer did not respond to first line therapy or if there is disease
progression after first line therapy has been completed. *Salvage therapy* is another term for second line treatment.

*Palliative therapy* is treatment given to relieve symptoms caused by advanced cancer. Palliative therapy is not curative and does not alter the course of the disease, but can significantly improve *quality of life*. The effectiveness of palliative therapy is usually described in terms of percent response and *time to progression*. Time to progression is the length of time the treatment is able to keep the cancer from growing and/or spreading.

**Treatment Effectiveness: Making Sense of the Numbers**

Treatment effectiveness is expressed using data from clinical trials. For information about clinical trials, see *Chapter 8*. Treatment effectiveness is described in many different ways. Before discussing some common terms used to describe treatment effectiveness, a word of caution about numbers. Clinical trials are conducted to evaluate the safety and effectiveness of new treatments. The numbers generated in clinical trials are very important because they allow researchers to compare one treatment to another. However, when it comes to an individual person trying to make treatment decisions, effectiveness numbers should not be over interpreted. Effectiveness numbers can help you compare the probability that one treatment versus another will lead to the response you seek. They should not be taken to indicate your *personal* chance of responding to a given therapy. For example, you may hear treatment with a certain chemotherapy drug is associated with a 40% response rate. This means 40% of all people treated with the drug in a clinical trial setting responded to it. It does *not* mean you personally have a 40% chance of responding to the drug.

Currently, no one can tell you your personal chance of responding to a given therapy because each person’s situation is unique. Researchers are working hard to find reliable tests to predict how an individual person’s cancer will respond to a specific treatment. However, such tests are not yet available. Many factors contribute to whether an individual person responds to a specific treatment. The genetic makeup of the cancer, the immune system of the patient, the presence of other illnesses, age, and gender are examples of the many factors that may contribute to whether a specific cancer responds to a given therapy.
People are not statistics. In the end, what matters is your response to a specific treatment not the response rates seen in clinical trials. Use response rates to help you make treatment decisions, but do not allow them to influence your overall state of mind or to destroy your sense of optimism. Your experience with lung cancer will be unique and may vary greatly from the statistics you read and hear.

It was very discouraging when I saw the raw numbers. I thought this is almost a death sentence. I was at the library, and went to the gentleman at the reference desk and said, “I think this book may be out dated.” The gentleman said, “Look, you really only have two statistics to chose from – 0% or 100%”. You have to handle statistics like water off a duck's back … I chose to take control and think positively about my recovery.

− Larry, diagnosed with Stage IIIA NSCLC at age 61

Cancer survival statistics are given in specific timeframes. One-, two-, and five-year survival statistics are commonly discussed. One-year survival is the percentage of people on a specific treatment who are alive one year after beginning treatment. Two-year survival is the percentage of people alive two years after beginning a specific treatment. Five-year survival is the standard marker for cure. People alive and cancer-free five years after beginning treatment are generally considered cured of their disease. When you read or hear about cancer survival statistics, these refer to five-year survival unless another time interval is specifically stated. Five-year survival is sometimes called long-term survival.

It is important not to overestimate the applicability of treatment trial numbers to your personal situation. While these numbers are very important, they cannot predict your personal response to any given treatment. No one can predict this. Similarly, no one can predict the outcome of your disease. Survival statistics for lung cancer can be discouraging. Keep in mind, there are survivors. You may well be one of them!

**Statistical Terms**

You may come across some unfamiliar statistical terms in your search for information about lung cancer. You will certainly come across some of these terms if you look at medical journals. The term *mean* is another word for the average value in a set of measurements. It is calculated by adding all the measurements together and dividing by the number of
measurements taken. For example, consider the following results from a study measuring time to disease progression for people receiving a new treatment for lung cancer.

<table>
<thead>
<tr>
<th>Person</th>
<th>Time</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>10 months</td>
</tr>
<tr>
<td>2</td>
<td>6 months</td>
</tr>
<tr>
<td>3</td>
<td>10 months</td>
</tr>
<tr>
<td>4</td>
<td>7 months</td>
</tr>
<tr>
<td>5</td>
<td>2 months</td>
</tr>
<tr>
<td>6</td>
<td>10 months</td>
</tr>
<tr>
<td>7</td>
<td>10 months</td>
</tr>
<tr>
<td>8</td>
<td>1 month</td>
</tr>
</tbody>
</table>

Mean time to disease progression = \( \frac{10+6+10+7+2+10+10+1}{8} = \frac{56}{8} = 7 \text{ months} \)

Median is the middle value in a set of measurements. Using the same information from the previous example, the middle number is half-way between 7 and 10. In this example, the median time to disease progression is 8 ½ months, the midway point between 7 and 10.

Both measures of effectiveness are based on the same set of results. However, this example clearly demonstrates how the statistical term chosen to describe the effectiveness of a treatment affects the value of the number reported.

Studies of treatment effectiveness usually report a \( p \)-value along with significant findings. A \( p \)-value is a numeric representation of how certain researchers are that their findings are true. The lower the \( p \)-value, the more likely it is the finding is true and not due to coincidence. The \( p \)-value is usually represented in parentheses after an important finding, for example \( (p=0.01) \) or \( (p<0.001) \).

You may encounter the term \textit{confidence interval} or CI. A confidence interval is a range of values that is reasonably certain to contain the true value. For example, researchers may report a median time to disease progression of 8 months with a 95% CI of 6.5-9.0. This
means researchers are 95% certain the true median time to disease progression is between 6.5 and 9 months.

**CHEMOTHERAPY**

**What Is Chemotherapy?**

Chemotherapy is broadly defined as the use of medicines to treat disease. In the field of cancer, chemotherapy is the use of drugs (medicines) to kill cancer cells. Cancer chemotherapy drugs are also called *cytotoxic drugs*.

Cancer cells divide rapidly. They divide at a higher rate than most normal cells of the body. Chemotherapy drugs use this characteristic of cancer cells to preferentially cause their death while leaving most normal cells unharmed. Some cytotoxic drugs interfere with the cell division cycle. This prevents cancer cells from reproducing. Other chemotherapy drugs cause genetic damage the cancer cell is unable to repair ultimately leading to cell death. Although chemotherapy drugs work in different ways, they all target mechanisms active in cells that are rapidly growing and dividing. Chemotherapy drugs with different mechanisms of action are frequently used together to increase the overall response to treatment.

![Figure 1: Intravenous Infusion Setup*](image)

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**Why Is Chemotherapy Used?**

Cancer chemotherapy is *systemic therapy*, meaning the entire body is exposed to the treatment. Chemotherapy is used when there is clear evidence the cancer has spread beyond the original tumor or if there is reason to suspect there may be undetectable cancer cells (*micrometastasis*) in the body. Chemotherapy may be used in lung cancer treatment for one or more reasons:

- to achieve a complete response and potential cure
- to slow cancer growth and prolong life
- to prevent cancer spread
- to shrink tumors and relieve disease related symptoms
Even when chemotherapy does not lead to cure, studies have consistently shown it can help people with lung cancer live longer, more comfortable lives.

**How Are Chemotherapy Drugs Given?**

Many chemotherapy drugs must be given directly into the blood stream by an intravenous (IV) line (see Figure 1). This *route of administration* (how a drug is given) is necessary for chemotherapy drugs that would be broken down and inactivated by the digestive processes of the stomach and intestines. However, some chemotherapy drugs can be taken by mouth without any loss of anti-cancer activity.

Chemotherapy drugs are administered on different schedules. Some drugs are given over a few hours; others are given in continuous drip over a few days. Whatever the specific administration schedule, most chemotherapy drugs are given in cycles. Drugs given in cycles are administered periodically with breaks between doses. Each complete administration of the chemotherapy drugs you are taking (including breaks) is called a *treatment cycle*. Chemotherapy drugs are given in cycles because it takes time for the drugs to have the desired effect on the cancer cells. Cyclic treatment also allows normal cells time to recover between chemotherapy treatments. Chemotherapy treatments may be weekly, biweekly, monthly, or on another schedule. The time between treatment cycles depends on the drug(s) used. The number of cycles used in a treatment protocol also depends on the drug(s) used.

**Chemotherapy Side Effects**

Chemotherapy can cause a wide range of side effects. Many of the side effects are related to the fact that these drugs do not selectively kill cancer cells but interfere with the processes of any rapidly dividing cell. Therefore, tissues in the body that normally grow and divide rapidly can be damaged as a side effect of chemotherapy. For example, bone marrow cells that produce *red blood cells*, white blood cells, and platelets can be damaged by chemotherapy drugs causing the levels of these blood elements to drop. This condition is called *myelosuppression*. The cells lining the inside of the mouth and throat also divide rapidly and are susceptible to chemotherapy drugs. As a result, many people on chemotherapy experience mouth sores, dryness, and taste changes. Hair follicles can also be damaged by
chemotherapy drugs leading to partial or complete hair loss (alopecia). These are just a few examples of possible chemotherapy side effects.

*Dose-limiting side effects* of chemotherapy are severe physical side effects that can be potentially life threatening. Myelosuppression is a common example of a dose-limiting side effect. These side effects may make it necessary to lower the dose of the offending drug and/or prolong the time between treatments. In extreme cases, treatment with the offending drug may need to be discontinued.

Each chemotherapy drug has the potential to cause different side effects. The list of possible side effects associated with a particular chemotherapy drug is called its *side effect profile*. The number and severity of side effects experienced from any given drug varies greatly from person to person. The drug, its dosage, and your body’s reaction to the drug influence the occurrence of chemotherapy side effects and their severity.

Possible side effects associated with various chemotherapeutic drugs used to treat lung cancer include:

* • constipation
* • diarrhea
* • *fatigue*
* • hair loss (alopecia)
* • loss of appetite (*anorexia*)
* • mental fatigue, slow thinking, faulty memory
* • mouth sores, dry mouth, taste changes
* • myelosuppression including *anemia* (low red blood cell count), *neutropenia* (low white blood cell count), and *thrombocytopenia* (low platelet count)
* • nausea and vomiting
* • numbness, tingling, pain in the hands and feet (*peripheral neuropathy*)

The appendix *Chemotherapy Side Effect Profiles* contains information about the potential side effects of specific chemotherapy drugs commonly used to treat lung cancer. Chapter 10:
Supportive Care contains detailed information about the prevention and treatment of chemotherapy side effects.

RADIATION THERAPY

What Is Radiation Therapy?
Many people with lung cancer are treated with radiation therapy or radiotherapy.
Radiotherapy uses high-energy radiation called ionizing radiation to stop cancer cell division. This prevents the formation of new cancer cells. Ionizing radiation reacts with the water inside cells causing damage to the genetic material. Normal cells can usually repair this type of damage, but most cancer cells cannot. The damaged cancer cells eventually die as a result. The dose or amount of energy deposited in a treatment area is expressed in rads or gray (Gy).

\[
1 \text{ Gy} = 100 \text{ rad} \\
1 \text{ rad} = 0.01 \text{ Gy}
\]

The dose of radiation given for cancer therapy is several thousand times greater than the amount of radiation you are exposed to during an imaging x-ray. A machine called a linear accelerator is usually used to deliver radiotherapy.

Why Is Radiation Therapy Used?
Radiotherapy is a local form of cancer therapy. This means it affects only cells in the treatment area as opposed to a systemic therapy (like chemotherapy) that affects cells throughout the body.

Radiotherapy is frequently used in lung cancer as adjuvant therapy, which means it is used in combination with surgery and/or chemotherapy. The goal of radiotherapy used in this way is to cure the cancer. Adjuvant radiotherapy can be used to:

- shrink a tumor before surgery
- increase the response of cancer cells to treatment by administering it along with or following chemotherapy
- destroy any remaining cancer cells that may be left behind after cancer surgery
Radiotherapy is also used as palliative therapy to relieve disease-related symptoms and prolong life when cure is not possible. Palliative radiotherapy is often lower dose and given over a shorter period of time than adjuvant radiotherapy. Radiation therapy is also used to treat or prevent brain metastasis.

**How Are Radiation Treatments Given?**

Radiation treatments can be given externally or internally. *External beam radiation* is radiotherapy delivered from outside the body. *Brachytherapy* is radiation delivered from within the body. Currently, standard radiation treatments for lung cancer are delivered externally. Brachytherapy is an area of active lung cancer research.

*Radiation oncologists* are doctors who specialize in the use of radiotherapy to treat cancer. Planning is an important aspect of radiotherapy. A radiation oncologist decides the total dose of radiation you will receive and the treatment schedule. The total radiation dose is divided into smaller doses or *fractions* that are administered over a period of weeks. Fractionating the total radiation dose limits damage to healthy tissues without compromising treatment effectiveness. The total radiation dose and treatment schedule depend on:

- the size and location of the tumor(s)
- other treatments you are receiving
- the presence of distant metastasis
- your overall health

Fractionated radiation treatments are usually given five days per week with weekends off. The time off gives normal cells time to recover from radiation damage. Treatments continue for 2-7 weeks depending on the intent of the therapy. It is very important not to miss any scheduled treatments. Missed treatments decrease the total radiation dose delivered and can reduce overall treatment effectiveness.

Before your external radiation treatments begin, you will go through a process called *simulation*. Simulation allows doctors to precisely map the radiotherapy target area and limit
the exposure of healthy tissue to the radiation. The radiation target area is called the treatment field or port.

**Radiotherapy for Brain Metastasis**

Metastatic brain tumors are often treated with *whole brain radiation therapy* (WBRT). This external beam radiotherapy is used for people who have one or more metastatic brain tumors. WBRT is usually effective at relieving symptoms associated with these tumors.

*Stereotactic radiosurgery* (SRS) is another form of radiation treatment for metastatic brain tumors. SRS is generally used on people who have one small brain tumor (less than 3 cm or 1¼ inches). It can also be used on multiple tumors if they are small. SRS treatment requires immobilization of the head to prevent any movement during treatment. In some cases, this involves placing a metal halo called a skeletal fixation device on the head. The halo is fixed to the bones of the head. It is removed after treatment is completed. Some newer SRS systems use tiny metal markers placed in the bones of the head instead of a halo. The halo or markers allow doctors to precisely map the area of the brain to be treated.

SRS treatment directs high-energy radiation toward the tumor in a very accurate way that limits radiation damage to healthy brain tissue. Unlike WBRT that takes place over several weeks, SRS is performed in a single treatment. There are three forms of SRS: cobalt 60 or photon systems, linear accelerator systems, and particle beam or proton systems. Photon systems are widely available in specialized radiologic treatment centers. The most common SRS photon system is known by the brand name Gamma Knife®. Linear accelerator systems are also widely available and are often referred to by the abbreviation ‘linac.’ Brand names of linac systems include X-Knife®, CyberKnife®, and Clinac®. Proton systems are in limited use in the United States. The type of SRS equipment used does not appear to be related to treatment outcome.

**Side Effects of Radiation Therapy**

Side effects of radiation therapy are largely due to radiation damage of healthy tissues. Small fractional doses are usually associated with fewer and less severe late-occurring side effects
than larger doses are. Most side effects from radiotherapy are local, that is, they occur only in the treatment field. Common side effects of radiotherapy include:

- cough
- shortness of breath
- chest discomfort
- fatigue – usually begins the second or third week of treatment and often increases over time during treatment
- hair loss in the treatment field
- loss of appetite
- mouth problems – mouth sores, dry mouth, cavities in the teeth
- skin problems in the treatment field – redness, irritation, dryness, itching, skin darkening
- sore throat, hoarseness and/or difficulty swallowing (esophagitis)
- impaired mental functions (with whole brain radiation)

Skin is a rapidly dividing tissue, which makes it susceptible to radiotherapy. Skin in the treatment field often gradually becomes red or darkened, much like a sunburn or tan. The area may be sore, dry, and/or itchy. Washing with warm water, mild soap, and avoiding tight or itchy clothes will help keep the irritation under control. Talk with your radiation oncologist before using any lotions or creams as some can interfere with the delivery of radiation to the target area. Protect the treatment field with a hat or other clothing if you are going to be in the sun.

Radiation to the lungs is associated with short-term side effects and late complications that can develop after treatment is completed. Esophagitis is inflammation of the esophagus (the tube that takes food from the mouth to the stomach). Radiotherapy directed toward the center of the chest can damage the cells lining the esophagus. This causes sore throat, pain, and difficulty swallowing. A diet of liquids and soft foods can make eating easier during treatment. Pain medication may be needed. The lining of the esophagus usually heals within one month after treatment has been completed.
Radiation pneumonitis occurs in 2-9% of people who receive radiation therapy for lung cancer. It is the result of damage to the lining of the airways and air sacs. Women are slightly more prone to develop this complication than men are. Smoking increases the risk for both men and women. Radiation pneumonitis can occur anytime in the six months after completion of therapy but most commonly occurs 4-6 weeks after treatment completion. The symptoms of radiation pneumonitis are cough, low fever, shortness of breath, and/or pain with breathing. Contact your radiation oncologist immediately if you develop any of these symptoms. The steroid prednisone (Cortan®, Deltasone®) is commonly used to treat radiation pneumonitis. Azathioprine (Imuran®) and cyclosporine (Neoral®, Sandimmune®) are also used to treat this condition.

Radiation fibrosis may develop after radiation pneumonitis as the body tries to repair previously healthy lung tissue. Radiation fibrosis is lung tissue scarring that is the result of ongoing inflammation. Fibrosis develops gradually, usually over a period of 1-2 years after radiotherapy. Physical therapy and pulmonary rehabilitation can help prevent or alleviate the symptoms of radiation fibrosis.

Amifostine (Ethyol®) is being actively studied as a potential radioprotectant, a drug that protects healthy tissues from the damaging effects of radiotherapy without interfering with treatment effectiveness. Studies to date are encouraging especially with respect to esophagitis and radiation pneumonitis. However, results are still preliminary and additional research is needed to define the potential role of amifostine.

Whole brain radiation therapy can cause impairments in thinking processes in long-term cancer survivors. The severity of these impairments vary and can include such things as slowed thinking, impaired short-term memory, difficulty retrieving words, decreased ability to perform math functions, and others.

Chapter 10: Supportive Care has additional information about other possible radio-therapy side effects and their management.
SURGERY FOR LUNG CANCER

When Is Surgery Used?
Surgery is a local treatment for lung cancer. It is used to attempt a cure or to alleviate symptoms. Lung cancer that has not spread can potentially be cured with surgery, which is often combined with chemotherapy and/or radiotherapy. An overview of chest surgeries used to treat lung cancer is presented in this section. Specific situations in which surgery is used are discussed in Chapters 6 and 7.

Studies have shown that greater experience with lung cancer treatment is associated with more successful surgical outcomes. Surgical candidates are encouraged to find a thoracic surgeon who is experienced in lung cancer surgery. It is best to have your surgery at a hospital that also has experience caring for lung cancer surgery patients.

Surgical Chest Procedures
Lobectomy is the removal (resection) of the lobe of the lung affected by cancer. This is the most common surgery performed for lung cancer. Pneumonectomy is the surgical removal of the entire lung affected by cancer. This procedure is usually performed only if the cancer cannot be completely removed with a lobectomy. These two procedures are generally preferred over less extensive surgeries, if they can be tolerated by the patient. Preexisting lung problems such as chronic obstructive pulmonary disease (COPD) or chronic bronchitis may prevent use of these extensive lung surgeries.

*Figure 2: Surgical Procedures Used to Treat Lung Cancer*

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A wedge resection is the removal of a wedge-shaped section of tissue surrounding the cancerous tumor. A wedge resection is performed on growths near the surface of the lung when a more extensive procedure cannot be tolerated. A segmentectomy or bronchopulmonary segment resection is another lung sparing operation that involves removal of only the section or segment of the lung lobe that contains the tumor. A sleeve resection is a procedure used to remove tumors in the main airways (the right and left main bronchus). The area with the tumor is removed and the ends on either side are sewn together to re-establish airflow.

All lung cancer operations include examination and removal of lymph nodes in the mediastinum. Removal of multiple lymph nodes in the area is called mediastinal lymph node sampling. Removal of nearly all the lymph nodes is called a mediastinal lymph node dissection.7,8 Neither of these procedures insures the removal of all cancer cells that may be present.

Surgical resection of lung cancer is usually performed using an open chest procedure called a thoracotomy. The chest cavity is opened, the ribs are separated, and the lungs are exposed. A thoracotomy is major surgery and usually requires a hospital stay of at least one week. Video-assisted thoracoscopy (VATS) is a less invasive procedure that can be used for some lung cancer resections. The procedure is performed through a rigid tube called a thoracoscope, which is inserted into the chest through one or more small incisions. A tiny video camera is also inserted into the chest through another small incision. Pictures of the chest cavity are projected onto a screen in the operating room to give the surgeon a better view of the area. VATS is performed under general anesthesia, but the chest cavity is not opened and the ribs are not separated. Early studies indicate VATS may cause less postoperative pain than thoracotomy.9-12 Additional studies are needed to determine if VATS and thoracotomy are equally effective with respect to long-term outcomes.

A thoracic surgeon is a doctor who specializes in surgery of the chest. Lung surgery is complex. You are encouraged to seek a well-qualified thoracic surgeon if you are going to have surgical treatment for your lung cancer.
Surgical Side Effects and Possible Complications

All surgical procedures cause postoperative pain. The severity of the pain depends on the extent of the procedure, the surgical technique used to perform the operation, and your personal sensitivity to pain. Immediately after surgery, strong pain medicines are often needed. Morphine (MSIR, MS-Contin®, Roxanol®, Oramorph-SR®), oxycodone (Oxycontin®, Roxicodone®), hydromorphone (Dilaudid®, Hydromorphone®), and fentanyl (Duragesic®, Fentanyl Oralet®, Sublimaze®, Innovar®) are examples of medicines that may be used. As the pain becomes less intense, less potent pain relievers are used such as codeine, hydrocodone (Vicodin®, Lortab®), dihydrocodeine (DHC), oxycodone (Percodan®, Percocet®, Tylox®, Roxiprin®), meperidine (Demerol®), and propoxyphene (Darvon®, Darvocet®). Eventually, you will be switched to a mild pain reliever such as acetaminophen (Tylenol®), ibuprofen (Advil®, Motrin®, Nuprin®), or naproxen (Naprosyn®) until your pain is gone. Chapter 10: Supportive Care has additional information on pain management.

Possible complications of chest surgery include:

- bleeding
- infection
- air leakage from the lung
- fluid accumulation in the lung (pulmonary edema)
- poor inflation of an area of the lung (atelectasis)

Your surgeon will manage these complications with appropriate therapy if they arise.

FUTURE DIRECTIONS IN LUNG CANCER THERAPY

Many dedicated researchers are exploring new ways to treat lung cancer. This section presents a brief overview of some promising new fields of discovery. All the treatments discussed in this section are currently experimental. Whether these techniques come into routine use depends on if they are found to be safe and effective in ongoing clinical trials. You may have access to some of these treatments in a clinical trial setting.
Talk with your cancer care provider if you are interested in participating in a clinical trial. See *Chapter 8* for information about participating in a clinical trial.

**Radiation Therapy Research**

Researchers are working on several new techniques to enhance the effectiveness of radiation therapy. Areas of active research are reviewed in the following pages.

**Radiosensitizers**

*Radiosensitizers* are substances that make cancer cells more susceptible to the effects of radiation. Some radiosensitizers being studied increase the oxygen level in cancer cells. A low level of oxygen in cancer tumors reduces the effectiveness of radiation therapy. Other radiosensitizers promote cell death by disabling DNA repair mechanisms. Additional mechanisms for enhancing the radiosensitivity of cancer cells are also being investigated.

**Radioprotectants**

The total dose of radiation used to treat cancer is often limited by damage to healthy tissues in the radiation treatment field. Radioprotectants are substances that protect healthy tissues from radiation damage without reducing its effectiveness on cancer cells. An effective radioprotectant would potentially permit an increase in the total radiation dose, which could enhance cancer control and/or elimination.

**Treatment Schedule Variations**

Radiation oncologists have known for quite some time that small doses of radiation given over a protracted time interval are more effective than larger doses given over a shorter period. Splitting a total radiation dose into smaller doses is called *fractionation*. Researchers are currently exploring the use of various *hyperfractionation* schedules in which people receive two or three separate radiation doses per day. If the individual doses are adjusted so that the total radiation dose is delivered in a shorter timeframe than would normally be
required, the treatment is referred to as *accelerated hyperfractionation*. Various hyperfractionated and accelerated hyperfractionated treatment schedules are currently under investigation for the treatment of lung cancer.

**Brachytherapy**

*Brachytherapy* is radiotherapy delivered from within the body. Brachytherapy is a well-established treatment for prostate cancer in men and cervical cancer in women. It can also be used to shrink lung tumors causing airway blockage. The process involves placing a small tube in the airway near the tumor and then inserting tiny radioactive pellets into the tube. The pellets are left in place for several hours before being removed. One or two treatments are usually sufficient to relieve the blockage. Researchers are studying the possibility of using brachytherapy along with external beam radiotherapy to enhance response to treatment. Investigators are also studying the effectiveness of *intraoperative brachytherapy*, which involves placing small radioactive pellets at specific sites in the chest during lung cancer surgery.

**Chemotherapy Research**

Several new chemotherapy drugs have been developed in recent years. These agents are being studied in clinical trials to determine the safest and most effective dosage, timing, and drug combinations.

**Predicting Response to Therapy**

Scientists can currently use a tissue sample from your cancer and test to determine if it is likely to respond to specific chemotherapy drugs. At present, this testing is experimental because the overall accuracy of testing and its effect on treatment outcomes have not been clearly established. However, easily accessible and reliable testing to predict the response of a specific cancer to specific drugs is being actively researched.

**Inhaled Chemotherapy**

Lung cancer arises from cells lining the airways of the lungs. This allows the opportunity for a unique form of delivering anticancer therapy by breathing the
agent into the airways. Resmycin® is an inhaled form of the chemotherapy drug doxorubicin that is currently in clinical trials. Researchers are also examining the inhaled administration of other anticancer agents.

Targeted Therapy

Most chemotherapy drugs act on any rapidly dividing cells, not just cancer cells. Targeted therapy is designed to act on unique characteristics, damage, or activities of cancer cells. These therapies are designed to act specifically on cancer cells while leaving normal cells unaffected. The development of targeted therapies requires defining the abnormalities of cancer cells, and then designing drugs that affect the targeted abnormalities. See Table 1 for examples of targeted therapy drugs for lung cancer in clinical trials at the time of this writing.

Table 1: Experimental Targeted Therapies for Lung Cancer

<table>
<thead>
<tr>
<th>Generic Name</th>
<th>Trade Name</th>
<th>Target Activity</th>
</tr>
</thead>
<tbody>
<tr>
<td>OSI-774, erlotinib</td>
<td>Tarceva®</td>
<td>anti-epidermal growth factor receptor (EGFR)</td>
</tr>
<tr>
<td>lonafarnib</td>
<td>Sarasar®</td>
<td>farnesyl transferase inhibitor</td>
</tr>
<tr>
<td>tipifarnib, R115777</td>
<td>n/a</td>
<td>farnesyl transferase inhibitor</td>
</tr>
<tr>
<td>imatinib</td>
<td>Gleevec®</td>
<td>tyrosine kinase inhibitor</td>
</tr>
<tr>
<td>ZD6474</td>
<td>n/a</td>
<td>VEGF receptor tyrosine kinase inhibitor</td>
</tr>
<tr>
<td>7-hydroxystaurosporine, UCN-01</td>
<td>n/a</td>
<td>G kinase inhibitor</td>
</tr>
<tr>
<td>suberoylanilide hydroxamic acid</td>
<td>n/a</td>
<td>histone deacetylase (HDAC) inhibitor</td>
</tr>
<tr>
<td>bortezomib</td>
<td>Velcade®</td>
<td>proteasome inhibitor</td>
</tr>
</tbody>
</table>

Antiangiogenic Compounds

As cancer cells multiply and grow, tumors must establish a blood supply to survive. The process of growing new blood vessels is called angiogenesis. Researchers have identified several substances that slow or inhibit the process of angiogenesis. These substances are called antiangiogenic compounds. Endostatin and angiostatin are two such compounds that have received extensive media attention. Many ongoing clinical trials are investigating the effectiveness of these and other antiangiogenic compounds in combination with standard forms of lung cancer treatment.
The drug thalidomide (Thalomid®) became famous in the 1950s when it was found to cause serious birth defects in the children of women who took the drug to control nausea and vomiting. In recent years, thalidomide has become a drug of interest to cancer researchers because of its antiangiogenic properties. Clinical trials with thalidomide and thalidomide-like compounds are currently underway.

Other antiangiogenesis compounds currently under investigation for lung cancer treatment include:

- 2-methoxyestradiol (2-ME)
- AE-941 (Neovastat®)
- carboxyamidotriazole (CAI)
- celecoxib (Celebrex®)
- combretastatin A4 phosphate
- squalamine

Matrix Metalloprotease Inhibitors

Matrix metalloproteases (MMPs) are a group of naturally occurring enzymes that help break down the structures between cells to make room for healthy new tissue. These enzymes are important in many normal body processes including new blood vessel development, tissue growth, and wound healing. MMPs are used by cancer cells to invade surrounding healthy tissue and spread to other parts of the body. MMPs may also contribute to the development of new blood vessels that allow tumors to grow.

Drugs that block the actions of MMPs are called matrix metalloprotease inhibitors (MMPIs). In recent years, several clinical trials involving MMPIs have been stopped before their completion because of toxic side effects. At the time of this writing, the only MMPI in clinical trials was BMS-275291. However, scientists continue to search for safe MMPIs that may help slow or arrest lung cancer growth.
Antineoplastons

Antineoplastons are small protein molecules (called peptides) that were first described by Dr. Stanislaw R. Burzynski in 1976. Dr. Burzynski reports that these peptides act to ‘normalize’ cancer cells. However, there have been no scientific studies to date to verify his claims. Recently, the National Cancer Institute funded clinical studies to determine if antineoplastons have a role in cancer therapy. Antineoplastons A10 and AS2-1 are currently being tested in lung cancer trials.

Immunotherapy and Biological Response Modifiers

The immune system plays a major role in the body’s response to cancer. Immunotherapy is a broad term that refers to a variety of ways the immune system might be used to treat cancer. Some immunotherapy methods use substances called biological response modifiers (BRMs). BRMs can affect immune responses and other body functions. Cancer researchers are exploring the possibility that BRMs may be able to alter the body’s response to cancer and prevent cancer metastasis.

Cytokines

Cytokines are naturally occurring proteins that act as messengers and regulators of the immune system. Interferon, interleukin, and tumor necrosis factor are cytokines that have anticancer activity. However, this effect is highly variable from one person to another and has only been seen with certain cancers. There are significant side effects associated with use of cytokine therapy. Use of these agents is currently experimental, but cytokine research continues.

Monoclonal Antibodies

Antibodies are proteins manufactured by immune cells. They attach to specific sites on cells thereby marking them for destruction by the immune system. Antibodies are very specific. Each antibody type will only interact with a specific attachment site much like a lock and key (see Figure 3).
The specific binding of antibodies makes them attractive for cancer therapy. If antibodies can be developed that bind to cancer cells but not normal cells, they would be ideal cancer therapy delivery vehicles. This concept led to the term ‘magic bullets’ to describe monoclonal antibody therapy.

A monoclonal antibody solution contains a huge number of identical copies of a single, specific antibody. The antibody is mass-produced using cloning technology. Trastuzumab (Herceptin®) is a monoclonal antibody approved by the Food and Drug Administration (FDA) for use in women with breast cancer. The binding site of trastuzumab (the HER2 receptor) is also found on cancer cells from other sites in the body including the lung, prostate, and colon. Clinical studies are currently underway to determine if Herceptin® can be used effectively with these other cancer types. Other monoclonal antibodies currently being investigated for the treatment of lung cancer include:

- bevacizumab, rhuMab-VEGF (Avastin®)
- cetuximab (Erbitux®)
- LCG-Mab (lung cancer gene monoclonal antibodies)
- BEC2 (Mitumomab®)
- TriGem®
- anti-anb3 integrin (Medi-522®)
- ABX-EGF

**Immunotoxins**

*Immunotoxins* are monoclonal antibodies that have a toxin (a cell destroying substance) attached to them. Two immunotoxins currently in lung cancer clinical trials are LMB-9 and SSI (dsFv)-PE38.

*Figure 3: Antigen-Antibody Binding*
**Immonoconjugates**

*Immonoconjugates* are monoclonal antibodies that have chemotherapy drugs attached to them. These substances are intended to deliver chemotherapy only to cancer cells while leaving healthy cells untouched. An example of an immunoconjugate currently in clinical trials is SGN-15, which delivers the chemotherapy drug doxorubicin.

**Cancer Vaccines**

A *vaccine* is a substance given to stimulate the immune system to act against a specific target. Scientists are studying several different vaccines that could eventually be used to treat lung cancer. Examples include:

- SRL172 (*Mycobacterium vaccae*)
- GVAX® and other autologous tumor cell vaccines (vaccines made from a sample of a person’s tumor)
- p53 peptide vaccines

**Chemoprevention**

*Chemoprevention* is the use of specific substances to reverse, suppress, or prevent cancer. Lung cancer chemoprevention is being studied to find substances that will:

- prevent lung cancer in people at risk for the disease such as current and former smokers
- reverse pre-cancerous changes in the airways of people who have not yet developed lung cancer
- prevent recurrence in people who have been treated for lung cancer
- prevent second lung cancers in people who have been cured of lung cancer

Many potential chemopreventive substances are currently in various stages of testing (see Table 2). You should not begin taking any substance for chemoprevention without first discussing it with your doctor. Some substances have actually been found to increase lung cancer risk. Taking any substance without first consulting with your doctor could end up doing more harm than good.
Table 2: Substances With Lung Cancer Chemopreventive Potential

<table>
<thead>
<tr>
<th>Non-Steroidal Anti-Inflammatory Drugs (NSAIDs)</th>
</tr>
</thead>
<tbody>
<tr>
<td>aspirin</td>
</tr>
<tr>
<td>ibuprofen</td>
</tr>
<tr>
<td>sulindac (Clinoril®)</td>
</tr>
<tr>
<td>celecoxib (Celebrex®)</td>
</tr>
<tr>
<td>rofecoxib (Vioxx®)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Retinoids and Carotenoids</th>
</tr>
</thead>
<tbody>
<tr>
<td>9-cis-retinoic acid</td>
</tr>
<tr>
<td>13-cis-retinoic acid</td>
</tr>
<tr>
<td>N-4-hydroxyphenyl retinamide (4-HPR)</td>
</tr>
<tr>
<td>all-trans retinoic acid (ATRA)</td>
</tr>
<tr>
<td>bexarotene</td>
</tr>
<tr>
<td>TAC-101</td>
</tr>
<tr>
<td>6-[3-(1-adamantyl)-4-hydroxyphenyl]-2-naphthalene carboxylic acid (CD437)</td>
</tr>
<tr>
<td>inhaled retinyl palmitate</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Targeted Agents</th>
</tr>
</thead>
<tbody>
<tr>
<td>farnesyl transferase inhibitors</td>
</tr>
<tr>
<td>ZD1839 (Iressa®), tyrosine kinase inhibitor</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Nutritional Supplements</th>
</tr>
</thead>
<tbody>
<tr>
<td>selenium</td>
</tr>
<tr>
<td>vitamins C, D, and E</td>
</tr>
<tr>
<td>N-acetylcysteine (NAC)</td>
</tr>
<tr>
<td>polyphenols</td>
</tr>
<tr>
<td>(from green and black teas)</td>
</tr>
<tr>
<td>curcumin</td>
</tr>
<tr>
<td>(from the spice turmeric)</td>
</tr>
<tr>
<td>allyl sulfur compounds</td>
</tr>
<tr>
<td>(as in garlic)</td>
</tr>
<tr>
<td>isothiocyanates</td>
</tr>
<tr>
<td>myoinositol</td>
</tr>
<tr>
<td>anethole dithiolethione (ADT, Sialor®)</td>
</tr>
<tr>
<td>4-methyl-5-pyrazinyl-3H-1, 2-dithiolw-3-thione (oltipraz)</td>
</tr>
<tr>
<td>terpenes (found in cherries and lavender)</td>
</tr>
<tr>
<td>limonene (found in citrus fruits, black pepper, and mangoes)</td>
</tr>
</tbody>
</table>

Cryoablation

Cryoablation is the use of very cold temperatures to kill cancerous tissue with little damage to surrounding healthy tissues. A small metal guide about the size of pencil lead is used to deliver argon gas to the target tissue. The gas kills the tissue by causing immediate freezing. This technique is FDA-approved for prostate cancer therapy and certain gynecological procedures. Investigators are studying the potential use of this technique to treat pre-cancerous and early lung cancer lesions. Cryoablation currently has no role in established lung cancer.
Gene Therapy
Lung cancer occurs when the genetic material of cells lining the airways is damaged. *Gene therapy* aims to interrupt the cancerous process by replacing lost or damaged genes, or blocking the expression of damaged genes. Replacement genes are inserted into cancer cells by genetically altered viruses that do not cause disease. The expression of damaged genes is blocked by substances that interfere with the processes that lead to production of proteins by cancer cells. Clinical trials are ongoing with the following:

- G3139, oblimersen (Genasense®)
- Angiozyme®
- RPR/INGN 201, Ad p53 (adenovirus p53)

Radiofrequency Ablation
*Radiofrequency ablation* is a technique involving placement of a small wire or electrode into a target tissue and transmitting radio waves to destroy the cells in the area around the electrode. This technique is commonly used to treat some types of abnormal heart rhythms. Researchers are exploring the use of this process to control lung cancer.

**MAKING TREATMENT DECISIONS**

Treatment decisions for people with lung cancer are complex. There is no such thing as a standard treatment that is suitable or advisable for every person with a specific type and stage of lung cancer. It is often said that the practice of medicine is both a science and an art. The best of the science of lung cancer treatment as we know it today is presented in *Chapter 6: Treatment of Small Cell Lung Cancer* and *Chapter 7: Treatment of Non-Small Cell Lung Cancer*. These chapters present treatment guidelines and recommendations based on clinical trial data. However, a guideline recommendation should not be interpreted to mean that the recommended treatment is the best possible option for everyone. Each person with lung cancer is different. The disease manifests itself differently in each person. Each person’s underlying circumstances are also unique. Therefore, lung cancer treatment must be individualized to meet the specific needs and circumstances of each person on a case-by-case
basis. This is where the art of medicine comes into play along with trust in your care providers.

The treatment guidelines presented in Chapters 6 and 7 should be used as a framework to help you know what questions to ask when you are discussing treatment options with your cancer care providers. The guidelines should not be considered treatment recommendations. Only your cancer care providers, who have access to your medical history and are aware of all the specifics of your case, can make treatment recommendations. Ultimately, the decision about what treatment options you want to pursue is up to you. The information presented in this book is here to provide you with background information to assist you with the decision making process, not to tell you what to choose.

SUMMARY

Lung cancer is treated with various forms of surgery, chemotherapy, and radiation therapy. Surgery and radiation therapy are local treatments used to treat cancer in specific areas of the body. Chemotherapy is a systemic treatment, a therapy used to treat cancer cells throughout the body. Lung cancer treatment usually involves a combination of different therapies. The treatment options for your cancer will depend on the type of cancer you have, the spread of the disease, other illnesses you have, your overall health, and your personal preferences.

Members of your cancer care team will advise you about the possible advantages and risks associated with each of your treatment options. Teamwork among your health care providers is a cornerstone of quality care for lung cancer. You are encouraged to seek the advice of qualified lung cancer specialists with whom you feel comfortable and who are willing to work with the other members of your cancer care team. Evaluate your treatment options in terms of what therapies best match your treatment goals. While others can provide you with expert advice, all treatment choices are ultimately up to you.
CHAPTER 6: TREATMENT FOR SMALL CELL LUNG CANCER

INTRODUCTION

This chapter provides an overview of treatment for small cell lung cancer (SCLC). Treatment options are presented based on the extent of disease. As you read this chapter, keep in mind that each person’s treatment plan is unique to his or her situation. This chapter provides information to help you discuss your treatment options with your cancer care team. However, it will not provide you with treatment recommendations. Many factors unique to your situation must be taken into account to make these crucial decisions. Only your cancer care team can make treatment recommendations.

Ongoing clinical trials are evaluating how best to treat SCLC. This chapter presents current treatment standards at the time of its writing. However, state of the art lung cancer care is constantly evolving. Ask your cancer team about new treatment options and clinical trials you may want to consider. You may want to seek the advice of more than one expert before deciding on a treatment plan.

Chemotherapy and radiation treatments are the mainstays of treatment for SCLC. A medical oncologist is an expert in the chemotherapeutic treatment of cancer. A radiation oncologist is the professional to consult about radiotherapy. In special circumstances, surgery may be used to treat SCLC. If surgery is a possibility for you, consult with a thoracic surgeon, a surgeon who specializes in chest surgery.

Your cancer care team will provide you with information about your treatment options, but all treatment decisions are ultimately up to you. No one is more qualified than you are to make decisions about what treatments best suit your goals and preferences. Seek information and expert advice, and then decide what is best for you.
OVERVIEW OF SMALL CELL LUNG CANCER

Lung cancer arises from abnormal *epithelial cells* in the airways of the lungs. Epithelial cells cover all free surfaces in the body including the airways. Lung cancer is divided into two main types based on how it looks under the microscope: small cell lung cancer and non-small cell lung cancer (NSCLC). As the name implies, the cancerous epithelial cells of SCLC are abnormally small. This appearance led to the term *oat cell carcinoma* to describe SCLC because the cells resemble oat grains (see Figure 1). SCLC is sometimes called small cell undifferentiated carcinoma. In the United States, approximately 20% of lung cancers are SCLC.

SCLC and NSCLC differ in the sites of their genetic damage and their patterns of growth and spread. SCLC typically grows more quickly than NSCLC does. SCLC generally spreads to *lymph nodes* and *metastasizes* earlier in the course of the disease than does NSCLC. Overall, SCLC is initially much more responsive to chemotherapy and radiotherapy than NSCLC is.

Characteristic features of SCLC include:

- There is a strong relationship between SCLC and tobacco smoking. Only about 1% of SCLC occurs in people who have never smoked.
- SCLC often occurs in one of the larger airways. Therefore, SCLC tumors are often located near the center of the lung.
- Most people with SCLC have metastases or spread of the disease beyond the original tumor at the time of diagnosis.
- Combined small cell carcinoma is a variant of SCLC.

See *Chapter 3: Lung Cancer Overview* for additional information about lung cancer development, growth, and spread.

*Figure 1: Microscopic View of Small Cell Lung Cancer*
BEFORE TREATMENT

SCLC Staging
Accurate staging of SCLC is critical because treatment options depend on the extent of your disease. Most health care providers categorize SCLC as either limited or extensive based on a system created by the Veterans Administration Lung Cancer Study Group. SCLC is staged according to the spread of disease in the chest. People whose disease is confined to one lung, the mediastinum, and/or the regional lymph nodes have limited stage SCLC. Limited stage disease can be treated in a single radiotherapy field. Approximately 30% of people with SCLC have limited stage disease at diagnosis. Limited stage SCLC corresponds to stages I through IIIB of the TNM staging system. See Chapter 4: Lung Cancer Diagnosis and Staging for information about the TNM staging system.

Extensive stage SCLC has spread to the contralateral lung (the lung opposite the one with the original tumor), is associated with a malignant pleural effusion, and/or is accompanied by distant metastasis. Approximately 70% of people with SCLC have extensive stage disease at the time of diagnosis. Extensive stage SCLC corresponds to stage IIIB with pleural effusion, and stage IV of the TNM staging system.

Staging must be accomplished before treatment options can be considered. The National Comprehensive Cancer Network (NCCN) has published practice guidelines for the treatment of SCLC. According to these guidelines, SCLC staging should include the following tests and activities:

- medical history and complete physical examination
- chest x-ray
- CT scan of the chest, liver, and adrenal glands
- MRI or CT scan of the head (brain)
- bone scan
- blood tests including a complete blood count (CBC), platelet count, liver function tests, calcium, lactate dehydrogenase (LDH), blood urea nitrogen (BUN), and creatinine

Your doctor may order additional tests based on the results of these tests.
Positron emission tomography (PET) scanning is being studied as a staging tool for people with SCLC. Results from early studies indicate PET scans may be useful for detecting unsuspected metastasis. While results from early studies are promising, PET scans are not currently recommended for routine SCLC staging.

Long-term survival is more likely for people with limited stage SCLC than for people with extensive disease. Median survival time among people treated for limited SCLC is 16-24 months. Five-year survival is approximately 10-20%. Median survival among people treated for extensive SCLC is 6-12 months. Long-term survival with extensive SCLC is uncommon. However, no one can predict your personal chance of survival. There are always people who beat the odds; you may be one of them. While the statistics for SCLC are rather discouraging, remember, there are survivors!

**Treatment Preparations**

Researchers have found a person’s performance status affects his or her SCLC prognosis. Performance status is a measure of how well a person is able to perform ordinary tasks and carry out daily activities. As you prepare for treatment, you may want to assess your lifestyle and health habits. Does your lifestyle enhance your overall health?

If you are a smoker, it would be best to stop smoking. Some people believe that once they have been diagnosed with lung cancer, it does not matter if they continue to smoke. This is not true. Studies have shown that people with limited SCLC who continue to smoke have a less favorable prognosis than those who stop smoking. Although surgery is an option for only a small percentage of people with SCLC, thoracic surgeons strongly encourage people to stop smoking before surgery. Smoking can worsen many of symptoms of lung cancer and its treatment including mouth sores, shortness of breath, and peripheral neuropathy.

Smoking damages your health. Stopping smoking will greatly enhance your overall health. Smoking cessation is difficult because nicotine addiction is very powerful. Talk with your cancer care providers about smoking cessation programs, nicotine replacement therapy, and use of the drug bupropion (Zyban®) to help you successfully stop smoking.
Lung cancer treatment is hard on the body. You need to take in enough calories to meet the energy demands treatment places on your body. If you are losing weight or are having problems with your appetite, you may want to talk with a nutritionist or dietician before beginning treatment. He or she can advise you about the number of calories you need and give you tips to ensure you are getting adequate nutrition.

Exercise is an important factor in your overall health. Continue your current program if you already exercise regularly. You may need to modify your routine if the energy demands of treatment cause fatigue. If you are not currently exercising, talk with your health care providers about beginning a gentle exercise program. All forms of exercise are helpful and there are many choices. Anything that gets you up and moving is exercise including walking, biking, gardening, golfing, dancing, yoga, swimming, and many other activities. Be sure to discuss your exercise program with your health care providers to ensure it is safe for you.

Urgent dental work should be done before beginning treatment. Mouth sores and problems with the teeth are common side effects of chemotherapy and some forms of radiotherapy. Healthy gums and teeth help prevent or reduce the severity of these problems.

When To Begin Treatment
Lung cancer grows for many years it is large enough to be detected. Once you have been diagnosed, you may be anxious to begin treatment right away. However, unless your doctor tells you otherwise, you may benefit from taking a few days to organize your thoughts and make plans before starting treatment. You may want to use the time to arrange time off from your job, plan for household help, or collect information about your disease. Planning can help reduce your stress, which can make it easier to cope with the challenges of treatment. You may want some quiet time with loved ones and friends to gather your physical and emotional strength before treatment begins.

While taking a few days before beginning treatment will not affect your prognosis, lengthy treatment delays should be avoided. A long delay could give your cancer time to grow and/or spread.
I did a lot of research [before beginning treatment]. Mind you, this was before the Internet, so it took some effort. I also got a second opinion. Even though I had confidence in my doctor, I needed that extra verification. Once I got a second opinion and it concurred with my doctor, I felt secure. I was comfortable when I started treatment because I researched my treatment options and got a second opinion. Doing this it put me in control of the situation. I did not feel like a victim.

– Elaine, diagnosed with limited stage SCLC in 1989 at age 58

Talk with your cancer care providers about any symptoms you are experiencing. Initiating treatment of disease-related symptoms before therapy begins can make cancer treatments easier to tolerate. Supportive care treatments can begin while you and your cancer care team are developing your treatment strategy.

It is up to you what treatments you want to receive. Discuss the purpose, potential side effects, and expected results of each treatment option with your cancer care team. Use your cancer care providers as consultants to aid you in making decisions. Alternatively, you may decide to give your primary cancer doctor permission to choose the treatment he or she believes to be the best option for you. This is as valid a decision as any other you might make. You are the most qualified person to decide how you want to manage your cancer care.

LIMITED STAGE SMALL CELL LUNG CANCER TREATMENT

Single SCLC Tumor Without Evidence of Spread

Most experts recommend a mediastinoscopy for people with limited stage SCLC who have a single tumor and no evidence of spread on their initial staging workup. A mediastinoscopy is a surgical procedure in which a rigid instrument called an endoscope is inserted through a small incision at the base of the neck or near the breastbone into the central area of chest called the mediastinum. The mediastinum contains the heart and the large blood vessels entering and leaving it, the trachea, the esophagus, and the mediastinal lymph nodes. A mediastinoscopy is performed to examine the mediastinal structures and take tissue samples from local lymph nodes. Lymph node samples are examined under a microscope to determine if there are lung cancer cells present. Mediastinoscopy is performed under general anesthesia and usually requires an overnight hospital stay.
If there is no evidence of cancer in the mediastinal lymph nodes, surgery is usually performed to remove the lobe of the lung containing the tumor. This procedure is called a *lobectomy*. Area lymph nodes are sampled during surgery. Tissue samples are sent to the laboratory to check for cancer cells.

**Figure 2: Treatment for Single SCLC Tumor Without Evidence of Spread**

<table>
<thead>
<tr>
<th>Mediastinoscopy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cancer in mediastinal nodes</td>
</tr>
<tr>
<td>Concurrent chemotherapy &amp; radiotherapy</td>
</tr>
<tr>
<td>Cancer in surgical nodes</td>
</tr>
<tr>
<td>Concurrent chemotherapy &amp; radiotherapy</td>
</tr>
</tbody>
</table>

After recovery from surgery, chemotherapy is given to people whose surgical lymph node samples show no evidence of cancer. Chemotherapy is given to eliminate undetected cancer cells that may still be present in the body. If cancer cells are detected in the surgical lymph node samples, chemotherapy is given along with radiotherapy to the mediastinum. This combined approach is called *concurrent* treatment, meaning both treatments are given at the same time. Radiotherapy is added to boost the chances of controlling cancer cells that may be present in the remaining mediastinal lymph nodes.

**Limited SCLC Beyond The Original Lung Tumor**

Your overall health is a factor in choosing the best treatment if you have limited stage SCLC that has spread beyond the original lung tumor. Oncologists use very specific criteria to assess your overall health and performance status. The ECOG and Karnofsky scales are commonly used to gauge performance status (see Tables 1 and 2).
Most experts recommend concurrent chemotherapy and radiotherapy for people with good performance status who do not have underlying lung disease. Investigators have found the addition of early radiotherapy to chemotherapy improves survival with limited SCLC. The decision whether to include radiotherapy along with chemotherapy for people whose performance status is compromised by other illnesses is made on a case-by-case basis.

### EXTENSIVE STAGE SMALL CELL LUNG CANCER TREATMENT

Chemotherapy is the primary form of treatment for extensive stage SCLC. SCLC is usually very responsive to first line chemotherapy. Lung cancer management guidelines compiled by the American College of Chest Physicians recommend a platinum-based chemotherapy.
regimen for people with extensive SCLC. This involves use of either cisplatin or carboplatin (platinum containing chemotherapy drugs) plus one or more additional chemotherapy agents.

Radiation therapy is often used to control metastatic disease symptoms. Areas commonly treated include bone lesions and the brain. See Chapter 5: Lung Cancer Treatment Overview for information about radiation treatments for brain metastasis.

CHEMOTHERAPY OPTIONS FOR SMALL CELL LUNG CANCER

Chemotherapy is the cornerstone of treatment for SCLC. SCLC is typically very responsive to first line chemotherapy. Reported response rates range from 80-100% for limited disease and 60-89% for extensive disease. Many chemotherapy agents are active against SCLC (see Table 3). Chemotherapy for SCLC is usually combination therapy, meaning two or more drugs are used. This approach has proven more effective than single drug therapy for SCLC. Four to six cycles of treatment are typically administered.

Table 3: Chemotherapy Drugs Active Against Small Cell Lung Cancer

<table>
<thead>
<tr>
<th>Generic Name</th>
<th>Trade Name</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>— Established Agents —</strong></td>
<td></td>
</tr>
<tr>
<td>carboplatin</td>
<td>Paraplatin®</td>
</tr>
<tr>
<td>cisplatin</td>
<td>Platinol®</td>
</tr>
<tr>
<td>cyclophosphamide</td>
<td>Cytoxan®, Neosar®</td>
</tr>
<tr>
<td>doxorubicin</td>
<td>Adriamycin®</td>
</tr>
<tr>
<td>etoposide</td>
<td>VePesid®, Etopophos®, Toposar®</td>
</tr>
<tr>
<td>ifosfamide</td>
<td>Ifex®</td>
</tr>
<tr>
<td>methotrexate</td>
<td>Amethopterin®, Folex®, Mexate®, MTX</td>
</tr>
<tr>
<td>teniposide</td>
<td>Vumon®</td>
</tr>
<tr>
<td>vincristine</td>
<td>Oncovin®, Vincasar PFS®, Vincrex®</td>
</tr>
<tr>
<td><strong>— Newer Agents —</strong></td>
<td></td>
</tr>
<tr>
<td>docetaxel</td>
<td>Taxotere®</td>
</tr>
<tr>
<td>gemcitabine</td>
<td>Gemzar®</td>
</tr>
<tr>
<td>irinotecan</td>
<td>Camptosar®</td>
</tr>
<tr>
<td>paclitaxel</td>
<td>Taxol®</td>
</tr>
<tr>
<td>topotecan</td>
<td>Hycamtin®</td>
</tr>
<tr>
<td>vinorelbine</td>
<td>Navelbine®</td>
</tr>
</tbody>
</table>
There is no single chemotherapy combination or protocol recommended for all people with SCLC. Several active chemotherapy combinations are in use. The choice of chemotherapy drugs used is individualized according to each person’s unique needs and circumstances. Drug choices are influenced by your overall health and other illnesses or conditions you may have. Examples of commonly used SCLC chemotherapy combinations are reviewed in this section. Keep in mind, there are many other regimens that are both active and appropriate in specific circumstances.

**Etoposide + Cisplatin**

This is the most common chemotherapy regimen used for SCLC. The National Comprehensive Cancer Network practice guidelines for the treatment of SCLC name this regimen as the treatment of choice to be used concurrently with radiotherapy for the treatment of limited stage SCLC. This regimen is also frequently used in people with extensive stage disease.

**Etoposide + Carboplatin**

The substitution of carboplatin for cisplatin is sometimes made to reduce the risks of nausea, vomiting, and peripheral neuropathy. However, this substitution has been associated with increased risk of myelosuppression (anemia, low white blood cells, and low platelets).

**Cisplatin + Doxorubicin or Epirubicin + Ifosfamide or Cyclophosphamide**

The National Comprehensive Cancer Network treatment guidelines state these combinations may provide a slight survival advantage for people with extensive stage disease based on the results of a few clinical trials. However, there may also be increased toxicity making the trade-off a matter for careful consideration.

**Cyclophosphamide + Doxorubicin + Vincristine**

The use of this chemotherapy combination is well established for SCLC. It can be used alone or concurrently with radiotherapy.
Many ongoing clinical trials are examining the effectiveness of different chemotherapy combinations using newer chemotherapy agents (see Table 4).

Table 4: Chemotherapy Combinations Being Studied for Small Cell Lung Cancer

<table>
<thead>
<tr>
<th>Platinum Based Regimens</th>
<th>Non-Platinum Based Regimens</th>
</tr>
</thead>
<tbody>
<tr>
<td>cisplatin-docetaxel (Platinol®/Taxotere®)</td>
<td>etoposide-irinotecan (Toposar®/Camptosar®)</td>
</tr>
<tr>
<td>cisplatin-irinotecan (Platinol®/Camptosar®)</td>
<td>etoposide-paclitaxel-epirubicin (Toposar®/Taxol®/epirubicin)</td>
</tr>
<tr>
<td>cisplatin-paclitaxel (Platinol®/Taxol®)</td>
<td>paclitaxel-doxorubicin (Taxol®/Adriamycin®)</td>
</tr>
<tr>
<td>cisplatin-paclitaxel-topotecan (Platinol®/Taxol®/Hycamtin®)</td>
<td>paclitaxel-topotecan (Taxol®/Hycamtin®)</td>
</tr>
<tr>
<td>cisplatin-etoposide-carboplatin (Platinol®/Toposar®/Paraplatin®)</td>
<td></td>
</tr>
<tr>
<td>cisplatin-vinblastine-mitomycin C (Platinol®/Velban®/Mitomycin C)</td>
<td></td>
</tr>
<tr>
<td>carboplatin-paclitaxel (Paraplatin®/Taxol®)</td>
<td></td>
</tr>
</tbody>
</table>

Use the examples of chemotherapy regimens presented here as talking points for your treatment discussions with your oncologist. However, do not consider the above examples as your only options, or even as the preferable options. There is no single chemotherapy regimen that is effective for every person with SCLC. The best chemotherapy choice must take into account many factors specific to you. An oncologist who has all your medical information and test results can discuss the potential advantages and disadvantages of various chemotherapy regimens in terms of your unique situation.

I am a nurse by trade, so as soon as I found out I had lung cancer I was pulling strings, researching, and talking to anyone who could provide information. I do have to say that being a nurse can be a double-edged sword. All the clinical information I received became overwhelming. I just had to sift through the information and only take what I needed. When I think back on how I felt at that time, all I can say is that it was complicated. I was very focused on getting the information — fast — and setting up another appointment with my doctor as soon as possible to start treatment. To be honest, during that initial diagnosis stage, it never occurred to me that the treatments might not work. I just had to go through chemo and radiation and that was that.

— Toni, diagnosed with limited stage SCLC in 1992 at age 39

RESPONSE TO THERAPY

Evaluation During Treatment

Your doctors will initially rely on physical signs and symptoms to gauge your response to therapy. While this not always completely accurate, stable or improving signs and symptoms
are a reasonably reliable indicator that your disease is also probably stable or responding to treatment.

After three or more cycles of therapy, your doctor may order a chest x-ray or CT scan to check tumor size. Therapy will probably be continued if the tumor size is unchanged or reduced and there is no evidence of disease progression. Tumor growth or other symptoms of disease progression indicate the treatment is not active against your cancer. In this situation, treatment should be stopped. Your doctor may recommend trying another treatment regimen.

PET (positron emission tomography) scans are being investigated as a tool to determine response to treatment. PET scans detect changes in the activity of cells rather than measuring tumor size. As a result, PET scans may be capable of identifying changes in cancer cell activity earlier in the course of therapy than CT scans or x-rays. PET scanning to monitor response to therapy is being studied in clinical trials. Because of its experimental status, many insurance companies do not cover the cost of PET scans used for this purpose.

**Evaluation After Completion of Treatment**

Upon completion of your initial therapy, you will be thoroughly re-evaluated to check your response to treatment. The assessment of treatment response usually includes:

- chest x-ray
- CT scan of the chest, liver, and adrenal glands
- imaging tests to check areas known to have cancerous spread before treatment; the tests used depend on the site of the cancer
- blood tests including a complete blood count, liver function tests, and possibly others

People who have had a complete response to therapy (the disappearance of all signs of cancer) are candidates for prophylactic cranial irradiation or PCI. A prophylactic treatment is one used to act against or prevent a condition. PCI is a series of radiation treatments to
the brain intended to kill undetected cancer cells that may be present. PCI is often used with SCLC because:

- SCLC is known to metastasize early in the disease process.
- The brain is a common site of SCLC metastasis.
- Chemotherapy drugs used to treat SCLC do not get into the brain in high enough concentrations to kill cancer cells that may be present.
- Small areas of metastases (micrometastasis) may be present in the brain but are too small to be detected with imaging tests.

PCI is strongly recommended by many cancer experts for people with limited SCLC who have had a complete response to therapy. People with extensive disease who have had a complete response to initial therapy are usually also given the option of PCI. While PCI has been shown to reduce the risk of brain metastases, it is not without potentially harmful side effects. Research has shown that long-term SCLC survivors who have had PCI are at risk for impairments in their mental functions. The severity of these impairments is highly variable. It is important to discuss this risk with your doctor before making a decision about whether to have PCI.

RECURRENT DISEASE

Many people who partially or completely respond to initial treatment for SCLC have a relapse. In complete responders, this means the disease comes back either at the site of the original cancer or at another location. For partial responders, this means the disease begins to grow and/or spread after having been stable for a time.

The National Comprehensive Cancer Network guidelines recommend the following monitoring for people who had a complete response to initial treatment:

- Visit your oncologist every two months for the first year, every three months for the second year, and every six months after that.
- At each visit, you should have a physical examination, chest x-ray, and blood tests.
A significant number of people who relapse respond to second line chemotherapy (also called *salvage therapy*). However, the response rates are not nearly as high for salvage therapy as they are for first line treatment. The choice of second line chemotherapy depends on the drugs used for first line treatment, the response to that therapy, and the time to disease progression after initial treatment.

**SUMMARY**

Varieties of treatments are available for SCLC. Chemotherapy is the cornerstone for the treatment of SCLC. In limited stage disease, chemotherapy and radiotherapy are often used together. Limited stage disease consisting of an isolated tumor may be treated surgically. Extensive stage disease is treated primarily with combination chemotherapy. Radiation therapy is often used to treat disease-related symptoms. Many SCLC clinical trials are available. You may want to consider participating in a clinical trial when evaluating your treatment options.

The choice of treatment will depend on the stage of your disease, your overall health, personal preferences, and other factors. No single approach can be used effectively for all cases of SCLC. Your treatment plan must be individualized to meet your specific situation, needs, and preferences.

Asking your cancer care team questions can help you better understand your treatment options and feel more comfortable with your decisions. Additional sources of information can be found in the *Resource Directory*. 
CHAPTER 7: TREATMENT FOR NON-SMALL CELL LUNG CANCER

INTRODUCTION

This chapter provides an overview of treatment for non-small cell lung cancer (NSCLC). Treatment options are discussed according to the spread of the disease. As you read this chapter, keep in mind that each person’s treatment plan is unique to his or her situation. Information is provided to help you discuss treatment options with your cancer care team. However, treatment recommendations are not given. Many factors unique to your situation must be taken into account to make these crucial decisions. Only your cancer care team can make treatment recommendations.

Ongoing clinical trials are evaluating how best to treat NSCLC. This chapter presents current treatment standards at the time of its writing. However, state of the art lung cancer care is constantly evolving. Ask your cancer care team about new treatment options and clinical trials you may want to consider. You may want to seek the advice of more than one expert before deciding on a treatment plan.

Surgery, chemotherapy, and radiation treatments are used to treat NSCLC. A medical oncologist is an expert in the chemotherapeutic treatment of cancer. A radiation oncologist is the professional to consult about radiotherapy. Surgical candidates should consult a thoracic surgeon, a surgeon who specializes in chest surgery.

Your cancer care team will provide you with information about your treatment options, but all treatment decisions are ultimately up to you. No one is more qualified than you are to make decisions about what options best suit your goals and preferences. Seek information and expert advice, and then decide what is best for you.
OVERVIEW OF NON-SMALL CELL LUNG CANCER

Lung cancer arises from abnormal epithelial cells in the airways of the lungs. Epithelial cells cover all free surfaces in the body including the airways. Lung cancer is divided into two main types based on how it looks under the microscope: small cell lung cancer (SCLC) and non-small cell lung cancer. In the United States, approximately 80% of lung cancers are NSCLC and 20% are SCLC. SCLC and NSCLC have different patterns of growth and spread. They are also treated differently. In 1999, the World Health Organization (WHO) and the International Association for the Study of Lung Cancer (IASLC) updated their classification system for lung tumors. The information presented in this chapter uses the terminology of the 1999 WHO/IASLC classification system.¹

There are three major types of NSCLC: adenocarcinoma, squamous cell carcinoma, and large cell carcinoma. NSCLCs are grouped together because they have similar growth patterns and treatments. Each of the three major types of NSCLC has variants or subtypes. The names of the variants describe patterns of growth visible under a microscope. Following is a brief summary of characteristics of the three types of NSCLC.

Adenocarcinoma

Adenocarcinoma cells have a glandular appearance (see Figure 1). The majority of these tumors produce a thick fluid called mucin.

The incidence of adenocarcinoma has increased over the past three decades. Scientists are not certain why this has occurred but influences may include changes in smoking habits, dietary patterns, and environmental and occupational factors.

Characteristics of adenocarcinoma include:

* Adenocarcinoma accounts for approximately 40% of all lung cancers in the United States and approximately 55% of NSCLCs.

Figure 1: Microscopic View of Adenocarcinoma*

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Variants of adenocarcinoma include acinar adenocarcinoma, papillary adenocarcinoma, bronchioloalveolar adenocarcinoma, and other mixed subtypes.

- Adenocarcinoma is the most common form of lung cancer in women and people who have never smoked. This form of lung cancer is also the most common type seen in people less than age 50.
- Adenocarcinomas are the most common form of lung cancer associated with scarring of the lung tissue.
- Adenocarcinomas most often occur in the outer regions of the lungs.
- A subtype of adenocarcinoma called bronchioloalveolar adenocarcinoma (BAC) arises in the alveoli (the air sacs of the lung). BAC tends to be slow growing and appears less likely to metastasize than other forms of NSCLC. For this reason, BAC has a more favorable prognosis than other forms of NSCLC.

**Squamous Cell Carcinoma**

Squamous cell carcinoma (SCC) is also known as *epidermoid carcinoma*. This form of NSCLC has decreased in frequency over the past three decades but is still the most common form of lung cancer among men who are current or former smokers. Squamous cells are large, flat cells (see Figure 2).

*Figure 2: Microscopic View of Squamous Cell Carcinoma*

These tumors often produce a substance called *keratin*, which is seen under the micro-scope. Characteristics of SCC include:

- SCC accounts for approximately 25-30% of lung cancer in the United States.
- Variants of SCC include papillary SCC, clear cell SCC, small cell SCC, and basaloid SCC.
- SCC occurs most frequently in men and in people over age 65 of both sexes.
- SCC usually starts in one of the large airways. Therefore, these tumors tend to be located in the central area of the lung.
- SCC has a tendency to metastasize somewhat later than other forms of NSCLC.
SCC tumors often invade neighboring structures.

- SCC rarely occurs in people who have never smoked.

**Large Cell Carcinoma**

The cells of large cell carcinoma (LCC) are the largest of the various types of NSCLC. The cells are generally highly undifferentiated or immature in appearance (see Figure 3).

Some experts believe these tumors represent adenocarcinomas or squamous cell carcinomas that are so undifferentiated as to be unrecognizable. Characteristics of large cell carcinoma include:

- LCC accounts for 10-15% of lung cancers in the United States.
- There are several variants of large cell carcinoma including clear cell LCC, basloid LCC, lymphoepithelioma-like carcinoma, and large cell neuroendocrine carcinoma.
- LCC can occur in any part of the lung.
- The prognosis for large cell carcinoma is generally less favorable than for other forms of NSCLC.

See *Chapter 3: Lung Cancer Overview* for additional information about lung cancer development, growth, and spread.

**OVERVIEW OF NON-SMALL CELL LUNG CANCER STAGING**

Accurate *staging* of NSCLC is critical because treatment options depend on the spread of the disease. Staging is the process of classifying the extent of spread of the cancer from the original tumor to other parts of the body according to standard criteria. Staging is important for two reasons. It helps your doctors determine which treatments are likely to be most effective for you and what the course of your illness (your prognosis) is likely to be. Lung cancer stage is the primary factor that influences prognosis.

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Lung cancer stages are based on three factors. These factors are expressed using the TNM classification system. The three factors of the TNM system are:

- **T**: tumor characteristics including size, location, and local invasion
- **N**: regional lymph node involvement
- **M**: metastasis status

Non-small cell lung cancer is divided into four stages using the TNM classification system. Stages range from I through IV. Stages are typically expressed using Roman numerals where I = one, II = two, III = three, and IV = four. In general, the lower the stage, the less the cancer has spread. The higher the stage, the more extensive is the spread of the disease. The general trend in terms of prognosis is the lower the stage, the better the prognosis. The distribution of stage at diagnosis for people with NSCLC\(^2\) is:

<table>
<thead>
<tr>
<th>Stage</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>13-24%</td>
</tr>
<tr>
<td>II</td>
<td>5-10%</td>
</tr>
<tr>
<td>III</td>
<td>31-44%</td>
</tr>
<tr>
<td>IV</td>
<td>32-39%</td>
</tr>
</tbody>
</table>

### Non-Small Cell Lung Cancer Stages

#### Stage I
Stage I NSCLC represents a cancerous tumor that has not spread. There is no evidence of cancer in any lymph nodes. The major difference between stage IA and IB disease is the size of the primary tumor. In stage IA disease, the tumor is 3 cm (1½ inches) or less in size. In stage IB disease, the tumor is larger than 3 cm (1½ inches). Stage I NSCLC is local disease. It is potentially curable with surgery.

#### Stage II
Stage II NSCLC is characterized by a primary tumor that has spread to the hilar lymph nodes (the N1 area) on the same side as the tumor (see Figure 4). In stage IIA, the tumor is a T1 (3 cm or less). In stage IIB, the tumor is a T2 (greater than 3 cm). A tumor involving the chest wall without hilar lymph node involvement (T3, N0) is also
considered stage IIB disease. Stage II NSCLC is potentially curable with surgery. However, the chance of recurrence is higher than for people with stage I disease.

**Stage III**

Stage III is the most complex of the NSCLC stages. There are significant differences in the treatment of stage IIIA versus IIIB disease. Stage IIIA disease includes a tumor that has invaded the chest wall, diaphragm, or the pleura of the mediastinum or heart, and has ipsilateral hilar or mediastinal lymph node involvement (T3N1M0 or T3N2M0). The term ipsilateral refers to structures on the same side of the chest as the primary tumor (see Figure 4). Smaller tumors that involve the ipsilateral mediastinal lymph nodes are also stage IIIA (T1N2M0 or T2N2M0). Stage IIIA is potentially operable disease. Preoperative treatment is used for some people and is currently under evaluation in clinical trials.

Stage IIIB disease includes any size tumor that has invaded any of the vital structures of the mediastinum, the carina, or a bone of the spine (T4 tumors), with or without regional lymph node involvement (T4N0M0, T4N1M0, T4N3M0). Smaller tumors (T1-3) associated with contralateral lymph node involvement or supraclavicular lymph node involvement are also stage IIIB. The term contralateral refers to structures on the opposite side of the chest as the primary tumor. A separate tumor nodule in the same lobe of the lung as the primary tumor

*Figure 4: Regional Lymph Nodes of the Lungs Used to Determine Stage*

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is called a *satellite lesion*. This is stage IIIB disease regardless of the size of the primary tumor. If there is a second tumor in a different lobe from the primary tumor, this is stage IV disease.

A unique form of stage IIIB disease involves a lung tumor and the presence of cancer cells in pleural fluid (malignant *pleural effusion*), but no evidence of metastatic disease. This situation is often referred to as ‘wet IIIB’ disease. It is treated the same way as stage IV disease. Most clinical trials involving people with stage IV disease also include patients with wet IIIB disease.

People with stage IIIB disease are generally not candidates for surgical cure because it is usually not possible to remove all the cancerous tissue with this degree of spread. People with T4N0 tumors are sometimes an exception to this general rule. A thoracic surgeon should thoroughly evaluate anyone with T4N0 disease to determine if surgical removal of the cancer is possible.

**Stage IV**

Stage IV NSCLC is assigned whenever there is distant metastasis, that is, spread of the disease beyond the regional lymph nodes.

**Special Cases**

Stage 0 (zero) represents carcinoma *in situ*. This unique situation refers to the presence of a local area of cancer cells that have not grown through the top lining of the lung. Carcinoma *in situ* is curable and incapable of spreading. The TNM designation for carcinoma in situ is Tis. Since there is currently no recommended screening for lung cancer, the percentage of people diagnosed with lung cancer who have stage 0 disease is very low.

Occult lung cancer is another uncommon situation in which tumor cells are found in the sputum or *bronchial washings* (rinse solution obtained during *bronchoscopy*), but no primary tumor can be seen on imaging tests or with direct examination using a bronchoscope. The TNM designation for occult lung cancer is Tx.
Most people with lung cancer wonder about their prognosis. The spread of disease at diagnosis is clearly linked to prognosis. Cancer survival statistics are given in specific timeframes. One, two, and five-year survival statistics are commonly discussed. One-year survival is the percentage of people alive one year after diagnosis. Two-year survival is the percentage of people alive two years after diagnosis or beginning a specific treatment. Five-year survival is the standard marker for cure. People alive and cancer-free five years after diagnosis are generally considered cured of their disease. When you read or hear about cancer survival statistics, these refer to five-year survival unless another time interval is specifically stated. Five-year survival is sometimes called long-term survival. Table 1 shows one and five-year survival rates for NSCLC by stage at diagnosis.

<table>
<thead>
<tr>
<th>NSCLC Stage</th>
<th>One-Year Survival</th>
<th>Five-Year Survival</th>
</tr>
</thead>
<tbody>
<tr>
<td>IA</td>
<td>up to 90%</td>
<td>61-67%</td>
</tr>
<tr>
<td>IB</td>
<td>72-94%</td>
<td>38-57%</td>
</tr>
<tr>
<td>IIA</td>
<td>84-88%</td>
<td>37-55%</td>
</tr>
<tr>
<td>IIB</td>
<td>60-77%</td>
<td>24-39%</td>
</tr>
<tr>
<td>IIIA</td>
<td>52-64%</td>
<td>13-23%</td>
</tr>
<tr>
<td>IIIB</td>
<td>33%</td>
<td>5%</td>
</tr>
<tr>
<td>IV</td>
<td>17%</td>
<td>&lt;1%</td>
</tr>
</tbody>
</table>

Survival statistics for lung cancer can be discouraging. Remember, no one can predict the outcome of your disease. Keep in mind, there are survivors! You may well be one of them.

BEFORE TREATMENT

Pretreatment Evaluation

A diagnosis of NSCLC is based on the results of a tissue sample (biopsy) of your tumor. After diagnosis, you will undergo a series of tests called the initial work-up or evaluation. The
National Comprehensive Cancer Network treatment guidelines for NSCLC recommend the following tests and procedures for the initial NSCLC work-up:

- medical history and complete physical examination
- chest x-ray
- CT scan of the chest, abdomen (belly), and adrenal glands
- blood tests including red blood cell count, white blood cell count, platelet count, liver tests, and kidney function tests

Your health care providers will determine a presumptive stage of your disease based on the initial work-up. At this point, the stage of your disease is presumptive because additional tests may show the actual stage is different from what it appears to be based on the initial work-up.

Depending on the presumptive stage of your disease after initial work-up, you may need additional pretreatment tests.

**Additional Work-Up for Presumptive Stage I and IIA**

People with presumptive stage I or IIA NSCLC are often advised to undergo a bronchoscopy and/or mediastinoscopy. Alternatively, if the CT scan is normal or shows suspicious lymph nodes that can clearly be removed at surgery, the doctor may recommend surgical removal of the cancer and a complete evaluation of the mediastinal lymph nodes at the time of surgery.

Bronchoscopy involves putting a small, flexible tube called a bronchoscope into the large airways of the lungs. The bronchoscope allows the doctor to see inside the airways and take tissue samples. A bronchoscopy is recommended for people with presumptive stage I and IIA disease to check for cancer in the regional lymph nodes, central airways, and other areas of the lungs.

Mediastinoscopy is a surgical procedure in which a rigid instrument called an endoscope is inserted through a small incision at the base of the neck or just above the breastbone into the central area of the chest (the mediastinum). This procedure is
performed in presumptive stage I or IIA NSCLC to sample the mediastinal lymph nodes. In some cases, mediastinal nodes can be sampled using a needle inserted through the esophagus instead of performing a mediastinoscopy. Ultrasound is used to guide this sampling process. Disease that has spread to the mediastinal nodes will be re-categorized as stage III.

Positron emission tomography (PET) scanning is another staging tool sometimes used in people with NSCLC. Results from early studies indicate PET scans may be useful for non-invasive staging of the mediastinal lymph nodes. The National Comprehensive Cancer Network NSCLC practice guidelines state PET scans are optional as part of the pretreatment evaluation of people with stage I and IIA disease. The guidelines further state positive PET scan findings should usually be confirmed by tissue sampling or another radiologic test. The American College of Chest Physicians guidelines recommend PET scans to evaluate the mediastinal lymph nodes of all people who are surgical candidates.

Additional Work-Up for Presumptive Stage IIB and IIIA
People with presumptive stage IIB or IIIA NSCLC are advised to undergo a bronchoscopy and mediastinoscopy to check for additional tumors and/or mediastinal lymph node spread. The risk of distant spread is higher with these stages than it is with lower stages. Therefore, a magnetic resonance imaging (MRI) scan of the brain and a bone scan are recommended to check for unsuspected metastasis. The American College of Chest Physicians and the National Comprehensive Cancer Network guidelines both recommend PET scans as part of the pretreatment evaluation for people with stage IIB and IIIA NSCLC.

Treatment Preparations
Researchers have found a person’s performance status affects his or her NSCLC prognosis. Performance status is a measure of how well a person is able to perform ordinary tasks and carry out daily activities. Oncologists use very specific criteria to gauge your overall health and performance status. The ECOG and Karnofsky scales are commonly used to gauge performance status (see Tables 2 and 3). As you prepare for treatment, you may want to assess your lifestyle and health habits. Does your lifestyle enhance your overall health?
Table 2: ECOG Performance Status Scale

<table>
<thead>
<tr>
<th>Grade</th>
<th>ECOG Performance Status</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>Fully active, able to carry on all pre-disease performance without restriction</td>
</tr>
<tr>
<td>1</td>
<td>Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature, e.g., light house work, office work</td>
</tr>
<tr>
<td>2</td>
<td>Ambulatory and capable of all self-care but unable to carry out any work activities. Up and about more than 50% of waking hours</td>
</tr>
<tr>
<td>3</td>
<td>Capable of only limited self-care, confined to bed or chair more than 50% of waking hours</td>
</tr>
<tr>
<td>4</td>
<td>Completely disabled. Cannot carry on any self-care. Totally confined to bed or chair</td>
</tr>
</tbody>
</table>

Table 3: Karnofsky Performance Status Scale*

<table>
<thead>
<tr>
<th>Descriptor</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Normal health</td>
<td>100%</td>
</tr>
<tr>
<td>Minor symptoms</td>
<td>90%</td>
</tr>
<tr>
<td>Normal activity with some effort</td>
<td>80%</td>
</tr>
<tr>
<td>Unable to carry on normal activity but able to care for oneself</td>
<td>70%</td>
</tr>
<tr>
<td>Requires occasional help with personal needs</td>
<td>60%</td>
</tr>
<tr>
<td>Disabled</td>
<td>50%</td>
</tr>
<tr>
<td>Requires considerable assistance and medical care</td>
<td>40%</td>
</tr>
<tr>
<td>Severely disabled, in hospital</td>
<td>30%</td>
</tr>
<tr>
<td>Very sick, active support needed</td>
<td>20%</td>
</tr>
<tr>
<td>Moribund</td>
<td>10%</td>
</tr>
</tbody>
</table>

*originally developed by Drs. David Karnofsky and Joseph Burchenal

If you are a smoker, it is best to stop smoking. Some people believe that once they have been diagnosed with lung cancer, it does not matter if they continue to smoke. This is not true. A recent study showed current smoking was associated with a less favorable prognosis among people who underwent surgery for NSCLC. Most thoracic surgeons strongly encourage people to stop smoking before surgery because smoking increases the risk of complications. Smoking can worsen many symptoms of lung cancer and its treatment including mouth sores, shortness of breath, and peripheral neuropathy.

Smoking damages your health. Stopping smoking will greatly enhance your overall health. Smoking cessation is difficult because nicotine addiction is very powerful. Talk with your
cancer care providers about smoking cessation programs, nicotine replacement therapy, and use of the drug bupropion (Zyban®) to help you successfully stop smoking.

Lung cancer treatment is hard on the body. You need to take in enough calories to meet the energy demands treatment places on your body. Talk with your doctor if you are losing weight or are having problems with your appetite. He or she may suggest a consultation with a nutritionist or dietician before beginning treatment. He or she can advise you about the number of calories you need and give you tips to ensure you are getting adequate nutrition.

Exercise is another important factor in your overall health. Continue your current program if you already exercise regularly. You may need to modify your routine if the energy demands of treatment cause fatigue. If you are not currently exercising, talk with your health care providers about beginning a gentle exercise program. All forms of exercise are helpful and there are many choices. Anything that gets you up and moving is exercise including walking, biking, gardening, golfing, dancing, yoga, swimming, and many other activities. Be sure to discuss your exercise program with your health care providers to ensure it is safe for you.

Urgent dental work should be performed before beginning treatment. Mouth sores and problems with the teeth are common side effects of chemotherapy and some forms of radiation therapy. Healthy gums and teeth help prevent or reduce the severity of these problems.

**When To Begin Treatment**

Lung cancer grows for many years before it is large enough to be detected. Once you have been diagnosed, you may be anxious to begin treatment right away. However, unless your doctor tells you otherwise, you may benefit from taking a few days to organize your thoughts and make plans before starting treatment. You may want to use the time to arrange time off from your job, plan for household help, or collect information about your disease. Planning can help reduce your stress, which can make it easier to cope with the challenges of
treatment. You may want some quiet time with loved ones and friends to gather your physical and emotional strength before treatment begins.

While taking a few days to gather your thoughts and make plans can be beneficial before beginning treatment, lengthy delays should be avoided. Long delays could lead to tumor growth and/or spread of disease, lessening your chance for a cure.

I had six days to think about my surgery. I met and talked with a lot of professional people in that time period. So, by the date of the surgery, I felt that [it] was my best option.
– Sandra, diagnosed with stage II NSCLC in 1998 at age 53

Talk with your cancer care providers about any symptoms you are experiencing. Initiating treatment of disease-related symptoms before therapy begins can make cancer treatments easier to tolerate. Supportive care treatments can begin while you and your cancer care team are developing your treatment strategy.

It is your choice what treatments you want to receive. Discuss the purpose, potential side effects, and expected results of each treatment option with your cancer care team. Use your cancer care providers as consultants to aid you in making decisions. Alternatively, you may decide to give your primary cancer doctor permission to choose the treatment he or she believes is the best option for you. This is as valid a decision as any other you might make. You are the most qualified person to decide how to manage your cancer care.

**TREATMENT FOR NON-SMALL CELL LUNG CANCER**

Deciding on the appropriate treatment for NSCLC is a complex, multi-step process. Treatment options depend on the stage of disease and other factors. There are eight categories of NSCLC stages, and 18 different TNM classifications of these stages. Table 4 shows the TNM classes included in each of the lung cancer stages.
Table 4: TNM Classifications in the Four Stages of NSCLC

<table>
<thead>
<tr>
<th>NSCLC Stage</th>
<th>TNM Classification</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>TisN0M0</td>
</tr>
<tr>
<td>IA</td>
<td>T1NOMO</td>
</tr>
<tr>
<td>IB</td>
<td>T2NOMO</td>
</tr>
<tr>
<td>IIA</td>
<td>T1N1M0</td>
</tr>
<tr>
<td>IIB</td>
<td>T2N1MO, T3NOMO</td>
</tr>
<tr>
<td>IIIA</td>
<td>T3N1M0, T1N2M0, T2N2M0, T3N2M0</td>
</tr>
<tr>
<td>IIIB</td>
<td>T4N0M0, T4N1M0, T4N2M0, T1N3M0, T2N3M0, T3N3M0, T4N3M0</td>
</tr>
<tr>
<td>IV</td>
<td>anyT any N M1</td>
</tr>
</tbody>
</table>

Factors other than the T, N, and M characteristics of the disease that are taken into consideration when deciding on treatment options include:

- the number of lymph nodes with cancer cells present in them
- the presence or absence of tumor cells in the edges of surgical specimens
- performance status
- coexisting illnesses, especially pre-existing lung diseases

Clearly, decision making in NSCLC can get quite complex. It is not possible to present all the potential combinations of factors that lead to specific treatment recommendations. Each person’s situation is unique. Only qualified cancer care professionals, who have access to your medical records and test results, are able to make treatment recommendations. The overview of NSCLC treatment presented in this section provides you with general treatment concepts. Use these concepts as points of discussion when talking with your cancer care providers about treatment options. As you read the treatment overviews, keep in mind there are exceptions and other considerations that may lead your doctor to make recommendations that differ from what you read here.
The American Cancer Society and The National Comprehensive Cancer Network (NCCN) have collaborated to produce *Lung Cancer Treatment Guidelines for Patients*. This document presents the NCCN lung cancer treatment guidelines that were originally written for cancer care providers in easy-to-understand language for patients. Consult these guidelines if you have questions about your treatment options. The guidelines can be downloaded free of charge from the American Cancer Society (ACS) Internet site at [www.cancer.org/docroot/ETO/ETO_10.asp](http://www.cancer.org/docroot/ETO/ETO_10.asp). You can also obtain the guidelines by calling the American Cancer Society toll-free at 800-ACS-2345. The NCCN Internet site has an interactive version of these guidelines. The interactive format will take you through a treatment decision-tree based on your stage of disease and other specific circumstances. The NCCN/ACS interactive lung cancer guidelines are available at [www.nccn.org/patient_gls/_english/_lung/index.htm](http://www.nccn.org/patient_gls/_english/_lung/index.htm).

### Stage 0 (Carcinoma in Situ)
Carcinoma in situ is cancer confined to a small area of the lung that has not grown through the lining of the airway. This is stage 0 disease (TisN0M0). Stage 0 disease is uncommon.

The standard treatment for stage 0 NSCLC is surgical removal of the cancer. A limited procedure such as a *wedge resection* or *segmentectomy* is usually performed. If the lesion occurs in a lobar bronchus (the main airway of a lung lobe), a lobectomy is considered the standard of care. *Photodynamic therapy* is being studied as an alternative to surgery for stage 0 disease.\textsuperscript{15,16} At this time, it is an option for people who do not want surgery or cannot tolerate surgery for medical reasons. The long-term effectiveness of photodynamic therapy compared to surgery has yet to be determined. Electrocautery, *cryoablation*, and *brachytherapy* are being investigated as other non-surgical treatment options for stage 0 disease.\textsuperscript{17-20}

### Stage IA (T1N0M0), IB (T2N0M0), and IIA (T1N1M0) NSCLC
Surgical removal of the cancer is usually recommended for people who have had a bronchoscopy and a mediastinoscopy without evidence of spread to the mediastinal lymph nodes. A *lobectomy* (removal of the affected lobe of the lung) or *pneumonectomy* (removal of the entire affected lung) are the preferred procedures.\textsuperscript{21-23} You may not be able to tolerate these extensive procedures if you have pre-existing lung disease such as *chronic obstructive pulmonary*
disease (COPD) or chronic bronchitis. In such circumstances, a less extensive procedure may be chosen such as a wedge resection, segmentectomy, or sleeve resection. The surgeon will thoroughly examine the primary tumor and lymph nodes in the chest during surgery. Lymph nodes can be sampled more thoroughly during surgery than during a mediastinoscopy. The American College of Chest Physicians guidelines state all patients undergoing surgical resection for stage I or II NSCLC should have an intraoperative mediastinal lymph node evaluation. Some surgeons prefer to do a complete mediastinal lymph node dissection while others prefer systematic sampling of the lymph nodes.

If unexpected, suspicious lymph nodes are found during surgery, they can be sampled and sent to the laboratory to check for cancer cells while you are still in the operating room. The results from the samples will be reported back to the surgeon. In cases where the surgeon finds cancer in the mediastinal nodes that can be surgically removed, he or she will proceed with removal of the cancer along with a mediastinal lymph node dissection. If unsuspected cancer is found that cannot be completely removed, the surgical resection may be abandoned.

<table>
<thead>
<tr>
<th>exploratory surgery and resection (if possible)</th>
</tr>
</thead>
<tbody>
<tr>
<td>↓</td>
</tr>
<tr>
<td>no cancer in surgical margins</td>
</tr>
<tr>
<td>↓</td>
</tr>
<tr>
<td>no additional treatment or radiotherapy ± chemotherapy*</td>
</tr>
<tr>
<td>↓</td>
</tr>
<tr>
<td>cancer cells in surgical margins</td>
</tr>
<tr>
<td>↓</td>
</tr>
<tr>
<td>additional surgery or radiotherapy ± chemotherapy*</td>
</tr>
</tbody>
</table>

*Chemotherapy is not routinely recommended by the American College of Chest Physicians.7

The piece of lung removed during surgery will be sent to the laboratory. The edges of the removed tissue (the surgical margins) will be examined under a microscope to be sure there are no cancer cells present. Additional therapy is generally not needed if there is no evidence of cancer in the surgical margins. If cancer cells are found in the surgical margins, the National Comprehensive Cancer Network guidelines recommend either another surgery to remove more lung tissue or radiotherapy with or without chemotherapy to treat the remaining cancer cells.8
Radiation therapy is usually the recommended for people are unable to tolerate surgery or choose not to have surgery.24

**Stage IIB (T3N0M0) and IIIA (T3N1M0) NSCLC**

Stage IIB and IIIA tumors are more extensive than stage I and IIA tumors. They may have spread to lymph nodes near the tumor within the lung, and/or invaded the chest wall or other structures near the lungs such as the ribs, diaphragm, or the covering of the mediastinum. The greater extent of disease increases the likelihood that the cancer may have spread beyond the chest. The National Comprehensive Cancer Network and American College of Chest Physicians guidelines both recommend pretreatment PET scans for stage IIB and IIIA disease.5, 9 The National Comprehensive Cancer Network guidelines also recommend an MRI of the brain and a bone scan for people who have these presumptive stages of disease.5

If the MRI and bone scan show no evidence of distant spread and your surgeon decides he or she can probably remove the tumor, exploratory surgery is usually recommended (see Treatment Pathway 1). Lymph nodes will be thoroughly examined and sampled during surgery. If there are no unexpected findings during surgery, the cancer will be removed.

Complete resection may be the full extent of your treatment. In specific circumstances, radiation therapy with or without chemotherapy may be recommended after surgery if there is any suspicion residual cancer cells may have been left behind during surgery.

![Treatment Pathway 1](image)

If the location or spread of your tumor make it unresectable, your cancer care providers may recommend initial treatment using radiotherapy with or without chemotherapy (see
Treatment Pathway 2). After initial treatment, the tumor may become resectable. Your oncologist and surgeon will determine if this is possible. If surgical removal is not possible, additional chemotherapy and/or radiotherapy may be recommended depending on your initial treatment.

**Treatment Pathway 2**

<table>
<thead>
<tr>
<th>radiotherapy ± chemotherapy</th>
<th>surgery</th>
<th>no surgery; cancer cannot be resected</th>
</tr>
</thead>
<tbody>
<tr>
<td>no additional treatment</td>
<td>additional radiotherapy± chemotherapy</td>
<td></td>
</tr>
<tr>
<td>or</td>
<td>radiotherapy ± chemotherapy</td>
<td></td>
</tr>
</tbody>
</table>

The treatment of stage IIB and IIIA NSCLC is being studied by many investigators. Many unanswered questions remain about what therapeutic protocols constitute the most effective treatment for these stages of disease. A clinical trial may represent an opportunity to take advantage of the latest research and treatments if participating in a clinical trial is of interest to you. Talk your options over carefully with the members of your cancer care team.

**Stage IIIA NSCLC (T1N2M0, T2N2M0, T3N2M0)**

The three TNM classifications in this treatment group have in common N2 lymph node involvement. This means the mediastinal lymph nodes on the same side of the chest as the original tumor have cancer cells in them. People with this presumptive stage of disease are advised to have a bronchoscopy, mediastinoscopy, or another procedure to permit sampling of the mediastinal lymph nodes. Cancer cells found in contralateral lymph nodes or in nodes above the collarbone (supraclavicular nodes) lead to reclassification as stage IIIB. An MRI scan of the brain, a bone scan, and a PET scan are recommended to check for distant metastasis. If distant metastasis is found, the disease is reclassified as stage IV.

Exploratory surgery may be indicated for some people to check more thoroughly for lymph node involvement. If lymph node involvement is limited and the surgeon is able to remove all visible cancer, a resection will be performed. Radiotherapy with or without chemotherapy is recommended in the National Comprehensive Cancer Network guidelines for people with stage IIIA disease after recovery from primary surgery (see Treatment Pathway 1).
However, your doctor will evaluate your specific circumstances before making a recommendation.

In some cases, chemotherapy with or without radiotherapy is the initial treatment for stage IIIA disease (see Treatment Pathway 2). If the cancer responds to these treatments, surgical resection may then be performed. Surgery may be followed with additional chemotherapy and/or radiation therapy.

**Treatment Pathway 1**

- surgery
  - radiotherapy ± chemotherapy†

**Treatment Pathway 2**

- chemotherapy ± radiotherapy
  - cancer responds
    - surgery and completion of radiotherapy ± chemotherapy†
  - cancer does not respond
    - completion of radiotherapy + chemotherapy

†Chemotherapy is not routinely recommended according to the American College of Chest Physicians Lung Cancer Diagnosis and Management Guidelines.25

The American College of Chest Physicians guidelines state platinum-based chemotherapy should be used in addition to radiotherapy for people with stage IIIA NSCLC who have good performance status but are not surgical candidates.25

**Stage IIIB NSCLC (T4N0M0, T4N1M0, T4N2M0)**

These are unique TNM classifications of stage IIIB NSCLC. The tumor is large and has invaded nearby structures but has no or limited spread to the regional lymph nodes. Bronchoscopy, mediastinoscopy, MRI of the brain, a bone scan, and a PET scan are recommended to check for more extensive regional lymph node spread and distant metastasis.
tumor is resectable (some T4N0 or N1)  ⇒  Treatment Pathway 1 or 2

tumor is not resectable (T4N2)  ⇒  radiotherapy ± chemotherapy‡

‡Combined radiotherapy and chemotherapy is considered the standard of care by the American College of Chest Physicians for people with unresectable stage IIIB NSCLC who have good performance status and minimal weight loss.21

After testing, people with apparent T4N0 or T4N1 disease are likely to be referred to a thoracic surgeon to evaluate whether the cancer can be completely resected. However, the surgical treatment of people with T4N1 disease is controversial and must be decided on a case-by-case basis. Those with T4N1 disease who do undergo surgery are often given induction therapy to shrink the tumor before surgery.

In cases where the cancer is judged resectable, surgery may be performed as initial treatment. Surgery is usually followed by radiotherapy with or without chemotherapy (see Treatment Pathway 1). However, in most cases, chemotherapy with or without radiation therapy is recommended before surgery. Surgery is usually followed with radiotherapy if it has not already been given (see Treatment Pathway 2).

Unresectable tumors (T4N2) are usually treated using radiotherapy with or without chemotherapy. In some cases, unresectable disease may become resectable following chemotherapy and/or radiotherapy. A percentage of people who undergo surgical resection in these circumstances achieve long-term survival. It is not currently known whether surgical resection in this situation offers improved survival.

**Treatment Pathway 1**

- surgery
  - radiotherapy ± chemotherapy

**Treatment Pathway 2**

- chemotherapy ± radiotherapy
  - surgery
  - radiotherapy (if not already given)
**Stage IIIB NSCLC (T1N3M0, T2N3M0, T3N3M0, T4N3M0)**

These TNM classifications of stage IIIB disease all have N3 lymph node involvement. This means the disease has spread to the contralateral lymph nodes (those on the opposite side of the chest from the original tumor). This degree of spread is not treatable with surgery because the cancer cannot be completely removed. Bronchoscopy, mediastinoscopy, MRI of the brain, a bone scan, and a PET scan are recommended to check for correct staging and distant metastasis. Recommended treatment for these classifications of IIIB disease is chemotherapy and radiotherapy. Recent studies suggest giving chemotherapy and radiotherapy at the same time (concurrently) may be slightly more effective than giving one treatment followed by the other. However, the differences appear to be small, and there is greater toxicity when chemotherapy and radiation are given concurrently rather than in succession. Discuss the relative risks and benefits of concurrent treatment with your oncologist.

**Stage IV NSCLC**

NSCLC is categorized as stage IV if there is evidence of distant metastasis. With rare exceptions, stage IV disease is generally incurable. Treatment for stage IV disease is primarily palliative and supportive. Treatments are used to prolong life, improve quality of life, and relieve symptoms. Studies have shown that people with good performance status at the time of diagnosis have a more favorable prognosis than those with poor performance status. It is up to you how aggressive you want your treatment to be.

Chemotherapy is the primary treatment for advanced NSCLC. Chemotherapy options are reviewed in the following section. Radiation therapy is commonly used for symptom relief. *Chapter 10: Supportive Care* has information about treatments for many of the symptoms associated with advanced NSCLC.

A small percentage of people with stage IV NSCLC have a single brain tumor as the only site of metastasis. In this situation, the American College of Chest Physicians recommends aggressive treatment of both the primary lung tumor and the brain tumor because this is potentially curable disease. A thorough search for other sites of metastasis should be undertaken. This often includes bronchoscopy or mediastinoscopy, a bone scan, and a PET scan.
scan. However, the work-up for each person is individualized. If there is no evidence of other sites of disease, a complete resection of the lung tumor may be recommended. Surgery may be combined with radiotherapy and/or chemotherapy. The brain tumor may be treated surgically or with stereotactic radiosurgery. See Chapter 5: Lung Cancer Treatment Overview for additional information about the treatment of brain metastasis. The five-year survival for people in this unique group of stage IV NSCLC who are aggressively treated is 16-30%.

Similarly, a single adrenal gland tumor with a primary lung tumor and no other metastatic disease may be treated aggressively with curative intent. Complete surgical resection of both the adrenal and lung tumors is associated with a five-year survival of 10-23%, although this treatment has been attempted in only a small number of patients. The National Comprehensive Cancer Network guidelines state that even if cure is not achieved, prolonged life and improved quality of life are possible.

CHEMOTHERAPY OPTIONS FOR NON-SMALL CELL LUNG CANCER

Chemotherapy is an important tool in the treatment of NSCLC. It is used as neoadjuvant, primary, and adjuvant therapy. Neoadjuvant therapy is treatment given before the primary treatment to increase the chance of a cure. Adjuvant therapy is treatment given after the primary treatment to increase the chance of a cure.

Many chemotherapy agents are active against NSCLC. The choice of chemotherapy agents, timing of treatment, and dosing schedule are individualized to meet each person’s unique situation, needs, and preferences.

Neoadjuvant and Adjuvant Chemotherapy

As of this writing, there is no clear consensus regarding what the optimal neoadjuvant and adjuvant chemotherapy regimens are for the different stages of NSCLC. Numerous clinical trials are currently underway to answer these important questions. Table 5 shows some of the drugs included in previous and ongoing trials.
Table 5: Chemotherapy Drugs Being Studied for NSCLC Neoadjuvant and Adjuvant Treatment

<table>
<thead>
<tr>
<th>Generic Names</th>
<th>Trade Names</th>
</tr>
</thead>
<tbody>
<tr>
<td>— New Agents Being Studied —</td>
<td></td>
</tr>
<tr>
<td>docetaxel</td>
<td>Taxotere®</td>
</tr>
<tr>
<td>gefitinib</td>
<td>ZD1839, Iressa®</td>
</tr>
<tr>
<td>gemcitabine</td>
<td>Gemzar®</td>
</tr>
<tr>
<td>irinotecan (CPT-11)</td>
<td>Camptosar®</td>
</tr>
<tr>
<td>paclitaxel</td>
<td>Taxol®</td>
</tr>
<tr>
<td>topotecan</td>
<td>Hycamtin®</td>
</tr>
<tr>
<td>vinorelbine</td>
<td>Navelbine®</td>
</tr>
<tr>
<td>— Other Agents Being Studied in Combination Protocols —</td>
<td></td>
</tr>
<tr>
<td>5-fluorouracil (5-FU)</td>
<td>Adrucil®</td>
</tr>
<tr>
<td>carboplatin</td>
<td>Paraplatin®</td>
</tr>
<tr>
<td>cisplatin</td>
<td>Platinol®</td>
</tr>
<tr>
<td>cyclophosphamide</td>
<td>Cytoxan®, Neosar®</td>
</tr>
<tr>
<td>doxorubicin</td>
<td>Adriamycin®</td>
</tr>
<tr>
<td>etoposide</td>
<td>VePesid®, Etopophos®, Toposar®</td>
</tr>
<tr>
<td>ifosfamide</td>
<td>Ifex®</td>
</tr>
<tr>
<td>— Other Agents Being Studied in Combination Protocols (cont.) —</td>
<td></td>
</tr>
<tr>
<td>mitomycin</td>
<td>Mitomycin C®, Mutamycin®</td>
</tr>
<tr>
<td>teniposide</td>
<td>Vumon®</td>
</tr>
<tr>
<td>uracil + fторafur</td>
<td>Uracl + Tegafur®</td>
</tr>
<tr>
<td>vinblastine</td>
<td>Velban®</td>
</tr>
<tr>
<td>vincristine</td>
<td>Oncovin®, Vincasar PES®, Vincrex®</td>
</tr>
<tr>
<td>vinodesine</td>
<td>Eldisine®</td>
</tr>
</tbody>
</table>

Chemotherapy for Advanced NSCLC

The National Comprehensive Cancer Network and American College of Chest Physicians lung cancer guidelines both state the standard of care for first line therapy for stage IV NSCLC is platinum-based chemotherapy with one of the newer chemotherapy agents.\textsuperscript{5,31} Platinum-based therapy is combined treatment with cisplatin (Platinol®) or carboplatin (Paraplatin®) plus one or more other chemotherapy drugs. Table 6 shows chemotherapy combinations currently considered standard of care. To date, these choices are considered comparable, that is, none of them is clearly superior to the others.
Table 6: Standard of Care First Line Chemotherapy
For Stage IV NSCLC\textsuperscript{31,36}

<table>
<thead>
<tr>
<th>Generic Names</th>
<th>Trade Names</th>
</tr>
</thead>
<tbody>
<tr>
<td>docetaxel + carboplatin</td>
<td>Taxotere\textsuperscript{®} + Paraplatin\textsuperscript{®}</td>
</tr>
<tr>
<td>docetaxel + cisplatin</td>
<td>Taxotere\textsuperscript{®} + Platinol\textsuperscript{®}</td>
</tr>
<tr>
<td>gemcitabine + carboplatin</td>
<td>Gemzar\textsuperscript{®} + Paraplatin\textsuperscript{®}</td>
</tr>
<tr>
<td>gemcitabine + cisplatin</td>
<td>Gemzar\textsuperscript{®} + Platinol\textsuperscript{®}</td>
</tr>
<tr>
<td>paclitaxel + carboplatin</td>
<td>Taxol\textsuperscript{®} + Paraplatin\textsuperscript{®}</td>
</tr>
<tr>
<td>paclitaxel + cisplatin</td>
<td>Taxol\textsuperscript{®} + Platinol\textsuperscript{®}</td>
</tr>
<tr>
<td>vinorelbine + carboplatin</td>
<td>Navelbine\textsuperscript{®} + Paraplatin\textsuperscript{®}</td>
</tr>
<tr>
<td>vinorelbine + cisplatin</td>
<td>Navelbine\textsuperscript{®} + Platinol\textsuperscript{®}</td>
</tr>
</tbody>
</table>

There is no single chemotherapy combination or protocol recommended for all people with advanced NSCLC. Several active chemotherapy combinations are in use. The choice of chemotherapy drugs is individualized on a case-by-case basis. The choice of drugs is influenced by your overall health, other illnesses or conditions you may have, and your personal preferences.

Several drugs are in clinical trials for first and second line treatment of advanced NSCLC, most in combination with drugs that have known activity against NSCLC. Examples include bevacizumab (Avastin\textsuperscript{®}), bexarotene (Targretin\textsuperscript{®}), celecoxib (Celebrex\textsuperscript{®}), DEAE-rebeccamycin, exisulind (Aptosyn\textsuperscript{®}), infliximab (Remicade\textsuperscript{®}), irinotecan (Camptosar\textsuperscript{®}), lonafarnib (Sarasar\textsuperscript{®}), oblimersen (Genasense\textsuperscript{®}), pemetrexed (Alimta\textsuperscript{®}), polyglutamate paclitaxel (Xyotax\textsuperscript{®}), suramin, tipifarnib, thalidomide (Thalomid\textsuperscript{®}), and tretinoin (Retin-A\textsuperscript{®}). Talk with your cancer care team if you are interested in participating in a clinical trial.

There is no clear consensus about the number of chemotherapy cycles needed for maximum benefit.\textsuperscript{35} However, research has shown that with current chemotherapy regimens, treatment beyond six cycles for first line therapy is probably not useful and adds to treatment-related toxicity. The National Comprehensive Cancer Center Network guidelines recommend 4-6 cycles of chemotherapy.\textsuperscript{3} The American College of Chest Physicians guidelines recommend 3-4 cycles of chemotherapy.\textsuperscript{31} Clinical trials are underway to address this issue.
RESPONSE TO THERAPY

Evaluation During Treatment: Is It Working?
There are many ways to determine if treatment is working. Your symptoms are a possible indicator of response to treatment. Symptom improvement may be an indication that treatment is helping. Your doctor will perform a physical examination at each office visit. He or she will check for any changes that may give information about how your body is responding to treatment. The examination also helps your doctor decide if any tests need to be done. Imaging tests such as chest x-rays or CT scans are often used to check the size of the tumor(s) in response to therapy. The timing of these tests varies. Your doctor may check tumor size after your first cycle of chemotherapy or may wait until after several cycles have been administered. How your cancer care team monitors you for treatment response depends on what treatments are being used, how you are tolerating treatment, and other factors. Discuss your specific monitoring protocol with your providers.

Follow-Up After Completion of Curative-Intent Treatment
People who have no apparent signs of cancer after completing treatment must be carefully monitored for recurrent disease and the development of a second primary lung cancer. The National Comprehensive Cancer Network guidelines recommend a physical examination and chest x-ray every three to four months for two years, then every six months for three years, then yearly thereafter. These guidelines also recommend an annual spiral CT scan of the chest because it is more sensitive than a chest x-ray. However, there was not complete agreement among NCCN members on this recommendation.\(^5\)

The American College of Chest Physicians recommendations for follow-up after curative intent treatment are slightly different. These guidelines recommend physical examination and chest x-ray or CT scan every six months for two years, then annually thereafter.\(^6\) Discuss your specific follow-up plan with your cancer care team. Be sure to attend every follow-up visit. Also, be aware of signs and symptoms that may indicate a recurrence of disease. Talk this over with your cancer care doctor. Call your doctor immediately if you experience any new symptoms that may indicate a recurrence of disease. Do not wait until your next scheduled appointment.
Monitoring for Disease Progression in Advanced NSCLC

People with advanced NSCLC are usually treated with 3-6 cycles of chemotherapy. Many people will experience stabilization of their disease, or a partial or complete response to treatment. Your ongoing care will depend on your symptoms, supportive care treatments, and other needs. Physical examinations, symptoms of disease, chest x-rays, blood tests, and other tools are used to monitor for disease progression.

TREATMENT FOR DISEASE PROGRESSION IN ADVANCED NSCLC

The majority of people treated for advanced NSCLC will eventually experience progression of their disease. Disease progression means the cancer begins to grow again and may possibly spread. People who experience disease progression but are still feeling relatively well may decide to try second line chemotherapy. The use of second line chemotherapy in people with good performance status is supported by both the National Comprehensive Cancer Network and American College of Chest Physician NSCLC treatment guidelines.\textsuperscript{5,31} The choice of second line chemotherapy is dependent on the first line treatment used, your overall health, and other factors. Recently, gefitinib (ZD 1839, Iressa\textsuperscript{®}) was approved by the Food and Drug Administration as second line, single agent therapy after treatment failure with platinum-based combination therapy and docetaxel. Clinical trials are also available to people who have had disease progression after first line therapy. Regardless of whether you have second line chemotherapy, your cancer care team will continue to provide supportive care.

TREATMENT FOR RECURRENT DISEASE

NSCLC can recur locally or as distant metastasis. Local recurrence is return of the cancer at the original site. Table 7 shows the National Comprehensive Cancer Network treatment recommendations for problems caused by local recurrences.
Local recurrence will trigger a work-up much like the initial work-up to evaluate the spread of disease. If there is no evidence of distant metastasis and the recurrence can be removed, surgery is usually recommended. This is usually followed with radiotherapy and/or chemotherapy.

The presence of distant metastasis leads to treatment for advanced NSCLC. Platinum-based chemotherapy is recommended for systemic (whole body) control of disease. Local symptoms are treated as they are for anyone who has advanced NSCLC. It is up to you how aggressive you want to be with treatment for recurrent disease. No matter what you choose, your cancer care team will continue to provide the supportive care you need.

**SUMMARY**

Treatment for NSCLC is based on the extent of your disease. Local disease with limited spread may be cured with surgery. More advanced spread often requires combination treatment with surgery, chemotherapy, and/or radiotherapy. Advanced NSCLC is treated primarily with chemotherapy. Radiotherapy is commonly used to treat local symptoms of advanced disease. Many supportive and palliative care techniques are available to help alleviate disease symptoms. You may want to consider one of the many NSCLC clinical trials available when evaluating your treatment options.
The choice of treatment depends on the stage of your disease, overall health, personal preferences, and other factors. No single approach can be used effectively for all cases of NSCLC. Your treatment plan must be individualized to meet your specific situation, needs, and preferences.

Questioning your cancer care team can help you better understand your treatment options and feel more comfortable with your decisions. Additional sources of information can be found in the *Resource Directory*. 
CHAPTER 8: CLINICAL TRIALS

INTRODUCTION

The mainstream health care system in the United States is predominantly an evidence-based system. This means that new drugs and treatments go through a series of research studies in people to determine if they are safe and effective before they become accepted medical practice. The studies used to determine the effectiveness and safety of new drugs and treatments are called clinical trials.

This chapter explains different types of clinical trials and the processes involved in each type of trial. Potential advantages and disadvantages are discussed. If you are interested in participating in a clinical trial, discuss your interest with your health care providers.

WHAT IS A CLINICAL TRIAL?

Clinical trials are medical research studies in which people enrolled as participants help doctors find out if a new treatment or procedure is safe and effective. Clinical trials are used to test all types of medical interventions. New tests and procedures are tested to find out if they are safe and effective for diagnosing disease. New drugs, treatment schedules, and surgical procedures are tested to determine if they are safe and effective treatments for specific diseases. Dietary regimens, nutritional supplements, exercise programs, and other interventions are tested to discover if they are able to prevent disease safely and effectively. Most new medical interventions are tested in clinical trials before being made available to the general public.

Each clinical trial is carefully designed to answer a specific medical question. Clinical trials are controlled to ensure that at the end of the trial, researchers are able to answer the
question being considered. With the help of people who enroll, clinical trials enable doctors to find better ways to prevent, diagnose, and treat cancer.

This book is written primarily for people who have recently been diagnosed with lung cancer and their families. Therefore, this chapter will focus on treatment clinical trials. Many types of cancer treatments are tested in clinical trials. New chemotherapy drugs, surgical procedures, radiation techniques, vaccines, and biological therapies are a few examples. The importance of clinical trials in bringing new therapies to people facing cancer cannot be overstated. Every new cancer therapy made available to people afflicted with cancer has been tested in clinical trials. The treatment options available to people facing cancer today were made possible by people with cancer who have participated in clinical trials in the past.

*Quality of life* studies are another type of clinical trial of interest to people currently facing cancer. Quality of life trials are also called supportive care trials. These trials study drugs, procedures, and other measures that are intended to improve the comfort and quality of life of people with cancer. These trials are conducted in much the same way as treatment trials. For the sake of simplicity, treatment trials will be used to discuss the clinical trial process. Keep in mind that most of what is said about treatment trials also applies to supportive care trials.

**CLINICAL TRIAL OVERVIEW**

Before any new cancer treatment is tested in people, it is first studied in the laboratory. Various techniques are used to test different types of treatments. Drugs and biological treatments are often tested using cancer cells that are grown in a laboratory. Some treatments are tested in animals. Regardless of the techniques used, all new treatments have undergone extensive testing before they are considered for clinical trials. The testing performed in the laboratory before clinical trials begin is called *preclinical testing*.

In the United States, the Food and Drug Administration (FDA) oversees clinical trials in which new drugs or treatments are studied. In cancer research, these clinical trials are
conducted to find cancer treatments that are more effective and/or safer than treatments that are already in use. Individual doctors, groups of doctors, medical schools, cancer centers, or other medical institutions can sponsor cancer treatment trials. Drug companies and diagnostic equipment companies also sponsor clinical trials.

Clinical Trial Funding
Most cancer trials conducted in the United States are fully or partially supported with federal money. The National Cancer Institute (NCI) sponsors many cancer clinical trials through four nationwide programs.

- **The Cancer Centers Program**
The Cancer Centers Program of the NCI supports cancer research at major academic and research institutions throughout the United States. This program supports both laboratory-based research and clinical trials.

- **The Clinical Trials Cooperative Group Program**
The Clinical Trials Cooperative Group Program supports organizations that conduct clinical trials consistent with national priorities for cancer treatment research. The groups in the program are able to rapidly enroll patients from multiple centers into a clinical trial. This helps ensure that large trials can be completed as quickly as possible. As of 2005, 12 Cooperative Groups were funded by this program. Cooperative Groups participating in lung cancer research in 2005 are listed below.

  - American College of Radiology Imaging Network
  - American College of Surgeons Oncology Group (ACOSOG)
  - Cancer and Acute Leukemia Group B (CALGB)
  - Eastern Cooperative Oncology Group (ECOG)
  - National Cancer Institute of Canada, Clinical Trials Group
  - North Central Cancer Treatment Group (NCCTG)
  - Radiation Therapy Oncology Group (RTOG)
  - Southwest Oncology Group (SWOG)

- **Community Clinical Oncology Program**
The Community Clinical Oncology Program (CCOP) encourages community-based doctors to work with scientists conducting NCI-supported clinical trials. The CCOP increases the number of patients and doctors who can participate in clinical trials.
operated at major research centers. It also helps researchers conduct large-scale cancer studies quickly.

- **Specialized Programs of Research Excellence**
  In 1992, the NCI established the Specialized Programs of Research Excellence (SPOREs) to promote clinical and laboratory research. The goal of the SPORE program is to bring new ideas and discoveries from the laboratory to the clinical care setting quickly. The SPORE programs sponsor many unique, innovative clinical trials. As of 2005, there are six lung cancer SPORE programs. An exploratory program (*) is also underway.

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**The Clinical Trial Protocol**

The action plan for a clinical trial is called the trial protocol. The protocol outlines the purpose of the trial and the research questions being investigated. The protocol also describes the trial design and study procedures. This includes specific medical criteria for determining who will be enrolled in the trial, what drugs will be administered and their dosing schedule, testing and follow-up procedures, and other study details.

The protocol ensures that all people enrolled in a trial are treated the same way, even if they are treated at different locations. Strict compliance with the clinical trial protocol is necessary to insure reliable study results. The clinical trial protocol is developed by the trial’s lead researcher who is called the principal investigator. The protocol must be reviewed and approved by the organization sponsoring the clinical trial. Each location participating in the
trial must also submit the protocol to their Institutional Review Board for the Protection of Human Subjects in Research (IRB). As the name implies, the function of the IRB is to protect the rights and welfare of people who participate in clinical research. All protocols are reviewed to insure that:

- participants are selected fairly
- stringent informed consent procedures are in place
- all risks for participants have been minimized
- participants’ privacy and confidentiality will be protected

No participants can be enrolled in a clinical trial until IRB approval has been obtained.

**Informed Consent**

All people enrolled in clinical trials are required to sign an informed consent form. When you sign an informed consent form, you are confirming that you:

- have discussed the clinical trial protocol with your doctor and/or nurse,
- have been told about the possible risks and benefits of participating and not participating in the trial, and
- are participating in the trial because you choose to do so of your own free will

If you have any questions about the clinical trial protocol, discuss them with your health care provider. Be certain you understand all the possible risks and benefits of the trial and your responsibilities. If you are unclear about anything having to do with the trial, ask for clarification before signing the informed consent form. You can always talk with your doctor, nurse, or someone else on the clinical trial team if additional questions come up during the trial.

You can withdraw from a clinical trial at any time if you choose to do so. Signing an informed consent form does not prevent you from withdrawing from a clinical trial.

**TYPES OF CLINICAL TRIALS**

Three types of clinical trials must be successfully completed before the FDA will approve a new drug for a specific condition or disease. The three types of trials are called phase I,
phase II, and phase III trials. Each phase trial has a different purpose, which will be explained later in this section. The process of evaluating a new drug in people begins with a phase I trial. If the results of the phase I trial demonstrate acceptable safety, testing progresses to a phase II trial. If acceptable safety and benefit are demonstrated in the phase II trial, a phase III trial is conducted. A phase IV clinical trial is sometimes conducted after a drug becomes available to the public.

**Phase I Trials**

Phase I trials involve the first testing of a new drug in humans. The focuses of a phase I trial are the safety of the drug and how best to administer it. The purposes of a phase I treatment trial are:

- to find out the best way to administer the drug, for example, by mouth, injected into the blood, or injected into the muscle
- to study how often should the drug be given
- to determine the highest, safe dose that can be administered
- to discover if there are any negative side effects from the drug

A phase I trial enrolls a small number of people, usually 10-20. People enrolled in phase I cancer treatment trials have often exhausted all other treatment options. They are enrolled with the hope that the new drug may benefit them, although determining clinical benefit from the drug is not the primary purpose of a phase I treatment trial.

**Phase II Trials**

A phase II trial is conducted on new drug or drug combination that appeared safe in a phase I trial. The purposes of a phase II treatment trial are:

- to continue to evaluate the safety of the drug
- to study how the body *metabolizes* and eliminates the drug (this is known as pharmacokinetic data)
- to collect preliminary data about the effectiveness of the drug for a specific condition
A phase II trial enrolls between 20-100 people. The goals of a phase II treatment trial are to confirm drug safety and determine if there appears to be sufficient benefit to patients to warrant further study. The FDA requires phase II clinical trial information to prove the safety of a new drug before allowing it to be sold.

**Phase III Trials**

Phase III treatment trials are conducted for new drugs or drug combinations that show promising results in phase II trials. The purpose of a phase III trial is to compare a new drug or drug combination to other available treatments. The study design used for most phase III treatment trials is called a *randomized controlled trial*. These trials have at least two treatment protocols or treatment arms. People in the *experimental treatment arm* receive the new drug. People in the *control arm* receive the current standard of care, in other words, the best currently approved treatment. Some phase III trials have additional treatment arms to allow multiple comparisons between different treatment protocols. Phase III trials require large numbers of people to enable researchers to reliably answer the study questions. Phase III trials typically enroll 200-1,000 people or more. These trials usually enroll people from many different sites located throughout the country. A phase III treatment trial must conclusively show effectiveness through objective measures of patient benefit before the FDA will approve a new drug to treat a specific condition or illness. After the completion of the phase III trial, the sponsor of a new drug can file a New Drug Application (NDA) with the FDA. The NDA is the final step required to make a new drug available to people outside a research setting.

People enrolled in phase III treatment trials usually must agree to a process called *randomization*. In the randomization process, you are assigned by chance to one of the treatment groups. In other words, you do not have a choice about what treatment you receive. Further, many phase III treatment trials are *blinded trials*. In a blinded trial, you will not know whether you are receiving experimental or standard treatment. Blinding is important to ensure that the results of the trial are valid. In a double-blind trial, neither you nor your health care providers will be aware of what drugs you are receiving.
**Phase IV Trials**

Phase IV clinical trials examine the long-term effects of drugs or treatments after they have received FDA approval. Since this type of trial is not required to market a drug, it is not as common as the other types of clinical trials. Phase IV trials are most often sponsored by pharmaceutical companies. Another term used for phase IV clinical trials is *post-marketing surveillance studies*.

**FDA REVIEW AND APPROVAL PROCESSES**

Clinical trials that propose to evaluate a new drug must first submit an Investigational New Drug (IND) application to the FDA. The application contains all the information that has been gathered in preclinical testing of a new drug. If the FDA determines the drug is reasonably safe and may have clinical benefit, the IND is approved. This approval is required before clinical trials can begin.

When the results of phase I and II treatment trials for a new drug indicate the drug is safe and shows promise in terms of effectiveness, the sponsor has a pre-NDA meeting with the FDA. At this meeting, the sponsor, principal investigators, and the FDA decide what needs to be done in the phase III treatment trial to determine conclusively whether the new drug is safe and effective for a specific condition or disease. The phase III trial is conducted according to what has been agreed upon at the pre-NDA meeting.

Upon completion of a phase III cancer treatment trial, the drug sponsor submits a New Drug Application to the FDA. Once the NDA is filed, an FDA review team evaluates whether the information from the clinical trials show that the new drug is safe and effective for its proposed use. Review teams for cancer therapies include oncologists, chemists, statisticians, pharmacologists, and other experts. The review team also includes a cancer survivor who brings the patient perspective to the discussions. If the FDA decides the benefits of a new drug outweigh the risks, the drug receives approval for marketing in the United States.
An FDA approved drug is generally paid for by health insurance if it used for the purpose for which it was approved. However, a doctor can prescribe an FDA-approved drug for any purpose he or she determines is appropriate. If a drug is used for a purpose other than the one for which it was approved, this is called \textit{off-label use} or \textit{unapproved indications use}. This situation may come up in cancer treatment. For example, there are times when a drug approved for one cancer is still in trials for another form of cancer. Your doctor may such a drug is your best treatment option. Your doctor has every right to prescribe the drug for you, but its use in this case would be for an unapproved indication. Some health insurance companies will not pay for drugs that are used for unapproved indications. Cancer advocates are working to change this situation.

\section*{PARTICIPATING IN A CLINICAL TRIAL}

Clinical trials offer people with cancer an alternative to standard treatment. Many who participate in clinical trials see it as an opportunity to receive quality health care while making a valuable contribution to medical science and humanity.

\begin{quote}
I am such a believer in clinical trials, particularly because I am a part of what seems to be a pretty large percentage of people for whom chemotherapy was not effective. My first trial was a pretty easy choice because I was getting the trial drug in addition to what would have been the chosen protocol for my type and stage of lung cancer…. I also know that my oncologist, who is involved in a large number of clinical trials, does so at great expense in both time and money. He wouldn't do it if he wasn't really convinced that these trials are critical to finding help for his patients…. I am convinced that we must have a variety of weapons in our arsenal against cancer … no one treatment can possibly work for all of us. The more choices we have in treatment, the more likely we will find one that works. That can only happen if we have lots of research to find new and better ways to fight the disease.
—Ann, diagnosed with stage IIIIB NSCLC in 2002 at age 54
\end{quote}

The decision whether to participate in a clinical trial is a highly personal choice, especially when you are facing a potentially life-threatening illness. There are several factors to take into consideration when making such an important decision. This section provides information that will help you think through your options. If you are interested in clinical trials, discuss the option with your health care providers and those closest to you. The choice to participate, however, is yours and yours alone. You know best what is right for you.
Possible Advantages of Participating in a Clinical Trial

There are a number of possible advantages to participating in a clinical trial.

- Clinical trial participants are often treated by leading doctors in the field of cancer research.
- Participation may provide you with access to new drugs or treatments that are not yet available outside of a clinical trial.
- You may feel a greater sense of control over your health care situation by actively choosing to participate in a clinical trial.
- There is a possibility you may receive more effective treatment than the current standard of care.
- People who participate in clinical trials often derive a sense of satisfaction from making a valuable contribution to lung cancer research.
- The knowledge that you are helping other people with lung cancer may give you a sense of personal accomplishment.
- Part of your treatment may be provided free of charge.

I went on the Internet and checked out various types of clinical trials. There are many interesting studies going on. My oncologist thought that going into an Iressa™ study would be my best hope, and fortunately, it was. It shrunk my cancer, whereas before [going on Iressa™], chemo was not working [for me]. I am very happy participating in this trial. If for some reason I need to try something else, I will definitely be looking for another [clinical] trial.

− Judy, diagnosed with stage IV NSCLC in 2002 at age 59

Possible Disadvantages of Participating in a Clinical Trial

Participation in a clinical trial has possible disadvantages that should be considered. Although great efforts are made to protect the safety of people participating in clinical trials, there is no such thing as risk-free medical care. Generally, potential risks are greatest in phase I trials. Risks are usually diminished in phase II trials, and are lowest in phase III and IV trials. Some potential risks or disadvantages of clinical participation are:

- You may experience unexpected side effects. New drugs and procedures may have adverse effects or risks that are unknown to the trial sponsors and your health care providers.
• There is always the possibility that the new drug will prove to be ineffective or less effective than the current standard of care.

• If you are in a randomized trial, you may not receive the experimental drug you were hoping to receive.

• Even if the new treatment is effective for most people, it may not work for you.

• You may not like the idea of participating in a medical experiment.

• If you are participating in a blinded trial, you may find it hard to handle not knowing what treatment you are receiving.

• You may be uncomfortable with not having a choice about what treatment you receive if you participate in a randomized trial.

Health Insurance Coverage and Clinical Trials
As of January 2001, Medicare covers the costs associated with clinical trials involving cancer diagnosis or treatment. However, private health insurance coverage varies for clinical trials. Each plan has its own rules about what costs are covered when you are participating in a clinical trial. Some plans offer only partial coverage in a clinical trial setting if the plan considers the study treatment experimental or investigational. Health insurance companies decide what services they will pay for by developing coverage policies. Health plans usually designate a service as ‘established’ if there is sufficient evidence to show that it is safe and effective. If the plan judges the available data insufficient, a service may be deemed ‘investigational’ and not covered under the plan. Since each health insurance plan differs in terms of coverage of services rendered in a clinical trial, you need to check with a representative from your plan to determine their coverage for clinical trials.

Some health insurance plans have specific criteria a clinical trial must meet for the plan to cover associated costs. Other plans have specific limitations for clinical trial coverage. Examples of such criteria and limitations are listed below.

• The clinical trial must be sponsored by an organization whose review and oversight of the trial is scientifically rigorous.

• The clinical trial must be judged by plan administrators to be medically necessary. Often this judgment is made on a case-by-case basis.
• Coverage may be limited to phase III trials.
• Documentation may be required before the plan will approve participation in a clinical trial.
• Coverage may be limited to clinical trials the plan deems cost-neutral, meaning the cost to the insurance company is not more than would be required for standard treatment.
• A plan may cover only clinical trials involving conditions for which there are no standard therapies.
• An insurance company may require proof of the qualifications of the medical staff and the care facility before covering the costs of unique services.

There are two types of costs associated with clinical trials, patient care costs and research costs. Patient care costs are divided into two categories, usual care costs and extra care costs. Usual care costs include doctor visits, hospital stays, x-rays, and laboratory tests that would be necessary regardless of whether you are receiving standard treatment or are participating in a clinical trial. These costs are usually covered by health insurance plans and Medicare. Extra care costs are for visits, tests, or procedures that are required by a clinical trial, but would not be necessary if you were receiving standard treatment. Extra care costs are sometimes paid by the sponsoring organization or the research institution. If there are extra care costs that are not paid by the trial sponsor or research institution, you may be able to get your health insurance to pay these costs. You will have to work this out with your insurance provider in advance.

Research costs are the costs associated with conducting a clinical trial. These costs include data collection, investigators’ time, nurses’ time, data analysis, and other administrative costs. Study participants are not required to pay anything toward these costs. These costs are usually paid by the study sponsor.

**Talking With Your Health Care Providers**
If you are interested in participating in a clinical trial, talking with your current doctor is a good way to begin collecting information. He or she can answer your questions, or may put
you in contact with others who will be better able to assist you. If your health care provider seems hesitant about clinical trials, he or she may have concerns that have little to do with you such as:

- Health care providers who do not regularly participate in clinical research may feel unprepared to discuss the topic of clinical trials.

- Your doctor may be concerned about the demands on his or her time if you are participating in a clinical trial. He or she may be worried about having enough time to take care of you and the other patients in the practice.

- If you are not feeling well, your doctor may be worried that the demands of a clinical trial may be too much for you.

- Your doctor may be convinced that standard treatment is the best option for you, and reluctant to recommend another treatment option.

- Your doctor may be concerned about losing you as his or her patient if you participate in a clinical trial.

You may need to look for other sources of information if your current care provider is not able to answer all your questions. A list of resources for gathering information about clinical trials is included at the end of this section.

Once you have found a particular clinical trial you are interested in, you will probably want to consider specific information about the trial before making a final decision. Following is a sample list of considerations. You may want additional information.

- What is the purpose of the trial? Is the goal in keeping with your needs?

- What are the eligibility requirements? Are you likely to be eligible for the trial?

- Who will be in charge of your care?

- Will you be able to see your regular oncologist, or will you become someone else’s patient?

- Who will monitor your care and safety?

- Where will you receive your care?
• How long will the trial last?
• What can you reasonably expect if you participate in the trial? What can you reasonably expect if you do not participate in the trial?
• What will your responsibilities be if you participate in the trial?
• What are the possible short-term benefits of the trial? What are the possible long-term benefits?
• What kinds of treatments, procedures, or tests will you have to undergo? Are they painful?
• What are the possible side effects? Are they any worse than the possible side effects from standard treatment? Are there any long-term side effects? Who will monitor you for these side effects?
• Is participating in the trial going to affect your daily life? If so, how?
• Will you have to pay for treatment? Will any of the treatment be free? Who will help you answer insurance coverage questions?
• Will participating in this trial prevent you from receiving other therapies now or in the future?
• What is the follow-up care plan for the trial?
• Whom can you call if you have problems during the trial?

More Information About Clinical Trials

To learn more about clinical trials in general or about specific trials currently available for people with lung cancer, call or contact one or more of the following organizations, or check with some of the on-line clinical trial locators.

National Cancer Institute (NCI)
Cancer Information Service
800-422-6237
www.cancer.gov/clinicaltrials

Food and Drug Administration (FDA)
Office of Special Health Issues
301-827-4460
www.fda.gov/oashi/cancer/cancer.html
SUMMARY

All new lung cancer treatments are made available because people have participated in clinical trials to prove the effectiveness and safety of those new treatments. Clinical trials offer another treatment option for people with lung cancer. There are potential advantages and disadvantages to participating in a clinical trial.

To determine if a clinical trial is right for you, talk with your health care provider. Gather the information you need to make a knowledgeable choice. Ultimately, each person must decide what the best treatment option is for his or her goals.
CHAPTER 9: LIVING WITH LUNG CANCER

INTRODUCTION

A diagnosis of lung cancer can lead to many powerful feelings: shock, fear, denial, anger, anxiety, confusion, guilt, shame, uncertainty, loneliness, doubt, and others. These emotions are entirely normal responses to learning you have a life-threatening disease.

Facing cancer is one of the most difficult challenges a person can experience. This chapter discusses the feelings and challenges you may have to deal with once you have been diagnosed with lung cancer. How you deal with these challenges depends on your coping style. Coping is broadly defined as a person’s way of dealing with difficult situations. Though the definition is broad, a person’s individual coping strategies are quite specific. However, no two people have identical coping strategies.

There is no right way to cope with a diagnosis of lung cancer. People cope with cancer in different ways, just as people cope with other life problems in different ways. You will cope with your diagnosis in your way. The purpose of this chapter is not to tell you how to cope, but to provide you information that will hopefully help you cope your own way. A successful coping strategy is not one that matches some specific criteria, but rather, is one that suits your personality and contributes to your sense of well-being.

In the days and weeks after your diagnosis, you will face several difficult tasks including:

- coming to terms with the news,
- telling your immediate family about your diagnosis, and
- deciding how, when, and what to tell others in your life.

At the same time you are trying to deal with these emotionally draining tasks, you will also be entering a new medical world. This new world can be overwhelming at first.
There will be new words and procedures, treatment decisions to be made, and financial and health concerns. The enormity of these early weeks can be very bewildering. After the initial shock of your diagnosis wears off and you have had a chance to work out the details necessary to begin your treatment, things will begin to settle down. Our hope is that you will soon find a way to continue with your life in a satisfying way, that you will find your way of living with lung cancer.

COMING TO TERMS WITH YOUR DIAGNOSIS

Support
For most people, the days and weeks following a diagnosis of lung cancer are very difficult. Researchers have found that being diagnosed with a major illness is one of the most stressful life events anyone can experience. Most people experience a wide range of strong emotions such as disbelief, fear, sadness, anger, confusion, helplessness, and worry about the future. The number and intensity of these emotions can feel overwhelming at first. But remember, all of these feelings are normal and completely justified. In time, the intensity and frequency of these powerful emotions will begin to lessen. Your coping skills that have carried you through the rest of your life will help you through this, too.

The first reaction many people have after being diagnosed with lung cancer is shock. You may feel stunned, numb, and bewildered. The feeling of numbness may be particularly distressing but it is quite normal. It is your mind’s way of keeping you from being overwhelmed. Your thinking may seem disorganized at first, as your mind is likely to be filled with questions and concerns.

- Am I going to die?
- Why did this happen to me?
- What happens now?
- What will my treatment be like? Is it going to be difficult? Will it be painful?
- How will my family and friends react to the news?
• How will this change my life?
• Will I be able to work? How will this affect my family financially?

In 1969, psychiatrist Dr. Elisabeth Kübler Ross defined five stages of coming to terms with a significant loss.¹ It has since been shown that these five stages are commonly experienced by people who experience a life-threatening illness, too. The emotional reaction stages are:

**Denial** – feelings of shock and numbness
“This cannot be happening to me. There must be some mistake.”

**Anger** – anger at God, the people around you, or yourself
“I’m not a bad person. How could God do this to me?”

**Bargaining** – feelings of unwarranted guilt, trying to fix things
“If I’m cured, I’ll take better care of myself. I’ll live a better life.”

**Depression** – the reality of the situation begins to set in; feelings of helplessness, floundering, sadness, and despair
“I have cancer. My life is over. I can’t go on.”

**Acceptance** – the reality has been accepted, and a new beginning is found; feelings of hope, motivation, and peacefulness
“I have lung cancer. I’m going to do what I need to do to live each day to the best of my ability.”

Each person’s experience of these stages is unique, but most people find they have feelings related to each of the stages. It is common to fluctuate from one stage to another during the process of coming to acceptance. Acceptance is associated with a resumption of interaction with others and a sense of connectedness. Feelings of isolation are largely overcome.

The whirlwind of thoughts and feelings make some people wonder, “Am I losing my mind?” Rest assured, you are not losing your mind. You are reacting in a normal way to an extraordinarily difficult situation. The intensity and variety of feelings you are experiencing may be unlike anything else you have ever experienced. Human emotions are part of what makes the experience of living as rich and colorful as it is. However, when our emotions are running high, our ability to handle them may reach its limit. Psychologists who study human emotions tell us that intense emotions have to be released. Although there are many ways to release your feelings, one way all people have in common is talking with others.
It helped me to talk to people. I just knew the doctors were killing me – or so I thought. I was lucky. I had an amazing social worker, Sherilyn. I don’t know what I would have done without her. God sent me an angel. She would take me to her office, and I would just ball on her shoulder. I felt like I could go ahead and face it after I talked with her.

– Judy, diagnosed with limited SCLC in 1998 at age 57

There are people who are naturally communicative about their emotions. Others are more private about their emotions. Neither approach is right or wrong. Those who are normally more conversant about their feelings may find it easier to express themselves during a highly emotional time. However, even the most private people need to share their feelings during difficult times. Talking with a trusted loved one about your feelings can help lighten your load. While it is important to share this time with your loved ones, you may find that the people you usually turn to for support during times of stress are also reeling from the news. In fact, having a loved one diagnosed with a major illness is also one of the most stressful life events a person can experience. While it may be comforting to know that others share your sadness and fears, you may find those closest to you are temporarily unable to offer the support you need. Therefore, you may find it useful to talk to people who are not immediately involved in your life, too.

Many organizations may be useful to you in your journey with lung cancer. Contact information for some of these organizations can be found in the Resource Directory. Your community hospital might also be able to direct you toward resources that may be helpful to you.

Many communities have support groups for people with cancer. Some support groups are limited to people with lung cancer, others include people with different cancers. A support group can provide you opportunities to talk with others who are in circumstances similar to yours. Support groups share concerns, helpful tips, information, and resources.

I felt so isolated, as if there was no one out there going through this like I was. But when I went to the support group for the first time, it was amazing. You learn so much from talking with other patients who are going through [the experiences] rather than talking with your doctor or nurse who has never experienced it. I remember one meeting a new patient came and she cried through most of the meeting, but when she came back the next time, she told us how much we had helped her. She told us the night after the meeting was the first night she had been able to sleep since being diagnosed… It’s wonderful to be a survivor now and see
how you can help someone. We are like a family. When someone doesn't show up, then another member checks up on him and is there for him – always. It's really a great group of people.
– Larry, diagnosed with stage II NSCLC in 1991 at age 53

Coping Styles
The psychological impacts of being diagnosed with cancer are so broad and challenging that a specialized field of psychology called psycho-oncology has been created. The providers in the field of psycho-oncology work to help people with cancer adjust to living with cancer. They also study the interactions between the mind and body among people with cancer.

Stressful situations can potentially pose two problems, anxiety and depression. Coping mechanisms are those actions we automatically take to rid ourselves of excess anxiety and to keep ourselves from becoming overwhelmingly depressed. Each of us uses many different coping mechanisms daily without even thinking about them. Your unique personality, cultural background, religious or spiritual beliefs, life situation, philosophy of life, and other factors influence how you cope. There is no right or wrong way to cope with cancer. There are only coping mechanisms that are helpful to you, and those that are not. Helpful coping mechanisms are those that reduce your anxiety and distress, and allow you to adjust to your new situation.

While every person has his or her unique way of coping, researchers have found that people living with cancer usually cope in two general ways, attention and distraction. Attentive coping mechanisms are those used to regain control of the situation. Information seeking is a usually a big part of attentive coping for people with cancer. Cancer brings most people into a situation that is entirely new for them. The medical terms, procedures, and treatments are unknown to most people when their cancer is first diagnosed. Learning about lung cancer and its treatments may help you gain a sense of control in this new situation. Knowledge can help some people feel less fearful, anxious, and helpless.

I believe you should be educated about your disease [in order] to make informed decisions. You just need to stay away from the statistics; they don't really pertain to your situation. Statistics always have loopholes… I took control of my healing by making the most positive and educated choices I could.
– Larry, diagnosed with Stage IIIA NSCLC in 2001 at age 61
Distractive coping mechanisms are those that help you limit the anxiety associated with a situation by providing another focus for your attention. While some people may think of distractions in a somewhat negative way, distraction can be a very effective way to manage stress. Think of distractive coping as pleasant diversion. A walk outside, listening to your favorite music, a long bath, reading a book, and watching a good movie are examples of pleasant diversions that can help relieve the stress associated with a difficult situation. We all use distractions to cope with problems. In times of high stress, distractions may become an important way to keep your emotions from becoming overwhelming.

I read a lot to keep my sanity. I also watched movie after movie. My favorite was “Some Like it Hot.” This was just one of the ways I could escape my present situation and keep going.
– Janet, diagnosed with stage IV NSCLC in 2000 at age 46

Most people tend to prefer one coping strategy over the other, but nearly everyone uses both to some degree. Often, the situation dictates which coping strategy will be most useful. For example, imagine yourself in a traffic jam. Most of us dislike being in a traffic jam. It causes stress. An example of an attentive coping mechanism in this situation would be looking for another route to get to your destination. An example of a distractive coping mechanism would be turning on the radio to listen to some pleasant music. Some of us might first look for an alternate route. If one were not available, we might then turn to distraction to avoid becoming upset over something that cannot be changed. This simple example demonstrates how different coping strategies can be used effectively, both alone and together.

I felt I should become educated about my disease. However, I'm never going to be an oncologist, and the more I learn, the more I get confused. If I don't stop, I become a ball of anxiety. I simply could not survive this without distraction. During treatment, I found my distraction was talking with other people. And when I’m home, I often find myself in my garden working to the point of dusting each little leaf of my rose bushes. And boy, they are just gorgeous – nice and shiny.
– Lovell, diagnosed with stage IIIA NSCLC in 2002 at age 57

Following are lists of coping activities other people who have experienced cancer have found helpful. These lists are activities you may want to consider to help you cope and live with lung cancer. As you review the lists, remember they are not lists of things you should be doing, but are lists of suggestions you may find helpful.
Attentive Coping Activities

- Gather information about lung cancer.
- Research your treatment options.
- Talk to other people about their experiences.
- Prepare a list of questions to ask your doctor.
- Begin a journal of your experiences.

I've always had a journal and found it very useful during treatment. It was a way to go back and look over what had happened to me, and figure out what to do next time.

– Janet, diagnosed with stage IV NSCLC in 2000 at age 46

Pleasant Diversions

- Read a new book – an adventure, a mystery, a romance – whatever you enjoy.
- Listen to music that makes you feel calm, relaxed, or happy.
- Play some favorite card games or board games.
- Take a walk in a setting you enjoy.
- Watch some of your favorite movies or television shows.
- Spend time on your hobbies.
- Pamper yourself with a long bath or shower.
- Treat yourself to a new ‘toy’ – a new outfit, a new tool, some perfume or cologne, a new video, etc.
- Enjoy playtime with children, grandchildren, or other youngsters.

When I needed comfort or just an escape, I would call my grandchildren. My daughter would bring them over. There is just something amazing about the unconditional love in my grandchildren's eyes and the warmth of their hugs. When they look at you, they don't see that you're sick. There's a sparkle in their eyes. You just don't get that with adults. They don't mean to look at you differently, but unconsciously there's that look people give when you are sick.

– Sue, diagnosed with stage III NSCLC in 1997 at age 48

Other Helpful Hints for Your Consideration

- Focus your attention on things you can influence.
- Accept your feelings, no matter what they are.
• Stay involved in activities you enjoy as much as possible.
• Try to keep your focus on what needs to be done here and now.
• Take things one step at a time.
• Identify causes of anxiety and concern and address them.
• Avoid self-blame and self-criticism.
• When you are feeling overwhelmed, try to focus on what you have – the people you love, the people who love you, and other things in your life that bring you happiness.
• Try to keep your sense of humor. Laughter is a great way to release stress.
• Do not be afraid to ask for help. Asking for help is not a sign of weakness.

Living with cancer is very stressful, worse at some times than others. You will probably find that over time, you will need to use all your coping skills to manage your situation. You may find it helpful to explore new coping strategies you may not have used in the past. Again, there is no right or wrong way to cope with cancer. The goal is not to act a certain way or to do certain things. The goal is for you to find ways to adjust to your situation that feel comfortable and reduce your stress and anxiety.

Your coping strategy is uniquely yours and must suit your personality and needs. Some people take a very involved approach to their disease. They feel most comfortable when they know all the details of their treatment, and can be in control of every treatment decision. Other people take a more laid-back approach. They leave most of the worrying about their care and treatment to their health care providers, and prefer to focus their attention on the tasks of everyday living. Many people are somewhere in between these two styles. Whatever your coping style is and whatever your needs are, be sure you communicate them to your health care providers. Forming good relationships with your health care providers in which they understand your preferences and needs will, in and of itself, help reduce the stress and anxiety of living with lung cancer.

Researchers have found that believing in your ability to cope actually helps you cope.\textsuperscript{5,6} As the old saying goes, believing you can do something is the first step toward making it happen. Therefore, it is helpful to be confident that even though coping with cancer can be
overwhelming at times, you will handle it just as you have handled every other difficult situation you have faced in your life.

**ROADBLOCKS TO SUCCESSFUL COPING**

**Denying Your Feelings**

In recent years, the interactions between the mind and body in health and disease have become an area of intense research interest. This area of study is called *mind/body medicine*. Several years ago, some small, preliminary studies suggested there might be a link between individual coping styles and the probability of surviving cancer. Some similarly small, preliminary studies suggested that having a positive attitude could influence a person’s chance for surviving cancer. The small studies that suggested these links were far from conclusive scientific evidence. A more recent study that looked at the results of 26 studies that examined the influence of coping style on survival and recurrence of cancer found there was no convincing evidence that psychological coping style plays an important role in survival from or recurrence of cancer.

The publication of the studies that suggested certain attitudes and coping styles could affect the course of cancer and the misinterpretation of the results of these studies led to a most unfortunate and unintended consequence. Some people with cancer who have been made aware of these suggested links may suddenly feel a great burden. People who have heard that they must have a positive attitude in order to survive cancer become fearful when they have feelings other than hope and optimism. They feel as if they are somehow to blame if their prognosis is not favorable. Rather than alleviating anxiety and depression, the belief that an unrelenting positive attitude is necessary for survival can lead to increased guilt, fear, and anxiety.

While a positive attitude can help reduce stress, the reality of living with cancer is that there will be days when you will not feel particularly cheerful or optimistic. There will be days when you feel sad, scared, lonely, and/or overwhelmed. This is normal, healthy, and perfectly okay! Trying to pretend you are not scared, sad, or apprehensive (when you are) is
far more stressful and detrimental to your well-being than honestly acknowledging your feelings and sharing them with others. It is not healthy, physically or emotionally, to try to hide your feelings. There are pleasant feelings and there are upsetting feelings, but there is no such thing as a ‘good feeling’ or a ‘bad feeling.’ Some facts that may be helpful for you to keep in mind include:

- Hiding or deny your feelings is unhealthy.
- No one has a positive attitude all the time.
- A bad day is just that – a bad day. It does not mean you caused your cancer or that you have ruined your chances for successful treatment.
- Anger, sadness, confusion, fear, bewilderment, and many other feelings are normal responses to being diagnosed with cancer.

I felt like I had to be positive all the time and I did pretty good. But I would have my bad days where I’d just stay at home. I wouldn’t want to talk to anyone or do anything. Then eventually, I would have an appointment to have to go to or meet someone somewhere and have to get out of the house. And I found that if I kept myself busy, I felt a lot better and could be positive. I started working part time again as a nurse where I have to take care of people. You can’t complain to patients – you have to give them encouragement. It always makes me feel better after I get out of the house and help someone else. I love my job.
– Rita, diagnosed with stage I NSCLC in 2001 at age 58

Guilt and Blame

People who have lung cancer often face something no other people with cancer face – blame. This is tragic, regrettable, and horribly unfair. No one EVER deserves cancer of ANY kind! We are going to repeat that sentence because it is very important for you to understand and take to heart. It may well be the most important sentence in this entire book.

No one EVER deserves to get lung cancer!

The blame that many people with lung cancer are forced to deal with comes largely from the link between smoking and lung cancer. Since it has become clear that smoking is harmful to health, health care providers, public health advocates, and private citizens have strongly
voiced opposition to smoking. Unfortunately, negative feelings about smoking sometimes spill over as negative feelings toward people who smoke or have smoked. While it is true that smoking is bad for your health, people who smoke or have smoked in the past are not bad people.

Much of the guilt and blame many people with lung cancer must deal with come from judgmental feelings about unhealthy lifestyle choices. However, many people start smoking while they are teenagers. Further, nicotine is so addictive that continuing a smoking habit is more a matter of addiction than a choice. Smoking is not simply a bad habit. Smoking is a physical and psychological addiction to the nicotine in tobacco. Two recent reports have noted that nicotine is at least as addictive as heroin, and in some ways, is even more addictive than heroin or cocaine.8,9 A report issued by the Tobacco Advisory Group of Britain’s Royal College of Physicians concluded, “Most smokers do not smoke out of choice, but because they are addicted to nicotine.”9 The United States National Institute on Drug Abuse confirms this conclusion noting that 90% of people who try to quit smoking on their own (about 35 million Americans each year) relapse within one year, most going back to smoking within one week.10

The blame for lung cancer can also come from within. People with lung cancer often blame themselves. This is a very destructive. It can completely undermine your attempts to adjust to your diagnosis. Guilt can lead to severe depression, and depression can make it nearly impossible for you to participate in treatment. There is no need for guilt or blame when it comes to lung cancer. No one wants to get lung cancer. It is not your fault that you have lung cancer.

If you are struggling with feelings of guilt or blame, either from within or from people around you, you need to work through the feelings. You may need to talk to a counselor if you are not able to rid yourself of these feelings by talking with family, friends, or other supportive people in your life. You need your mental and emotional energy for other things such as adjusting to your diagnosis, preparing for treatment, and getting through treatment. The sooner you can get past the guilt or blame you may be feeling, the sooner you will be able to move on to the important tasks at hand.
I think the issue of self-blame was the biggest thing for me to deal with. The idea that I smoked and I caused this disease was very difficult. Of all things, I'm a nurse — I knew better. The self-blame was cutting into my ability to cope. I knew I needed to do something about it. So I got professional help which helped me a great deal.
— Toni, diagnosed with limited SCLC in 1992 at age 39

We do not blame someone who is overweight for getting diabetes. We do not blame a person who has not participated in regular exercise for having a heart attack. Similarly, people who have smoked should not be blamed for getting lung cancer — ever, by anyone.

**Overwhelming Depression and Anxiety**

When most people talk about being depressed, they are describing the experience of feeling very sad. People who are depressed often cry, lack interest in their normal activities, and/or experience low energy or tiredness. Depression is a completely normal response to a sad, disappointing, unexpected, and/or stressful situation. Health care providers often use the term *reactive depression* to describe this normal response to any of a variety of life situations, including being diagnosed with a potentially life-threatening illness like lung cancer. Most people who experience reactive depression also have symptoms of anxiety. Anxiety is described as a lingering feeling of uneasiness, worry, and/or being on edge. You may feel as if your mind is racing and have difficulty focusing. Anxiety can also be experienced as a sense of dread. Again, both anxiety and depression are normal responses to learning you have lung cancer. Nonetheless, these normal responses have the potential to interfere with your life and health if they become prominent. Some symptoms that you may experience that are characteristic of depression and anxiety are listed below.

**Symptoms Associated with Depression**

- persistent sad, anxious, or empty mood
- feelings of hopelessness or pessimism
- feelings of guilt, worthlessness, or helplessness
- loss of interest or pleasure in hobbies and activities that you once enjoyed including sex
- decreased energy, fatigue, or feeling slowed down
- difficulty concentrating, remembering, or making decisions
• difficulty sleeping or sleeping too much
• appetite and/or weight loss, or overeating
• thoughts of death or suicide
• restlessness or irritability
• persistent headaches that are not attributable to another cause and do not respond to treatment

Symptoms Associated with Anxiety
• sweating
• dizziness
• racing heart or irregular heart beat
• shakiness
• difficulty relaxing
• headaches
• irritability
• upset stomach, nausea, and/or diarrhea
• sleeping problems
• difficulty concentrating
• excessive watchfulness
• being easily startled

While depression and anxiety are normal reactions to stressful situations, they can become problems if they begin to interfere with your ability to function. If you or one of your loved ones notice that one or more of these symptoms are disrupting your life, it is important to discuss the situation with your health care provider. He or she may recommend counseling, medication, or another form of therapy such as relaxation techniques to help relieve your symptoms. The important message is that you should not ignore these symptoms, nor should you have to suffer from them for a prolonged period. Talk with your doctor or nurse. Anxiety and depression are normal reactions. They do not mean you are losing
control of your mind, and they are not signs of weakness. Nevertheless, they need to be controlled if they are interfering with your ability to function or your quality of life.

I remember the depression I fell in. I knew things had gotten bad when I actually put newspaper on the side windows of my front door so that people could not see in. I called my doctor and told him I was terribly, terribly depressed. I asked if there was anyone who counsels cancer patients that I could see. He gave me a name and number. I thought one appointment wouldn’t hurt me, and I am so glad I sought help! Don’t get me wrong, I have wonderful friends to support me. But the counselor listened to me. She had survived Hodgkin’s disease herself, so she knew how I felt – she had been there. She set up a plan for me to get through this and it worked. I am so thankful and glad to be alive.

– Barbara, diagnosed with extensive SCLC in 1997 at age 47

TELLING YOUR LOVED ONES THE NEWS

Other than being diagnosed with cancer yourself, one of the most stressful and upsetting events in life is learning that someone you love has been diagnosed with cancer. The people who love you will experience many of the same feelings that you are having in response to the news because they love you. They are likely to experience feelings of shock, fear, denial, anger, anxiety, confusion, guilt, shame, uncertainty, loneliness, doubt, and others – just as you have.

Telling your loved ones you have lung cancer can be a difficult task. Sometimes it is hard to know where to begin. The information offered in this section is here to help you. Keep in mind, there is no right or wrong way to tell someone you have lung cancer. What works well for some people may not work well for others. As you read this section, select what you think is best for your situation based on your personality and the personalities of your family and other loved ones. Generally, the sooner you are able to tell your loved ones about your cancer, the sooner you will be able to adjust and help each other through this challenging time.

Your Partner

Other than you, your partner is the person likely to be most deeply affected by your diagnosis. Knowing this can make it particularly hard to tell your partner about your lung
cancer. Some people consider not telling their partner because they do not want to upset him or her. While the notion of trying to protect your partner from pain may seem like a good idea, it is not the best option for most people. If the situation were reversed, would you want your partner to keep something like this from you? Most of us would answer no. We would want to help and support our partner in any way possible. Likewise, once the shock has worn off, it is likely your partner will want to share this experience with you and help you in any way he or she can. Partners often provide a huge amount of emotional and practical support, even when they are also experiencing intense feelings and many demands on their time and energy. Many people find their partner is their main source of support throughout their lung cancer experience.

We had been married for 2 years. Joe was married before, and had lost his wife to Lou Gehrig's disease. When I found out there was a possibility I had lung cancer, I was so scared to tell him. I thought I was going to lose my husband. He couldn't go through losing two wives within three years. I was waiting at home with my coworker crying when Joe walked in the door. He knew right away that it had been bad news from the doctor. He came over, gave me the biggest hug, and told me, "Don't worry. We are going to be fine." I didn't give him enough credit. He was much stronger than I was. He was my rock.

− Sue, diagnosed with stage III NSCLC in 1997 at age 48

How to tell your partner you have lung cancer will depend on the relationship you share. Although the two of you may not have faced something this serious before, it is likely that you have gone through other difficulties together. You can rely on those experiences to help guide you through the experience of telling your partner about your diagnosis. Listed below are a few things you may want to consider.

- Talking with your partner in a private place may make it easier for both of you. When you are in a private place, you do not have to be concerned about your words or actions being observed by others.

- Try to select a time when neither one of you is likely to be called away. This will allow you the freedom to talk about the situation and be together for as long as you like.

- Be prepared for the possibility of a strong emotional reaction, particularly if your diagnosis was unexpected. The news is likely to affect your partner very deeply, and his or her immediate reaction may be quite strong. Denial or a refusal to believe the diagnosis is a very common initial reaction to learning someone you love has cancer.
• Try to be aware of the fact that this situation is likely to be difficult for both of you. It is likely that you will both need one another’s support and understanding.
• Although it can be hard, being open and honest about your feelings is likely to help both of you support and help one another. You can only help one another if you are aware of what the other person is struggling with at the moment.

While you and your partner are likely to experience many of the same feelings in response to learning of your lung cancer diagnosis, be aware that there will also be some differences. For example, your partner may be concerned about figuring out how best to help you. Often, people become very bewildered because they simply do not know how to be helpful. Your partner may want to try to take over some of your regular chores for you, but may be concerned because he or she does not know how to perform some of the tasks you usually do. There may be financial concerns that worry your partner, but he or she may not mention them for fear of upsetting you. One concern that is often very upsetting and difficult to talk about is the possibility of losing a loved one. For many people, even the thought of living without their beloved partner is almost too painful to bear. Your partner may try to hide this concern from you because he or she wants to spare your feelings, but it is a concern that is likely to occupy your partner’s thoughts at various times. While it may be hard to discuss these feelings when you are both still trying to adjust to the news of your diagnosis, many couples find that as time goes on, they are able to talk about them. Often, being able to openly discuss our deepest fears and most painful emotions helps relieve them.

Peggy: We were so scared in the beginning. I didn't know what to say to him. I didn’t want to bring up anything that would make him feel I wasn't supportive. It was hard because Larry is a pessimist and I am an optimist, so when I said, “You'll be ok.” he took it as, “No, I'm not, and if that's what you have to say, then you don't really care about me.” I don't know how we made it through that stress in the beginning, but once we were able to really open up with each other it helped immensely.
Larry: When all this started 12 years ago, we were really two different people. I'm the kind of person who talks about things. I like to know what is going on in her mind. Peggy used to be real quiet and hold things in. Now she is much more comfortable communicating. It's uncanny. It's almost like telepathy between us now. We have really become the same person.
Peggy: We are really lucky we've had this much time to learn and grow together. We are so much closer now then when we started.
– Larry and Peggy; Larry was diagnosed with stage II NSCLC in 1991 at age 53
Lung cancer will present many challenges for both you and your partner over the coming months. Many partners of people with lung cancer have found that seeking their own outside sources of support helps them cope and enables them to be as supportive as they want to be of their partner. Friends, a local support group, a personal psychological or spiritual counselor, or another trusted person are possible sources of support for your partner.

How you and your partner handle your experience with lung cancer will depend on your personalities and relationship. If you are used to handling things together, your partner will probably be very involved in the decisions to be made, your treatments, and other aspects of your care. On the other hand, if you are both rather independent, you may decide to divide the responsibilities involved in your experience. For example, you may want to make treatment decisions but leave household decisions to your partner. These are only two examples. There are many other ways to handle the challenges you and your partner will face over the coming months. There is no right way for you and your partner to handle this situation. The two of you should handle the situation in whatever way works best for you as a couple.

**Your Children and Grandchildren**

Regardless of whether your children are youngsters or adults, it can be very difficult to tell your children you have lung cancer. Many parents have a tendency to want to protect their children. Telling your children you have cancer may seem to run counter to your desire to protect them. For this reason, parents sometimes consider not telling their children they have lung cancer. Although your intentions may be loving, keeping your diagnosis from your children is probably not in their best interest or yours.

The bond among family members is often such that when something is wrong with one person, the other family members can sense it. Even young children are very adept at sensing when something is wrong. If your children are youngsters, it is probably best to talk with their pediatrician, a youth counselor, oncology social worker, psychologist, or other mental health professional about exactly what to tell your children. In general, it is important to be honest, but also to tell your children information that is appropriate for their
age and level of understanding. Even the best parents often have trouble trying to decide how much information is appropriate for children of different ages, what words to use, and how to answer their children’s questions. A professional can talk with you about signs to look for that could indicate your children may be having trouble dealing with your illness. This will allow you to address potential problems early. If you do not have access to a professional who is knowledgeable about talking to children about illness, there are books available on this topic. Check with your local library or bookstore.

We were very nervous about telling our children. With them being in middle school though, we knew we had to tell them before someone said something at school. We wanted to make sure our kids knew up front. I had done some searching and received a pamphlet from the American Cancer Society on how to tell your children. I don’t think it said anything we didn’t already know, but it was a nice tool to have. The kids, of course, knew something was wrong. So we all sat down and talked about what mommy was going to go through. And yes, they asked, “Are you going to die?” We just told them we had the best doctors, and we were going to fight it, but that it was possible that I could die — but I could also die crossing the street. We reassured them that we would let them know when things happened, and we went from there. The kids didn’t seem to have a problem. We kept open communication with them and everything went fairly well.

— Susan, diagnosed with stage IIIB NSCLC in 1997 at age 40

One fact that needs to be made clear to all youngsters is that they are not to blame for your illness. Children tend to think magically, and as such, often feel responsible for everything that happens in their world. Therefore, be sure to make it very clear to your children that they are in no way to blame for your illness. You may need to repeat this message several times over the next few months. You may find your children ask you the same questions repeatedly. This is not cause for alarm. It is simply your child’s way of trying to understand something that may not be entirely clear to him or her. Children learn by repetition, so repeated questions are quite normal. Try to answer your children’s questions consistently and honestly. Be aware that the older your youngsters are, the more detailed their questions are likely to be. If your child asks a question you are not certain how to answer or are not prepared to answer, tell your child you are not sure of the answer but will get back to him or her later. This is perfectly okay to do, as long as you make sure you do in fact get back to the child about his or her question.

If your child is old enough to understand the concept of death (around age 5-6 years), he or
she will almost certainly ask if you are going to die. Young children see parents as their source of safety and security in the world. Therefore, all children fear losing their parents. Learning about your cancer may bring out this fear in your child. Having your child ask if you are going to die can be a very painful moment for a parent, which is why it is best to be prepared. Young children’s thoughts are largely focused in the present. They do not usually spend much time thinking about what happened yesterday, or what is going to happen further ahead than tomorrow or the next day. So, when a young child asks if you are going to die, he or she is talking about the immediate future. The truth is, each and every one of us is going to die one day—the question is when. Therefore, when a child asks if you are going to die, it is both honest and consistent with what he or she is asking to say something such as, “Everyone will die some day. No one knows for sure when he/she will die. But my doctors and I are doing everything we can to make sure I don’t die for a very long time.” Again, you may want to talk to a professional about how to answer this question before your child asks it because it is almost certain that he or she will eventually ask you and/or your spouse.

It is usually best to talk with your youngsters about your illness as soon as you feel comfortable doing so. The longer children sense there is something wrong but do not know what it is, the more likely it is that they will become anxious and fearful. It is often more frightening for children to be left to their very creative imaginations than it is for them to deal with the truth. Children regularly surprise adults with their ability to cope with and adapt to difficult situations.

Talking with your adult children can be challenging but rewarding. For a parent who is used to being a caretaker, it may be hard to admit to your adult children that you may be in a position where you need their help. Keep in mind, your children love you and will want to help you in any way they can. People whose loved ones are sick often feel frustrated because they want to help but do not know how to do so. Allowing your adult children to share in this experience with you is likely to help them as well as you and your partner.
Your Parents

Your parents are likely to be deeply affected by your diagnosis with lung cancer. Just as you feel responsible for your children, your parents feel responsible for you. They are likely to experience the same range of powerful emotions that you and your partner felt when you first found out about your cancer. Because of their strong sense of responsibility toward their children, many parents experience an irrational sense of guilt when their child becomes ill. They wonder if there was something they could have done to prevent the illness, or if they somehow inadvertently contributed to the illness. Your parents may need outside reassurance to rid themselves of these feelings of guilt. Friends, support groups, and individual psychological or spiritual counselors may be good sources of reassurance and support for your parents.

Some parents have a tendency to revert to treating their adult children like youngsters when the adult child gets sick. If your parents slip into this pattern of behavior, you or your partner may want to sit down with them and talk through the problem. Often parents slip into this behavior because they want to help, and not knowing how to help, fall back on how they used to help you when you were a younger. Like many adult children in a similar situation, you may find that giving your parents specific jobs and tasks will help both you and them cope with the situation.

HOW, WHEN, AND WHAT TO TELL OTHERS

How, when, and what to tell other people in your life about your diagnosis are decisions only you can make. People you may want to tell about your lung cancer include your brothers and sisters, aunts and uncles, cousins, nieces and nephews, grandchildren, and friends. Telling each person in your life about your diagnosis presents a new and different challenge because each relationship is unique. Some people find it is easiest to gather people in groups. For example, you may want to assemble several members of your extended family or a group of your close friends. Telling people who are close to both you and one another in a group setting has the advantage of taking some of the pressure off you since the various members of the group can help support one another. If face-to-face conversation seems too
difficult, consider writing letters to people. Again, you and your partner will need to decide what works best for you and your loved ones.

Telling family and close friends was real tough! In fact, I couldn't bear to do it. My husband was great; he intervened and let them know for me. It was almost harder to see the worry in their eyes than to deal with the worry myself. But they were wonderful. I never had a day where I had to sit at the hospital by myself. I had an amazing amount of support.
— Toni, diagnosed with limited SCLC in 1992 at age 39

One thing you may want to keep in mind when you talk with people about your illness is your feelings about them sharing the information with others. If you prefer that people not discuss your diagnosis with others, you should state that very clearly when you tell them about your illness. On the other hand, if you do not mind if people share the news of your situation with others, you may want to say that so your loved ones are not left to wonder about your feelings on this issue.

Another thought to keep in mind is that people react differently when they realize someone they care about is facing a life-threatening illness. Some people may respond by offering their heart and help in a completely open way. You may find you develop a deepened relationship with these people. Other people, despite their love for you, may be deeply frightened by your illness and pull away from you because they cannot manage their fears.

While this situation can be painful, try to remind yourself that it is not about you. It is about your loved one's ability to cope with his or her feelings of fear and uncertainty. If someone whose help and support you truly desire seems to be pulling away from you, it may be worthwhile to talk with him or her and share your feelings. If the situation does not change, do your best to rely on those who are willing and able to support and help you through this challenging time in your life.

I feel like I always need to tell people that I had cancer. It doesn't frighten me to let them know. In fact, it's been real positive. It's amazing — when I tell someone, they always seem to know someone else who has had cancer and you get to know someone better.
— Rita, diagnosed with stage I NSCLC at age 58

If you are working, you will probably have to tell your employer about your diagnosis because you are likely to need time off work for your treatment. How and exactly what you
tell your employer are up to you, but you should be honest about what you think your needs will be in terms of time off. This will allow you and your employer to make plans to cover your workload while you are off, which will probably help both of you have peace of mind. Whether you tell your coworkers about your diagnosis is up to you. If you do not want your supervisor to discuss your illness with your coworkers, be sure to state that clearly.

There are no right or wrong decisions about whom to tell about your illness, or what, when, or how to tell them. As you think through your decisions, ask yourself what is best for you and them. At first, learning about your lung cancer will probably be a shock to most everyone in your life. But ultimately, only those who know what you are dealing with will be able to help you through it.

ABOUT HOPE

Hope is a great power that can take many different forms. Hope involves focusing on the many joys life offers every day that give it meaning and purpose. The things that bring happiness and joy vary from one person to another, and change from one time of life to another. Some people have naturally hopeful, optimistic personalities. Other people develop their sense of hope through more active processes.

What inspires hope in you depends on many different things such as your personal values, your belief system, where you derive your sense of satisfaction, and what makes life meaningful for you. Just as different things inspire hope for different people, different situations we encounter can change our perspective and influence what inspires us. Each phase of your life has its own special hopes and dreams.

I remember the real turning point in my treatment. It was when my oncologist suggested that I should speak to a survivor. I remember the first time I spoke to a survivor of small cell lung cancer I thought, “My god this is really possible! You can survive this.” It was amazing. Now, over 10 years later, I still love hearing about survivors – and I am here to talk with others, to tell them that you can survive.
— Toni, diagnosed with limited SCLC in 1992 at age 39
You may find that at different times during your experience with lung cancer, you hope for different things. Although there may be moments when you doubt it, there are always reasons for people living with lung cancer to have a sense of hope – no matter what your diagnosis or prognosis.

Hope can take many different forms. We encourage you to interpret the definition of hope broadly enough so you can see the opportunities for hope that are present before you.

SUMMARY

There are many ways to cope with your lung cancer diagnosis. Understanding and acknowledging feelings are key elements in coping with cancer.

Your loved ones are likely to be deeply affected by your diagnosis. How you tell them the news and how they respond will depend largely on your existing relationship. Open communication and recognizing the needs of your loved ones while accepting their love and support are important components of living with lung cancer.

Hope is an essential part of coping for many people. Hope has the power to change your outlook and enrich your life. Hope comes in many different forms. What you hope for is unique to you. There are always reasons for people living with lung cancer to have a sense of hope – no matter what your diagnosis or prognosis.

My hope is that you have found information here that will help you adjust to your diagnosis and live fully in the months ahead. I wish you strength, hope, joy, and courage for your journey.
CHAPTER 10: SUPPORTIVE CARE

INTRODUCTION

Lung cancer and its treatment can cause many symptoms that may interfere with your ability to live as you normally would. Health care providers often refer to this interference as a reduction in quality of life or QOL. Supportive care is a term that refers to treatments used to eliminate or reduce symptoms that interfere with your quality of life. The aim of supportive care is to provide you with the best quality of life possible, so that you are able to participate in your treatment and do the things that bring you pleasure and happiness. More simply, the goals of supportive care are to maximize comfort and eliminate suffering.

Palliative care is very similar to supportive care. The difference between supportive and palliative care is the situation in which the treatment is given. Supportive care refers to symptom management while a person is receiving treatment to potentially cure his or her disease or extend life. Palliative care is symptom management and special care of a person whose disease cannot be cured. While there is a distinction between these two terms, there is a great deal of overlap between both the goals and methods used in these two types of care. Supportive and palliative care share the common goal of providing the best possible quality of life by maximizing your comfort and minimizing suffering. Palliative care often encompasses the treatment and support of both people who are sick and their loved ones. For simplicity, we use the term supportive care in this chapter. However, keep in mind that many supportive care treatments are also used for palliative care.

Many side effects of lung cancer treatment are common and well known. Often health care providers use medicines or other therapies to prevent these side effects from occurring, sparing you from experiencing these discomforts. Other symptoms and side effects are treated as they arise. In general, symptoms can be most successfully controlled if they are treated as soon as possible. Early treatment not only reduces suffering but also helps preserve the body’s ability to carry out its normal functions.
Each person’s experience with lung cancer is different. Supportive care plans are individualized to meet the unique experience of each person. Many supportive care measures are available to help people with lung cancer. Supportive care is most effective when you work in partnership with your health care team. Discuss your symptoms openly and honestly with your providers. If a recommended treatment is not helping the problem for which it was given, do not be afraid to tell your provider. Your health care providers are able to help you only if they are aware of what you are experiencing. Your job is to keep your health care providers informed about your symptoms. Their job is to ensure that your needs are met. Together, you and your providers will be able to develop a supportive care plan that works well for you.

A large number of symptoms are discussed in this chapter because lung cancer is capable of causing a wide variety of symptoms. Do not be alarmed by the number of symptoms discussed. The symptoms described are just a list of possibilities. Some of the symptoms are common, while others are relatively rare. We have tried to include a wide variety of potential symptoms to address the experiences of as many people as possible. It is likely you will never experience many of the symptoms described here. It is also possible you will experience some symptoms not included here. The important thing to keep in mind is that all symptoms are important and should be discussed with your health care providers. Your doctors and nurses want to help you feel your best but can only accomplish that goal with your help.

SIGNS & SYMPTOMS ASSOCIATED WITH LUNG CANCER

People living with lung cancer often experience different symptoms over the course of their illness. When you are examined by your health care provider, he or she may also discover signs of lung cancer. A symptom is something you experience such as a cough or shortness of breath. A sign is something observed by your doctor such as abnormal lung sounds heard with a stethoscope. Some things can be both a sign and a symptom. For example, you experience fever as a symptom that can also be observed as a sign of illness by your health
care provider. Signs and symptoms of lung cancer are usually grouped into the following categories.

- those related to the original lung tumor (the *primary tumor*)
- those related to spread of cancer in the chest (*intrathoracic* or local spread)
- those related to spread of the cancer outside the chest (distant *metastasis*)
- those related to *paraneoplastic syndromes*

Paraneoplastic syndromes are groups of signs and symptoms not caused by cancerous tumors themselves but by substances produced by the tumors. These syndromes can affect a number of organs and cause a wide variety of signs and symptoms. Studies have shown that approximately 10% of people with lung cancer have paraneoplastic syndromes.¹²

Before beginning a detailed description of the signs and symptoms of lung cancer, we want to say a few words about what to do if you experience a new sign/symptom or a change in a previously existing sign/symptom.

1. Do not ignore it.
2. Do not panic.
3. Report it!

Understandably, some people with lung cancer think any symptom they experience must be related to their cancer and ignore it. This is a mistake. Just because you have lung cancer does not mean that every symptom you experience is related to your cancer. You are subject to the same ‘normal’ things everyone else is. The only way to know if a symptom is cancer-related is to let your health care team evaluate the problem. It is not in your best interest to ignore something that may give your doctors important information about your cancer. It is also important not to ignore a symptom that may indicate something new is happening in your body.

While some people have a tendency to ignore their symptoms, others have a tendency to panic. Lung cancer is a life-threatening illness. It is perfectly understandable that some
people become frightened by the development of a new symptom because they assume it means the disease has gotten worse. Jumping to this conclusion can cause a great deal of worry and emotional distress – and may be completely wrong. For example, lung cancer that has spread to the brain can cause headaches. Nonetheless, sometimes a headache is just a headache. The point of this example is not to tell you to ignore a headache – in fact you most definitely should report any new headaches to your health care providers. The point is to encourage you to not jump to conclusions.

The best course of action to take when you experience a new symptom is to report it to your health care provider as soon as possible. He or she will evaluate the cause and take appropriate action to treat the underlying problem, regardless of whether it is related to your cancer or not.

Over the next several pages, the signs and symptoms of lung cancer are explained. Under each listing, there is also a discussion of supportive care measures used to control or alleviate the sign/symptom.

**SYMPTOMS ASSOCIATED WITH PRIMARY LUNG TUMORS**

**Cough**
Cough is the most common symptom experienced by people with lung cancer. Coughing is the body’s natural way of clearing the airways. Dust, chemicals, smoke, excessive phlegm, and other substances irritate the airways leading to the urge to cough. We have all had the experience of having something ‘go down the wrong way’, that is, going into the airway instead of the stomach. This causes irritation in the airways that leads to immediate and explosive coughing as the body tries to clear the lungs of a substance that should not be there.

There are two main types of coughs, dry coughs and productive coughs. Dry coughs are referred to as hacking or barking coughs because of how they sound. Dry coughs can be quite persistent but do not usually result in coughing anything up. Dry coughs are
commonly caused by inhaling smoke or another irritant, breathing cold air, viruses, allergies, sore throats, sinus infections, and certain forms of asthma. There are other causes for dry coughs, too.

Productive coughs have a loose sound and frequently result in coughing up phlegm. This type of coughing often feels as if it is coming from deeper in the chest than a dry cough. Productive coughs indicate congestion or excessive fluid in the lungs. The fluid may be watery or thick depending on the underlying cause of the cough. Phlegm that is bloody or streaked with blood is called hemoptysis, and is relatively common in people with lung cancer. Cold or flu viruses, pneumonia, and bronchitis are common causes of productive coughs. There are many other causes as well.

Despite the fact that many people with lung cancer have a cough related to their cancer, there are many other causes of cough. Your health care provider will evaluate you to determine the cause of your cough so that he or she can prescribe an appropriate treatment. It is important to accurately identify the cause of a cough in order to effectively treat it. For example, certain blood pressure medications can cause cough. A cough caused by medication can easily be alleviated by switching to another medicine, a much simpler and more effective solution than trying to suppress the cough.

Tumors that partially or completely block an airway can lead to pneumonia and a productive cough. Antibiotics are often used to treat pneumonia. Your doctor may also recommend a procedure to clear the blocked airway. This can help avoid repeated bouts of pneumonia.

Persistent coughing caused by a tumor irritating the airways can be a very troubling symptom. Coughing can interfere with sleeping, eating, and even conversation. Mild cough suppressants found in over-the-counter cough medicines may help some people but often do not adequately control this symptom. Coughs associated with lung cancer often require stronger medications. Medicines called bronchodilators may help relieve cough. Drugs called opiates such as codeine, oxycodone, and morphine are powerful cough suppressants and may be needed to control severe coughing. Inhaled morphine can suppress a cough while limiting its effects on the rest of the body. If one form of therapy does not adequately
control your cough, be sure to talk with your health care provider. There are several options available to help treat this troublesome and disruptive symptom.

**Breathing Difficulties (Dyspnea)**

*Dyspnea* is a common symptom of lung cancer. Dyspnea is defined as difficult, labored, or uncomfortable breathing. People with dyspnea describe it as a feeling of air hunger. Dyspnea is triggered when the cells of the body are not getting enough oxygen. Sensations of dyspnea may include tightness in the chest, fast breathing, and/or shortness of breath. Dyspnea and the effects of having too little oxygen in the body can seriously affect your quality of life.

Lung cancer can cause dyspnea in several different ways including blockage of the airways by a tumor, fluid in or around the lungs, anemia, and muscle weakness. Dyspnea caused by partial blockage of a large airway may cause noisy breathing or wheezing. Dyspnea can also be caused by other medical conditions such as asthma, chronic obstructive pulmonary disease (COPD), emphysema, pneumonia, or heart disease. Shortness of breath usually causes anxiety, which tends to make the problem worse.

To treat dyspnea effectively, the underlying cause must be determined. Your doctor may send you to a pulmonologist (an expert in the treatment of lung diseases) to help determine the specific cause of your dyspnea. The treatment recommended by your health care provider will depend on the underlying cause of the problem. Following are some of the treatments your doctor may recommend to help alleviate dyspnea.

**Supplemental Oxygen**

Supplemental oxygen increases the amount of oxygen taken in with each breath. This eases shortness of breath by providing the body with the oxygen it needs. Supplemental oxygen is moisturized to keep it from drying the airways.

**Medications**

A variety of breathing medications can be used to treat dyspnea. The choice of medications depends on the underlying cause of your symptoms. Drugs called
bronchodilators open up the airways. Steroids are also sometimes used. Some medications are taken by mouth; others are inhaled. Pain can worsen dyspnea. Therefore, pain medication such morphine sometimes helps alleviate severe dyspnea.

Treating Airway Obstruction
If one or more of your major airways is obstructed by a tumor, you doctor may recommend a procedure to clear the airway. The procedure recommended depends on the location of the tumor and other factors. Options include:

- external beam radiotherapy
- brachytherapy (internal radiation)
- dilation of the airway with a balloon
- laser treatment
- placement of a tubular device called a stent to hold the airway open
- cryoablalion (freezing)
- electrocautery (electrical current)
- argon plasma cautery (APC)
- photodynamic therapy (PDT)
- surgery – used in special circumstances to remove obstructing tumors

Treating Anemia
Anemia can cause or worsen dyspnea. The cause of your anemia will be evaluated by your doctor and he or she will treat you accordingly. Severe anemia may require a blood transfusion. If the need for blood is not immediate, your doctor may recommend another form of treatment. See the Treatment Related Symptoms section of this chapter for additional information on treatments for anemia.

Treating Malignant Pleural Effusion
A malignant pleural effusion is an accumulation of fluid in the sac surrounding the lung. It is caused by cancerous invasion of the sac. Seven to fifteen percent of people with lung cancer develop a pleural effusion. Approximately 50-77% of the people with
a pleural effusion develop shortness of breath associated with the effusion. Dyspnea is the main reason to treat a pleural effusion.

There are different ways to treat a malignant pleural effusion.

- Drain the fluid by inserting a needle into the pleural sac. Pleural fluid tends to reaccumulate, which may make it necessary to repeat the drainage process.
- **Pleurodesis** involves draining the pleural fluid and placing a substance (a *sclerosing agent*) in the pleural space to create irritation. The irritation causes the two sides of the pleural sac to stick together leaving no room for reaccumulation of fluid. Pleurodesis can be done two different ways. The chest tube method involves inserting a tube through the chest wall into the pleural space. The tube is attached to a suction device that gently draws out the pleural fluid. Once the fluid has been drained and a local painkiller has been administered, a sclerosing agent is injected into the pleural space. Alternatively, pleurodesis can be performed through an *endoscope*, which allows the surgeon to see the pleural space. The chest tube method is performed with a local painkiller and a sedating drug. The thoracosopic method is done under general anesthesia. Talc is the most commonly used sclerosing agent, but there are other substances in use including bleomycin and tetracycline.
- Other surgical procedures can be used to treat malignant pleural effusions that have not responded to less invasive treatments.

Some people with dyspnea have found the following self-help techniques useful in controlling this troubling symptom. While these techniques may help alleviate your shortness of breath, be sure to discuss your dyspnea with your health care provider. Dyspnea may indicate a serious underlying problem that requires medical treatment.

**Controlled Breathing**

Breathing normally takes place outside your conscious awareness. Focusing
attention on breathing and doing it in a controlled way may help alleviate shortness of breath. Begin by taking a normal breath in through your nose. Count the number of seconds you inhale. Breathe out through pursed lips for twice as long as you inhaled. Do not force the air; just breathe out in a controlled manner.

**Abdominal Breathing**

Abdominal breathing is a technique in which you use both your chest and abdominal (stomach) muscles to help you breathe more deeply. Babies and young children naturally breathe this way, which is why abdominal breathing is sometimes called baby breathing. As we grow older, we tend to change to chest breathing using primarily the muscles of the chest and the diaphragm (the large muscle under the lungs that separates the chest from the abdomen). Women are almost exclusively chest breathers whereas men tend to use both abdominal and chest breathing. With normal breathing, we typically use only 10-20% of our lung capacity. Abdominal breathing helps you use a much greater amount of your lung capacity with each breath.

Abdominal breathing is best learned while lying on your back with a pillow under your knees. Place one hand on your upper chest and the other on your abdomen below your ribs. Breathe out slowly through pursed lips. Squeeze your abdominal muscles upward and inward. Your abdomen will move inward toward your back. Breathe in through your nose. Your abdomen will rise. Once you have mastered abdominal breathing, you will be able to use it in any position. Abdominal breathing may greatly increase your ability to take in necessary oxygen. Some people with lung cancer have found this technique very helpful in reducing shortness of breath.

**Relaxation**

Relaxation can help reduce dyspnea in two different ways. When you are anxious, as people who are short of breath often are, you tend to take short, shallow breaths. Short, shallow breaths are not an effective way to breathe. When you relax, your breathing slows and becomes deeper. Deep breathing brings more oxygen into the lungs with each breath. In addition, when you are anxious, your muscles are tense.
Tense muscles use more oxygen than do relaxed muscles. Relaxing your muscles decreases their demand for oxygen, which helps reduce air hunger.

People relax in different ways. Soothing music, dim lighting, or a warm bath works for some people. Other people practice techniques that can be used no matter where you are such as visualization or meditation. Chapter 11: Complementary Healing has additional information about these and other relaxation techniques.

Posture and Body Position
Posture and body position can affect how deeply you breathe. Notice your posture. Slouching with your shoulders rolled forward prevents your rib cage from fully expanding with each breath. Try bringing your shoulders up and back. This opens the chest cavity and allows you to bring more air into the lungs.

Sit or lie down if you are short of breath. This decreases your need for oxygen to hold up your body weight and allows your muscles to relax. Sitting with your feet spread shoulder width apart while leaning forward with your elbows on your knees opens up the chest.

Chest Discomfort
Up to 50% of people with lung cancer experience chest discomfort. The pain often comes and goes. It is often vague rather than sharp pain. Some people experience aching pain. The chest discomfort caused by lung cancer is best alleviated by treating the underlying cancer. If the pain persists, your health care provider may recommend pain medication.

Weight Loss
Unintentional weight loss is a common symptom of lung cancer. Someone with lung cancer may lose weight for any of a number of reasons. The causes for weight loss often change over the course of the disease.

The most distressing and serious type of cancer-related weight loss is part of a complex process known as cancer cachexia. Cachexia most often accompanies advanced stage disease.
The hallmark of cachexia is substantial weight loss that involves not only fat but also *lean body mass*, that is, the non-fatty tissues of the body such as muscle and bone. Cachexia is usually accompanied by loss of appetite (*anorexia*) and weakness. Cachexia can be very upsetting to both patients and their loved ones. Loss of fat in the face can change its appearance. The eyes and cheeks may take on a sunken appearance, and the bones of the face tend to become more prominent especially around the eyes and the forehead.

Many people have heard that cancer causes people to lose weight because the cancer uses all the nutrients a person takes in, starving the rest of the body. While on the surface this makes some sense, the mechanisms of cachexia are far more complex. Researchers have found cancerous tumors can produce substances that affect the body’s metabolism. Other studies have shown that the body’s reaction to cancer can also influence metabolism. While all the details are not yet worked out, it seems the weight loss associated with cancer cachexia is due to complex processes influenced by both substances produced by tumors and the body’s reaction to the tumors.

Cachexia is notoriously difficult to treat. Simply increasing the number of calories in the diet often does not reverse true cachexia. The best treatment for cancer cachexia is to eliminate the cancer, if possible. While cachexia is quite serious and distressing, it is important to keep in mind that there are a number of less serious causes of weight loss for someone with lung cancer that are more easily and effectively treated.

A persistent cough can interfere with eating, which in turn can lead to weight loss. In this situation, controlling the cough allows normal eating to resume. This arrests or reverses weight loss. Similarly, breathing difficulties can interfere with normal eating. If the breathing problem can be controlled so that normal eating is possible, weight loss can be stopped. In rare instances, lung tumors can interfere with swallowing. Again, treating the swallowing difficulty will prevent further weight loss and allow normal eating. Depression is relatively common among people with lung cancer and frequently causes reduced appetite and weight loss. If depression is the underlying cause of weight loss, successful treatment of depression will halt further weight loss.
Medications can be used to counteract or stop the muscle wasting (loss of lean body mass) that accompanies substantial weight loss. The most commonly used drug for cancer-related weight loss is megestrol acetate (Megace®). Megestrol acetate is a synthetic form of the female hormone progesterone. It acts as an appetite stimulant. However, the weight gain most people experience while on megestrol acetate is primarily body fat, not lean body mass. Dronabinol (Marinol®) is another appetite stimulant and anti-nausea medication. Dronabinol is a prescription medicine that contains a synthetic form of one of the active ingredients in marijuana. Corticosteroids such as dexamethasone (Decadron®) and prednisone (Deltasone®, Orasone®) are sometimes used for short-term appetite stimulation. These steroids can only be used for four weeks or less because the appetite stimulating effect decreases over time. More importantly, these drugs actually promote muscle wasting over time.

Anabolic steroids are related to the male sex hormone testosterone. Anabolic steroids promote muscle building and have been used to treat the muscle wasting associated with cancer cachexia and other chronic illnesses. Examples of anabolic steroids include oxymetholone (Anadrol-50®), oxandrolone (Oxandrin®), and nandrolone decanoate (Deca-Durabolin®). Researchers are currently studying other treatments for cachexia including thalidomide and long-chain omega-3 fatty acids such as those contained in fish oil.

Weight loss can be a symptom of local, locally advanced, or metastatic lung cancer. However, profound weight loss and cachexia are most commonly associated with advanced, metastatic disease. Weight loss is included in this section under symptoms associated with the primary tumor because it seems to be related to the body’s reaction to the cancer itself.

For additional information on weight loss and nutrition, see Chapter 12: Nutrition and Lung Cancer.

SYMPTOMS ASSOCIATED WITH INTRATHORACIC SPREAD OF LUNG CANCER

When lung cancer spreads to other structures in the chest, it can cause specific symptoms depending on the structures involved.
**Chest Pain**

*Pleuritic pain* is sharp pain that occurs with breathing. It occurs when lung cancer invades the outer covering of the lung called the *pleura*. Cancer that has spread to the area in the center of the chest called the *mediastinum* can cause pain behind the breastbone. Pain in a specific spot on the chest (often called point tenderness) may indicate invasions of a tumor into the chest wall or a rib.

Chest pain caused by lung cancer spread is best alleviated by treating the cancer. Pain medication and other pain control measures may also be used.

**Dysphagia**

*Dysphagia* is difficulty swallowing. If lung cancer spreads to the *lymph nodes* of the chest causing them to greatly enlarge, they can press against the *esophagus* (the tube that takes food and liquids from the mouth to the stomach). This can cause difficulty swallowing. This is a rather unusual symptom of lung cancer. It is treated by reducing the size of the involved lymph nodes with chemotherapy, *radiotherapy*, or less commonly, surgery.

**Facial Swelling**

Lung cancer that spreads to lymph nodes near the *trachea* (the tube that takes air from the nose and mouth to the lungs) can press against a large vein called the *superior vena cava*. If flow is partially blocked, a condition called superior vena cava obstruction (SVCO) develops. Blood backs up in the face, neck, and chest. The veins become dilated and are often very noticeable. Facial swelling is most noticeable around the eyes if the obstruction is mild, but can become severe and involve the entire face and neck. SVCO is sometimes accompanied by headache, dizziness, drowsiness, and/or blurred vision.

SVCO can be treated by having a specialized radiologist (an *interventional radiologist*) place a tube (called a stent) in the superior vena cava to hold it open and permit normal blood flow. Radiation therapy to reduce the size of the enlarged lymph nodes is also used either alone or in combination with stenting.
Hoarseness or Change in Voice
Sudden, persistent hoarseness not associated with a cold or sore throat, or another change in the voice may indicate your lung cancer has spread to the nerve that controls the vocal cords. This symptom is usually accompanied by difficulty clearing phlegm when coughing. Invasion of the nerve is usually addressed by treating the underlying cancer.

Shoulder Pain
A lung tumor in the uppermost part of the lung (the apex) can invade the nerves and blood vessels nearby. A tumor in this location is called a Pancoast tumor. This type of tumor often causes a specific set of symptoms known as Pancoast syndrome. The most common symptom is shoulder pain. This is often accompanied by numbness, tingling, or weakness in the arm and/or hand. The skin of the arm and/or hand may be cool to the touch. A group of three symptoms known as Horner’s syndrome can also accompany a Pancoast tumor. Horner’s syndrome involves a drooping eyelid, a small pupil in the affected eye, and lack of sweating on the affected side of the face.

Pancoast tumors can often be successfully treated surgically after combined radiotherapy and chemotherapy. Surgery may reverse symptoms associated with the tumor.

SYMPTOMS ASSOCIATED WITH METASTATIC SPREAD OF LUNG CANCER
Lung cancer can metastasize to almost any organ of the body. The most common sites of lung cancer metastases are the brain, liver, bones, and adrenal glands. Symptoms associated with metastatic disease in these locations are discussed in this section. However, keep in mind that lung cancer may spread to other sites. Be sure to discuss any new symptoms with your health care provider.

Abdominal Pain
Metastatic liver tumors can cause pain on the right side of the body below the ribs. The pain is caused by tumor growth causing pressure in the liver. The liver is enclosed in a capsule
that has little capacity to expand. Anything that increases the size of the liver causes increased pressure leading to pain.

The adrenal glands are another common site of lung cancer metastasis. While adrenal tumors often do not cause symptoms, they can cause pain if they grow large or invade a blood vessel and cause bleeding into the gland. The pain associated with adrenal metastasis is typically located in the back, around waist-level, to the right or left of the spine.

The best ways to alleviate the pain associated with liver or adrenal metastasis are treating the cancer and pain medicine.

**Bone Pain**
Metastatic bone disease is usually accompanied by pain in the affected bone. Pain can range from mild to severe. Any bone in the body can be a site of metastatic lung cancer. Bones invaded by cancer tend to be weak because some of the bone has been eroded away. Eroded bones are prone to breakage. Bone breaks associated with metastatic cancer are called *pathological fractures*. These fractures typically occur without any history of a fall or an impact, or are associated with a minor impact that would not normally cause a bone to break.

Pain from bone metastasis is often treated with radiation therapy (RT) if the affected bone is in a suitable location. Corticosteroids such as prednisone may improve the pain relief provided by RT. If RT fails for provide adequate pain relief, other treatment options are available such as:

- bisphosphonates such as etidronate (Didronel®), pamidronate (Aredia®), alendronate (Fosamax®), risedronate (Actonel®), and zolendronate (Zometa®)
- calcitonin
- radiopharmaceuticals including strontium 89 (Metastron R®), samarium 153 (Quadramet®), rhenium 186, and rhenium 188
If the long bones of the arms or legs have been eroded by bone metastases, your doctor may recommend surgery to stabilize the bone with metal rods or other reinforcements. The surgery is done to prevent a future fracture that could be painful and disabling.

Pain medications are commonly used to treat metastatic bone pain. There are many pain medications available. If one medicine does not control your pain, a stronger medicine or a higher dosage can be used. When working toward pain control, close communication between you and your health care provider is very important. Do not be afraid to speak up when you are in pain. The only way your providers can help is if you are honest with them about your pain. See the section on Pain Control later in this chapter for more information about pain medicines.

**Central Nervous System Symptoms**

The symptoms of metastatic tumors in the brain vary depending on the size, location, and number of tumors present. Severe headaches, uncontrollable vomiting, and seizures are symptoms associated with increased pressure in the brain. Weakness or paralysis limited to a specific area of the body may indicate a tumor in the area of the brain that controls the affected part of the body. Changes in vision, difficulty speaking or swallowing, loss of balance or coordination, and confusion are other possible symptoms associated with metastatic brain disease.

The symptoms associated with metastatic brain tumors are alleviated by treating the tumors. Steroids such as dexamethasone can be used short-term to reduce brain swelling that often accompanies metastatic tumors. Steroids are particularly useful for alleviating symptoms such as headaches and uncontrollable vomiting. Brain tumors can also be treated with whole brain radiation therapy (WBRT). This therapy is often used for people who have more than one metastatic brain tumor. WBRT is usually effective at relieving the symptoms associated with these tumors.

*Stereotactic radiosurgery* (SRS) is another form of radiation treatment for brain tumors. SRS is generally used on people who have one small brain tumor (less than 3 cm or 1¼ inches). SRS usually involves placing a device on the head called a skeletal fixation device. This
allows the radiologist to direct high-energy radiation toward the tumor in a very accurate way that limits the radiation exposure and potential damage to normal brain tissue. Unlike WBRT that takes place over a number of days, SRS is performed in a single treatment. There are three forms of SRS: cobalt 60 or photon systems, linear accelerator systems, and particle beam or proton systems. Photon systems are widely available in specialized treatment centers. The most common SRS photon system is known by the brand name Gamma Knife®. Linear accelerator systems are also widely available and are often referred to with the abbreviation ‘linac.’ Brand names of specific linac systems include X-Knife®, CyberKnife®, and Clinac®. Proton systems are in limited use in the United States.

In some cases, metastatic brain tumors are surgically removed. Your doctors will consider several factors in deciding what treatment is best for your situation. The number of tumors and their location, your overall condition, current quality of life, and likely quality of life after the treatment are important factors in deciding on treatment options. Any treatment involving the brain involves a risk of brain injury. All treatment options and possible outcomes must be carefully considered.

Lung cancer can metastasize to the outer covering of the spinal cord. These tumors press on the spinal cord causing pain, numbness, and/or weakness in a specific area of the body. In severe cases, these tumors can cause paralysis. Losses of bowel and bladder control are other possible symptoms of this condition known as spinal cord compression. Radiation therapy is the most common treatment for this condition. Steroids may be given along with radiation therapy. In special circumstances, surgery may be an option. Your doctors will evaluate the location of the tumor and possible outcomes before recommending a specific treatment. Discuss these options with your doctor, including possible side effects of treatments and the probability of regaining lost function.

PARANEOPLASTIC SYNDROMES

Paraneoplastic syndromes (PNPs) are not due to the physical effects of cancerous tumors. They are caused by substances produced by the tumors acting on tissues in the body. Approximately 10% of people with lung cancer experience symptoms of a paraneoplastic
syndrome over the course of their illness. There are many different PNPs with a great variety of symptoms. In this section, some of the more common PNPs and their symptoms are discussed. However, many other symptoms can occur as part of a paraneoplastic syndrome. Be sure to discuss any new symptoms with your health care provider.

**Cushing Syndrome**

*Cushing syndrome* is caused by abnormally high levels of *adrenocorticotropin hormone* (ACTH). ACTH is normally produced by a small structure in the brain called the pituitary gland. ACTH acts on the adrenal glands, stimulating them to produce and release steroid hormones called *glucocorticoids*. *Cortisol* is the main glucocorticoid produced by the adrenal glands. Cortisol has many actions throughout the body.

Paraneoplastic Cushing syndrome is most commonly seen in people with small cell lung cancer. Normally, the adrenal production of ACTH is closely controlled by the pituitary gland. However, in lung cancer-related Cushing syndrome, cancer cells produce ACTH in an uncontrolled way. Excess ACTH can lead to signs and symptoms such as weakness, muscle wasting, a round appearance to the face, weight accumulation in the trunk of the body, high blood glucose, low blood potassium, high blood pressure, increased body hair, drowsiness, and confusion.

The signs and symptoms of Cushing syndrome usually disappear when the underlying cancer is treated. The drug ketoconazole (Nizoral®) is sometimes used to control the signs and symptoms of Cushing syndrome.

**Digital Clubbing and Hypertrophic Osteoarthropathy**

*Digital clubbing* is rounding of the ends of the fingers accompanied by a flattening of the normal angle between the nail and the nail bed (see Figure 1). Clubbing can occur in a single finger, only on the fingers of one hand, or can involve both hands. The toes can also be affected. Clubbing may be accompanied by a warm sensation in the affected fingertips.
Clubbing can be found alone or in combination with hypertrophic osteoarthropathy (HOA). In HOA, the outer layer of the long bones of the arms and/or legs is inflamed causing pain and swelling in the ankles, wrists, and knees. This inflammation can be seen on x-rays. Clubbing is more common than the combination of clubbing and HOA. Clubbing and HOA, both alone and in combination, can be seen with several conditions other than lung cancer.

Cancer-related clubbing and HOA may partially or completely resolve with successful treatment of the underlying lung cancer. Pain medications are used to control joint pain associated with HOA.

**Hypercalcemia**

People with lung cancer can have high levels of blood calcium (hypercalcemia) because of metastases to bones or a paraneoplastic syndrome. The paraneoplastic syndrome that leads to hypercalcemia is caused by production of a hormone-like substance by lung cancer cells. This paraneoplastic syndrome is most commonly seen with squamous cell carcinoma. Symptoms of hypercalcemia include thirst, dehydration, abdominal pain, decreased appetite, nausea, vomiting, constipation, excessive urination, muscle weakness, fatigue, irritability, and confusion.

Paraneoplastic hypercalcemia can be treated with medicines such as pamidronate (Aredia®), plicamycin (Mithracin®), calcitonin, and gallium nitrate. Treating the underlying cancer is the best way to resolve paraneoplastic hypercalcemia.

**Neurologic Syndromes**

There are several neurologic paraneoplastic syndromes, and any part of the nervous system can be affected. While these neurological syndromes are relatively rare, when they do occur, it is usually in conjunction with small cell lung cancer. PNP neurological syndromes are thought to be due to antibodies produced by the body against its own nerve tissues. These
neurologic syndromes sometimes appear before the diagnosis of lung cancer is made. Symptoms include numbness, burning or prickly sensations in the hands and feet, weakness, muscle aches, muscle stiffness or cramps, dry mouth, constipation, inability to empty the bladder completely, impotence, loss of balance, light sensitivity, night blindness, personality changes, confusion, and memory loss.

The primary treatment for PNP neurologic syndromes is treatment of the underlying cancer.

**Syndrome of Inappropriate Antidiuretic Hormone (SIADH)**

*Antidiuretic hormone* (ADH) is normally released into the body by a small gland in the brain called the pituitary gland. ADH acts on the kidneys to control water balance in the body. Its production is normally tightly controlled. Paraneoplastic SIADH is caused when lung cancer cells produce ADH in an uncontrolled way. This syndrome is most commonly seen in people with small cell lung cancer. The abnormally high amount of ADH causes a low blood sodium level and excess water accumulation in the body. Symptoms of SIADH include weakness, fatigue, headache, loss of appetite, and nausea. If the sodium level is extremely low, there can be confusion, seizures, and coma.

Mild SIADH can be treated by cutting back fluid intake. The medicine demeclocycline (Declomycin®) and intravenous salt solution may also be needed. Treatment of the underlying cancer usually results in rapid resolution of this paraneoplastic syndrome.

**Other Manifestations of Paraneoplastic Syndromes**

Several other uncommon paraneoplastic syndromes can accompany lung cancer. Following is a list of some of the signs and symptoms that may indicate the presence of a paraneoplastic syndrome:

- **Hormonal Problems**
  - breast enlargement (especially in men)
  - low blood sugar
  - high thyroid hormone
  - high female hormones
Kidney Problems
decreased urine production

Skin Problems
rashes
itching
hives

Blood and Blood Vessel Problems
inflamed blood vessels (*vasculitis*)
high blood platelets (*thrombocytosis*)
low blood platelets (*thrombocytopenia purpura*)
blood clots
low *red blood cells* (anemia)
high *white blood cells* (*leukocytosis*)

OTHER CANCER RELATED SYMPTOMS

Anemia
Anemia is a condition in which the number of red blood cells circulating in the body is abnormally low. Lung cancer can cause anemia as part of the cancerous process. The mechanisms that cause anemia in people with cancer are complex. Lung cancer treatments can also lead to anemia.

Anemia can cause many different symptoms including shortness of breath, fatigue, sleeplessness, and weakness. The treatments for cancer-related anemia and treatment-related anemia are generally the same. This information is discussed in the section on *Treatment Related Symptoms*.

Blood Clots
People with lung cancer have an increased risk for developing blood clots in their veins. This is particularly true for people with adenocarcinoma or large cell lung cancer. It is less common in people with squamous cell carcinoma or small cell lung cancer. Blood clots usually form in the veins of the legs. Unexplained swelling in your foot or lower leg may indicate the presence of a clot. Blood clots can also develop in the arms. This is especially a risk for people who have a long-term intravenous access device such as a central line (a
Groshong® catheter or Hickman® line), a port (Portacath®), or a PICC line. Contact your doctor immediately if you develop unexplained swelling in one of your extremities, neck, or face.

Blood clots are a potentially serious problem because pieces of the clot called emboli can break off and travel through the bloodstream to the lungs, heart, or brain causing damage to these vital organs. All these situations are serious and can be life threatening if they are not treated immediately.

A blood clot in a vital organ is often treated with a medicine that will dissolve the clot and restore normal blood flow. These drugs are called thrombolytics or clot busters. Examples of these drugs include reteplase (r-PA, Retavase®), alteplase (t-PA, Activase®), urokinase (Abbokinase®), streptokinase (Streptase®), and anisoylated purified streptokinase activator complex (APSAC, anistreplase, Eminase®).

People who develop blood clots in the veins (deep venous thrombosis or DVT) are often treated with anti-clotting medicines called anticoagulants or blood thinners. These medicines do not dissolve the clot but keep it from getting larger. Blood thinners also help prevent new clots from forming elsewhere. Three anticoagulants are used to treat venous blood clots.

**Heparin** (unfractionated)
Heparin is a naturally occurring anticoagulant. It is administered through an intravenous line (IV). People on heparin often have to be in the hospital.

**Low Molecular Weight Heparins** (LMWH)
This is a newer form of heparin therapy than unfractionated heparin. LMWH stays in the body for a longer period than standard heparin. This makes it possible to give LMWH in a shot under the skin once or twice per day rather than in a continuous IV. LMWH can often be administered at home rather than in a hospital.

**Warfarin** (Coumadin®)
Warfarin is taken by mouth but does not become effective until 4-5 days after beginning treatment.
Treatment of a DVT usually begins with heparin therapy (either standard or LMWH). Warfarin is usually started at the same time. Heparin therapy is continued until the warfarin takes effect. Once the warfarin has taken effect, heparin therapy is stopped. Your health care providers must closely monitor your blood when you are on anticoagulant therapy. A PTT blood test (partial thromboplastin time) is used to monitor the effects of heparin. A PT test (prothrombin time) is used to monitor the effects of warfarin. Your blood will be tested frequently while you are on anticoagulant therapy to make sure you are getting enough medicine to prevent clots without putting you at risk for bleeding. People who have had a DVT typically stay on anticoagulant therapy for six months or longer. During this time, the body’s normal mechanisms often partially or completely dissolve the original clot.

**Constipation**

The weakness, fatigue, lack of appetite, and reduced activity that many people with lung cancer experience can lead to constipation. Many pain medications also cause constipation. Increased activity can help relieve constipation. Walking is a relatively non-strenuous activity that can alleviate constipation. Abdominal breathing (described under Dyspnea in this section) can help improve bowel activity. Changes in diet may also be useful. Fruits, vegetables, and fiber often help improve bowel activity. Be sure to drink plenty of water. Low fluid intake can significantly worsen constipation. If needed, your health care provider can recommend medications or herbs that can alleviate constipation.

**Depression and Anxiety**

Many people with lung cancer are depressed at some point in their illness. When most people talk about being depressed, they are describing the experience of feeling very sad. People who are depressed often cry, lack interest in normal activities, and/or experience low energy or tiredness. Depression is a completely normal response to a sad, disappointing, unexpected, and/or stressful situation. Health care providers often use the term reactive depression to describe this normal response to any of a number of stressful life situations. Most people who experience reactive depression also have symptoms of anxiety. Anxiety is described as a lingering feeling of uneasiness, worry, and/or being on edge. You may feel your mind is racing and have difficulty focusing. Anxiety can also be experienced as a sense of dread. Again, both anxiety and depression are normal responses to learning you have
lunge cancer. However, these normal responses have the potential to interfere with your life and health if they become prominent. Some symptoms you may experience with depression and anxiety are shown in the following lists.

**Symptoms Associated with Depression**

- persistent sad, anxious, or empty mood
- feelings of hopelessness or pessimism
- feelings of guilt, worthlessness, or helplessness
- loss of interest or pleasure in hobbies and activities that you once enjoyed including sex
- decreased energy, fatigue, or feeling slowed down
- difficulty concentrating, remembering, or making decisions
- difficulty sleeping or sleeping too much
- appetite and/or weight loss, or overeating
- thoughts of death or suicide
- restlessness or irritability
- persistent headaches that are not attributable to another cause and do not respond to treatment

**Symptoms Associated with Anxiety**

- sweating
- dizziness
- racing heart or irregular heart beat
- shakiness
- difficulty relaxing
- headaches
- irritability
- upset stomach, nausea, and/or diarrhea
- sleeping problems
- difficulty concentrating
• excessive watchfulness
• being easily startled

While depression and anxiety are normal reactions to stressful situations, they can become problems if they begin to interfere with your ability to function. If you or one of your loved ones notice one or more of these symptoms are disrupting your life, discuss the situation with your health care provider. He or she may recommend counseling, medication, or another form of therapy such as relaxation techniques to help relieve your symptoms. The important message is that you should **not** ignore these symptoms, nor should you suffer from them for a prolonged period. Talk to your doctor or nurse. Anxiety and depression are normal reactions. They do not mean you are losing control of your mind, and they are not signs of weakness. However, they do need to be controlled if they are interfering with your ability to function or your quality of life.

Some symptoms of depression may be alleviated by talking through your feelings and concerns with others, whether it be in a support group, with family members, or in appointments with a counselor. *Psycho-oncology* is a field of psychology that focuses exclusively on people with living with cancer. Oncology social workers also specialize in working with and counseling people who have cancer. *Chapter 9: Living with Lung Cancer* has additional information on coping with lung cancer.

For many people with lung cancer, counseling and self-help measures are not enough to adequately control depression. This is nothing to be ashamed of; it is not a sign of weakness. Discuss your feelings with your health care providers. Medication may be recommended to help control your depression and anxiety. Many medications are available for these purposes. Some people worry that medications used to control anxiety and/or depression will put them to sleep or make them feel otherwise not themselves. While many older medications had some of these unwanted side effects, newer medications are greatly improved. Commonly used antianxiety medications include lorazepam (Ativan®), alprazolam (Xanax®), diazepam (Valium®), and many others. Fluoxetine (Prozac®), sertraline (Zoloft®), bupropion (Wellbutrin®), zaleplon (Sonata®), paroxetine (Paxil®), citalopram
(Celexa®), and venlafaxine (Effexor®) are just a few of the many medications available to control depression and its symptoms. If one medication does not work for you, you can try another. Many people who are not helped by the first medication they try are happily surprised when their symptoms are alleviated with another medication – so don’t give up.

Fatigue

Fatigue can be the most debilitating symptom associated with lung cancer and its treatment. Fatigue associated with lung cancer is different from everyday tiredness. It is an overwhelming, sustained sense of exhaustion. It is often accompanied by a decreased capacity for physical and mental work. Fatigue can have a profound impact on your ability to carry out normal life activities. While lung cancer itself can cause fatigue, treatments for lung cancer can also cause fatigue. This can make fatigue temporarily worse during treatment.

Fatigue varies in severity from one person to another, and often waxes and wanes over the course of the disease. At times, your fatigue may be mild and alleviated by simple measures such as napping during the day or cutting back on your most strenuous activities. At other times, fatigue can be severe and may force you to significantly alter your lifestyle and activities.

Fatigue can be difficult to treat. Lung tumors can reduce your breathing capacity. Lung cancer surgery involves removal of both diseased and healthy lung tissue, which also reduces breathing capacity. Both of these situations can cause fatigue because reduced breathing capacity decreases the amount of oxygen taken in by the lungs with each breath. The reduced ability to deliver oxygen to body tissues results in becoming easily fatigued with exertion. Anemia can worsen this problem by reducing the blood’s capacity to carry the oxygen taken in by the lungs. Your health care provider will monitor your blood regularly to check for anemia. Treating anemia often helps alleviate fatigue.

Table 1, *Suggestions for Energy Conservation*, offers a number of simple, practical suggestions for how to conserve energy in your everyday life when you are experiencing fatigue.
Table 1: Suggestions for Energy Conservation*

<table>
<thead>
<tr>
<th>HOUSEKEEPING</th>
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<tbody>
<tr>
<td>• Spread chores out over the week rather than trying to do them all in one day.</td>
</tr>
<tr>
<td>• Do a little bit at a time; rest when you get tired.</td>
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<tr>
<td>• Have someone help you with strenuous tasks and heavy lifting.</td>
</tr>
<tr>
<td>• Use a cart or apron to carry your supplies.</td>
</tr>
<tr>
<td>• Do whatever you can while sitting down.</td>
</tr>
<tr>
<td>• Use long-handled dusters, mops, and dust pans to avoid a lot of stooping.</td>
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<table>
<thead>
<tr>
<th>SHOPPING</th>
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<tbody>
<tr>
<td>• Make a shopping list; organize it by the store aisles.</td>
</tr>
<tr>
<td>• Combine errands to reduce the number of trips you need to make.</td>
</tr>
<tr>
<td>• Use a scooter cart if available to allow you to sit while you shop.</td>
</tr>
<tr>
<td>• Ask for assistance taking your purchases to and loading them into the car.</td>
</tr>
<tr>
<td>• Shop when the store is not busy to limit the amount of time at the store.</td>
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<tr>
<td>• Shop with a friend or ask a friend to shop for you.</td>
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<tr>
<th>PREPARING MEALS</th>
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<tbody>
<tr>
<td>• Assemble your ingredients before you begin.</td>
</tr>
<tr>
<td>• Use mixes and prepackaged, microwavable, heat-and-eat, ready-to-eat and other food products that reduce preparation and cooking time.</td>
</tr>
<tr>
<td>• Use appliances to reduce work and preparation time such as electric mixers, blenders, food choppers, and food processors.</td>
</tr>
<tr>
<td>• Use lightweight utensils.</td>
</tr>
<tr>
<td>• Use a jar opener.</td>
</tr>
<tr>
<td>• Use a rubber mat or wet towels to steady mixing bowls during stirring.</td>
</tr>
<tr>
<td>• Transport large items on a rolling cart.</td>
</tr>
<tr>
<td>• Serve food from the stove rather than carrying large serving dishes to the table.</td>
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<tr>
<td>• Store frequently used items in easy-to-reach places.</td>
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<tr>
<td>• Line your oven and drip pans with aluminum foil for easy clean up.</td>
</tr>
<tr>
<td>• Sit while preparing food.</td>
</tr>
<tr>
<td>• Use a dishwasher.</td>
</tr>
<tr>
<td>• Let the dishes soak instead of scrubbing.</td>
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<tr>
<td>• Let dishes air dry.</td>
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<tr>
<td>• Prepare double recipes and freeze half for later use.</td>
</tr>
<tr>
<td>• Use placemats for easy clean up.</td>
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<tr>
<td>• Use a wheeled garbage can.</td>
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<tr>
<th>LAUNDRY</th>
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<tbody>
<tr>
<td>• Use a laundry cart with wheels to move clothes.</td>
</tr>
<tr>
<td>• Sit while transferring clothes.</td>
</tr>
<tr>
<td>• Have others carry their dirty clothes to the laundry area.</td>
</tr>
<tr>
<td>• Ask others to put away clean clothes.</td>
</tr>
<tr>
<td>• Use pre-treaters and stain removers to avoid scrubbing stains.</td>
</tr>
<tr>
<td>• Wash bras, pantyhose, and stockings in a lingerie bag to avoid tangling.</td>
</tr>
<tr>
<td>• Drain hand-washables and press dry rather than wringing them out.</td>
</tr>
<tr>
<td>• Sit while ironing.</td>
</tr>
<tr>
<td>• Use a lightweight iron.</td>
</tr>
<tr>
<td>• Hang clothes on a doorknob rather than at the top of the door.</td>
</tr>
<tr>
<td>• Wear clothes that do not require ironing.</td>
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Table 1: Suggestions for Energy Conservation, continued

<table>
<thead>
<tr>
<th>CHILDCARE</th>
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<tbody>
<tr>
<td>• Plan activities such as doing puzzles, playing board games, coloring, reading, etc. that can be done sitting.</td>
</tr>
<tr>
<td>• Plan outings that will allow you to sit down such as going to a movie, storytelling, a play, etc.</td>
</tr>
<tr>
<td>• Take a nap when your child naps.</td>
</tr>
<tr>
<td>• Have ready-to-eat snacks available that don’t require preparation.</td>
</tr>
<tr>
<td>• Have your child crawl into your lap rather than picking him or her up.</td>
</tr>
<tr>
<td>• Engage children in household chores by making them into a game.</td>
</tr>
<tr>
<td>• Place toy containers at the children’s level so they can pick up their own toys.</td>
</tr>
<tr>
<td>• Take advantage of carpools to limit transporting the children to activities and school.</td>
</tr>
<tr>
<td>• Utilize programs that give mothers time off during the day.</td>
</tr>
<tr>
<td>• Delegate some childcare responsibilities among trusted family members and friends.</td>
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<tr>
<th>WORKPLACE</th>
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<tbody>
<tr>
<td>• Plan your workload around the times when you have the most energy.</td>
</tr>
<tr>
<td>• Arrange your workplace so that it’s energy efficient; keep frequently used items within easy reach.</td>
</tr>
<tr>
<td>• Sit when you can.</td>
</tr>
<tr>
<td>• Take regular rest breaks.</td>
</tr>
<tr>
<td>• Use the telephone, intercom, e-mail, faxes and other telecommunications to limit unnecessary trips to other locations.</td>
</tr>
<tr>
<td>• Discuss the possibility of working from home, if your job allows for this option.</td>
</tr>
<tr>
<td>• Discuss the possibility of a flexible work schedule or a reduction in your work hours.</td>
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<tr>
<th>ALLOWING OTHERS TO HELP</th>
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<tbody>
<tr>
<td>• Put someone else in charge of organizing the ‘To Do’ list and assigning the tasks.</td>
</tr>
<tr>
<td>• Do not forget to include the ‘little’ things on the ‘To Do’ list that others can do, for example: walk the dog, pick up the dry cleaning, weed the garden, do the mending, take the trash to the street, rake leaves, shovel snow, pick up or mail packages, etc.</td>
</tr>
<tr>
<td>• Do not feel the need to entertain your helpers; they are there to help.</td>
</tr>
<tr>
<td>• Try to get used to allowing others to help; you may actually be doing your loved ones a favor by allowing them to feel useful rather than helpless.</td>
</tr>
<tr>
<td>• Make plans, but don’t be afraid to change them. If you’ve made plans to do something but aren’t up to it when the day arrives, let others know how you’re feeling – they will understand.</td>
</tr>
<tr>
<td>• Do not worry about keeping up with thank you notes. Your loved ones are trying to reduce your workload not create more tasks for you to accomplish. Your family may want to post a general thank you in a church bulletin, local newspaper, or a group e-mail message.</td>
</tr>
</tbody>
</table>

*Adapted in part from the “Suggestions for Energy Conservation” Eileen Donovan, P.T. The University of Texas M.D. Anderson Cancer Center. Used with permission.

Other tips to help manage fatigue include:

- Avoid unneeded bed rest.

  While it is important to get the sleep you need, staying in bed when you do not need to can actually worsen fatigue. Inactivity leads to muscle weakness and decreased energy. We have all heard the phrase, “use it or lose it.” This is very good advice. In general, the less you do, the less you will feel like doing.
• Try to get some form of exercise each day.
On the surface, this advice may not seem to make sense. However, inactivity leads to muscle loss and weakness that contribute to fatigue. Continue whatever form of exercise you enjoyed before your diagnosis. You may need to reduce the time or intensity of your exercise program, but do not give it up altogether. If you were not getting exercise before your diagnosis, talk with your health care providers about beginning a gentle exercise program. Many people find walking is an enjoyable form of exercise that is not too strenuous.

Exercise can help you in many ways. Regular exercise helps maintain your muscle mass and tone. It also helps keep your respiratory muscles in shape, which may help alleviate dyspnea. Exercise has also been shown to be useful in alleviating depression. Exercise can take a variety of forms including such things as gardening, bowling, biking, walking, golfing, weight lifting, dancing, and yoga. Anything that gets you up and moving is exercise. Be sure to discuss your activities and exercise plan with your health care providers to ensure that your program is safe and effective for you.

• Take a break.
Short rest periods and quiet times throughout your day can help you regain your strength and energy for the things you need and want to do.

• Limit stress and emotionally draining situations.
Stress and emotionally difficult situations can quickly drain your energy. Examine your personal situation and try to determine what causes you the most stress. Once you have identified these stressors, work with family, friends, support groups, or counselors to find ways to minimize these stressors. Refer to *Chapter 9: Living with Lung Cancer* for additional information about coping with the stresses of living with lung cancer.
• Rest your mind.

There are many things to think about and many decisions to be made when you have lung cancer. These demands can lead to mental fatigue, a feeling of being unable to think clearly. Mental fatigue can often be relieved by giving your mind a break, much as you give your body break when you are physically tired. Listening to music, reading, watching a movie, bird watching, meditation, visualization, a warm bath, getting a massage, or any other activity that allows you to mentally relax can give your mind the rest it needs.

• Eat a well-balanced diet.

The food you eat provides the nutrients and calories (energy) you need. Eating a well-balanced diet with an adequate number of calories can help reduce fatigue. See Chapter 12: Nutrition and Lung Cancer for information on eating a healthy, energy-rich diet.

Discuss your fatigue with your health care providers and family. Your health care providers can make recommendations or provide treatments to help reduce your fatigue. Your family and friends may be able to help by taking over some of your energy-draining chores.

Weakness

Weakness (asthenia) is a common symptom of lung cancer. It is often associated with dyspnea, fatigue, anemia, and/or weight loss. Activity is generally the best way to counteract weakness. Even mild exercise can help rebuild lost muscle tone and increase strength. Discuss any weakness you experience with your health care provider. He or she will take into account other signs and symptoms you may be experiencing and make recommendations about how best to rebuild your strength. Several different treatment approaches may be recommended including such things as mild exercise, dietary changes, supplemental oxygen, anemia treatments, respiratory therapy, and physical therapy.
TREATMENT RELATED SYMPTOMS

Anemia

Lung cancer and its treatments can cause anemia, a reduced number of red blood cells circulating in the body. Red blood cells carry oxygen from the lungs to all the cells of the body. A shortage of red blood cells can deprive the body of needed oxygen, resulting in a variety of symptoms. Fatigue, shortness of breath, dizziness, cold hands and feet, rapid heartbeat, sleeplessness, and inability to concentrate are some of the symptoms associated with anemia.

Lung cancer treatments can cause anemia or worsen existing anemia. Lung cancer surgery can cause significant blood loss. Chemotherapy can cause anemia by destroying cells in the bone marrow that produce red blood cells. Certain chemotherapy drugs can also cause circulating red blood cells to die or be prematurely destroyed. If areas of the body that produce red blood cells are radiated, this can also contribute to anemia.

Your health care providers will monitor your blood counts throughout the course of your illness, but will monitor you mostly closely when you are on treatment. It is important to treat anemia not only to alleviate symptoms but also to reduce the effects of low tissue oxygen on the body. Low tissue oxygen can reduce the effectiveness of radiation therapy.

Anemia is treated in a variety of ways. Iron-rich foods can help replenish body iron if you have a deficiency. Blood transfusions are used if your red blood cell count is extremely low. Transfusions provide temporary relief of symptoms while other measures are used to promote red blood cell production by your body. Your doctor may recommend treatment with a man-made (synthetic) form of erythropoietin (Procrit®, Epogen®). Erythropoietin is a hormone produced by the kidneys that stimulates red blood cell production. The synthetic form of this hormone stimulates the same response in the body. Darbepoetin alfa (Aranesp®) is very similar to erythropoietin but is not taken as often as other synthetic erythropoietins.
Cognitive Problems

People undergoing treatment for lung cancer can experience cognitive problems. Cognitive functioning refers to the brain’s ability to focus attention, and process, store, and retrieve information. The most common cognitive problems encountered by people with cancer during treatment are:

- short-term memory difficulties
- easy distractibility
- trouble performing arithmetic
- difficulty focusing attention
- difficulty performing more than one task at a time

One study found approximately 20% of people undergoing chemotherapy experienced some form of cognitive side effects. These problems are sometimes referred to as chemo-brain, chemofuzzies, or mental fatigue. Radiation therapy to the brain can also cause cognitive side effects similar to those seen with chemotherapy. Symptoms of mental fatigue include:

- difficulty maintaining the attention necessary to read
- problems with everyday arithmetic such as balancing a checkbook or calculating a tip
- forgetting what you were talking about
- losing track of things such as your keys, purse, wallet, etc.
- repeating yourself

Discuss any cognitive problems you are experiencing with your health care providers. While cognitive problems can be understandably distressing, they are rarely permanent. Following are some suggestions that may help you minimize the effects of mental fatigue while you are receiving lung cancer treatment.

- Take mental breaks such as listening to calming music, relaxing in your favorite armchair, taking a bath, etc.
- Plan ahead whenever possible.
- Make lists to help you stay organized.
• Make sure you are getting enough sleep. Consider taking short naps during the day if you grow tired.
• Try not to get upset over forgetfulness or other lapses in mental clarity. Anxiety can worsen mental fatigue.
• Take things one step at a time.
• Keep your brain active by participating in mentally challenging activities such as solving puzzles, playing a musical instrument, doing crafts, writing letters or journal entries, playing board or computer games, playing cards, etc.
• Try to reduce unnecessary stress, which can worsen mental fatigue.
• Stay physically active. Physical activity encourages mental clarity.

**Constipation**

Lung cancer treatments can directly or indirectly cause constipation. Decreased appetite, nausea, inactivity, fatigue, surgery, and pain medications contribute to constipation. A variety of measures can be taken to alleviate or avoid constipation. Drinking plenty of fluids is a simple measure many people overlook. Your diet can also affect constipation. Large quantities of dairy products such as milk, ice cream, cheese, and yogurt can contribute to constipation. Fresh fruits and vegetables, whole grain cereals, nuts, and juices help prevent constipation by keeping the bowels active. Regular exercise also helps keep the bowels active.

Your doctor may prescribe a stool softener and/or a mild laxative especially if you are taking pain medication. Talk with your health care provider if you have not had a bowel movement in two or more days. You may need a higher dose of laxative or an enema.

**Hair Loss**

Hair loss (*alopecia*) can be one of the most traumatic side effects of cancer treatment for some people. From a medical standpoint, this side effect is considered minor since it does not cause any physical problems. However, it can be emotionally difficult to handle. Hair loss may be a constant reminder of your illness. It also makes it apparent to the people you encounter every day that something is amiss.
Chemotherapy can cause hair loss by weakening the hair follicles. This causes the hair to fall out at a much higher rate than normal. However, not all chemotherapy drugs used to treat lung cancer cause hair loss. Your health care provider can tell you if the drugs you are taking are likely to cause hair loss. Whole brain radiation treatments can also cause hair loss.

Hair loss associated with cancer therapy varies. Some people experience only thinning of the hair on their heads. Others lose all the hair on their heads along with their eyebrows, eyelashes, and other body hair. Hair loss from chemotherapy is not immediate. Most often, hair loss begins 2-6 weeks after chemotherapy has begun.

Treatment-related hair loss is usually not permanent. Hair lost during chemotherapy usually grows back. However, it may grow back with a slightly different texture or color than the hair you lost. Hair lost because of radiation therapy also usually grows back, but it may not grow back as thick as it was before your treatment. Hair regrowth after cancer treatment usually takes from 6 to 12 months.

While some people are not bothered by temporary hair loss, it is very upsetting to others. Some people use a wig or hairpiece during treatment. Having a hairpiece or wig available before treatment begins may make it less traumatic when your hair begins to fall out. Select local offices of the American Cancer Society have wigs available to loan. Hats and scarves are also options you may want to consider.

**Mouth Sores and Other Oral Problems**

Some chemotherapy drugs and whole brain radiation treatments for lung cancer cause mouth sores and other problems with your gums and teeth. The lining of the mouth is normally replaced every 10-14 days. Therefore, the cells that make up the lining of the mouth must replace themselves rapidly. When certain chemotherapy drugs or radiation treatments to the head are given, the division of these cells is slowed. When the lining of the mouth is shed, the slowed cell division makes it difficult to grow new tissue to replace it. As a result, sores or ulcers can develop in the mouth. This condition is called *mucositis* or *stomatitis*. Mucositis usually begins approximately two weeks after treatment begins. It can be very painful. The sores often heal slowly because cell production is decreased.
Open sores in the mouth can cause infections because the mouth is normally home to many microscopic organisms. These tiny organisms do not usually cause problems because the lining of the mouth serves as a barrier, keeping them from invading the body. However, open sores in the mouth can provide an entry point into the body for these organisms to invade and cause infection. This is particularly problematic for people receiving cancer therapy because treatments can reduce your ability to fight infections.

Dry mouth is another common symptom in people being treated for lung cancer. This occurs when the salivary glands do not produce a normal amount of saliva (spit). Dry mouth can cause any of the following symptoms.

- bleeding gums
- a sore tongue
- cracked lips and/or sores at the corners of the mouth
- difficulty wearing dentures
- altered sense of taste
- difficulty swallowing
- tooth decay

You can help avoid problems associated with cancer treatment by having your teeth cleaned before beginning therapy. It is best to have this done a month before beginning chemotherapy or radiation treatments, if you have the time. This will give your mouth time to heal before treatment begins.

During treatment, the following practices can help you avoid or reduce mouth problems.

- Brush your teeth at least four times per day. Floss at least twice per day.
- If possible, use toothpaste with fluoride to protect your teeth. If commercial toothpaste burns your mouth, use a solution of ½ teaspoon of salt and 2 tablespoons of baking soda in 8 ounces of warm water instead of toothpaste.
- Use a soft or extra-soft toothbrush to avoid small abrasions of the mouth and gums. Children’s toothbrushes are usually extra-soft.
- Apply fluoride gel to your teeth at bedtime.
• Rinse your mouth with a solution of ½ teaspoon of salt and 2 tablespoons of baking soda in 8 ounces of warm water at least 4-6 times per day. Follow the solution with a clear water rinse.
• Sip water or suck on ice chips throughout the day to reduce dryness. Adding a few drops of food grade glycerin (glycerin USP) to your water will help the water lubricate your mouth. You can also use glycerin swabs or a saliva substitute. Your health care provider can advise you about getting these items.
• Keep a spray bottle of water or water/glycerin solution nearby. Spray your mouth whenever it feels dry.
• Chew sugarless gum or suck on sugarless hard candy to keep your mouth wet by stimulating saliva production.
• Keep your lips moist with lip balm or petroleum jelly. Do not share these items with other people as they can spread infections.
• Avoid spicy foods that may increase the burning sensation in your mouth.
• Avoid carbonated beverages, orange juice, grapefruit juice, and acidic foods such as citrus fruits, vinegar, pickled foods, and ketchup.
• Avoid salty foods that can dry your mouth and lips.
• Avoid very hot liquids or foods that could burn your mouth or tongue.
• Avoid alcohol in beverages, foods, or other products such as mouthwash or fluoride rinses. Alcohol will cause burning and may increase the severity of mouth sores.
• Avoid eating foods with sharp edges that may scratch your mouth such as potato chips, hard breads, and some crackers.
• Avoid smoking and/or chewing tobacco.
• Eat foods that are soft, moist, and easy to chew. Yogurt, cooked cereals, rice, pasta, potatoes, applesauce, pudding, cooked carrots, peas, cheeses, eggs, soups, and casseroles are a few examples.
• Brush your teeth and rinse your mouth after eating foods or liquids with high sugar content.

People on chemotherapy whose white blood cell counts drop substantially may experience
an overgrowth of yeast in the mouth and/or throat. This is condition is called thrush. The yeast often causes a white, beige, or yellowish coating on the tongue and/or gums. Eating active-culture yogurt or rinsing your mouth with hydrogen peroxide (3%) may help control the growth and spread of thrush. Your doctor may prescribe an antifungal solution to gargle with, or antifungal medication to take by mouth.

**Low Blood Counts (Myelosuppression)**

Blood cells in the circulation come from the bone marrow, the soft center of the large bones in the body. Immature blood cells in the bone marrow produce red blood cells (RBCs), white blood cells (WBCs), and platelets when they are needed in the circulation. Many chemotherapy drugs that kill cancer cells also interfere with the production of RBCs, WBCs, and platelets. Reduced production of these cells is called myelosuppression. Low RBCs is called anemia. Low WBCs is called leukopenia or neutropenia. Low platelets is called thrombocytopenia.

Myelosuppression can be caused by chemotherapy or radiation therapy. Radiation treatments for lung cancer usually cause only mild myelosuppression because the bones in the treatment fields are responsible for only a small amount of the body’s blood cell production. Myelosuppression associated with chemotherapy for lung cancer is often more severe than that seen with radiation therapy. Myelosuppression is one of the major causes of reducing the dose of chemotherapy, altering the chemotherapy treatment schedule, or stopping treatment altogether. Health care providers take myelosuppression very seriously because it can be life threatening. However, reducing the dose of chemotherapy drugs or prolonging the interval between treatment cycles to allow the blood cell levels to return toward normal gives cancer cells time to grow and multiply.

*Hematopoietic growth factors* (HGFs) stimulate the bone marrow to increase production of blood cells. Therefore, HGFs are often given along with chemotherapy to maintain the optimal dose and timing of chemotherapy. The three forms of myelosuppression are discussed on the following pages along with specific HGFs.
Anemia
While anemia is one component of myelosuppression, there are other mechanisms for anemia related to lung cancer and its treatments. Please see the listing Anemia in this section for a detailed discussion of this common cancer-related problem.

Leukopenia/Neutropenia/Granulocytopenia
Leukopenia is an abnormally low number of WBCs in the blood. Neutrophils are a specific type of WBC in a group of blood cells called granulocytes. Neutrophils play an important role in fighting bacterial infections. An abnormally low number of neutrophils in the blood is called neutropenia. The term granulocytopenia is often used interchangeably with neutropenia.

Granulocyte colony-stimulating factor (G-CSF, Neulasta®, Neupogen®) stimulates the bone marrow to increase its production of granulocytes. This stimulation can help counteract the myelosuppressive effects of chemotherapeutic drugs, allowing the full dose to be given according to schedule.

Anyone on chemotherapy is at increased risk for infections regardless of whether G-CSF is also being taken. Therefore, you need to be aware of possible signs and symptoms of infection such as:

- fever greater than 100º F
- chills or sweats
- cough or sore throat
- redness or swelling around skin sores or at injection sites
- loose bowels or diarrhea
- burning sensation during urination
- unusual vaginal discharge or itching
- feeling not quite “right”

Call your doctor immediately if you experience any of these signs or symptoms. If you cannot reach your doctor, go to your nearest emergency room.
There are steps you can take to reduce your risk of infection while on chemotherapy. A list of precautionary measures includes:

- Avoid crowds and people with the flu or colds during the time your WBCs are at their lowest. Ask your doctor or nurse when this is most likely to occur with your treatment.
- Wash your hands frequently, especially before eating.
- Eat fully cooked foods. Wash fresh fruits or vegetables well before eating them. Peeling fruits can also reduce your risk.
- Use the hottest water cycle in your dishwasher.
- Do not share towels, drinking glasses, or dishes with others.

**Thrombocytopenia**

Thrombocytopenia is an abnormally low number of platelets in the blood. Platelets are one of the elements necessary for blood clotting. Drugs that cause myelosuppression can cause thrombocytopenia. A mild drop in your platelet count does not usually cause symptoms. Severely depressed platelet counts can cause easy bruising, nosebleeds, bleeding from the gums, prolonged bleeding from minor cuts or scrapes, and/or a pinpoint rash of tiny purplish spots called **petechiae**. Contact your health care provider immediately if you experience any of these signs or symptoms.

A transfusion of platelets may be needed if your platelet count drops significantly. This will provide short-term relief of symptoms. The platelet growth factor oprelvekin (Neumega®) stimulates the production of platelets. It is usually given only to people who have experienced dangerously low platelet levels in response to therapy.

**Nausea and Vomiting**

Many people have the idea that all chemotherapy causes severe nausea and vomiting. This is simply untrue. Not all chemotherapy drugs cause nausea and/or vomiting. Further, several highly effective drugs are available to prevent and control nausea and vomiting associated
with chemotherapy. Fortunately, the days of uncontrollable nausea and vomiting associated with chemotherapy are long gone.

Health care providers refer to the nausea and vomiting associated with chemotherapy as CINV (chemotherapy-induced nausea and vomiting). Different chemotherapy drugs have different levels of risk for CINV. In general, a combination of drugs is more likely to cause CINV than is a single agent. CINV can be acute (occurring within the first 24 hours of treatment) or delayed (occurring several days after treatment). The risk of CINV is predictable based on the drugs you are taking. Your health care provider will recommend treatment that matches the risk profile of the drugs you are taking. Table 2 shows the risk of CINV associated with chemotherapy drugs commonly used to treat lung cancer. Drugs that are FDA-approved for the treatment of small cell or non-small cell lung cancer appear in italics. However, your doctor may prescribe other drugs on the list. The choice of chemotherapy drugs is individualized to meet your specific circumstances and needs.

**Table 2: Risk of Chemotherapy-Induced Nausea & Vomiting (CINV) Associated with Common Lung Cancer Chemotherapy Drugs**

<table>
<thead>
<tr>
<th>Generic Name</th>
<th>Trade Name</th>
<th>Risk of CINV (without medication)</th>
</tr>
</thead>
<tbody>
<tr>
<td>carboplatin</td>
<td>Paraplatin®</td>
<td>high</td>
</tr>
<tr>
<td>cisplatin</td>
<td>Platinol®</td>
<td>high</td>
</tr>
<tr>
<td>cyclophosphamide</td>
<td>Cytoxan®</td>
<td>moderate to high</td>
</tr>
<tr>
<td>docetaxel</td>
<td>Taxotere®</td>
<td>mild</td>
</tr>
<tr>
<td>doxorubicin</td>
<td>Adriamycin®</td>
<td>moderate to high</td>
</tr>
<tr>
<td>etoposide</td>
<td>VePesid®</td>
<td>mild</td>
</tr>
<tr>
<td>fluorouracil</td>
<td>5-FU</td>
<td>mild</td>
</tr>
<tr>
<td>gefitinib</td>
<td>Iressa®</td>
<td>moderate</td>
</tr>
<tr>
<td>gemcitabine</td>
<td>Gemzar®</td>
<td>mild</td>
</tr>
<tr>
<td>ifosfamide</td>
<td>Ifex®</td>
<td>moderate</td>
</tr>
<tr>
<td>irinotecan</td>
<td>Camptosar®</td>
<td>mild</td>
</tr>
<tr>
<td>methotrexate</td>
<td>Mexate®</td>
<td>mild to severe</td>
</tr>
<tr>
<td>mitomycin</td>
<td>Mutamycin®</td>
<td>mild</td>
</tr>
<tr>
<td>paclitaxel</td>
<td>Taxol®</td>
<td>mild</td>
</tr>
<tr>
<td>topotecan</td>
<td>Hycamtin®</td>
<td>moderate</td>
</tr>
<tr>
<td>vinblastine</td>
<td>Velban®</td>
<td>very low</td>
</tr>
<tr>
<td>vincristine</td>
<td>Oncovin®</td>
<td>very low</td>
</tr>
<tr>
<td>vinorelbine</td>
<td>Navelbine®</td>
<td>very low</td>
</tr>
</tbody>
</table>
If there is a risk of CINV associated with your chemotherapy regimen, you will be premedicated with drugs to prevent these side effects before chemotherapy is administered. It is much easier to prevent nausea and vomiting than it is to get it under control once it starts. Often, a combination of drugs is used because combined treatment has been found to be more effective than use of any single drug.

Drugs currently used to control CINV are shown in the following list. The choice of drugs used and their dosing will depend on your chemotherapy regimen.

- alprazolam (Xanax®)
- aprepitant (Emend®)
- dexamethasone (Decadron®)
- diphenhydramine (Benadryl®)
- dolasetron (Anzemet®)
- dronabinol (Marinol®)
- droperidol (Inapsine®)
- granisetron (Kytril®)
- hydroxyzine (Atarax®)
- lorazepam (Ativan®)
- methylprednisolone (Medrol®)
- metoclopramide (Reglan®)
- ondansetron (Zofran®)
- prochlorperazine (Compazine®)

In addition to medications, self-help techniques can be useful in controlling nausea and/or vomiting.

- Eat small amounts throughout the day rather than three large meals. Filling your stomach increases the likelihood of nausea and vomiting.
- Eat slowly and chew your food well.
- Be sure you drink enough fluids. Dehydration can cause nausea and vomiting.
- Avoid spicy and greasy foods. Greasy foods are hard to digest and stay in the stomach for extended periods, sometimes up to 12 hours.
- If cooking odors bother you, eat cold meals or ask someone else to prepare your meals and bring them to you on difficult days. Avoid foods with strong odors.
- If you feel nauseous, get some fresh air and take deep breaths.
- Rinse your mouth often if it is dry or has a bad taste.
- Suck on ice chips or hard candy.
Talk with your health care providers if you are having problems with nausea and/or vomiting. Many options are available to control these symptoms effectively. There is no reason to suffer. If you are taking medication but are still experiencing breakthrough nausea or vomiting, your treatment can be changed to another regimen that works better for you.

Peripheral Neuropathy

Some chemotherapy drugs can injure the peripheral nerves of the body, that is, those outside the brain and spinal cord. The condition that results from damage to peripheral nerves is called peripheral neuropathy. While peripheral nerves are located throughout the body, peripheral neuropathy usually affects only the hands and/or feet. There are many causes of peripheral neuropathy other than chemotherapy drugs.

Chemotherapy-induced peripheral neuropathy is usually experienced as:

- tingling, burning, or pain in the affected areas
- loss of sensation (numbness)
- loss of balance (if the feet are affected)

Peripheral neuropathy can cause clumsiness. Normal coordination depends on the peripheral nerve messages to the brain telling it the position of your arms, legs, hands, and feet. Peripheral neuropathy can interrupt these messages. The result is clumsiness or loss of coordination. Loss of information about the position of the limbs is called loss of position sense. You may have trouble buttoning your shirt without looking. You may also trip more than usual or have a tendency to drop things.

Peripheral neuropathy is not a side effect of all chemotherapy drugs. Chemotherapy agents commonly used to treat lung cancer that can cause peripheral neuropathy include carboplatin (Paraplatin®), cisplatin (Platinol®), paclitaxel (Taxol®), docetaxel (Taxotere®), etoposide (VePesid®), topotecan (Hycamtin®), vinblastine (Velban®), vincristine (Oncovin®), vinorelbine (Navelbine®), and gemcitabine (Gemzar®). Of these drugs, peripheral neuropathy occurs most commonly with paclitaxel, docetaxel, cisplatin, and vincristine.
Peripheral neuropathy can occur at different times during the course of therapy depending on the drug(s) being used. The toxic effects of chemotherapy on peripheral nerves are cumulative. This means once symptoms occur, they tend to get worse as additional treatments are administered. In cases of severe peripheral neuropathy, the dosage of the chemotherapy drugs may have to be decreased. In rare instances, treatment with the offending drug must be stopped. In most instances, chemotherapy-induced peripheral neuropathy gradually goes resolves after treatment has been completed. In some cases, symptoms only partially resolve. There can be residual symptoms.

There is some evidence that peripheral neuropathy may be at least partially preventable. Studies using the supplements glutamate and glutathione have shown some promise in preventing or reducing the severity of chemotherapy-induced neuropathy. The drugs amifostine (Ethyol®) and carbamazepine (Tegretol®) have also shown promise in protecting against chemotherapy-induced neuropathy. However, no agents are currently in routine use to prevent chemotherapy-induced peripheral neuropathy.

Loss of position sense can make you prone to injuries. Some simple measures can help reduce the risk of injuries.

- Keep the rooms in your home well lit. When you have lost some position sense, the brain automatically begins to rely on your other senses to help coordinate movements. Good lighting helps give your brain good visual information.
- Keep a nightlight on to light your way should you need to get up during the night.
- Wear shoes that tie, buckle, or have Velcro® fasteners instead of slip-on shoes. It is easy to slip out of a shoe that is not firmly adhered to your foot. This can lead to falls and potential injuries. High heels should be avoided.
- Consider lowering the temperature on your hot water heater to avoid accidentally burning yourself. Test bath water with your elbow before getting in the tub.
- Watch your hands when you are working with a sharp object. In this way, you are using your eyes to provide information to your brain for what you may be lacking due to peripheral neuropathy.
• Consider having someone else drive for you if you experience numbness in your hands or feet.
• Use potholders or hot mitts if you are uncertain of the temperature of something while cooking.
• Wear mittens or gloves to prevent frostbite in cold weather. Early symptoms of frostbite are very similar to the symptoms of peripheral neuropathy and can be easily missed. Keep your feet warm and dry for the same reason.
• Use the railing when walking up or down stairs. Watch your feet.

Prescription medications are available that may help control the symptoms of peripheral neuropathy. You may need to try more than one of these medications to find one that works for you. Options include topical lidocaine, gabapentin (Neurontin®), carbamazepine (Tegretol®), phenytoin (Dilantin®), lamotrigine (Lamictal®), amitriptyline (Elavil®), and others. Over-the-counter and prescription pain relievers can also be used. The drug causing the problem may need to be discontinued if your symptoms become severe.

Weight Loss
Weight loss is a common side effect of lung cancer treatments including surgery, chemotherapy, and radiation therapy. The key factors in cancer treatment-related weight loss are:
• loss of appetite
• nausea and/or vomiting
• diarrhea
• taste changes and/or sensitivity to odors
• fatigue

Weight loss is discussed in detail in Symptoms Associated With Primary Lung Tumors in this chapter. There are also suggestions for managing weight loss associated with lung cancer treatments included in Chapter 12: Nutrition and Lung Cancer.
PAIN CONTROL

Pain is one of the most feared symptoms of cancer. Chronic pain can significantly reduce
your quality of life and make even simple tasks seem overwhelming. Pain can be caused by
the effects of cancer in your body or may be a side effect of treatment. Regardless of the
cause, good pain control is possible in nearly every situation. Many effective treatment
options are available to control pain. Cancer pain has been well researched. Pain control
has become a sophisticated science. Many advances have been made in the field of pain
management in recent years. Oncology doctors and nurses are well trained in the both the
assessment and treatment of pain.

The first step toward effective pain control is telling your doctor or nurse about your pain.
Although this may seem obvious, many people do not tell their providers about their pain
until it becomes intolerable. Do not fall into the trap of thinking that telling your provider
about your pain is a sign of weakness. Your health care team wants you to live your life as
fully and normally as possible. While pain is an important way for the body to let you know
something is wrong, chronic pain serves no useful purpose and can significantly disrupt your
life. There is no reason to tolerate chronic pain in silence. Be sure to tell your health care
provider about any new or changing pain you experience.

Pain often changes over time. The location and severity of pain can be highly variable.
Different types of pain require different treatments. In general, it is easier to achieve good
pain control if the pain can be addressed early in its course rather than later when the pain
becomes severe. The treatments, drugs, and dosages of drugs used to control pain are
individualized to your specific symptoms. The goals of pain management are to minimize
the experience of pain while limiting unwanted side effects from pain control treatments.

When you talk with your health care provider about your pain, you will need to describe
your pain. This helps your provider decide how best to treat you. Consider keeping a log of
your pain, especially if your pain comes and goes. Important aspects of your pain should be
recorded.
• Where is the pain located?
• What does the pain feel like? (sharp, dull, achy, stabbing, burning, etc.)
• What, if anything, brings on the pain?
• What, if anything, alleviates the pain?
• How long does the pain last?
• On a scale of 1 to 10 (with 10 being the worst pain you’ve ever experienced), how would you rate the pain?

The World Health Organization (WHO) developed a pain control model called the Analgesic Ladder\textsuperscript{19,20} (see Figure 2). \textit{Analgesic} is another word for a pain relieving medicine. The model helps providers rate pain and use appropriate medicines to control it. The WHO approach instructs health care providers to match the intensity of pain with the potency of the drug: the more severe the pain, the stronger the pain reliever. Treatment of severe pain does not begin at the bottom of the ladder. Strong pain relievers are given immediately. Combining low potency pain relievers with stronger pain relievers often increases pain control. The goal is to maintain a constant level of pain relievers in the body so that pain cannot ‘break through.’ In other words, pain medications are taken on a regular schedule rather than only in response to pain. The three levels of the WHO Analgesic Ladder are summarized on the following pages.

\textbf{Mild to Moderate Pain:} 1-3 on a scale of 10
Non-opioids (drugs not related to morphine) are used. Examples include aspirin, acetaminophen (Tylenol\textsuperscript{®}), ibuprofen (Advil\textsuperscript{®}, Motrin\textsuperscript{®}, Nuprin\textsuperscript{®}), naproxen (Naprosyn\textsuperscript{®}), and others. Drugs such as corticosteroids that are not pain relievers themselves are added if they help treat the underlying cause of the pain. These drugs are referred to as \textit{adjuvants}.

\textit{Figure 2: WHO Analgesic Ladder for Pain Control}

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**Moderate to Severe Pain:** 4-6 on a scale of 10

People reporting moderate pain or people whose pain was not controlled using the measures from the lower step on the ladder should be treated with an opioid (a drug related to morphine) for moderate pain. Drugs that may be used include codeine, hydrocodone (Vicodin®, Lortab®), dihydrocodeine (DHC), oxycodone (Percodan®, Percocet®, Tylox®, Roxiprin®), propoxyphene (Darvon®, Darvocet®), and tramadol (Ultram®). Acetaminophen is often used with these drugs. Adjuvants are used to enhance pain control.

**Severe Pain:** 7-10 on a scale of 10

People who report severe pain or have not gotten sufficient pain relief from less potent medicines are treated with strong opioids. Morphine (MSIR, MS-Contin®, Roxanal®, Oramorph-SR®), oxycodone (Oxycontin®, Roxicodone®), hydromorphone (Dilaudid®, Hydrostat®), levophanol (Levo-Dromoran®), methadone (Dolophine®, Methadose®), and fentanyl (Duragesic®, Fentanyl Oralet®, Sublimase®, Innovar®) are examples of strong opioids. Non-opioid drugs and adjuvant drugs are also used to enhance pain control.

Pain control medications come in many forms including tablets, liquids, patches, suppositories, and solutions for injection. Your health care provider will work with you to determine what form of pain medication works best for you.

**Barriers to Pain Control**

Misunderstandings and other factors can stand in the way of good pain control. Some barriers to good pain control are related to concerns people with cancer have about pain medicines.

"I don’t want to complain."

People are sometimes hesitant to tell their health care providers about their pain. You may be concerned about your doctor thinking you are a ‘complainer.’ You may worry that talking about your pain will make your providers think less of you. These concerns are understandable but misplaced. Keep in mind that one of your doctor’s jobs is to make you as comfortable as possible. Your health care providers cannot help you with your pain if they are not aware of it. You did not ask for your pain,
and you do not need to suffer in silence. Be open and honest with your doctors and nurses when discussing your pain.

“I’m afraid I’ll get addicted.”
Many people worry about becoming addicted to pain medications. While people who abuse pain relievers for recreational purposes may become addicted to them, people who use pain relievers to control pain rarely become addicted. This fact has been proven in scientific studies. The dose needed to control your pain may need to be gradually increased if you are on pain medicine for a prolonged period. This is not an indication that you have become addicted to your pain medication. It is a normal body response called tolerance, which means your body requires more medication to produce the same effect.

“I don’t want to sleep all the time or feel doped-up.”
Opioid pain medicines cause sleepiness when you first start taking them, but this side effect only lasts a few days. Opioids can also cause you to feel somewhat odd, a feeling many people describe as being similar to being slightly intoxicated. However, this side effect also diminishes over a few days. People who are in chronic pain usually find the side effects from opioid pain medicines are much less disruptive to their lives than chronic pain is.

“If I start taking pain medicine now, there won’t be anything left to treat my pain if it gets worse later.”
Opioid pain medicines do not lose their effectiveness over time. Your dose can be increased if your pain becomes more severe over time. There are always options available for pain control regardless of how long you have been on pain medication.

“I don’t want to give in to the cancer.”
You may feel that admitting you are in pain is somehow giving in to your cancer. This is not the case. Pain can interfere with your ability to sleep and eat normally. Sleep deprivation and poor nutrition can interfere with your quality of life and your
body’s ability to respond to cancer treatment. Controlling pain improves your quality of life and puts you in a better position to tolerate and respond to treatment.

Most health care providers working with people who have cancer are comfortable with assessing and treating pain. However, some are less adept at this aspect of cancer care than others are. If your oncologist seems hesitant to prescribe pain medicines, ask him or her for a referral to someone who is more comfortable with this aspect of cancer care. Alternatively, talk with your oncology nurse or social worker about resources in your community. Many cities have pain management centers that specialize in the treatment of chronic pain. Pain control is a very important part of cancer care, and should never be overlooked.

**Non-Pharmacologic Pain Control Measures**

There are pain control measures other than drugs that many people with cancer have found helpful. Surgery may be used if a tumor is pressing on an organ or nerve causing pain. Radiation therapy can be highly effective for controlling bone pain. Several self-help techniques may also be useful to you.

Biofeedback is a technique where a technician helps you learn to voluntarily relax your muscles. Pain often causes people to tense their muscles, which can worsen pain. Biofeedback helps people take voluntary control over this response. Biofeedback is often used along with pain medications.

Visualization and imagery are techniques to help take your mind off your pain by focusing on a pleasant mental picture. This distraction can cause relaxation, which may decrease the intensity of your pain. Less formal means of distraction such as watching a movie or television or listening to music can be used to accomplish the same goal of taking the focus off the pain. Visualization and other distraction measures are often most effective when used along with pain medicines.

Regular massages may help control your pain. Massage helps many people relax, which can reduce the intensity of their pain. No scientific studies have proven that massage is effective
for pain control, but many people find it helpful. Chapter 11: Complementary Healing has additional information about these techniques.

**SUMMARY**

There are many possible symptoms and side effects associated with lung cancer. Left untreated, these symptoms can rob you of your quality of life and ability to function. Supportive care can have a very positive impact on your quality of life while living with lung cancer.

You are encouraged to discuss your symptoms with your health care providers as soon as they appear. Working together with your providers, you can eliminate or control nearly every symptom caused by your lung cancer or its treatment. New supportive care treatment options are emerging every day. I hope you will benefit from these advances and enjoy your life as symptom-free as possible.
CHAPTER 11: COMPLEMENTARY HEALING

INTRODUCTION

What is health? Is it the absence of disease and disability or is it something broader?
Consider the following examples.

Mary exercises regularly, eats well, and has no signs or symptoms of disease. However, Mary always feels unhappy. Is Mary healthy?

John is 50 pounds overweight. He has no signs or symptoms of disease. He has a happy home life. Is John healthy?

Susan lost her left leg to bone cancer when she was a teenager. She now gets around in a wheelchair. She is happily married, has two children, and a job she enjoys. Is Susan healthy?

These examples illustrate the fact that health is more than just the absence of disease or disability. Many factors contribute to your health and well-being.

Thus far, this book has focused on the physical aspects of health. This chapter examines health, wellness, and healing more broadly. The purpose is to help you achieve not only physical health, but also an overall sense of wellness in your life.

THE WELLNESS WHEEL

The wellness wheel is a model used to demonstrate the different factors that contribute to a person’s complete health (see Figure 1). It is based on ancient Eastern and Native
American concepts. According to this model, five aspects of your life contribute to your sense of well-being – physical, social, spiritual, emotional, and intellectual.

![Wellness Wheel]

The factors that contribute to each of these areas are:

- **Physical wellness** – lifestyle, fitness, nutrition, adequate sleep, activity level, illness
- **Social wellness** – relationships with family and friends, a sense of community
- **Spiritual wellness** – a sense of purpose, meaning in your life, values, ethics, religious or spiritual practice, philosophy of life
- **Emotional wellness** – feelings, a sense of worth, managing stress
- **Intellectual wellness** – productivity, enjoyable work, alertness, creativity, learning

Each area of wellness can affect your sense of well-being in other areas. For example, if you are unhappy with your work, you may begin to experience physical symptoms such as headaches or stomach upset. Similarly, a physical illness may affect your emotional well-being by causing stress or irritability. These feelings can affect your relationships with family
members and friends. Therefore, wellness involves addressing the health of each area of life that contributes to your overall sense of well-being.

SYSTEMS OF HEALING

Western Medicine
The United States, Canada, and many other industrialized nations primarily utilize a system of healing which is commonly called western medicine or conventional medicine. There are two types of doctors who practice western medicine, allopaths (medical doctors or MDs) and osteopaths (osteopathic doctors or DOs). Both MDs and DOs attend four years of medical school that includes classroom study in the sciences of the human body, and practical study of physical examinations, testing, and medical care. After completion of medical school, MDs and DOs must pursue additional training (called post-graduate education) to learn the art of medical practice. In the U.S., 94% of conventional doctors are MDs and 6% are DOs.

Western medicine is based on science and experimental testing. For the most part, western doctors group people into categories (diseases) based on their signs and symptoms. Generally, treatments are put into use after they have been shown to be effective for a specific disease or condition in scientific studies called clinical trials. See Chapter 8: Clinical Trials for a description of the clinical trial process.

Complementary and Alternative Medicine
Complementary and alternative medicine (CAM) is a generic term that refers to the many healing systems, philosophies, and practices that fall outside the realm of conventional or western medicine. There are many different types of CAM including:

- naturopathic medicine
- homeopathic medicine
- ayurvedic medicine
- traditional Chinese medicine
- modern Chinese medicine
Different forms of CAM utilize a variety of healing approaches. Examples of common CAM therapies include:

- acupuncture
- massage
- chiropractic manipulation
- craniosacral manipulation
- homeopathic remedies
- herbs
- nutritional supplements
- dietary therapy
- meditation
- visualization
- creative expression – art, dance, music
- biofeedback
- prayer
- movement or exercise – yoga, tai chi, qi gong
- aromatherapy
- crystals

**Complementary therapy** is used in addition to rather than in place of conventional treatment. The combined use of western medicine and CAM is called integrated medicine. **Alternative therapy** is treatment used instead of conventional treatment. Most people with lung cancer who utilize CAM use it in combination with western treatments. Nevertheless, some people choose to use alternative methods alone or after conventional treatments have failed. Most conventional lung cancer experts strongly advise against using CAM instead of western therapy. However, the choice is yours.
When I first found out I was now stage IV, of course I was initially shocked. I wanted to do everything possible to survive. I recognized that conventional medicine is positive, but they don't have all the answers. Through my research, I decided the key to my treatment would be keeping my immune system up. So the first step [for me] was integrated medicine.

– Barbara, diagnosed with stage IV NSCLC in 1999 at age 49

This chapter reviews some popular CAM therapies used by people with lung cancer. Each section notes whether there is scientific evidence to support the use of each treatment or product. Most complementary and alternative therapies have not been studied in a clinical trial setting, which means there is no scientific proof of their effectiveness. The use of many CAM therapies is based on years of experience passed down from one generation to another.

The author takes no position on the effectiveness of CAM treatments. The treatments presented in this chapter are included because they are frequently asked about. The inclusion of a particular CAM treatment does not mean the author endorses the treatment. Similarly, the absence of a particular CAM treatment does not mean the author opposes use of that treatment. The decision about what treatments (western or CAM) to include in your treatment plan is entirely up to you. However, the author encourages you to thoroughly research any form of therapy you are considering before making a decision about whether to include it in your treatment plan.

Before adding any new therapy to your treatment plan, it is very important to discuss it first with all of your health care providers. Different forms of therapy can interact with one another. Some therapies interfere with the beneficial effects of other treatments whether they are western or CAM therapies. For example, certain drugs, foods, herbs, or nutritional supplements may increase the side effects of western treatments or decrease their effectiveness. Some treatment combinations may actually be harmful. Your health care providers can only provide you with the best possible care if they are completely informed about all the treatments you are using. It is your responsibility to keep each of your health care providers informed about all your current treatments.
Many forms of CAM are not covered by health insurance. Check with your insurance company before pursuing a costly therapy that may not be covered under your plan. This will allow you to make an informed decision with respect to your financial situation.

Issues you may want to think about if you are considering complementary healing include:

- Find out about the CAM provider’s expertise.
  - How much experience does he or she have?
  - What kind of training has he or she received?
  - Is he or she certified or licensed to practice in their field?
- What is the cost of treatment?
  - Will your insurance cover the cost?
- What do you hope to accomplish? What is likelihood of accomplishing your goals with the treatment you are considering?
- Are there risks associated with treatment?
- Are there side effects from treatment?
- Has the treatment been evaluated in clinical trials? Are there ongoing trials?
- Will the treatment interfere with other forms of treatment you are receiving?

CAM DISCIPLINES

There are many different CAM disciplines. This section presents a brief overview of some of the more popular CAM disciplines used by people with lung cancer.

Ayurvedic Medicine

The word ayurveda comes from two Sanskrit words, ayur meaning life and veda meaning knowledge. Ayurveda was founded in India. It is one of the oldest forms of medicine known to man. Ayurvedic medicine involves detoxification, diet, exercise, herbs, and other techniques to improve mental and emotional health. In ayurveda, good digestion is considered the key to good health.
According to ayurvedic principles, each person has a unique makeup or constitution. Your constitution is determined by the balance of three vital energies in the body called doshas. The three doshas are known by their Sanskrit names of vata, pitta, and kapha. Each dosha has its own role in the body. Health is maintained when the three doshas are in balance. Ayurveda focuses on maintaining health. It does not offer cures for cancers.

Ayurvedic practitioners are not licensed in the United States, and ayurvedic practice is not regulated by state or federal agencies. At this time, the ayurvedic medical degree (from ayurvedic medical schools in India) is not recognized in the U.S. or Canada. American ayurvedic schools are typically part-time certification courses that take one to two years to complete.

**Chiropractic Medicine**

Chiropractic medicine concerns itself with the relationship between the nervous system and the health of the body. This form of medicine is based on the fact that the nervous system controls the function of every cell, tissue, organ, and system of the body. Chiropractic principles state the functions of the body can be disturbed by misalignments in the spinal column or backbone (made up of 24 bones called vertebrae). A misalignment of one of the backbones is called a vertebral subluxation. Vertebral subluxations are corrected using spinal adjustments in an attempt to restore normal body function.

Chiropractors (chiropractic physicians) usually obtain a bachelor’s degree before attending a school of chiropractic medicine to earn a DC degree (doctor of chiropractic medicine). All 50 states and the District of Columbia regulate chiropractic medical practice. Most DC programs are structured around a four-year academic schedule.

Licenses are granted to chiropractors who meet the educational requirements of their state and pass a state-approved board examination.

**Homeopathic Medicine**

Homeopathic medicine was developed in the early 1800s by Dr. Samuel Hahnemann, a German doctor and pharmacist. This form of medicine treats the whole person rather than
just the symptoms he or she is experiencing. This is called a holistic medicine approach.

Homeopathy is based on the principle of treating like with like. This is called the principle of similars. Homeopathic remedies are made from extremely small amounts of animal, vegetable, or mineral substances that are used to stimulate the body’s natural healing systems. Homeopathic remedies are regulated by the Food and Drug Administration (FDA) and are manufactured by established pharmaceutical companies under strict guidelines. Symptoms are considered a positive finding. There is no attempt to suppress symptoms as there is in western medicine.

Homeopathic training programs vary from 2-day seminars (designed for licensed health care professionals) to 4-year programs. In the United States, the American Board of Homeotherapeutics certifies MDs or DOs who meet their educational standards and pass both oral and written exams. Successful candidates are awarded the designation of diplomate in homeopathy (DHt).

There is no legal licensing or governmental regulation of homeopathic practitioners in the U.S. or Canada. Most state laws either do not address homeopathy or assume that it belongs under the supervision and jurisdiction of medically licensed doctors. A few states such as Arizona formally state that homeopathy belongs only under the jurisdiction of licensed medical doctors. Other states allow homeopathy within the scope of practice for specific health professionals such as acupuncturists. However, laws vary widely from state to state.

**Naturopathic Medicine**

Naturopathic medicine blends natural, non-toxic therapies with current advances in the study of health. The basis of naturopathy is the belief that the body has the ability to heal itself. Naturopathic doctors use many different forms of therapy to assist the body in its ability to heal itself including diet, exercise, nutrition, massage, acupuncture, homeopathic remedies, herbal medicines, nutritional supplements, and others. The focus is on whole-patient wellness, disease prevention, and self-care. Naturopathic medicine attempts to find the underlying cause of a person’s condition rather than focusing solely on treatment of symptoms.
Naturopathic doctors (NDs) attend a 4-year, post-bachelor’s degree naturopathic medical school. NDs are educated in the same basic sciences as MDs, but focus on holistic (mind and body) and nontoxic approaches to therapy. There is a strong emphasis on disease prevention and optimizing wellness. NDs are trained in clinical nutrition, acupuncture, homeopathic medicine, botanical medicine, and psychology. Licensed naturopathic doctors take rigorous professional board exams. As of this writing, 12 states and four Canadian provinces allow the practice of naturopathic medicine: Alaska, Arizona, Connecticut, Hawaii, Kansas, Maine, Montana, New Hampshire, Oregon, Utah, Vermont, Washington, British Columbia, Manitoba, Ontario, and Saskatchewan. Puerto Rico and the U.S. Virgin Islands also have licensing laws for naturopathic doctors.

**Traditional Chinese Medicine**

Traditional Chinese medicine (TCM) is a healing system that was developed in China over 3,000 years ago. TCM is based on the idea that the laws of nature can be used to understand the workings of the human body. TCM principles state the body is similar to the universe at large in that it is subject to constant battling between opposing forces such as heat and cold, dampness and dryness, masculinity and femininity, joy and sadness, etc. Health is a state of balance between the opposing forces in the body and disease is the result of imbalances. Imbalances manifest themselves in the body as too much or too little activity in particular organs or systems. Chinese medicine describes a vital energy called *qi* (pronounced chee) that travels through body along internal pathways called *meridians*. Imbalances in the body can cause blockages in the flow of qi. TCM practitioners use acupuncture, therapeutic massage (*tui na*), and herbal remedies to help restore the flow of qi and bring the body back into harmony and wellness.

Over 40 states have laws requiring licensure for acupuncturists; requirements for licensure vary according to state law. Many acupuncture schools do not require candidates to have an undergraduate degree. However, other schools give strong preference to people who have earned a bachelor’s degree. In states that do not recognize acupuncturists as licensed medical practitioners, acupuncturists may be required to work under the supervision of another medical professional such as an MD, DO, or ND. In a few states, the practice of acupuncture is restricted to medical doctors or their equivalent.
Dispensing herbal medicines is not currently regulated by federal or state laws. Many herbs are available over-the-counter at health food stores, nutrition stores, and via the Internet.

Resources for Finding Qualified CAM Practitioners

The laws and regulations for the oversight of CAM are highly variable from one state to another. Many areas of CAM remain unregulated. Therefore, clients of CAM must be careful to choose qualified, experienced practitioners. The following organizations are useful resources to help you learn about the philosophy, education, training, and licensure requirements (if applicable) for various CAM practitioners. Many of these organizations can also help you locate a practitioner in your area.¹

Acupuncture and Oriental Medicine Alliance
Telephone: 253-851-6896
Internet: www.aomalliance.org
The Acupuncture and Oriental Medicine Alliance (AOMA) works to support the development of acupuncture and oriental medicine. AOMA maintains an active patient referral service of over 10,000 state-licensed and nationally certified acupuncture and oriental medicine practitioners via fax, phone, and the Internet. They support acupuncture and oriental medicine at the state and federal level to provide inclusion in research and health benefits. AOMA provides information regarding the benefits of acupuncture and oriental medicine, and works to insure that all practitioners who use acupuncture and oriental medicine modalities in their practice do so using sound, professional, clinical-based standards.

Alternative Medicine Foundation
Telephone: 301-581-0116
Internet: www.amfoundation.org
The Alternative Medicine Foundation is a nonprofit organization formed to provide evidence-based research resources for health care professionals, and responsible and reliable information for patients and consumers about the integration of alternative and conventional medicine. Current projects include the development of global information databases available via the Internet. HerbMed® is an interactive, evidence-based herbal formulary and TibetMed® is an interactive, community information resource on Tibetan medicine. The Alternative Medicine Foundation develops and distributes public information materials and resource guides.

¹ Listings are from the National Library of Medicine, Special Information Services, Directory of Health Organizations. Listings are Internet accessible at: dirline.nlm.nih.gov.
American Association of Acupuncture and Oriental Medicine
Telephone: 888-500-7999 (toll free)
Internet: www.aaom.org
This association was established in 1981 as the unifying force for American
acupuncturists who are committed to high educational standards and an ethical, well-
regulated profession to ensure the safety of the public. As the umbrella organization
representing the acupuncture profession in the U.S., AAAOM assisted in the
formation of both the National Commission for the Certification of Acupuncturists
(NCCAOM) and the National Council of Acupuncture Schools and Colleges
(CCAOM) in 1982.

American Association of Naturopathic Physicians
Telephone: 866-538-2267
Internet: www.naturopathic.org
The American Association of Naturopathic Physicians (AANP) is an association of
practitioners who are trained as specialists in natural medicine and are licensed or
eligible for licensure in states that license naturopathic physicians. They treat disease
using botanical medicine, oriental medicine, herbal medicine, homeopathy, physical
medicine, exercise therapy, counseling, and acupuncture. AANP lobbies to increase
the place of naturopathic medicine on the national health care agenda, supports
associations in their efforts to obtain licensing, and promotes research agendas
among federally recognized colleges.

American Association of Oriental Medicine
Telephone: 888-500-7999 (toll-free)
Internet: www.aaom.org
The American Association of Oriental Medicine (AAOM) was formed in 1981 as a
professional organization dedicated to supporting and promoting acupuncturists in
the United States. AAOM goals are: to protect and promote the philosophy,
science, and art of acupuncture and oriental medicine; establish and maintain the
practice of acupuncture and oriental medicine as a separate and distinct primary care
healing art and profession; educate legislators, regulators, and the public regarding
the nature and scope of the field; and develop and maintain standards of education
and professional competence. Staff answers inquiries, distributes publications, and
makes referrals to other sources of information.

American Chiropractic Association
Telephone: 800-986-4636 (toll-free)
Internet: www.amerchiro.org
The American Chiropractic Association (ACA) improves the public's awareness and
utilization of chiropractic medicine and conducts chiropractic survey and statistical
studies. Chiropractors practice, "the science and art which utilizes the inherent
recuperative powers of the body and the relationship between the musculoskeletal
structures and functions of the body, particularly of the spinal column and the
nervous system in the restoration and maintenance of health."
American Institute of Homeopathy
Telephone: 703-246-9501
Internet: www.homeopathyusa.org
The primary interests of the American Institute of Homeopathy are homeopathy and homeopathic therapeutics. Staff provides consulting, reference, translating, and document services; conducts summer schools; holds an annual conference; and sells books.

Ayurvedic Institute
Telephone: 505-291-9698
Internet: www.ayurveda.com
The Ayurvedic Institute was established in 1984 to promote the traditional knowledge of Ayurveda. The online Resource page has information about ayurvedic medicine and practices.

Council on Chiropractic Education
Telephone: 480-443-8877
Internet: www.cce-usa.org
The Council on Chiropractic Education (CCE) is recognized by the United States Secretary of Education as the accrediting body for programs and institutions offering the doctor of chiropractic degree. CCE works to ensure the quality of chiropractic education in the United States through accreditation, educational improvement, and public information. Through the accreditation process, CCE certifies the quality and integrity of chiropractic programs and institutions. CCE responds to inquiries; distributes publications; and makes referrals to other sources of information.

National Center for Homeopathy
Telephone: 877-624-0613 (toll-free)
Internet: www.homeopathic.org
The National Center for Homeopathy (NCH) is a national, nonprofit membership organization for the promotion of homeopathy through education, publication, research, and membership services. Homeopathic information and education is provided to promote public awareness and to educate the public, both lay and professional, through courses, seminars, and publications, as well as the support of homeopathic research and correlated subjects.

National Center for Complementary and Alternative Medicine, National Institutes of Health
Telephone: 888-644-6226 (toll-free)
Internet: www.nccam.nih.gov
The mission of the National Center for Complementary and Alternative Medicine (NCCAM) includes supporting research on complementary and alternative medicine, training researchers in CAM, and disseminating information to the public and professionals on which CAM modalities work, which do not, and why. NCCAM's areas of focus include: supporting clinical and basic science research projects in CAM by awarding grants across the country and around the world; awarding grants that provide training and career development opportunities for pre-doctoral, post-
doctoral, and career researchers; and sponsoring conferences, educational programs, and exhibits. NCCAM operates an information clearinghouse to answer inquiries and requests for information on CAM.

National Center for Complementary and Alternative Medicine Clearinghouse
Telephone: 888-644-6226 (toll-free)
Internet:  www.nccam.nih.gov/nccam
The National Center for Complementary and Alternative Medicine Clearinghouse serves as the communications arm of NCCAM and handles inquiries on complementary and alternative medicine. The clearinghouse serves the public, patients, and health professionals by: providing information; locating other information sources; and creating health information materials. The clearinghouse does not serve as a referral agency for various alternative medical treatments or individual practitioners. Staff answers a hotline and, in response to requests, mails out health education materials on complementary and alternative medicine.

National Certification Commission for Acupuncture and Oriental Medicine
Telephone: 703-548-9004
Internet:  www.nccaom.org
The National Certification Commission for Acupuncture and Oriental Medicine (NCCAOM) is dedicated to: establishing entry level standards of competency for the safe and effective practice of acupuncture, Chinese herbology and other oriental bodywork therapy; evaluating applicant qualifications; offering national board examinations and certifying practitioners of acupuncture, Chinese herbology, and oriental bodywork therapy who meet these standards of competency.

COMPLEMENTARY HEALING AND CANCER

When a person has cancer, western medicine views the cancer as the primary problem in the body that is causing disease. Practitioners of alternative medical disciplines often have a slightly different view. According to alternative medical philosophies, cancer occurs because there are underlying problems in the body that have allowed the cancer to occur and grow. Therefore, whereas western medical treatments focus primarily on killing the cancer cells in the body, alternative therapies tend to focus on restoring and supporting overall health to enable the body to fight the cancer to the best of its ability using its own defenses. While some CAM practitioners advocate using only CAM treatments for cancer, many others believe CAM is best used in conjunction with western treatment for cancer. This integrated philosophy uses the principles of both western and alternative medicine. Western treatments
are used to kill or eliminate cancer cells while alternative therapies help the body fight the
cancer using its own defense mechanisms.

Another philosophical difference between western treatments and CAM disciplines is the
attention given to the person as a whole. Traditionally, western medicine has focused on the
physical aspects of health and disease. Alternative medical disciplines are based on a holistic
approach that takes into account all aspects of wellness, not just the physical realm. The
holistic approach is based on the belief that there are complex interactions between the
mind, body, and spirit. According to a holistic philosophy, one cannot be physically well
unless he or she is also healthy mentally, spiritually, socially, and intellectually. According to
this philosophy, a balanced, peaceful mind and spirit are as essential to health as physical
well-being. In recent years, western medicine has begun to integrate non-physical aspects of
health into treatment plans. However, the primary focus continues to be on physical health
and disease.

The decision about whether to use western therapy alone, CAM therapy alone, or an
integrated treatment approach is entirely up to you. However, it is important to fully
understand all your options before making treatment decisions. While there are many
extensively educated, highly trained alternative medicine practitioners who want nothing
more than to help their patients achieve health and wellness, as with any other profession,
there are a few whose motives may not be as altruistic. Many CAM therapies have not been
studied in controlled, clinical trials. In the absence of clinical trial information, consumers of
CAM therapies must depend on other sources of information including that offered by their
practitioners, the word of other people who have used the treatment, background
information available in books and other reference materials, and the recommendations of
other professionals who have knowledge of and experience with the treatment.

Your treatment decisions may well be some of the most important decisions you will ever
have to make because lung cancer is a potentially life threatening disease. It is important to
choose carefully and make choices that are consistent with your personal goals and beliefs.
Common Concepts

Different complementary and alternative therapies often share common reasons for their use. This section briefly describes some of the common concepts you are likely to encounter if you are investigating the use of CAM therapies as part of your cancer treatment plan.

Optimizing Immune Function
The immune system has an important role in the body’s response to cancer. Specialized white blood cells known as T lymphocytes (T cells), natural killer cells, and macrophages seek out and destroy cancer cells. Some lymphocytes also produce anti-cancer chemicals known as cytokines, which include interleukin and interferon. Many complementary and alternative cancer treatments focus on supporting and maximizing the functions of the immune system. In this way, CAM treatments attempt to optimize the body’s natural ability to heal itself from cancer. Many products are available that claim to enhance immune function and help fight cancer.

Mind/Body Interactions
In general, CAM disciplines support the philosophy that the spectrum of health and disease is the result of complex interactions between the mind and body. Therefore, many complementary therapies for cancer focus on not only physical health, but also on your mental and emotional well-being.

Detoxification
Many complementary therapies are based on the idea that toxins (poisons) in the environment make their way into the body and contribute to the cancerous process. The goals of detoxification treatments are to remove toxins from the body, restore normal function, and eliminate the negative effects of toxins.

Nutrition
As discussed in Chapter 12: Nutrition and Lung Cancer, the food you eat provides the energy required for all body functions. It also provides the building blocks needed to heal damaged tissues and construct healthy new tissues. In other words, “You are
what you eat.” Many complementary therapies focus on providing your body with
the best possible nutrition to optimize normal functions and help the body heal itself
from cancer.

STRESS REDUCTION AND EMOTIONAL, MENTAL, AND SPIRITUAL
HEALTH

Several studies conducted in recent years suggest ongoing stress can suppress normal
immune function. Scientific evidence supports the concept that health and disease are
influenced not only by physical factors but also by emotional, mental, spiritual, and social
factors as well. The complementary healing techniques presented in this section focus on
stress reduction and/or your emotional and mental well-being to support your immune
function and overall health. The therapies presented in this section are only a sample of the
many healing techniques available; they are arranged in alphabetical order.

Art Therapies
Music, art, dance, movement, and drama therapies utilize the arts and the senses to help
achieve stress relief, relaxation, and an overall sense of well-being. These forms of therapy
are often collectively referred to as art therapies.

Art therapy uses art media, images, the creative process, and client responses to the created
products as reflections of an individual's development, abilities, personality, interests,
concerns, and conflicts. Art therapy can help people reconcile emotional conflicts, foster
self-awareness, develop social skills, manage behavior, solve problems, reduce anxiety, and
increase self-esteem. Art therapy includes painting, sculpting, drawing, and many other
forms of art.

I have found that art therapy really makes a difference. When diagnosed with
cancer, you can feel as though it is a death sentence and that you will never be able
to live without the constant thought of your cancer. When I paint, I can escape. I
can lose myself into the world of my painting.

– Dorothy, diagnosed with stage IIA NSCLC in 1999 at age 64
Based on the notion that body and mind are interrelated, dance/movement therapy is defined by the American Dance Therapy Association as, "the psychotherapeutic use of movement as a process which furthers the emotional, cognitive and physical integration of the individual." Dance therapy effects changes in feelings, thinking, physical functioning, and behavior. Dance therapy can provide stress relief, improve body image and self-esteem, decrease fears, provide an outlet for your emotions, decrease body tensions, and reduce chronic pain. There are many forms of dance therapy, which is also sometimes called movement therapy.

Music therapy is a highly effective relaxant for many people. Research supports the effectiveness of music therapy in many areas such as physical rehabilitation, facilitating movement, increasing motivation to become engaged in treatment, providing emotional support for clients and their families, and creating an outlet for expression of feelings.

I went into [my cancer] operation listening to John Coltrain on my disc player. Going into the operation, I was calm. When I came out, I wasn't afraid. I used music therapy a lot after my operation. If I was home alone and got scared, I would put on Gregorian chants and I would feel better, calm. It was part of my healing process. It's so wonderfully uplifting and healing.

− Dorothy, diagnosed with stage IIA NSCLC in 1999 at age 64

Drama therapy is defined by the National Association for Drama Therapy as, "the systematic and intentional use of drama/theater processes, products, and associations to achieve the therapeutic goals of symptom relief, emotional and physical integration and personal growth." Drama therapy is an active approach that helps clients tell their stories, solve problems, release their feelings, and extend the depth and breadth of inner experience. Cancer presents many challenges to people that they have never faced before in their lives. Drama therapy can help people work through these challenges.

Art, music, dance, movement, and drama therapists are trained health care professionals. Your cancer care providers can help you find art therapy programs in your area if you are interested in participating in one or more of these therapies. Many people with cancer find these therapies very helpful as part of their overall treatment plan.
For additional information about art therapies, you may wish to contact one or more of the following professional organizations.

- American Art Therapy Association  
  888-290-0878 (toll-free)  
  [www.arttherapy.org](http://www.arttherapy.org)
- American Dance Therapy Association  
  410-997-4040  
  [www.adta.org](http://www.adta.org)
- American Music Therapy Association  
  301-589-3300  
  [www.musictherapy.org](http://www.musictherapy.org)
- National Association for Drama Therapy  
  202-966-7409  
  [www.nadt.org](http://www.nadt.org)
- National Coalition of Creative Arts Therapies Associations  
  201-224-9146  
  [www.ncata.com](http://www.ncata.com)

**Biofeedback**

Biofeedback is a treatment technique in which people are trained to improve their health by using signals from their own bodies. All body functions are controlled by the brain, but this control often takes place outside our conscious awareness. Biofeedback techniques teach people how to gain control over specific body functions. Monitoring machines are used to measure body functions. The information gathered from the monitors is provided to the person receiving biofeedback training to help him or her gain mental control over the target body functions.

Biofeedback has been used by people with lung cancer to help control anxiety, stress, breathing problems, and pain. If you are interested in biofeedback training, discuss it with your doctor to make sure it is safe for you. Your doctor or one of the nurses on your cancer care team may be able to refer you to a biofeedback professional. Alternatively, you may try contacting one of the agencies listed below.

- The Association for Applied Psychophysiology and Biofeedback  
  800-477-8892 (toll-free)  
  [www.aapb.org](http://www.aapb.org)
- Biofeedback Certification Institute of America  
  303-420-2902  
  [www.bcia.org](http://www.bcia.org)
**Hypnosis**

Hypnotists tell us that hypnosis is a natural state of mind we have all experienced. For example, have you ever been engrossed in a television program or book and failed to hear someone calling you or the telephone ringing? Hypnotists say this experience is similar to a mild hypnotic trance. Another familiar example is when you are driving and suddenly realize you have passed your turn or exit.

In the hypnotic state, you are awake but your mind is not actively analyzing, questioning, rationalizing, or judging. Each of us passes through a hypnotic state as we fall asleep and again when we wake up. In the hypnotic state, people are open to suggestions. This characteristic of the hypnotic state is used to help people control their conscious experiences and behaviors. While movies and television programs sometimes imply that people can be forced to do things through hypnosis, professional hypnotists report that any hypnotic suggestion must be acceptable to the client or else it will have no effect.

I was a dentist and used hypnosis for blood control. I am a strong believer in imaging and hypnosis. I know most people think I am crazy for believing it, but I was a stage IIIB with non-small cell lung cancer and in five weeks with chemo, my two-inch tumor was gone. So yes, I’m a strong believer.

– Richard, diagnosed with stage IIIB NSCLC in 1999 at age 78.

Hypnosis has been used by people with cancer for stress management, pain control, and to manage fears of medical procedures. Some people have had success using hypnosis to control nausea and vomiting associated with chemotherapy. Talk to your cancer care providers if you are interested in trying hypnosis. The following organizations may be able to assist you in finding a qualified hypnotherapist in your area. Ask specifically for a therapist who has had experience working with people who have cancer. In some cases, a hypnotherapist may be able to teach you how to hypnotize yourself to help control your symptoms.

- **American Association of Professional Hypnotherapists**  
  650-323-3224  
  [aaph.org](http://aaph.org)
- **American Council of Hypnotist Examiners**  
  818-242-1159  
  [www.sonic.net/hypno/ache.html](http://www.sonic.net/hypno/ache.html)
- **American Psychotherapy & Medical Hypnosis Association**
Massage

Massage therapy is the assessment and treatment of the soft tissues (primarily muscle and connective tissues) of the body. Therapeutic massage is used to prevent disability, relieve stress and pain, and promote relaxation and overall health. Massage therapy encompasses a wide range of different techniques, which can affect the circulatory, musculoskeletal, nervous, and respiratory systems. Hydrotherapy (water therapy), stretching and strengthening exercises, breathing instruction, and assessment and correction of posture are also tools that massage therapists regularly employ in their treatment protocols.

I was introduced to massage therapy through hospice when my partner was ill. I saw how beneficial it was. When I was diagnosed with lung cancer and started chemo, I also started massage therapy. I think it does three main things. It was a wonderful reward to my body after having chemo. It relaxed not only my body but my mind. And [because of the first two benefits], I think it helps the body's immune system. When treatment was tough, I had massages twice a week then once a week. Now, five years after diagnosis, I still do it monthly. It's wonderful.
— Dorothy, diagnosed with stage IIIA NSCLC in 1998 at age 68

There are many forms of massage therapy. A brief overview of some common forms of massage therapy is presented on the following pages.

Acupressure

Acupressure is similar to acupuncture but does not use needles. This technique involves pressing on certain points of the body to relieve pain and other symptoms. Acupressure attempts to promote maximal flow of the qi. Chinese acupressure massage is also known by its traditional name tui na.
Bowen Technique
The Bowen massage technique involves a series of gentle moves over the muscles and connective tissues to reset the body and help it heal. The therapist leaves the treatment room for short periods between each set of moves to allow the client time to absorb the bodywork.

Craniosacral Therapy
Craniosacral therapy involves manipulation of the bones of the skull and lower spine (the sacrum). Practitioners of this form of therapy claim it loosens or releases blockages in the body that contribute to pain and abnormal body functions.

Deep-Tissue Massage
Deep-tissue massage uses slow strokes, direct pressure, or friction applied across the grain of the muscles with the fingers, thumbs, or elbows. Deep-tissue massage works deeply into the muscles and connective tissue to release chronic aches and pains.

Lymph Drainage Massage
Lymph drainage massage involves the application of light, rhythmic strokes. This technique is primarily used to help conditions related to poor lymph flow such as inflammation, edema, and peripheral neuropathy.

Neuromuscular Massage
Neuromuscular massage is applied to specific muscles. It is often used to increase blood flow, release knots of muscle tension, or release pain/pressure on nerves. Trigger point therapy is a specific form of neuromuscular massage in which concentrated finger pressure is applied to ‘trigger points’ of muscular pain.

Reflexology
Reflexology is based on a system of points on the hands and feet that are thought to correspond to other areas of the body. The points on the hands and feet are
stimulated by massage techniques to help promote health and healing in the corresponding body part.

**Rolfing**
Rolfing is a specific type of massage that relies on deep pressure on tissues that cover muscles and internal organs. Rolfing is done to realign different areas of the body that can be pulled out of alignment by gravity such as the head, torso, spine, and legs. Rolfing can be uncomfortable or slightly painful during the treatment.

**Shiatsu**
Shiatsu is a form of massage that was developed in Japan. It involves finger-pressure massage (much like acupressure), stretching, and elements of western massage. The pressure points along the channels for the flow of qi (the meridians) are the focus of this form of massage. Treatment is intended to unblock these passages and restore the flow of qi. It is believed that blocked meridians can cause physical discomfort and inhibit normal body functions. Shiatsu has been used to relieve stress, anxiety, insomnia, and pain. It is also used to control nausea, vomiting, diarrhea, and constipation.

**Swedish Massage**
Swedish massage is the most common form of massage practiced in most parts of the U.S. It involves manipulation of the muscles and connective tissues of the body for relaxation and health maintenance. Swedish massage uses five basic massage techniques to relax muscles and body tissues.

**Thai Massage**
Thai massage therapy is an ancient blend of movements from yoga and acupressure massage. The therapist slowly moves the client’s body into traditional yoga poses and integrates acupressure massage.
Trager Therapy
Trager therapy involves a therapist who puts the client through a series of gentle movements while he or she lies on a massage table. There is also an active component to this therapy. The client repeats the movements performed by the therapist later on his or her own. The intent of therapy is to release stress and tension.

There are well over 100,000 massage therapists practicing in the U.S. Training requirements for massage therapists vary from state to state. As of this writing, more than 30 states have licensing regulations for the practice of massage therapy.

Talk with your cancer care providers if you are interested in pursuing massage therapy to be sure it is safe for you. If you have bone metastases, be sure to tell your massage therapist. Your care providers may be able to recommend a massage therapist who works with people who have cancer. You can also consult the following professional massage organizations.

- American Massage Therapy Association
  847-864-0123
  www.amtamassage.org
- Associated Bodywork & Massage Professionals
  800-458-2267 (toll-free)
  www.abmp.com
- National Certification Board for Therapeutic Massage and Bodywork
  800-296-0664
  www.ncbtmb.com

Meditation
Meditation is an exercise of the mind. In our usual state, the mind is incessantly bouncing from one thought to another. The stream of thoughts is never-ending in our every waking moment. Most of the thoughts that stream through our head seem to come of their own accord; most people have little control over this process. In meditation, people learn to control their thought processes and quiet the endless stream of thoughts. By quieting the mind, people experience a state of peacefulness and calm. When you are able to control your thoughts, you can choose what to focus your mind on and rid yourself of unpleasant or destructive thoughts. People practice meditation to help relieve stress and relax. For many people, meditation is part of their daily spiritual practice as well.
I practice a kind of American Indian ideology; meditation is just one aspect of it. It all started with my grandfather; he is half Cherokee. As a boy, he taught me how to meditate when we went out in the woods. It lets me know my body. You are basically in touch with your whole body. I usually know when something is wrong before the doctors do. I definitely think meditation has helped me, not only with lung cancer, but also through out my lifetime. It takes a lot of training and practice, but I’ve been using it since I was a kid.

—John, diagnosed with stage IV NSCLC in 2002 at age 48

Visualization is a form of meditation in which the person focuses on an image in his or her mind. Often, people visualize something they would like to see occur. For example, some people visualize themselves free of cancer or visualize the cancer cells in their body dying. Other people visualize a pleasant place or experience. The choice of what to visualize is entirely up to you. Guided imagery is similar to visualization except someone directs the visualization process. This can be accomplished in person or using recordings.

Visualization and guided imagery are just two examples of the many different meditation techniques available. The Meditation Society of American lists 108 different meditation techniques on their Internet site. While each technique is slightly different, they all share the common goal of quieting the mind. The choice of technique depends largely on your personal preferences and what works best for you. Meditation can be learned from books, tapes, videos, or personal instruction. Meditation requires practice and commitment. However, those who practice meditation regularly find it helpful for maintaining a clear and peaceful outlook on life. Consult with your care providers, friends, family members, or members of your support group for their recommendations about meditation techniques. You can also check at your local library or bookstore; there are many books and other materials available on this topic.

**Mind/Body Exercise**

Gentle exercise can help improve mood, relieve stress and anxiety, stimulate the immune system, build physical strength, stamina, and flexibility, and contribute to an overall sense of well-being. Holistic medicine involves working with both the mind and the body. Certain forms of exercise are particularly helpful for achieving this unity of mind and body.
Yoga is an ancient practice from India that dates back thousands of years. Yoga originated as one part of an overall spiritual practice that trains the mind to control the body, thoughts, and emotions. There are many different forms of yoga; some are very gentle while others are more rigorous. The most common form of yoga practiced in the U.S. is hatha yoga. Specific forms of yoga include Ashtanga, Bickram, Iyengar, Kundalini, Kripalu, Sivananda, and Viniyoga. In addition to making the body strong and flexible, yoga practitioners say the practice improves respiratory, circulatory, digestive, and hormonal functions, and brings about emotional stability and clarity of mind. Some of us envision yoga as being only for people who are able to bend and twist their bodies in almost unfathomable ways. The truth is that some form of yoga can be practiced by nearly everyone, regardless of your current weight or level of flexibility.

Yoga has been an incredible, incredible boost to helping me deal with my [peripheral] neuropathy from the chemotherapy. Yoga uses certain postures that really involve you hands and feet. I've gained back about 90% of what I had lost from the neuropathy. Yoga is awesome. It is not just an exercise, it's a lifestyle. You get in touch with your incredible strength and power. It becomes spiritual. I've found that you become an inspiration to others in the sense that you gain this calmness about you that people can feel. I will never give this up – I don't care how old I am!

–Barbara, diagnosed with stage IV NSCLC in 1999 at age 49

Qi gong (pronounced chee gung) is derived from traditional Chinese culture. It uses visualization, breathing, body positions, and slow movements to cleanse the body and the mind, restore energy, and strengthen body functions. The practice promotes the circulation of both blood and qi in the body. Qi gong focuses on the use of specific breathing techniques that are intended to open up the meridians allowing energy to flow to all parts of the body healing every organ in its path.

I came about to qi gong by way of a Chinese couple I helped a while ago who in turn led me to a Chinese healer. I was living on Dilaudid™ (a very strong painkiller) - six pills a day. The first day the Chinese healer came over, she placed her hands on me for about an hour. The following day, I only took three painkillers. She came back again and placed her hands on me for an hour, and it lessened my pain again. Through her, I learned the art of meditation and how to apply energy to places that needed healing. I learned to balance my qi. There are over 100 forms of qi gong. The form I use is one that was easier for me. It was something that I felt I could do. It's a way of healing. It is wonderful for restoring and reducing stress. I really do think it helped in my healing. It was marvelous.

–Alice, diagnosed with stage III NSCLC in 2001 at age 58
Tai chi originated in China and has been practiced for thousands of years. Tai chi involves slow gentle movements that are designed to improve health and build muscle tone. The beginning movements of tai chi are relatively simple to perform and are appropriate for almost everyone. This form of exercise increases qi in the internal organs and helps release stress. Once a certain level of training is obtained, the practitioner can learn to move energy to different parts of the body through the different positions and movements. The practice of tai chi improves balance and coordination.

Before beginning any exercise program, discuss it with your doctors to be sure it is safe for you. Most people find the three forms of mind/body exercise presented here are best learned from someone who has studied and mastered these techniques. However, there are also videotapes and DVDs available for beginners. Check with your local library, bookshop, or health store about availability of these materials.

**Prayer, Religion, and Spirituality**

Prayer and religious and spiritual practices have been shown to have an important role in coping with serious illness including cancer.\textsuperscript{25, 26} Faith in a specific religious or spiritual tradition has also been shown to reduce depression in response to cancer.\textsuperscript{27, 28} Studies also suggest religious/spiritual practice has a positive impact on quality of life among people with cancer.\textsuperscript{29}

Religious and spiritual practices are highly personal choices. Research has shown that these practices, regardless of what they are, can help people with cancer accomplish improvement in their overall sense of well-being. Faith, religion, and spirituality and their impact on health and coping are being actively studied.

I have a strong spiritual faith...I believe it is the Lord's will whether I remain here...Apparently, there is a reason I am still here. I am totally amazed that as I went through treatment I did so well. My side effects were minimal. I feel the power of prayer is extremely, extremely powerful. It is like my meditation. It is that and [my] belief in the Lord that has carried me through. My spiritual walk gives me a great deal of peace and contentment, which helps by calming my nerves and whole being. I honestly don't fear death.

– Darlene, diagnosed in 1995 with stage II NSCLC at age 61
Support Groups

Cancer support groups can help people living with cancer in many ways including:

- providing an outlet for expressing your feelings
- reducing feelings of being alone with your cancer experiences
- learning about others’ experiences, which may help you make decisions about your own care
- bolstering your sense of hope
- regaining a sense of control over your life

Each of these benefits can help reduce stress, anxiety, and depression while improving your overall sense of well-being, especially among people who have a limited support network.

In addition to local support groups, there are also Internet support groups. Ask your oncology social worker or nurse about support groups in your area. Your community hospital may also have information about local support groups. Other resources for information about cancer support groups include:

- American Cancer Society
  800-ACS-2345 (800-227-2345)
- Association of Cancer Online Resources (Internet support groups)
  www.acor.org
- Cancer Care
  800-813-HOPE (800-813-4673)
- The Wellness Community (local and Internet-based support groups)
  888-793-WELL (888-793-9355) or www.thewellnesscommunity.org

NUTRITIONAL SUPPLEMENTS

Chapter 12: Nutrition and Lung Cancer provides basic information about nutrition and how to meet your dietary needs while living with lung cancer. This section gives information about nutritional supplements, that is, vitamins, minerals, and other products that are used to provide additional nutrients beyond those obtained through your diet.

Many products are marketed to people with cancer. It can be challenging to decide what products may be appropriate for you. The Physicians’ Desk Reference for Nonprescription Drugs and Dietary Supplements is a good source of information about nutritional
supplements. However, it is written in technical language that can be difficult to understand. The book is available at most public libraries, or can be purchased from your local or online bookstore. If you read something in the book you do not understand, discuss it with your health care provider.

This section reviews some of the products about which the author regularly gets questions. If there is scientific evidence available to support the use of specific products, it is noted. It is important to thoroughly research any product you are considering taking. It is even more important to discuss any products you are considering with your cancer care providers. This is critical to ensure that you will not be taking potentially dangerous combinations of drugs and supplements, and to be certain the therapies you are using do not cancel out or reduce the effects of one another.

People often modify their nutritional intake after being diagnosed with cancer. Some choose to eat only organic foods or to stop eating animal products. Others decide to adopt a specific diet regimen. However you choose the foods you eat, it is important to discuss your diet with your doctors or a nutritionist to be sure you are getting the calories and basic nutrients you need.

Vitamins

Vitamins are small chemicals the body needs to carry out many of its essential functions. The body cannot make vitamins from scratch. Therefore, vitamins or their precursors must be supplied through your diet or nutritional supplements. A list of vitamins is shown in Table 1. Fat-soluble vitamins (shown in purple) can be stored by the body. Water-soluble vitamins (shown in blue) are not stored and must be supplied frequently through the diet to keep up with the body's needs.
<table>
<thead>
<tr>
<th>Vitamin</th>
<th>Other Names</th>
<th>Actions/Sites of Body Most Affected</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>retinol</td>
<td>eyes and skin</td>
</tr>
<tr>
<td></td>
<td>carotenoids*</td>
<td>tissue &amp; bone growth</td>
</tr>
<tr>
<td></td>
<td>beta-carotene*</td>
<td>reproduction</td>
</tr>
<tr>
<td>B1</td>
<td>thiamine</td>
<td>nervous system</td>
</tr>
<tr>
<td></td>
<td></td>
<td>skin</td>
</tr>
<tr>
<td></td>
<td></td>
<td>essential for energy production</td>
</tr>
<tr>
<td>B2</td>
<td>riboflavin</td>
<td>skin</td>
</tr>
<tr>
<td></td>
<td></td>
<td>essential for energy production</td>
</tr>
<tr>
<td>B3</td>
<td>niacin</td>
<td>skin</td>
</tr>
<tr>
<td></td>
<td></td>
<td>nervous and digestive systems</td>
</tr>
<tr>
<td></td>
<td></td>
<td>cell reproduction</td>
</tr>
<tr>
<td>B5</td>
<td>pantothenic acid</td>
<td>essential for energy production</td>
</tr>
<tr>
<td></td>
<td></td>
<td>red blood cell production</td>
</tr>
<tr>
<td></td>
<td></td>
<td>hormone production</td>
</tr>
<tr>
<td>B6</td>
<td>pyridoxine</td>
<td>nervous system</td>
</tr>
<tr>
<td></td>
<td></td>
<td>fat metabolism and protein production</td>
</tr>
<tr>
<td>B9</td>
<td>folic acid</td>
<td>genetic material production</td>
</tr>
<tr>
<td></td>
<td></td>
<td>red and white blood cell production</td>
</tr>
<tr>
<td>B12</td>
<td>cyanocobalamin</td>
<td>red blood cell production</td>
</tr>
<tr>
<td></td>
<td></td>
<td>nervous system</td>
</tr>
<tr>
<td>C</td>
<td>ascorbic acid</td>
<td>physical stress relief</td>
</tr>
<tr>
<td></td>
<td></td>
<td>immune system</td>
</tr>
<tr>
<td></td>
<td></td>
<td>red blood cell production</td>
</tr>
<tr>
<td>D</td>
<td>calciferol</td>
<td>bone formation &amp; repair</td>
</tr>
<tr>
<td></td>
<td></td>
<td>teeth</td>
</tr>
<tr>
<td>E</td>
<td>tocopherol</td>
<td>red blood cell production</td>
</tr>
<tr>
<td></td>
<td></td>
<td>anti-cotting</td>
</tr>
<tr>
<td></td>
<td></td>
<td>fat metabolism</td>
</tr>
<tr>
<td>K</td>
<td>phylloquinone</td>
<td>blood clotting</td>
</tr>
<tr>
<td></td>
<td>menaquinone</td>
<td>bone health</td>
</tr>
<tr>
<td></td>
<td></td>
<td>calcium absorption &amp; metabolism</td>
</tr>
<tr>
<td>H</td>
<td>biotin</td>
<td>protein and fat metabolism</td>
</tr>
<tr>
<td></td>
<td></td>
<td>B vitamin metabolism</td>
</tr>
</tbody>
</table>

*Vitamin A precursors - converted into vitamin A by the body

Lung cancer and its treatments can affect your appetite and interfere with eating in several different ways (see *Chapter 10: Supportive Care* and *Chapter 12: Nutrition and Lung Cancer* for additional information). If you are having problems eating a healthy, balanced diet, you may need to supplement your vitamin intake. Consult your doctor and/or a nutritionist to see if you need supplemental vitamins, which ones are needed, and what dosage to take. It is very important not to take supplemental vitamins without first discussing it with your doctors. Fat-soluble vitamins, which are stored in the body, can be toxic if taken in excessive amounts.
amounts. Some vitamins may interact in a negative way with treatments or cause nutritional imbalances if taken in large amounts.

Many recent and currently ongoing studies are examining the role of vitamins in lung cancer prevention. However, the effects of specific vitamins on lung cancer that has already developed have not been thoroughly evaluated in clinical trials. Currently, most lung cancer experts agree that a multivitamin may be important if you are not getting adequate vitamins from your diet. However, there are no studies to date showing that vitamins affect your long-term prognosis.

Minerals and Trace Elements

Minerals and trace elements are substances found in foods that are essential for normal body function. Minerals and trace elements cannot be manufactured by the body. They must be supplied from your diet or nutritional supplements. While the body must have minerals and trace elements to function normally, the amounts needed vary widely. Table 2 shows some minerals and trace elements necessary for normal body functions.

<table>
<thead>
<tr>
<th>Name</th>
<th>Chemical Symbol</th>
</tr>
</thead>
<tbody>
<tr>
<td>calcium</td>
<td>Ca</td>
</tr>
<tr>
<td>iron</td>
<td>Fe</td>
</tr>
<tr>
<td>magnesium</td>
<td>Mg</td>
</tr>
<tr>
<td>phosphorus</td>
<td>P</td>
</tr>
<tr>
<td>sodium</td>
<td>Na</td>
</tr>
<tr>
<td>potassium</td>
<td>K</td>
</tr>
<tr>
<td>sulfur</td>
<td>S</td>
</tr>
<tr>
<td>cobalt</td>
<td>Co</td>
</tr>
<tr>
<td>copper</td>
<td>Cu</td>
</tr>
<tr>
<td>chromium</td>
<td>Cr</td>
</tr>
<tr>
<td>fluoride</td>
<td>F</td>
</tr>
<tr>
<td>iodine</td>
<td>I</td>
</tr>
<tr>
<td>manganese</td>
<td>Mn</td>
</tr>
<tr>
<td>molybdenum</td>
<td>Mo</td>
</tr>
<tr>
<td>selenium</td>
<td>Se</td>
</tr>
<tr>
<td>silicon</td>
<td>Si</td>
</tr>
<tr>
<td>zinc</td>
<td>Zn</td>
</tr>
</tbody>
</table>
Some minerals and trace elements have been considered to have a potential role in lung cancer prevention or as supplements to lung cancer therapy. These supplements are briefly reviewed on the following pages.

Calcium
Calcium is the most abundant mineral in the human body. Every cell of the body contains calcium. The majority of calcium in the body is in the bones and teeth.

Calcium has many important functions in the body. Inside cells, calcium is a necessary component or cofactor for many enzymes. Enzymes are proteins that propel many of the chemical reactions that take place continuously in the body. Examples of the many other body functions that involve calcium include blood clotting, nerve impulse conduction, muscle contraction, maintenance of blood pressure, regulation of the heart beat, and bone formation and healing.

Many foods contain calcium. Dairy products are among the best sources of calcium in the diet. People who do not drink milk or eat many dairy products, or otherwise do not get enough calcium from their diet may require calcium supplements.

A new calcium product called coral calcium has recently been introduced. As the name implies, coral calcium is made from sea coral. It is rich in calcium and contains up to 70 other minerals. It is available as capsules, tablets, powder, or as ‘tea’ bags. Coral calcium has the advantage of being better absorbed from the digestive tract than some other forms of calcium on the market. However, claims of 100% absorption are untrue. The actual absorption of coral calcium is around 65-70%. Some marketers of coral calcium claim it protects against cancer. There are no studies to substantiate this claim, nor many of the other claims about coral calcium’s curative powers. No controlled studies have shown that coral calcium has any effect on the long-term prognosis of people with cancer of any kind. On June 10, 2003, the Federal Trade Commission (FTC) ordered the marketers of coral calcium to remove advertising from the television and Internet that claims coral calcium is effective for the treatment of cancer and other diseases.
Selenium
Selenium is essential for healthy immune function. It has been found to stimulate the activity of white blood cells, which are important components of the immune system. Brazil nuts, yeast, whole grains, and seafood are good sources of dietary selenium.

Research has shown that selenium activates an enzyme called glutathione peroxidase, which may help protect the body from cancer. Selenium has also been shown to have a role in programmed cell death, a normal process that goes awry in cancer cells. Blood levels of selenium have been reported to be low in patients with many cancers, including lung cancer. One large study of 1,312 Americans who were treated daily with either selenium or an inactive substance for 4.5 years and then followed for an additional two years found a 46% decrease in lung cancer incidence and a 53% drop in deaths from lung cancer associated with supplemental selenium.

While these studies point toward a role for selenium in lung cancer prevention, the role of selenium in established lung cancer (once you already have the disease) is not yet clear.

Zinc
Zinc is a component of more than 300 enzymes in the human body. Enzymes are proteins needed to propel the chemical reactions that keep the body functioning. Zinc is important in wound repair, fertility, tissue growth, and immune function. Oysters, meat, eggs, seafood, black-eyed peas, tofu, and wheat germ are all good sources of zinc.

Some lung cancer patients have been reported to lose excessive amounts of zinc in the urine. In one trial, supplementing such patients with zinc led to an improvement in some aspects of immunity. However, there have been no studies to examine whether supplemental zinc helps prevent lung cancer or improve survival in patients already diagnosed with the disease.
Other Nutritional Supplements and Products

Many other nutritional supplements have been given consideration with respect to their role in lung cancer. A brief review of some common supplements and what we know about them is presented in this section.

Coenzyme Q10 (Ubiquinone)

Coenzymes are substances required by enzymes to propel specific chemical reactions in the body. Coenzyme Q10 (coQ10) is present in every cell of the body. It helps with several vital chemical reactions, especially those involved with energy production. CoQ10 is found in foods such as organ meats (heart, liver and kidney), beef, soy oil, sardines, mackerel, peanuts, and other foods. In addition to being derived from the diet, CoQ10 is also made by the body.

CoQ10 proponents claim it has many health benefits including protection against heart disease, Parkinson’s disease, Huntington’s disease, and brain aging. Claims have also been made that CoQ10 has a role in protecting against genetic damage that can lead to cancer. Normal cell processes produce substances called free radicals. Free radicals can damage cells and their genetic material. The body neutralizes free radicals with a variety of compounds that are collectively known as antioxidants. CoQ10 is one example of the antioxidants used by the body to neutralize free radicals and keep them from damaging cells. One study found an increased incidence of CoQ10 deficiency in people with cancer compared to people without cancer. CoQ10 has been shown to have anti-tumor and immune stimulating effects in laboratory animals. However, large-scale studies in people with cancer have not been conducted to determine if these laboratory observations hold true for humans with cancer. At this time, there is no conclusive evidence that CoQ10 has any effect on the prognosis of people with lung cancer.

Citrus Pectin

Modified citrus pectin (MCP) is a product made from the peel and pulp of citrus fruits. It is modified to make it more easily absorbed in an active form into the body. A component of MCP has been shown in laboratory studies to inhibit the proteins
on the surface of cancer cells that allow them to stick to new sites or blood vessels. MCP has also been shown to inhibit prostate cancer and melanoma (skin cancer) in laboratory animals, and to cause a reduction in the size of cancerous colon tumors in mice. However, there have been no controlled clinical trials to prove or disprove that MCP has an effect on cancer cells in humans.

Glutamine
The tissues of the body are largely made up of proteins. Amino acids are the building blocks for proteins; there are over 20 different amino acids. Glutamine is the most abundant free amino acid in the human body. It can be manufactured by all cells of the body, but is primarily manufactured by muscle cells. Some of the many functions of glutamine in the body include:

- main fuel source for several types of immune cells and the cells of the intestine
- essential for gene production for cell division
- essential for protein production
- important for various immune functions
- antioxidant activity to prevent free-radical damage to cells

Cancer cells have been shown to utilize glutamine at a rapid rate. The role of glutamine in people with cancer is being actively investigated. On a theoretical level, supplemental glutamine may be helpful for people with cancer because it supports immune function and has antioxidant activity. On the other hand, supplying too much glutamine may give cancer cells an advantage by providing cancer cells with the glutamine they require for continued growth and replication. Preliminary studies in cancer patients are being conducted using an enzyme that breaks down glutamine. The idea is that starving cancer cells of glutamine may actually cause them to die. Scientists are working to find answers to these questions, but currently, the answers are unclear.
Nonetheless, several preliminary studies suggest glutamine may be helpful in terms of limiting some of the side effects of cancer therapy. Swishing a glutamine solution in the mouth has been shown in one small study to help reduce mouth sores that can occur with chemotherapy and/or radiation therapy. However, another study using ingested glutamine failed to show any benefit. Studies are also being conducted to examine whether ingesting supplemental glutamine can help prevent the nerve damage (peripheral neuropathy) that can occur with some chemotherapy drugs. One study found glutamine may be protective against this potentially dose-limiting side effect, but results were not conclusive. Research continues into the possible uses of glutamine to prevent or minimize side effects of cancer therapy.

**IP-6**

IP-6 is a naturally occurring molecule in the cells of all mammals. IP-6 is also known as phytic acid and inositol hexaphosphate. The theory behind the use of IP-6 as an anti-cancer agent is that the administration of IP-6 leads to increased cellular levels of IP-3, which is an important regulator of cell growth and proliferation. Several studies performed in animals have shown that IP-6 has anti-cancer activity. However, carefully controlled clinical trials in people with cancer have not been reported. Without clinical trial data, it is impossible to know with certainty whether IP-6 will prove to be beneficial as an anti-cancer agent.

**Melatonin**

Melatonin is a hormone released by a small gland in the brain. Melatonin is best known as the hormone that regulates our sleep cycle, but it has other functions as well that have led to interest in melatonin’s potential role in cancer prevention and treatment. Melatonin is a powerful antioxidant. It acts as a scavenger of free radicals and regulates the level of specific antioxidant enzymes. Melatonin also affects the immune system. Studies have shown melatonin can enhance immune responses and correct immunodeficiency states that may follow acute stress, viral diseases, or drug treatment. Melatonin has been shown to have anti-cancer effects in laboratory animals, and has shown some potential as an anti-cancer agent in preliminary studies in humans. Melatonin has been most widely studied in women with breast cancer.
It has been studied to a lesser extent in people with brain, colorectal, blood, liver, lung, kidney, pancreas, prostate, and skin cancers. There have been reports of slowed disease progression and improvements in cancer-related weight loss and quality of life. While these initial, small studies show some promise, the potential role of melatonin in cancer care and more specifically, in the care of people with lung cancer, is still being investigated.

Noni Juice
Noni fruit (Morinda citrifolia) grows in the tropics and is particularly plentiful in Tahiti. Noni juice has been reported to have many health benefits including anti-cancer properties. Proponents of noni juice have reported that chemicals contained in the juice may help suppress tumor growth by stimulating the immune response to cancer cells. Studies in animal models have shown some support for this theory. However, clinical studies to prove this theory in humans have not yet been conducted.

Shark and Bovine Cartilage and Extracts
In the 1970’s, researcher Dr. Judah Folkman proposed inhibiting new blood vessel formation (angiogenesis) as a potential mechanism to treat cancer. Scientists theorized that tumors must establish their own blood supply to live, grow, and spread. However, at least one study has shown that some lung tumors are able to exploit the rich blood supply already present in the lungs without growing new blood vessels. In the 1980’s, researchers discovered substances in shark and bovine (cow) cartilage that prevented blood vessel formation in the laboratory. For the past twenty years, interest in angiogenesis inhibitors has flourished among people with cancer and researchers.

Shark and bovine cartilage powders, capsules, and liquids are widely available and marketed by many manufacturers. The quality and purity of shark and bovine cartilage preparations are not under the oversight of the FDA. Most researchers agree there are several active substances in shark and bovine cartilage that can inhibit angiogenesis and may act via other mechanisms to prevent cancerous tumor growth.
and metastasis. The concentration of these substances in different shark and bovine cartilage products is highly variable.

While several new antiangiogenic drugs such as angiostatin and endostatin have been developed by pharmaceutical companies and are currently being tested in clinical trials, the utility of shark and bovine cartilage for anti-cancer therapy remains controversial and study data is conflicting. Some preliminary studies have shown promising results in terms of laboratory response and prolonged survival\textsuperscript{68-71}, others have not shown benefits from treatment with shark cartilage.\textsuperscript{72-74} Aeterna Laboratories has developed a purified shark cartilage extract called Neovastat\textsuperscript{™} (AE-941) that is currently in phase III clinical trials among people with non-small cell lung cancer. Results are expected in 2005.

Soy
Soybeans and soy products contain isoflavones, chemicals that are similar in structure to the hormone estrogen. For this reason, isoflavones are sometimes called phytoestrogens (‘phyto’ meaning plant). Genistein and daidzein appear to be the most potent isoflavones in soy products and have been reported to have many effects in the body. There are other active substances in soy in addition to isoflavones such as protease inhibitors, phytates, saponins, phytosterols, and lecithin. Genistein has been shown to have anti-cancer effects in some animal models.\textsuperscript{75, 76} However, there have been some studies that have shown an increased risk of lung and other cancers in other animal models treated with genistein and/or daidzein.\textsuperscript{77, 78} In short, the efficacy of soy supplementation, either from the diet or as a nutritional supplement, for the treatment of cancer is not yet clear. There are many soy supplements available in a variety of forms including powders, milk, capsules, and tablets.
Sun’s Soup

Sun’s Soup and Selected Vegetables are the names of several different mixtures of vegetables and herbs that have been promoted as treatments for cancer and many other medical conditions. The original formulation contained shiitake mushroom (*Lentinus edodes*), mung bean, *Hedyotis diffusa* (also known by the Chinese herbal name Bai Hua She She Cao), and barbat skullcap (*Scutellaria barbata*; also known by the Chinese herbal name Ban Zhi Lian). Some varieties of these products are reported to also contain soybean, red date, scallion, garlic, leek, lentil, Hawthorn fruit, onion, ginseng, Angelica root, licorice, dandelion root, senega root, ginger, olive, sesame seed, and parsley.

According to the National Cancer Institute (NCI), “The use of Selected Vegetables/Sun’s Soup as a treatment for human cancer has been investigated in only a limited manner. All available resources … [including] the published reports of two clinical studies have identified fewer than 50 treated patients.” The results from these studies are available on the NCI Internet site at cancer.gov/cancerinfo/pdq/cam/vegetables-sun-soup. While results from two small studies involving 27 people with lung cancer appeared promising, it is not possible to draw scientific conclusions from such a small sample of patients. NCI recommends, “Additional larger, well-designed clinical studies that test identical formulations of vegetables and herbs are necessary to determine more clearly whether Selected Vegetables/Sun’s Soup can be useful in the treatment of non-small cell lung and other types of cancer.”

**HERBS AND BOTANICALS**

Herbs and botanicals are plant-derived substances used for the prevention or treatment of disease. Chinese medicine, naturopathy, ayurveda, and many folk remedies make use of herbs and botanicals. Herbal and botanical preparations may contain a dried mixture of the whole plant or parts of the plant such as the stems, leaves, flowers, or roots. Botanicals can be administered in pill or capsule form, but are also sometimes dispensed as loose material.

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2 Information about Sun’s Soup is derived from the National Cancer Institute PDQ Internet site at cancer.gov/cancerinfo/pdq/cam/vegetables-sun-soup.
that is made into a tea. Teas are most commonly used by traditional Chinese medicine practitioners.

This section provides a brief review of some of the most common herbs and botanicals used by people with lung cancer. It is important not to take any herbs, botanicals, or other supplements without first discussing it with each of your cancer care providers.

**Astragalus**

*Astragalus membranaceus* has been used by Chinese medicine practitioners for thousands of years. The dried root of the plant is usually used in formulas and remedies. Astragalus proponents state the herb enhances immune function, promotes wound healing, and combats generalized weakness. There is some laboratory evidence using animal models supporting the immune-enhancing effects of astragalus.

However, large-scale studies to determine whether astragalus has beneficial effects for people with lung cancer have not been performed.

**Chinese Herbal Remedies**

Traditional Chinese medicine practitioners usually dispense herbal remedies that are a mixture of herbs specifically selected to meet a patient’s unique medical situation. More than 5,000 Chinese herbs have been categorized and classified according to the various properties they possess. In China and in parts of the U.S. with large populations of people of Chinese heritage, prescriptions for herbal remedies can be filled in herbal pharmacies. However, herbal pharmacies in the U.S. are not subject to the same regulations and oversight as conventional pharmacies that dispense prescription drugs. As Chinese medicine has grown in popularity in the U.S., many Chinese medicine practitioners and some herb manufacturers have begun selling and marketing herbal therapies with preset formulas. Many of these products are produced with great care to insure the quality and purity of the herbs. Nevertheless, unfortunately, there have been instances when these formulas were found not to contain the quantity or quality of the herbs that were supposed to be in the remedy. There have also been cases in which marketed remedies contained contaminants such as unwanted prescription drugs, toxins, or microbes. If you decide to take any herbal formulas,
it is important to get your products from reputable Chinese medicine practitioners or from manufacturers that use scrupulous production practices.

Chinese herbal remedies are based on the experience of Chinese medicine practitioners over thousands of years. Many people have been helped by the use of herbal remedies. However, the scientific study of the effectiveness of Chinese herbal remedies is limited outside of China. Laboratory research indicates that some Chinese herbs and formulas have activity against lung cancer cells. One published report from a small study showed a Chinese herbal formula taken in combination with chemotherapy improved survival. There are no published reports of large-scale clinical trials to determine the effects of specific Chinese herbal formulas among people with lung cancer.

If you decide to take one or more herbal remedies, it is very important to know what herbs are included in the remedy and to provide this information to your cancer care providers. You do not want to take herbs that may interfere with your other treatments or cause potentially dangerous side effects.

**Essiac Tea**

Essiac tea is a mixture of herbs. The formula contains burdock root (*Arctium lappa*), slippery elm bark (*Ulmus fulva*), sheep sorrel (*Rumex acetosella*), and Turkish or Indian rhubarb (*Rheum palmatum* or *Rheum officianale*). Essiac tea is marketed with other trade names including FlorEssence™, Tea of Life™, and Vitalitea™. Some of the herbs contained in essiac tea have been shown to have anti-cancer effects in laboratory tests. For example, burdock root has been shown to inhibit development of cancer in laboratory animals, and rhubarb extracts have shown activity against cancer cells in the laboratory. Promoters of essiac tea claim it enhances immune function, reduces tumor size, relieves pain, and extends survival. However, essiac tea has not been tested in clinical trials. Therefore, there is no scientific evidence to prove or disprove the proposed effects of essiac tea.

**Green Tea (Camillia sinesis)**

Green tea is made from the steamed, dried leaves of the *Camillia sinesis* plant. It is also known as Chinese tea. The difference between green tea and black tea is that the leaves
are fermented to make black tea. Green tea contains chemicals called polyphenols that act as antioxidants. Catechins are polyphenol compounds found in green tea that have been studied for their anti-cancer properties. Laboratory studies have shown that catechins may inhibit specific enzymes that could lead to reduced cancer cell division.\textsuperscript{87-89} However, there have been no clinical trials to show that green tea is of benefit to people with lung cancer. A recent phase II trial conducted among men with prostate cancer failed to show any benefit from consumption of green tea.\textsuperscript{90}

**Licorice**

The dried root of the licorice plant (\textit{Glycyrrhiza glabra} and \textit{Glycyrrhiza uralensis}) has been used in Chinese medicine for thousands of years as an herbal remedy to treat digestive disorders, skin disorders, liver diseases, and to enhance immune function. Glycyrrhizin is considered the primary active ingredient in licorice root. There is some evidence that glycyrrhizin protects against the development of liver cancer, especially among those with chronic hepatitis.\textsuperscript{91, 92} However, the effects of glycyrrhizin on lung cancer have not been studied either in the laboratory or among people with the disease.

Licorice root has been known to cause some unwanted side effects including headaches, fatigue, water retention, high blood pressure, diarrhea, and muscle weakness. Licorice root should not be taken by people with kidney problems or high blood pressure. Consult your doctor before taking licorice or any other herb or nutritional supplement.

**Milk Thistle**

Milk thistle is the common name for the plant \textit{Silybum marianum}. The active ingredient of milk thistle is a chemical called silymarin. The ingredient label on any milk thistle product should list the silymarin content. Most experts state milk thistle extracts should contain 80% silymarin. Milk thistle has been used in Europe since the Middle Ages to treat liver disorders. Silymarin has been shown in laboratory experiments to have potent antioxidant effects.\textsuperscript{93-96} It has also been shown to inhibit the growth of specific types of
cancer cells in laboratory experiments including prostate\textsuperscript{97,98}, skin\textsuperscript{99}, and breast cancers\textsuperscript{100}. Clinical studies to determine the possible effects of milk thistle on people with lung cancer have not been conducted.

**Turmeric**

Turmeric root has been used for centuries in Chinese and ayurvedic medicine. Other common names of turmeric include Indian saffron, Indian valerian, jiang huang, radix, and red valerian. Turmeric is from the plant *Curcuma longa*. The active ingredient in turmeric is curcumin. Turmeric and curcumin have been studied extensively over the past several decades and have been found to have many actions including inhibition of several types of cancer cells in the laboratory. This inhibition seems to be the result of curcumin’s antioxidant properties and a variety of metabolic actions on the cancer cells\textsuperscript{101}. Curcumin appears to be safe and non-toxic. Experimental models have shown that curcumin may help prevent metastasis of lung cancer cells in the laboratory\textsuperscript{102,103}. While all of the laboratory studies appear promising, turmeric has not been tested in clinical trials to determine its effect on people with lung cancer.

**ACUPUNCTURE AND RELATED THERAPIES**

Acupuncture and related therapies have been practiced for nearly 5,000 years in Asia. Acupuncture is based on the concept that energy or qi flows through the body along specific channels called meridians (see Figure 2). Acupuncture uses very fine needles inserted at specific points along the meridians to restore the flow of qi, treat disease, and relieve symptoms. Acupuncture can be used with heat produced by burning a specific herb called mugwort in a process known as *moxibustion*. Massage therapy that involves manipulation of acupuncture points without the use of needles is called acupressure or tui na. *Cupping* is another type of acupuncture-related treatment. It involves stimulating acupuncture points by applying suction using a metal, wood, or glass jar in which a partial vacuum has been created. This technique causes blood to pool at the cupped site stimulating the acupuncture point without the use of needles.
Acupuncture has been used by many people with cancer to treat several symptoms including chronic pain, nausea and vomiting, anxiety, depression, and others. Studies have shown acupuncture is helpful in controlling chemotherapy-induced and post-operative nausea and vomiting.\textsuperscript{104-108} The studies are convincing and led to the National Institutes of Health to state, “acupuncture is a proven effective treatment modality for nausea and vomiting.”\textsuperscript{109} Acupuncture has also been used to treat constipation, diarrhea, and loss of appetite. However, there is no conclusive clinical trial data to support the effectiveness of acupuncture for treating these common cancer-related symptoms.

There is some experimental evidence that acupuncture affects immune functioning in people with cancer.\textsuperscript{106-117} However, there have been no published reports to prove that acupuncture manipulation of the immune system affects cancer progression or prognosis.

Acupuncture has been used to treat many different types of pain, including cancer-related pain. Results from clinical trials have yielded mixed results with some showing apparent benefit\textsuperscript{104, 118, 119} and others not finding this effect. Large-scale clinical trials are not yet available to determine if acupuncture is effective treatment for cancer pain, but reports based on individual experiences have noted benefits.

**SUMMARY**

Health and disease are part of a continuum and involve many different realms including your physical, mental, spiritual, social, and intellectual well-being. Many health care professionals now believe that effective treatment involves a holistic approach that treats not only physical symptoms but also addresses other aspects of well-being.
There are many different approaches to optimizing your physical, mental, spiritual, social, and intellectual health. Although western medicine is the primary form of treatment for cancer in the United States, other medical disciplines can be used in conjunction with western care such as ayurveda, chiropractic medicine, homeopathy, naturopathy, traditional Chinese medicine, and others.

If you are interested in pursuing any of the topics discussed in this chapter, additional information can be obtained from your local library, bookstore, the Internet, or the Resource Directory at the back of this book. Your oncology nurse or loved ones may also be good sources of information on complementary healing approaches. Complementary care practitioners are often very willing to spend time explaining the treatments they offer and the rationale behind the treatments. Remember to discuss any treatment decisions you make with all your cancer care providers to ensure safety and maximize the effectiveness of your treatment approach.

The author is providing information on complementary healing to help you have the information you need to make informed treatment choices. The inclusion or exclusion of any particular treatment or supplement does not constitute an endorsement or a denial of efficacy.

I hope this information contributes to your well-being in every aspect of your life.
CHAPTER 12: NUTRITION AND LUNG CANCER

INTRODUCTION

Lung cancer and its treatments place great energy demands on the body. Food is the body’s energy source. Adequate nutrition while living with lung cancer is very important, but can be challenging as some symptoms of lung cancer and side effects of treatment can interfere with eating and nutrition. This chapter reviews the basic principles of nutrition and gives tips on healthy eating for people living with lung cancer. The information can help you plan a diet that ensures your body is getting the energy and nutrients it needs.

FOOD AND ENERGY

The human body is always active. Even while you sleep, your body is working. The heart is beating, the lungs are breathing, the kidneys are filtering blood, old cells are being broken down, and new cells are being made. All body activities require energy much like a car needs gas to run. Food is the body’s energy source. The food we eat is broken down by the digestive system into its simplest forms that are used to fuel the body’s activities.

All foods are composed of different amounts of three types of nutrients: proteins, fats, and sugars. The digestive system breaks down all foods into these three basic nutrients. Foods also contain vitamins and minerals. Sugars are the main source of energy for the body. In times of great demand, the body can also utilize fats and proteins for energy.

The energy supplied by food is expressed in calories. Calories are a measure of the energy supplied by a specific food. The higher the number of calories in a food, the more energy it supplies to the body. The body requires a certain number of calories each day to carry out its functions. Most adults require 2,000-2,500 calories each day to maintain their body weight. The exact number of calories needed each day varies from one person to another.
Your daily calorie requirement depends on many factors including:

- body size
- daily activity level
- rate of metabolism
- amount of tissue loss and growth
- presence of infection

Metabolism is the term used to describe the total activities of the body, which includes fueling body functions, breaking down tissues, and building up new ones. People have different natural rates of metabolism. People with a low metabolic rate require fewer calories than do people with a fast metabolic rate. Your natural metabolic rate is similar to the fuel efficiency of a car. Fuel-efficient cars can go longer distances on a gallon of gas than less fuel-efficient cars. Similarly, people with a slow metabolism use the energy from their food very efficiently. They require fewer calories than do people with faster metabolic rates. The faster your metabolic rate, the more calories you require.

Regardless of your normal metabolic rate, having cancer and receiving treatment tend to increase the number of calories needed each day to maintain your body weight. It can be a challenging to keep up with the increased need for calories, especially if you are dealing with symptoms and side effects such as nausea, shortness of breath, mouth sores, altered taste, and/or decreased appetite. For these and other reasons, weight loss is common among people with lung cancer. Unintentional weight loss occurs when your body is not getting sufficient calories to keep up with energy demands. Weight loss indicates the body is in a negative energy balance. This means the body is using more energy than it is being taking in. The body cannot function optimally when there is a negative energy balance.

**COMPONENTS OF A HEALTHY DIET**

A healthy diet is one that provides the necessary calories and nutrients required to promote and maintain health. The United States Departments of Agriculture (USDA) and Health and Human Services (HHS) released a new food pyramid in 2005 as a guide to help adults eat a healthy, nutritious diet (see Figure 1). The new graphic is called “My Pyramid.”
The pyramid is divided into six food groups:

- **Grains** including bread, cereal, rice, and pasta (orange)
- **Fruits** (red)
- **Vegetables** (green)
- **Dairy** including milk, yogurt, and cheese (blue)
- **Meat & Beans including** meat, poultry, fish, beans, eggs, and nuts (purple)
- **Oils** including fats, oils, and sweets (yellow)

![Figure 1: USDA Food Guide Pyramid*](image)

*United States Departments of Agriculture and Health and Human Services

**Grains**

Grains include foods such as bread, cereal, rice, and pasta group. The foods in this group are called starches or *complex carbohydrates*. Complex carbohydrates are broken down into sugars by the digestive system.

Grains are divided into whole grains and refined grains. Refined grains have been milled and much of the fiber content removed. Whole grains have high fiber content. The USDA recommends that at least half of the grains you eat be of the whole grain variety.

Table 1 shows examples of foods from this group and the amount of each that equals one serving.
### Table 1: Foods and Servings from the Grains Group

<table>
<thead>
<tr>
<th>Food</th>
<th>Serving Size</th>
</tr>
</thead>
<tbody>
<tr>
<td>bagel</td>
<td>½ bagel</td>
</tr>
<tr>
<td>bread</td>
<td>1 slice</td>
</tr>
<tr>
<td>cooked oatmeal or grits</td>
<td>½ cup</td>
</tr>
<tr>
<td>cooked pasta</td>
<td>½ cup</td>
</tr>
<tr>
<td>cooked rice</td>
<td>½ cup</td>
</tr>
<tr>
<td>dinner roll</td>
<td>1 (small, approx. 2 inches across)</td>
</tr>
<tr>
<td>dry cereal</td>
<td>1 ounce (see package for the amount in cups)</td>
</tr>
<tr>
<td>English muffin</td>
<td>½ muffin</td>
</tr>
<tr>
<td>graham crackers</td>
<td>2 squares</td>
</tr>
<tr>
<td>saltine crackers</td>
<td>5 crackers</td>
</tr>
<tr>
<td>tortilla</td>
<td>1 (6 inches across)</td>
</tr>
</tbody>
</table>

Many people are surprised when they see the amount of food that equals one serving. Servings are usually much smaller amounts than expected.

Few of us weigh our food or measure it before eating. However, you can learn to judge the approximate number of servings by comparing the amount of food you are eating to common items. For example, a baseball is about the same size as one cup of food. Similarly, a half cup of food is about the size of a half baseball. Thinking in these terms, you can begin to judge the number of servings you are eating of various foods.

You will get the most nutrient value from the foods in this group if you follow this simple rule of thumb – the browner, the better. White flour is made from wheat that has been bleached. The bleaching process removes many of the natural nutrients. When buying bread, get whole wheat, multi-grain, rye, or another dark bread instead of white bread. Brown rice contains more nutrients than white rice. Similarly, whole wheat, rye, or other whole grain crackers are more nutritious than white crackers.

**Fruits and Vegetables**

Fruits and vegetables provide vitamins, minerals, sugars, and fiber. The USDA previously recommended numbers of daily servings are 2-4 servings of fruits and 3-5 servings of
vegetables. However, the new food pyramid makes recommendations based on your age, sex, and activity level (see www.mypyramid.gov).

A serving of fruit is:

- one cup of fresh cut fruit
- a medium-sized, round fruit such as an apple, orange, or peach (about the size of a baseball)
- ½ cup of canned or cooked fruit
- ¼ cup of dried fruit
- ¾ cup (6 ounces) of fruit juice

A serving of vegetables is:

- ½ cup of chopped raw vegetables
- ½ cup cooked vegetables
- 1 cup chopped leafy vegetables such as lettuce or fresh spinach
- ¾ cup (6 ounces) of vegetable juice

Two words to keep in mind to get the most nutrient value from fruits and vegetables are raw and colorful. Raw fruits and vegetables have more nutrients than cooked or canned produce. If raw fruits or vegetables are not available, frozen varieties have more nutrients than canned products. When planning meals and shopping for fruits and vegetables, think colorful. Eating a variety of different colored fruits and vegetables means you are getting a wide variety of nutrients.

Proteins: Meats, Beans, and Dairy Products

Protein in comes from two main sources, dairy products (milk, yogurt, and cheese) and the non-dairy protein (meat, poultry, fish, beans, eggs, and nuts). Proteins are the building blocks for all body tissues.

Table 2 shows foods in the dairy group and their serving sizes.

<table>
<thead>
<tr>
<th>Food</th>
<th>Serving Size</th>
</tr>
</thead>
<tbody>
<tr>
<td>cheese</td>
<td>1½ - 2 ounces (4 squares the size of dice)</td>
</tr>
<tr>
<td>cottage cheese</td>
<td>2 cups (16 ounces)</td>
</tr>
<tr>
<td>milk</td>
<td>1 cup (8 ounces)</td>
</tr>
<tr>
<td>yogurt</td>
<td>1 cup (8 ounces)</td>
</tr>
</tbody>
</table>
The non-dairy protein includes meat, poultry, fish, beans, eggs, and nuts. The beans in this group include kidney, navy, lima, and other dried beans. Green and yellow beans are not included because they are vegetables. Table 3 shows foods in the non-dairy protein group and their serving sizes.

**Table 3: Foods and Servings from the Non-Dairy Protein Group**

<table>
<thead>
<tr>
<th>Food</th>
<th>Serving Size</th>
</tr>
</thead>
<tbody>
<tr>
<td>beans (cooked)</td>
<td>½ cup</td>
</tr>
<tr>
<td>eggs</td>
<td>2 eggs</td>
</tr>
<tr>
<td>meat, poultry, and seafood</td>
<td>4 ozs. before cooking, 3 ozs. after cooking</td>
</tr>
<tr>
<td></td>
<td>(about the size of a deck of cards)</td>
</tr>
<tr>
<td>nuts</td>
<td>⅓ cup (a small handful)</td>
</tr>
<tr>
<td>peanut butter</td>
<td>4 tablespoons</td>
</tr>
<tr>
<td>soy milk</td>
<td>1 cup (8 ounces)</td>
</tr>
<tr>
<td>tofu</td>
<td>4 ounces</td>
</tr>
</tbody>
</table>

Your nutrient value from this group is maximized when you choose a variety of different foods. Lean meats are healthier than fatty meats such as sausage and bacon. Unsalted nuts are healthier than salted varieties. Eggs are a very good, inexpensive source of protein.

**Oils and Fats**

This food group includes cooking oils, fats in other foods, butter, margarine, and fats from snack foods. There are no recommended servings per day for foods in this group. The recommendation for disease-free adults is to include these foods sparingly in your diet. The reason for this recommendation is these foods often have little nutrient value but are usually high in calories. Particularly when you are having difficulty keeping up with your body’s nutritional needs, these foods can detract from your nutrition rather than helping. Snack foods satisfy hunger because they are high in calories, but they often do not provide your body with needed nutrients.

While most adults should limit their intake of foods from this group, people with cancer may be encouraged to increase their fat intake. Fats can help people with cancer keep up with their increased calorie needs. Fats provide a high number of calories in a small quantity of food. Try to make food choices that provide both calories and nutrients. If you are hungry
for something sweet, rather than eating candy you might try fruit, yogurt, pudding, or a milk shake. Roasted nuts, trail mix, dried fruits, and granola are good alternatives to snack foods such as potato chips, corn chips, or pretzels. The old saying, “You are what you eat” is true. Try to make sure every bite of food you eat provides your body with the nutrients and energy it needs.

**Customizing Your Diet to Meet Your Needs**

Each person with lung cancer is unique. Your diet should be customized to meet your special needs and circumstances. Factors to be considered when planning your diet include:

- your cancer treatment plan
- your current height and weight
- recent unintentional weight loss
- other illnesses such as diabetes, kidney problems, heart disease, and high blood pressure

People with cancer are often advised to increase their protein and fat intake. Proteins are important during treatment because they provide the building blocks for restoring normal tissues that have been injured as a side effect of therapy. Proteins are also essential for healing after surgery. If you have kidney disease, your protein intake may need to be closely monitored. Including more fats in your food preparation and selections can greatly increase your calorie intake without substantially increasing the amount of food you eat in a day. On the other hand, your fat intake may need to be limited if you have heart disease.

Your doctor will advise you about your diet. He or she may also refer you to a dietician or nutritionist to help with your dietary questions and needs. Dieticians and nutritionists are health care professionals who are experts on the relationships between nutrition, health, and disease. They advise people about their food intake to help promote good health and healing. A dietician can tell you how many calories you need each day and how to distribute those calories across the different food groups. Your diet may need to be adjusted several times during the course of your illness depending on where you are with your treatments and what symptoms you are experiencing.
Nutrition is very important. Doctors are good but it’s your body that has to do all the work. So when I was diagnosed, I immediately went to a nutritionist. I told him I needed to build up my immune system as much as possible. I took Vitamin C, E, and a whole bunch of things.* During chemotherapy, my blood levels never dropped and my doctors were amazed I did so well. They said it was like I never went through chemo. Right before surgery, my nutritionist gave me a booster shot. I came out of it just flying. I was out of the hospital within four days even [after they] had removed two sections of my rib.

–Joan, diagnosed with stage IIIB NSCLC in 1999 at age 60

*NOTE: It is important not to begin taking any vitamins or other supplements without first discussing it with your doctors.

MANAGING NAUSEA & VOMITING

Nausea and, much less commonly, vomiting can be associated with chemotherapy treatments for lung cancer. Health care providers refer to the nausea and vomiting that may be associated with chemotherapy as CINV (chemotherapy-induced nausea and vomiting). Many people have the idea that all chemotherapy causes severe nausea and vomiting. This is simply untrue. Not all chemotherapy drugs cause nausea and/or vomiting. Further, there are many highly effective drugs to prevent and control CINV. Nonetheless, you may experience occasional nausea and/or vomiting due to chemotherapy or other causes during the course of your illness. Persistent nausea and vomiting can substantially interfere with your ability to eat well.

Chapter 10: Supportive Care discusses medications used to treat nausea and vomiting. Following are some self-help techniques that may also help you manage nausea and vomiting, regardless of the cause.

- **Have someone else prepare your meals and bring them to you.**
  Cooking odors can lead to nausea. If friends or family would like to help you, ask them to bring prepared meals to your home. This is especially helpful on days when you are most likely to experience treatment-related nausea. Ask your doctor or nurse when this is most likely to occur as some nausea and vomiting is delayed for a few days after treatment.

- **Prepare meals ahead of time.**
  You can prepare meals ahead of time if someone else is not bringing your meals. Freeze single serving portions that can be easily reheated.
• **Do not eat for two hours before or after a chemotherapy treatment.**
  An empty stomach reduces the risk of nausea and vomiting.

• **Consuming ginger may help prevent nausea.**
  Ginger has been used to prevent nausea in many cultures for centuries. Studies have shown that ginger can help prevent nausea in some people, but it is not effective for everyone. Ginger is available in many forms including capsules, syrups, and teas. Talk with your cancer doctor or nurse if you are interested in trying this preventive technique. Ginger is unlikely to help if you are already nauseous or vomiting.

• **Acupuncture and acupressure at specific wrist points may help reduce nausea and vomiting.**
  According to traditional Chinese medicine, there is a point on the inside of the wrist (p6) that is related to nausea and vomiting. Stimulating this point has been shown in clinical trials to help prevent nausea and vomiting and improve the effectiveness of anti-nausea drugs in some people. While not effective for everyone, some people have experienced significant relief from this treatment. There are different ways to stimulate the p6 point including traditional acupuncture therapy, self-administered acupressure, and wristbands such as ReliefBands® and BioBands®. Talk with your cancer doctor or nurse if you are interested in trying acupuncture or acupressure. He or she can refer you to a qualified acupuncturist or put you in touch with someone who can help you find out more about these techniques.

• **Eat small amounts throughout the day rather than three large meals.**
  Filling and stretching your stomach increases the likelihood of nausea and vomiting.

• **Eat sitting up. Do not lie down immediately after eating.**
  A reclining position or lying down can cause food to back up into the esophagus (the tube between the mouth and the stomach). This back up can stimulate vomiting.

• **Eat slowly and chew your food well.**
Eating slowly helps decrease the amount of air swallowed with your food. A large amount of air stretches the stomach, which can trigger nausea and vomiting. Chewing your food well helps it move more quickly from the stomach into the intestines, which also decreases the risk of nausea and vomiting.

- **Eat easily digested, low fat foods.**
  The more quickly foods pass from the stomach into the intestines, the less likely they are to cause nausea and vomiting. High-fat foods stay in the stomach for many hours, which can provoke nausea and vomiting. Fibrous foods such as raw vegetables and seeds are also slow to digest. Uncooked fruits such as apples, oranges, grapefruits, and pineapples should probably be avoided during your most difficult days. Examples of low-fat, easily digested foods include baked crackers, pretzels, toast (unbuttered), soft breads, oatmeal, Cream of Wheat®, baked or boiled potatoes (without butter or sour cream), plain noodles, white rice, skinless chicken or turkey (white meat), mild soups, applesauce, canned peaches or pears, gelatin (Jell-O®), and freezer pops (Popsicles®).

- **Do not try to eat if you are feeling nauseous.**
  Eating will not make chemotherapy-induced nausea go away. It may actually cause vomiting. Wait until the nausea passes before trying to eat.

- **Avoid strong odors.**
  Any strong odor can stimulate nausea and vomiting. Avoid cooking odors and eating fragrant foods such as garlic, onions, peppers, horseradish, eggs, fish, broccoli, cabbage, cauliflower, and brussel sprouts. Perfumes and colognes can also be bothersome. Some people even find the fragrances added to soaps and detergents unpleasant. If this is a problem for you, try fragrance-free products. Do not be afraid to ask others spending time with you not to wear perfume or cologne.

- **Avoid greasy foods.**
  Greasy foods are hard to digest and stay in the stomach for extended periods, sometimes up to 12 hours. Foods to avoid include deep-fried foods, potato
chips, butter, salad dressing, peanut butter, nuts, milk, cheese, hamburger, bacon, sausage, and luncheon meats.

- **Avoid carbonated drinks.**
  Carbonated drinks such as soda pop, club soda, and carbonated water release gas that causes the stomach to stretch. This stretching may trigger nausea and vomiting.

- **Take small amounts of cold or frozen liquids to calm your stomach.**
  Small amounts of ice water, ice chips, iced tea, frozen ices, and sorbets can help calm an upset stomach. Mint teas can also be soothing.

- **Keep your mouth clean.**
  Keeping your teeth brushed and flossed can help get rid of bad tastes in your mouth that can lead to nausea and vomiting.

Cool yourself down if you are nauseous. Open the windows, turn on a fan, or go outside. Place an ice pack or cold cloth on your neck and/or forehead. Take slow, deep breaths. If you vomit, rinse your mouth with water and brush your teeth to get the taste out of your mouth. Do not eat or drink anything for at least 30 minutes to give your stomach a chance to settle down. If the nausea has passed after 30 minutes, try a small sip or two of water or a spoonful of ice chips. Wait 15 minutes before trying a little more water or ice chips. Continue this pattern of small amounts with breaks in between gradually increasing the amount you take in each time. If you are not nauseous after two hours, try eating one or two crackers. Stick with eating very small amounts. It is much better to take in small amounts for a few days than to try eating larger amounts and not keeping anything down.

*The main thing for me was to be able to conjure up enough patience to try to eat. When you’re nauseated, the last thing you want to do is try to eat. Even if I just tried to drink water, it would come right back up. I found that Popsicles™ were wonderful. They would just melt in your mouth. You didn’t need to chew and the cool liquid tasted good and went down slowly.* – Sue, diagnosed with stage III NSCLC in 1997 at age 48
MANAGING TASTE CHANGES AND LACK OF APPETITE (Anorexia)

Appetite and taste are closely related. The taste of food makes eating an enjoyable experience. When taste is diminished or other problems make eating difficult, the pleasure of eating and your appetite are often also reduced.

There are four basic taste sensations: sweet, sour, bitter, and salty. We sense the taste of foods with taste buds on the tongue. Taste and smell interact with one another. The smell of food enhances your sensation of taste.

Taste and appetite can be affected by cancer treatments in different ways.

- Chemotherapy drugs affect all rapidly dividing tissues of the body including the taste buds. Chemotherapy can lead to a temporary decrease in the number and activity of the taste buds. This results in altered or decreased taste sensation.
- Chemotherapy and radiotherapy to the head can affect the salivary glands causing decreased saliva (spit) production. A dry mouth decreases taste sensations and can make chewing and swallowing difficult.
- Chemotherapy and radiotherapy to the head can cause an overgrowth of yeast in the mouth and throat, a condition called thrush. Thrush can alter taste sensations and cause inflammation making it difficult to eat and swallow.

I used to just love Haagen-Dazs™ chocolate chip ice cream. Boy, did chemo cure me of that. About the only thing I found that tasted good was Campbell's™ chicken noodle soup. Everything else just tasted like pond scum.
–Judith, diagnosed with stage IIIB NSCLC in 2001 at age 60

Following are some self-help techniques that may help you manage taste changes and lack of appetite.

- Suck on a mint, lemon drop, or other hard candy during chemotherapy treatment to help relieve unpleasant tastes in your mouth.

Platinum-based chemotherapy drugs such as carboplatin (Paraplatin®) and cisplatin (Platinol®) and some other chemotherapy drugs used to treat lung cancer can cause an unpleasant taste in your mouth. The memory of this taste can interfere with appetite and eating.
• **Avoid bitter foods.**
  Some people on chemotherapy become very sensitive to bitter tastes. Beef and other red meats you once enjoyed may suddenly taste bad or spoiled to you. Non-bitter foods such as white chicken or turkey, mild fish, eggs, mild cheeses, peanut butter, and beans are good sources of protein if you cannot tolerate red meats.

• **Use herbs and spices to enhance the taste of foods.**
  Temporary decreases in the number of taste buds can reduce your ability to taste food. This can be at least partially overcome by adding more herbs and spices to your food. Be careful to avoid hot spices such as ground chili, curry, and pepper that can irritate your mouth. Large quantities of salt can also be irritating.

• **Try eating pleasantly fragrant foods.**
  Foods that have a pleasant smell can enhance your perception of taste because the sense of smell contributes to taste. Depending on what appeals to you, consider adding onions, garlic, basil, rosemary, thyme, vanilla, almond flavoring, wine, or other pleasant smelling ingredients to your foods.

• **If you are sensitive to food odors, try eating cold or room temperature foods.**
  While on treatment, some people find food odors unpleasant. Cold or room temperature foods may be easier to eat than warm foods because they emit less fragrance.

• **Make your food visually appealing.**
  Any good chef will tell you that part of the overall appeal of food is the visual presentation. Foods that look good are often more appetizing. Colorful foods arranged in a pleasing way on a plate may help increase your appetite.

• **If you have a metallic taste in your mouth, try using plastic eating utensils.**
  Some people who have a metallic aftertaste from chemotherapy find it very unpleasant to put a metal eating utensil in their mouth. Plastic utensils are an easy way to avoid this unpleasantness.

• **Keep your mouth clean.**
  Keeping your teeth brushed and flossed can help get rid of bad tastes in your mouth.
The mineral zinc is needed for normal taste bud function. Abnormally low levels of zinc are associated with decreased taste sensation. If a zinc deficiency is affecting your taste sensation, supplemental zinc may improve your ability to taste. Talk with your doctor if you are interested in trying a zinc supplement. You should not begin taking any supplements without first discussing it with your doctor.

MANAGING WEIGHT LOSS

Unintentional weight loss is a common symptom of lung cancer. Someone with lung cancer may lose weight for any of several reasons that often change over the course of the disease. Factors that contribute to unintentional weight loss can be disease- or treatment-related and include:

- substances produced by the cancer
- the body’s reaction to the cancer
- persistent coughing
- difficulty swallowing
- pain
- difficult, labored breathing
- mouth sores
- altered taste sensation
- nausea and/or vomiting
- diarrhea

Weight loss can be a troubling and persistent problem for people with lung cancer. In its most extreme form, weight loss can lead to a condition called cachexia. The hallmark of cancer cachexia is substantial weight loss that involves not only fat but also lean body mass, that is, the non-fatty tissues of the body such as muscle and bone. Cachexia is usually accompanied by loss of appetite (anorexia) and weakness. Chapter 10: Supportive Care has additional information about disease- and treatment-related weight loss.

Following are some suggestions that may help you avoid or decrease unintentional weight loss. A dietician or nutritionist should be consulted if you have ongoing weight loss.
• **Eat early in the day.**
  Your appetite is usually greatest at the beginning of the day. Take advantage of your appetite by making breakfast your largest meal of the day.

• **Eat whenever you are hungry.**
  Many of us were taught as children to eat at mealtimes and avoid between meal snacks. While this may be reasonable advice for people who are trying not to gain weight, it is not helpful for those dealing with weight loss. If you are having a problem with weight loss, eat whenever you are hungry. Do not wait for your usual mealtime.

• **Eat small amounts throughout the day.**
  It is often easier to eat several small meals throughout the day rather than three large meals. For example, try planning five or six small meals (eating every 2 to 2½ hours). Small meals can be less overwhelming than large meals and often result in consuming more food over the day than you would with larger meals. If you are hungry, eat small snacks between meals.

• **Eat calorie-rich foods.**
  Most of us are used to limiting the amount of high-calorie foods we eat. When you are losing weight, this limitation no longer applies. Try to be sure everything you eat or drink supplies your body with both calories and nutrients. You can add calories to your normal meals by adding gravies, using cooking oils liberally, substituting heavy cream for milk or water in recipes, and spreading butter on bread and rolls or melting it over vegetables. Although you want to eat calorie-rich food, avoid high-calorie foods such as candy that fill you up but do not provide many nutrients.

• **Try liquid or pureed meals.**
  Liquid meals may be easier and more appealing than solid foods if you are struggling to eat. Use a blender to make milk shakes and frozen fruit drinks. The protein content of these drinks can be greatly increased by adding powdered protein mix that can be purchased at most health food and nutrition stores. Vegetable drinks are usually not helpful for people losing weight because most vegetables are low in calories.
Some people find blending the contents of their meals and eating them as a thick soup is more appealing than solid food. For example, if you are having chicken and gravy, take the chicken off the bone and put it in the blender with the gravy to make a thick chicken soup. You can do this with almost any food. You may also want to try baby foods. They have the consistency of foods pureed in the blender without the extra preparation time.

- **Plan your own meals.**

  You know better than anyone else does what foods appeal to you. Many people receiving cancer treatment find their tastes and food preferences are different than they had been in the past. You may be hungry for foods you rarely ate in the past. On the other hand, you may find you can no longer tolerate foods you used to enjoy. Do not be alarmed by these changes; they are quite common. Eat whatever you are hungry for now. If others want to help by preparing meals for you, be sure to ask for foods you want to eat.

- **Avoid low-calorie foods and beverages.**

  When trying to maintain your weight, everything you eat should provide both calories and nutrition. Low-calorie or non-nutritious foods and drinks should be avoided. Examples of foods and beverages to keep to a minimum and some possible substitutions are shown in Table 4.

### Table 4: Low-Calorie Foods and Possible Substitutions

<table>
<thead>
<tr>
<th>Low-Calorie Foods</th>
<th>Possible Substitutions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Coffee†</td>
<td>latte, mocha, coffee-flavored milkshake</td>
</tr>
<tr>
<td>tea, soda pop</td>
<td>fruit juice, milkshake, fruit shake, whole milk, soy milk</td>
</tr>
<tr>
<td>skim milk</td>
<td>whole milk</td>
</tr>
<tr>
<td>broth-based soups</td>
<td>stews, creamed soups</td>
</tr>
<tr>
<td>plain cooked vegetables</td>
<td>vegetables with cheese or hollandaise sauce</td>
</tr>
<tr>
<td>plain raw vegetables</td>
<td>vegetables with peanut butter, cheese spread, blue cheese, or another salad dressing</td>
</tr>
<tr>
<td>vegetable salad</td>
<td>pasta salad or potato salad</td>
</tr>
</tbody>
</table>

† Large quantities of caffeine should be avoided because caffeine increases your metabolic rate leading to increased use of calories.
• **Limit the amount of low-calorie liquids you drink at mealtime.**
  Once your stomach sends the message to your brain that it is full, your appetite is turned off. This occurs whether your stomach is full of food or liquid. Limit the amount you drink with meals to increase the amount of high-calorie foods you consume. Sip on a high-calorie beverage after your meal or as a between meal snack.

• **Eat in a pleasant environment.**
  A pleasant environment can decrease the stress and pressure that can accompany mealtimes. A flower in a vase on the table, pretty tableware, enjoyable music, a lighted candle, eating outside on a sunny day, and dining with people whose company you enjoy are ways to increase the pleasure of mealtimes.

• **Try some light exercise before meals.**
  Exercise increases your appetite. Talk with your doctor or nutritionist about doing some light exercise such as walking or gentle calisthenics before meals.

• **Supplement your diet with high-calorie drinks.**
  Ready-to-drink, high-calorie protein beverages (Boost Plus®, Ensure Plus®, Resource Plus®, ProSure®, Sustacal Plus®, and others) can be a good source of calories and nutrition. These drinks come in many different flavors. You can drink them plain, over ice, or blended with fruit or ice cream. Special formulations are available for people who are diabetic or have kidney problems. Carnation Instant Breakfast® and Nestle Sweet® are less expensive drink mixes that can also be used to make nutritious drinks. Adding protein power will further boost the nutritional value of these drinks.

• **Take snacks with you when you are away from home.**
  It is important to eat whenever you are hungry, regardless of where you are. Examples of high-calorie, nutritious snacks you may want to take with you when you’re going to be away from home for several hours include trail mix, granola bars, dried fruits, nuts, and nutrition or energy bars (PowerBar®, Clif Bars®, Balance® Bars, Luna® Bars, and many others).
I was thin to begin with, so I wanted to make sure not to lose weight. I ate whenever I was hungry and indulged in everything fat-filled. I remember when the radiation made it so I couldn't even swallow my own spit, but I found I could eat watermelon, which was wonderful.
—Toni, diagnosed with limited SCLC in 1992 at age 39

Simple changes in food preparation can help you significantly increase your total calorie intake. For example:

- Use cream instead of milk on your cereal. Consider topping your cereal with nuts, coconut, and/or dried fruit.
- Substitute cream for milk or water in your recipes.
- Add extra cooking oil when preparing your meals.
- Use gravies and sauces in your meals.
- Add mayonnaise and cheese to your sandwiches.
- Use butter, cream cheese, or nut butters on your bread and rolls.
- Top desserts, pancakes, and waffles with whipped cream.
- Add honey or sugar to beverages.
- Avoid ‘light’ products that have reduced fat or sugar content.
- Add shredded cheese to casseroles, vegetables, and pasta dishes.
- Add powdered milk or eggs, or cream to casseroles, mashed potatoes, and soups.
- Dip fruits in whipped cream, honey, melted caramel, or another dipping sauce.

*Chapter 10: Supportive Care* has information about medicines and supplements that are sometimes used to increase appetite and prevent or reverse weight loss.

**MANAGING DIARRHEA**

Diarrhea is a common problem for people on chemotherapy. It interferes with good nutrition because food moves too rapidly through the intestines to be properly digested and absorbed. Chemotherapy drugs cause diarrhea by injuring the rapidly dividing cells.
that line the intestines. These drugs can also cause cramping belly pain, which decreases appetite.

The foods and beverages you eat can either aggravate diarrhea or help avoid it. Foods to avoid or limit if you have diarrhea include:

- **raw fruits and vegetables**
  Fibrous vegetables and fruits that contain natural laxatives can cause or significantly worsen existing diarrhea. All raw fruits and vegetables can have a laxative effect, but foods to be sure to avoid include celery, lettuce, cabbage, broccoli, brussel sprouts, spinach, cauliflower, asparagus, kale, corn, rutabagas, prunes, pears, peaches, pineapples, and rhubarb.

- **nuts and seeds**
  pepitas, sunflower, pumpkin, and sesame seeds)

- **large quantities of fruit juices and sports drinks** (Gatorade®, Powerade®, and others)
  These beverages can aggravate diarrhea because of their high sugar content. Apple, pear, and prune juice should be avoided because they act as natural laxatives. It is usually best to limit the amount of other fruit juices and sports drinks in your diet. If you want a small amount of one of these beverages, drinking it along with food or diluting it with water can help decrease the risk of diarrhea.

- **dairy products** (if you have an intolerance)
  Some people on chemotherapy develop a problem digesting milk products. This is caused by a temporary lack of the enzyme lactase that digests milk sugar. Dairy products can cause belly cramps, gas, and diarrhea in people with a lactase deficiency. These symptoms can be avoided by eliminating dairy products (milk, cheese, yogurt, ice cream, etc.) from your diet. However, dairy products are a good source of protein and a dairy-free diet can be a substantial change for many people. Rather than eliminating dairy products from your diet, you can take supplemental lactase when you eat dairy products. These products are
available over-the-counter and include brand name products such as Lactaid®, Dairy Ease®, Dairy Relief®, Lacteeze®, and others.

- **fats**
  Limit your fats (butter, cooking oils, margarine, etc.) until the diarrhea is under control.

- **large quantities of sugar**
  Any food with a high concentration of sugar can worsen diarrhea.

- **caffeinated coffee, tea, colas, and carbonated beverages**
  Caffeinated and carbonated drinks can stimulate the bowel, making diarrhea worse.

- **alcohol**
  Alcohol can irritate the lining of the bowel and increase the action of the bowel leading to worsening diarrhea.

- **foods containing sorbitol**
  *Sorbitol* is a natural sugar found in certain fruits such as prunes, pears, peaches, and apples. Sorbitol is a natural laxative and can significantly worsen diarrhea. It is also often used as a sweetener in reduced calorie chewing gum and candies. Generally, people with cancer should not consume reduced calorie products unless specifically advised to do so by their doctor or nutritionist.

- **extremely hot or cold foods**
  Extremes of temperature can increase the activity and cramping of the intestines. Slightly warm or room temperature foods are usually easier to digest than very hot or cold foods.

Foods to eat that can help slow or prevent diarrhea include:

- baked or boiled potatoes, and potato soup
- bean soups
- boiled carrots
- white rice, rice or oat porridge, and barley
- bread, bagels, and English muffins
- saltine crackers and pretzels
• dry cereals (not bran cereal)
• plain boiled pasta
• bananas (slightly green) and applesauce
• soy bean products such as tofu and soy milk
• non-fat or low-fat yogurt with active cultures
• tomato juice or mixed vegetable juice; add powdered soy to increase your protein intake
• baked chicken or turkey without the skin
• baked lean beef
• hard boiled eggs
• the spice nutmeg decreases the activity of the intestine; sprinkle it on your foods

Depending on the chemotherapy drugs you are taking, the severity of your diarrhea, and how the diarrhea responds to dietary changes, your doctor may prescribe medicines to help control your diarrhea.

MANAGING CONSTIPATION

Constipation is a common side effect of opioid pain medications (those related to morphine). Constipation can also be caused by lack of eating, decreased fluid intake, and lack of activity. Constipation interferes with good nutrition because fullness in the belly decreases or eliminates appetite.

The foods and beverages you eat can either aggravate constipation or help avoid it. One of the most important things you can do to avoid or recover from constipation is drink plenty of fluids – at least 8-10 glasses per day. Fruit juices and water are your best choices.

Other foods that help reverse or avoid constipation include:
• raw fruits and vegetables, especially those with skins and seeds such as plums, cherries, grapes, figs, strawberries, raspberries, blueberries, oranges, grapefruits,
carrots, corn, broccoli, cabbage, cauliflower, brussel sprouts, zucchini, lettuce, spinach, bok choy, and kale

• dried fruits, especially prunes, apricots, dates, and raisins
• fruit juices, especially prune and pear juice
• whole grain breads
• bran and whole grain cereals (Shredded Wheat®, All-Bran®, Bran Flakes®, and many others)
• brown rice
• whole grain pasta
• nuts and seeds (pepitas, sunflower, pumpkin, and sesame seeds)
• beans such as chick peas, lentils, kidney, navy, black, and limas beans

Foods to avoid when your bowels are inactive because they can cause or worsen constipation include:

• cheese, milk, and other dairy products
• large amounts of meat
• eggs
• high fat foods
• applesauce
• bananas
• white rice
• white breads
• chocolate

Warm or hot fluids are helpful, especially in the morning and at the beginning of meals. Exercise is also important to keep the bowels moving. Talk with your doctor about a gentle exercise program if you are not currently getting regular exercise.

When you feel the urge to move your bowels, go to the bathroom right away. Waiting to go can cause excessive water to be absorbed from the bowel contents leading to constipation.
Prevention of constipation is usually the best treatment strategy. Your doctor may put you on a regimen of stool softeners and/or laxatives to prevent constipation if you have had problems with constipation or are taking opioid pain medications. If constipation develops and does not resolve with dietary changes and other treatments, an enema may be needed. Contact your doctor if you are having a problem with constipation. The longer the problem persists, the more difficult it can be to treat.

**MANAGING MOUTH & SWALLOWING PROBLEMS**

Chemotherapy and radiotherapy to the head or chest can irritate the lining of the mouth, throat, and esophagus. This irritation can make eating and swallowing difficult, interfering with good nutrition. Irritation of the mouth lining is called *stomatitis* or *mucositis*; irritation of the esophagus is called *esophagitis*. Chapter 10: Supportive Care has additional information about the development and symptoms of stomatitis and esophagitis.

Good mouth care is very important if you have mouth soreness. Tips for good mouth care include:

- Brush your teeth at least four times per day. Floss at least twice per day.
- Use toothpaste with fluoride to help protect your teeth. If commercial toothpaste burns your mouth, use a solution of ½ teaspoon of salt and 2 tablespoons of baking soda in 8 ounces of warm water instead of toothpaste.
- Use a soft or extra-soft toothbrush to avoid small abrasions of the mouth and gums. Children’s toothbrushes are usually extra-soft.
- Apply fluoride gel to your teeth at bedtime.
- Rinse your mouth with a solution of ½ teaspoon of salt and 2 tablespoons of baking soda in 8 ounces of warm water at least 4-6 times per day. Follow the solution with a clear water rinse.
- Be sure to brush your teeth and rinse your mouth after eating foods or liquids with high sugar content.
- Keep your lips moist with lip balm or petroleum jelly. Do not share these items with other people as they can spread infections.
Following are some suggestions that can help make eating easier when you have a sore mouth and/or throat. Call your cancer care provider right away if the pain from these problems becomes so severe that you are unable to eat or drink.

- Avoid spicy foods that may increase the burning sensation in your mouth or throat. Spices such as ground pepper, chili, curry, mustard, and others can be particularly irritating.
- Avoid carbonated beverages, orange juice, grapefruit juice, and acidic foods such as citrus fruits, vinegar, salad dressings, pickled foods, ketchup, steak sauce, barbeque sauce, and Worcestershire sauce.
- Avoid salty foods that can dry your mouth and lips.
- Avoid very hot liquids or foods that could burn your mouth, tongue, or throat.
- Avoid alcohol in beverages, foods, or other products such as mouthwash or fluoride rinses. Alcohol will cause burning and may increase the severity of mouth sores and throat irritation.
- Avoid eating foods with sharp edges that may scratch your mouth or throat such as potato chips, hard breads, crackers, and granola.
- Eat foods that are soft, moist, and easy to chew. Yogurt, oatmeal, grits, rice, pasta, potatoes, yams, applesauce, pudding, cooked carrots, peas, cheeses, eggs, soups, stews, and casseroles are a few examples.
- Use a blender to puree foods to make them easier to swallow. This is especially helpful for vegetables. Baby foods can be a good alternative to solid foods.
- Use a straw to drink liquids and pureed foods. Using a straw bypasses much of the mouth and tongue avoiding further irritation.

**FOOD SAFETY**

Lung cancer and its treatments are often associated with an increased susceptibility to infections. The immune systems of people with cancer often do not function as effectively as they normally would. This is especially true for people who are on chemotherapy drugs that reduce the number of white blood cells in the circulation. Because cancer can reduce the immune system’s ability to fight infections, you need to take measures to decrease your risk of exposure to infectious agents.
Eating is one route by which infectious particles can enter the body. Simple food safety measures can significantly reduce your risk of infections from food.

- Wash your hands thoroughly with soap and water before and after handling food. Rub your hands together with soap for at least 15 seconds. Use a nailbrush to clean thoroughly under your nails especially if you have long fingernails.

- Keep uncooked meat, fish, and poultry separate from your ready-to-eat foods in the refrigerator. Be sure to wash your hands with soap and water before handling or eating ready-to-eat foods, especially if you have touched uncooked meat.

- Thoroughly wash any utensils used on uncooked meat, fish, or poultry before using them on other foods. Use dish soap in hot water and a thorough hot rinse, or a dishwasher to clean dirty utensils. Cutting boards must also be thoroughly cleaned between uses. Glass or acrylic cutting boards are easier to keep clean than wood cutting boards.

- If you are barbequing or pan-frying meat, use a clean utensil to remove the cooked meat. Reusing the same utensil used to put the uncooked meat into the pan or over the coals may contaminate the cooked meat with bacteria from the uncooked meat.

- Cook meat, fish, and poultry thoroughly. A meat thermometer is helpful when cooking large pieces of meat to be sure the inside reaches the proper cooking temperature.

- Do not eat raw fish (sushi) or shellfish such as oysters.

- Refrigerate cold foods from the store as soon as possible.

- Keep your refrigerator temperature at or below 40° F.

- Check the expiration date on all food items. Never eat something after its expiration date.

- Do not eat uncooked dough or batter that contains eggs.

- Do not put raw eggs into salad dressings or blended drinks that will not be cooked before eating.
• Avoid eating uncooked foods you have not prepared yourself such as sushi and foods from restaurant salad bars. Food from street vendors should also be avoided.

• If you are getting ice cream from a vendor, hard ice cream is less likely to be contaminated with disease-causing bacteria than soft-serve ice cream.

• Do not keep cooked foods at room temperature for more than two hours before refrigerating. If the food has been out for more than two hours, throw it away.

• Do not eat any food with mold on it, even if it appears to be in just one area that can be cut off. Throw it away.

• Wash fresh fruits and vegetables thoroughly before eating. Many people wonder if soaps or commercially available products are needed to wash fresh fruits and vegetables. The United States Department of Agriculture, Environmental Protection Agency, and Food and Drug Administration are the three federal agencies involved in food safety activities. All three recommend washing fresh fruits and vegetables in plain water without soap or other products. Turn the tap water on and allow running water to pour over the item while rubbing the outside gently with your fingers. Remove stems that may be present and thoroughly rinse the stem area. Dry the item with a clean, dry towel. Use a vegetable brush to wash the outside of items with tough skins such as carrots, potatoes, and yams. Remember to keep your vegetable brush clean by regularly rinsing it with boiling water or running it through your dishwasher. Be sure to wash melons even though you do not eat the outside. Bacteria from the outside of the melon can contaminate the inside when you cut through the fruit. Lettuce, spinach, and other leafy vegetables can be rinsed using a salad spinner that removes excess rinse water. Wash your spinner between uses.

• Once you have cut a piece of fruit or a vegetable, store the unused portion in the refrigerator.

• Avoid eating uncooked alfalfa or bean sprouts. It is difficult to clean these vegetables thoroughly.

• Do not eat unpasteurized dairy products.
Many people with lung cancer wonder if there are certain foods, herbs, vitamins, minerals, or other nutritional supplements that will increase their chance of recovery from lung cancer. Numerous products and nutrition books are available recommending different supplements and dietary plans to people with cancer. These numerous products and recommendations leave many people wondering what to do.

The human body is complex. Determining the effectiveness of various practices, supplements, and medicines on specific diseases is also complex. Clinical trials are carefully designed scientific studies that are carried out in a very specific way to answer questions about the safety and effectiveness of medical treatments. Reports about the effects of medical treatments outside clinical trials are called anecdotes. Anecdotes report the use of treatments and the course of an illness, but an anecdotal report cannot determine if the course of the illness is related to the treatment. Only a clinical trial can determine if a specific treatment is related to a specific outcome. Treatments that have not been studied in clinical trials may or may not be effective – we simply have no way to know for sure. Chapter 8: Clinical Trials has additional information about clinical trial design and participation.

Studies have shown that many different dietary factors and supplements may have a protective effect in terms of preventing lung cancer (see Table 5). However, there is no evidence from scientifically designed clinical trials to show that specific dietary habits or nutritional supplements influence prognosis or treatment outcome once lung cancer has developed.
Table 5: Dietary Factors and Nutritional Supplements That May Help Prevent Lung Cancer

<table>
<thead>
<tr>
<th>Dietary Factors</th>
</tr>
</thead>
</table>
| beta-carotene\[
\] and carotenoids\[18, 23\]               |
| carrots\[13\]                               |
| dark green leafy vegetables\[12\]             |
| diets rich in fruits and vegetables\[10, 19, 21\] |
| flavonoids\[15, 17\]                         |
| folate\[16, 23\]                            |
| glutathione\[18\]                           |
| margarine\[13\]                             |
| plant sterols\[22\]                         |
| selenium\[11\]                              |
| soy\[14\]                                   |
| vitamin C\[16, 23\]                         |

**KEEPING YOUR NUTRITION IN PERSPECTIVE**

There is no question that adequate nutrition is important for good health. Your body must get sufficient calories and nutrients to function properly. However, nutrition sometimes becomes a source of anxiety for people with lung cancer. Having lung cancer can leave people feeling helpless at times. Some find focusing on their nutrition helps relieve the sense of helplessness by giving them something to actively work on. The same can be true for family members. They want to help you get better and may start making food to encourage you to eat. In some cases, the whole family can become preoccupied with your eating habits and nutrition. While good nutrition is important, an intense preoccupation with eating can become burdensome and stressful. The anxiety associated with the pressure to eat can backfire.

I had lots of pressure to eat. The more everyone tried to get me to eat, the worse I felt about eating. John [her husband] kept cooking all these meals and I just couldn't handle the smell of them. I wouldn't eat them – then he would get discouraged, and I just kept feeling worse. Finally, I just had to tell him to stop. As long as I would drink Ensure\textsuperscript{TM}, that was okay. But it was hard with everyone being so concerned about me eating. Once people stopped pushing me to eat all the time, it got better.

—Joanne, diagnosed with stage IIIA NSCLC in 2001 at age 52
Do your best to eat nutritious foods that support your body functions. At the same time, do not be too hard on yourself if you struggle at times with your eating. Many factors influence your appetite and ability to eat a healthy diet during the course of lung cancer. Like most other experiences in life, you will probably have good days and not-so-good days when it comes to eating. Just do the best you can. Based on everything we know to date, nothing you eat or do not eat is going to determine the long-term outcome of your illness. Remember, nutrition is just one part of your overall cancer treatment plan.

**SUMMARY**

Food is your body’s source of energy and building materials. Good nutrition is needed for your body to function properly. Lung cancer and its treatments increase the energy and nutritional demands of your body but can also interfere with eating. Many different food options and self-help tips can make it easier to get good nutrition when you have eating difficulties. Medications can also be used to treat symptoms, making good nutrition easier and more pleasant.

Discuss eating and nutrition problems with your cancer care team. A dietician or nutritionist can help you customize an eating plan that meets your specific needs. Do your best to eat a nutritious diet without becoming burdened by an intense preoccupation with food.

Eating is one of the pleasures we all share. We hope the information provided in this chapter helps you enjoy healthy eating.
CHAPTER 13: MANAGING YOUR HEALTH CARE

INTRODUCTION

Most of us are unfamiliar with the internal workings of the health care system and health insurance providers until we need to use them. This chapter provides basic information about the health care system and how to get the best possible care available. Information is a powerful tool for planning and obtaining good health care. Gaining an understanding of the topics in this chapter will help you explore your options, ask focused questions, and make informed decisions.

BEING AN INFORMED HEALTH CARE CONSUMER

The health care system is a service industry. You are a consumer of the services offered. Informed health care consumers know what they need and how to get it. One of the first steps toward ensuring the best possible care is educating yourself. You will be in the best position to find optimum health care that suits your needs and preferences if you are knowledgeable about lung cancer, the health care system, and your rights as a health care consumer.

The health care system is complex and can be confusing. During the course of your illness, you will meet new people, hear new language, and have new experiences. The newness and complexity of the health care system can seem overwhelming at first. But like anything else, once you become familiar with it, it becomes manageable. Learning the ins and outs of the systems you need to utilize helps ensure you receive the best possible care.

People newly diagnosed with lung cancer are often amazed at the medical knowledge and ease with which others talk about their illness. Rest assured, after a surprisingly short period of time, you will be doing the same.
Gathering Information About Lung Cancer

You can take an active role in obtaining good health care by seeking information and educating yourself. Unless you work in a medical profession, you probably had little knowledge about lung cancer before your diagnosis. Learning about lung cancer is important because it will help you:

- gain a sense of control over the situation you are currently facing
- make treatment decisions
- understand and manage your symptoms
- plan for the future

The more you know about your disease, the less confused and anxious you are likely to feel about your treatment. Reading this book, you have already taken an important step in educating yourself about lung cancer. Many resources are available to add to the knowledge you have already gained.

Your Cancer Care Team

A good place to start gathering information is from the members of your cancer care team. Following is a list of commonly asked questions you might consider asking your doctor or nurse. You may have many other questions of your own. Remember, there is no such thing as a stupid question. If you want to know something, ask.

Questions About Your Diagnosis and Treatment Options

- In non-medical terms, what is wrong with me?
- Is it certain, without any doubt, that I have lung cancer?
- What specific type of lung cancer do I have?
- What is the stage of my disease?
- What are the best treatment options for my stage of disease?
- What treatments do you recommend?
- What are the benefits of the treatment(s) you are recommending?
- Are there any risks or side effects associated with the treatment(s) you are recommending? What are they?
• Are there other treatment options?
• What are the benefits of the other treatments? What are the possible risks and side effects?
• Are there treatments available for my condition that are popular, but not approved by the Food and Drug Administration? If so, why have they not approved? What do you think of them?
• How will treatment most likely affect the course of my disease?
• What is likely to happen if I do not take treatment?
• Would another institution be able to offer me more treatment options?
• Are there clinical trials that might be appropriate for me?

**Questions About A Specific Treatment Plan**

• What doctors and specialists will be involved in my treatment?
• Who will coordinate my overall care?
• Whom should I contact with questions about my treatment or if I experience a problem?
• What is the goal of my treatment? (cure, pain control, symptom control, enhanced quality of life, etc.)
• How can I expect my life to change during treatment and how should I plan for this?
• Will I be able to work during treatment?
• Will I be able to care for my family during treatment?
• How long will treatment last?
• What is the treatment schedule?
• Can I schedule treatments around my work schedule, special dates, or other events?
• Can I drive myself home after a treatment?
• How long do I need to rest after a treatment session before I can return to work or other activities?
• How will you know if the treatment is working?
• What are the names and dosages of the medications I will be taking?
• What does each medication do?
• What should I do if I miss a dose of one of my medicines?
• What are the side effects of treatment?
• What can be done to control side effects?
• Are there any types of clothes I should avoid wearing?
• Are there foods or liquids I should plan to eat or avoid?
• What costs will I incur from this treatment?

Questions About Care After Treatment Is Completed
• After treatment ends, how often will I need follow-up visits and what will these consist of?
• How will I be monitored for recurrence of my disease or disease progression?
• Are there any specific signs or symptoms I should look for that may indicate disease recurrence or progression?

Every appointment with your cancer care provider is an opportunity to get answers to questions you may have. It is helpful to organize your thoughts ahead of time since the length of your visit will be limited. Writing your questions down is a good idea. It helps organize your thoughts and prioritize your questions. Put your two or three most important questions at the top of the list.

When you meet with your doctor, hand him or her your list of questions. He or she may see something on the list that is more important than you realized – something that could indicate a problem requiring immediate attention. You may want to give the list to your doctor ahead of time so she or he can be prepared, especially if your question list is lengthy.

You can talk with your oncology nurse or nurse practitioner if your doctor does not
have time to answer all your questions or if you are uncomfortable asking the doctor some of your questions. Oncology nurses are very knowledgeable and can often answer questions about your treatment and care. Most oncology nurses are easy to approach and go out of their way to make sure you get the information you need as quickly as possible. Other members of your cancer care team such as nutritionists, pharmacists, rehabilitation therapists, radiation therapists, and others are also good sources of information. You may want schedule an extra visit with your doctor if you need more time to get your questions answered.

Your cancer care team may have patient education materials in the form of pamphlets, brochures, videotapes, and books. These materials cover many different topics of interest to people with cancer. Ask about other sources of information if the materials available in your oncologist’s office are not sufficient to meet your needs.

**National Cancer Institute Resources**

The National Cancer Institute (NCI) is another good resource for information on lung cancer. The NCI Internet site at [www.nci.nih.gov](http://www.nci.nih.gov) has extensive information about lung cancer, its treatment, and related issues including:

- diagnosis
- staging
- treatment
- coping with cancer
- treatment side effects
- clinical trials
- lung cancer statistics
- medical terminology dictionary
- cancer literature
- cancer support groups
- emotional concerns
- finances
- hospice care
- resources for people with lung cancer and their caregivers
One feature of the NCI site is the Physician Data Query or PDQ. PDQ is an NCI database that contains the latest information about cancer treatment, screening, prevention, genetics, and supportive care. There is also a searchable database of active clinical trials. PDQ cancer information summaries are reviewed monthly by cancer care experts. They are updated as needed based on recent developments in cancer care.

CancerFax® makes portions of PDQ and other NCI information available to the public via a fax-back document delivery system. Selected information is available in Spanish. CancerFax® contains:

- PDQ full-text summaries on cancer treatment, screening, prevention, genetics, and supportive care
- fact sheets on current cancer topics
- topic searches from the CANCERLIT (cancer literature) database

CancerFax® can be accessed with a touch-tone telephone or fax machine with a telephone handset. Call 800-624-2511 and follow the voice prompts to receive the information you need.

CancerMail uses e-mail to access the same information available through CancerFax®. To access CancerMail, send an email message to cancermail@cips.nci.nih.gov with the word "help" in the body of the message. A contents list and instructions will be e-mailed back to you.

All the information available on NCI’s Internet site is also available through the Cancer Information Service (CIS).

The Cancer Information Service is NCI's link to the public, interpreting and explaining research findings in a clear and understandable manner. Through a network of 14 regional offices located throughout the country, the CIS serves the entire United States, Puerto Rico, and the U.S. Virgin Islands.

To receive a personalized response to your specific questions about cancer, we encourage U.S. residents to call the Cancer Information Service (CIS) at 800–4–CANCER (800–422–6237) Monday through Friday from
9:00 AM to 4:30 PM local time to speak with a Cancer Information Specialist. Deaf and hard of hearing callers with TTY equipment can call 800–332–8615. Callers also have the option of listening to recorded information about cancer 24 hours a day, 7 days a week.1

Free NCI publications can be requested by calling CIS, or can be viewed or ordered from the CIS Internet site at www.cissecure.nci.nih.gov/ncipubs.

From either the NCI or CIS Internet homepage, you can receive live, online help through a service called Cancer.gov LiveHelp. LiveHelp can assist you with general cancer questions or provide assistance in navigating the NCI Internet sites. LiveHelp is available Monday through Friday from 9 AM to 10 PM (Eastern Time).

Other Lung Cancer Information Resources
Medical journal articles are good sources of information for the latest in lung cancer research and treatments. However, the information is written in technical language that may be difficult to understand. Members of your treatment team may be able to suggest or provide articles you might be interested in reading. If your treatment team cannot provide you with the materials you are interested in, they can direct you toward where to look for them. A hospital librarian can also help you locate relevant material.

Support groups are another source of information. Talking to others who have been through treatment can help you to gain a better understanding of what to expect before you begin. Your oncology nurse or social worker may be able to help you locate established support groups in your area.

Cancer Care is a non-profit organization that offers a variety of cancer education materials for people living with cancer. Their educational programs include live and previously recorded teleconferences, lung cancer lectures that can be viewed over the Internet, and a variety of downloadable and preprinted materials. For information

1 From the National Cancer Institute Cancer Information Service Internet site at http://cis.nci.nih.gov/index.html.
about CancerCare’s educational programs and materials, visit their Internet site at 
www.cancercare.org/EducationalPrograms/
EducationalProgramsMain.cfm, or call toll-free at 800-813-HOPE (4673).

Lung Cancer Online is an Internet clearinghouse of information about lung cancer. 
The site was created by a lung cancer survivor. It is a gateway to lung cancer 
resources for the benefit of people with lung cancer and their families. It is intended 
to facilitate the time consuming and often-frustrating process of learning about lung 
cancer, treatment options, and support services. The Lung Cancer Online site can 
be found at www.lungcanceronline.org.

There are many other informative books, Internet sites, and literature from various 
organizations that address lung cancer and related cancer care issues. The Resource 
Directory at the end of this book has contact information.

Patients’ Rights
As a health care consumer, you have the right to speak out on your own behalf to ensure 
you receive quality health care. This right applies to all health care consumers regardless of 
the source of payment for services. Whether you have fee-for-service health care insurance, 
are a member of a health maintenance organization (HMO), are insured by Medicare, or are 
uninsured – you have a right to receive quality health care.

In November 1997, then president William Clinton established the Advisory Commission on 
Consumer Protection and Quality on the Health Care Industry. The Commission was co-
chaired by the Secretary of Health and Human Services and the Secretary of Labor, and was 
comprised of 34 members including consumers, business owners, labor leaders, health care 
providers, health plan representatives, and health care quality and financing experts. The 
Commission issued the Patients' Bill of Rights and Responsibilities. The Commission's final 
report, "Quality First: Better Health Care for All Americans," was issued in March 1998.²

² The complete report is available online at www.hcqualitycommission.gov/final.
The Patients' Bill of Rights and Responsibilities has three goals: to strengthen consumer confidence that the health care system is fair and responsive to consumer needs; to reaffirm the importance of a strong relationship between patients and their health care providers; and to reaffirm the critical role consumers play in safeguarding their own health. While the Commissions’ recommendations are not legally binding, they express the collective wisdom of some of the nations' leading health care stake-holders. The Patients’ Bill of Rights and Responsibilities outlines seven sets of rights and one set of responsibilities:

**The Right to Information** — Patients have the right to receive accurate, easily understood information to assist them in making informed decisions about their health plans, facilities, and [health care] professionals.

**The Right to Choose** — Patients have the right to a choice of health care providers that is sufficient to assure access to appropriate high-quality health care including … giving patients with serious medical conditions and chronic illnesses access to specialists [such as oncologists, pulmonologists, and thoracic surgeons].

**Access to Emergency Services** — Patients have the right to access emergency health services when and where the need arises.

**Being a Full Partner in Health Care Decisions** — Patients have the right to fully participate in all decisions related to their health care. Consumers who are unable to fully participate in treatment decisions have the right to be represented by parents, guardians, family members, or other conservators.

**Care Without Discrimination** — Patients have the right to considerate, respectful care from all members of the health care industry at all times and under all circumstances. Patients must not be discriminated against in the marketing or enrollment or in the provision of health care services, consistent with the benefits covered in their policy and/or as required by law, based on race, ethnicity, national origin, religion, sex, age, current or anticipated mental or physical disability, sexual orientation, genetic information, or source of payment.
The Right to Privacy — Patients have the right to communicate with health care providers in confidence and to have the confidentiality of their individually-identifiable health care information protected. Patients also have the right to review and copy their own medical records and request amendments to their records.

The Right to Speedy Complaint Resolution — Patients have the right to a fair and efficient process for resolving differences with their health plans, health care providers, and the institutions that serve them, including a rigorous system of internal review and an independent system of external review.

Taking on New Responsibilities — In a health care system that affords patients rights and protections, patients must also take greater responsibility for maintaining good health.

In recent years, most states have passed legislation addressing specific aspects of patients’ rights, especially with respect to members of health maintenance organizations. Several federal patients’ rights bills have been introduced. However to date, the bills have failed to pass both Houses of Congress. Many health care professional organizations and patient advocacy groups continue to push for a federal Patient Bill of Rights to establish minimum standards for all health care insurance plans.

Informed Consent

Your doctor is responsible for providing you with enough information about your treatment options for you to make an informed decision about what treatment you want to pursue. Your doctor cannot legally perform any non-emergency procedure on you without having a signed consent form.

Informed consent has several purposes. It specifies your doctor’s responsibility to explain:

- what the treatment or procedure involves
- what the likely effects will be
- possible side effects and complications
• why the treatment or procedure is being done
• the expected outcomes with and without the treatment or procedure
• alternatives to having the treatment or procedure

When you sign a consent form, you are indicating you understand all the information listed and give your consent to proceed with the treatment or procedure. Take the time to read the informed consent form carefully. If there is anything you do not understand or do not agree with, discuss it with your doctor. You do not have to sign the consent form if you are uncertain about a recommended treatment or procedure. You always have the right to refuse a treatment or procedure. You may want to take more time to investigate and consider your options. If you decide later that you want to go through with the treatment or procedure, you can reschedule it.

YOUR CANCER CARE TEAM

Quality lung cancer care requires a team of dedicated, expert, cancer care providers. Your cancer care team will include many different health professionals from a variety of health care fields. Each member of your cancer care team plays a critical role in your treatment. Depending on the treatments you decide to pursue, your cancer care team may include many or all of the following health care professionals.

dietician: a specialist trained to assist in determining dietary needs and planning; also called a nutritionist
dosimetrist: a person who determines the proper radiation dose for treatment
medical oncologist: a doctor who specializes in the non-surgical treatment of cancerous and non-cancerous tumors; he or she usually leads the treatment and supportive care team
oncology nurse: a nurse who specializes in the care and treatment of people with cancer; there may be one or more oncology nurses on your treatment team
oncology advance practice nurse (APN): an oncology nurse who has at least a master's degree and has participated in specialized education and training in the
treatment of cancer; advance practice oncology nurses are usually called oncology nurse practitioners or clinical nurse specialists; oncology APNs work with oncology doctors, but also often work independently

 pathologist: a doctor who specializes in disease diagnosis through analysis of body fluids and tissues; examines tissues under a microscope to determine the presence of cancer cells

 pharmacist: professional trained to prepare and dispense medications

 primary care provider: medical professional responsible for an individual’s overall care; may be a family physician, internist, gynecologist, or nurse practitioner

 pulmonary rehabilitation specialist: a pulmonologist who specializes in rehabilitating people with lung diseases including lung cancer

 pulmonologist: a doctor who specializes in the diagnosis and treatment of non-cancerous lung disorders; often the specialist recommended for people with lung symptoms; frequently the specialist who diagnoses lung cancer

 radiation oncologist: a doctor who specializes in the use of radiation therapy to treat cancer

 radiation physicist: a professional trained in the clinical uses of radiation therapy; the person who makes sure the radiotherapy equipment is working properly and delivering the correct radiation dose

 radiation technologist or therapist: a technician who prepares and positions people for radiation therapy treatments and runs the equipment that delivers the radiation

 radiation therapy nurse: a nurse who provides care and information about radiotherapy, including how to manage radiation side effects

 radiologist: a doctor who specializes in the use of x-rays and other forms of radiation to diagnose and treat disease

 social worker: a person trained to help people deal with the emotional aspects of having a disease; assists patients in accessing medical, social, financial, and supportive services; oncology social workers specialize in working with people living with cancer

 surgeon: a doctor who specializes in the treatment of disease by surgical operations

 thoracic surgeon: a surgeon who specializes in operations involving the chest including lung surgery
My oncology nurses were certainly very well trained and they always made me feel comfortable. But I felt closer to my radiation team. I got to know the technologists very well since I saw them every day for 28 days. They were very kind, helpful, and they were always happy to answer any questions I had. In fact, they encouraged me to ask questions.

– Barbara, diagnosed with stage IB NSCLC in 2000 at age 56

**Physician Qualifications**

As a health services consumer, you have the right to choose your health care providers. Your cancer care team will help you make decisions that greatly affect your life. It is important to feel comfortable with your providers and confident about the quality of care they provide. You are hiring health care providers to work with you to accomplish the goals you set forth.

Studies have shown the level of experience of both doctors and institutions where you receive health care for lung cancer affects procedure and treatment outcomes. It is important to have health care providers who are skilled and experienced in the treatment of lung cancer. One way to assess a doctor’s skills are to check his or her credentials.

**Medical Licensure**

Most doctors in the United States treating people with cancer are *allopathic physicians*. Allopathic physicians (doctors) have earned a medical doctor or MD degree. The education and training for an MD includes four years of premedical education at a college or university, four years of medical school to earn their degree, and 3-7 years of postgraduate education and training (a residency) in a specific medical specialty. Doctors must pass a licensing exam to practice medicine in their state. Each state or territory has its own requirements for licensing doctors. You can check to make sure your doctor is licensed by calling your state medical licensing board.

**Board Certification**

Doctors who have completed their residency training in a specific medical specialty can opt to become board-certified in that specialty. Independent specialty boards (unaffiliated with state medical licensing agencies) certify doctors if they fulfill specific requirements. In general, requirements include having a valid medical
license, meeting specific educational and training criteria, and passing an examination given by the specialty board. Doctors who pass the exam and meet the other requirements become board-certified in their specialty. They are then considered a diplomate of the specialty board. Board-eligible doctors have the required education and training to take the specialty board exam, but have not yet done so.

There are 24 medical specialty boards recognized by the American Board of Medical Specialties (ABMS) and the American Medical Association. Many of these specialty boards also have subspecialty exams. To be eligible for a subspecialty exam, the doctor must first be board certified in the umbrella specialty. ABMS boards of interest to people with lung cancer include:

- American Board of Internal Medicine; subspecialties include:
  - medical oncology
  - pulmonary diseases
- American Board of Pathology
- American Board of Radiology; subspecialties include:
  - diagnostic radiology
  - radiation oncology
  - radiologic physics
- American Board of Surgery
- American Board of Thoracic Surgery

**Professional Medical Society Membership**

Membership in professional medical specialty societies is another benchmark of expertise for a doctor. There are different requirements for membership in various professional medical societies, but they all require verification of specific education and training. Many medical societies have different levels of membership. Generally, fellowship in a professional society indicates a higher level of professional achievement than regular membership. Some societies offer the distinction of mastership to a few members who have achieved superior accomplishments in their field. A sample of professional medical societies for physicians of interest to people with lung cancer includes:
Many public libraries have guidebooks such as the American Medical Directory, Directory of Medical Specialists, and Top Doctors of America that may be good sources of information on specialty physicians.

Choosing Your Doctors

Assembling your cancer care team usually begins with selecting a medical oncologist who will coordinate your care. Finding a medical oncologist may begin with a referral from your primary care doctor or pulmonologist. You may also want to ask other people with lung cancer or other health care professionals for referrals to medical oncologists, thoracic surgeons, and radiation oncologists. Cancer survivors can be very helpful because they have been in your situation. Health care professionals can supply useful information based on their knowledge of other providers in your area. Be aware that some health care professionals may not feel comfortable criticizing one of their colleagues. If the person you are speaking with seems uncomfortable, vague, or unenthusiastic about another professional, this may suggest an unspoken concern. It is important to have people on your cancer care team who specialize in lung cancer.

Local hospitals often have a patient referral service, as do some local medical societies. Many other resources are available for finding doctors to treat your cancer including:

National Cancer Institute

- Cancer Information Service at 800–4–CANCER (800–422–6237)
- A listing NCI Cancer Centers and doctors at those institutions is available on the Internet at cis.nei.nih.gov/fact/1_2.htm
American Board of Medical Specialties

- The Official ABMS Directory of Board Certified Medical Specialists is available at most public libraries.
- You can find a doctor’s board certification status by calling 866–275–2267 (866–ASK–ABMS) or checking online at www.abms.org/login.asp. These services are free, but the Internet service requires registration.

American Medical Association

- Physician Select is a free, online search service that offers basic professional information on nearly all licensed physicians in the United States. This service can be accessed at www.ama-assn.org/aps/amahg.htm.

American Society of Clinical Oncologists (ASCO)

- ASCO offers a free, searchable, online list of ASCO members available at www.asco.org/ac/1,1003,.12-002215,00.asp.

Your insurance coverage may limit your choice of physicians. Health maintenance organizations (HMOs), preferred provider organizations (PPOs), and other types of managed care plans usually have a list of member providers from whom you must choose. Many insurance companies require a referral from your primary care provider in order for you to see a specialist. Be sure to get this referral. Your insurance company may not pay for the office visit without the required referral.

Your first meeting with someone you are considering to be your doctor is an opportunity to collect valuable information that will help you later decide whether you want him or her on your cancer care team. Questions you might consider asking a doctor you are considering for your cancer care team include:

- Do you accept my insurance?
- Are you board certified in your specialty?
- How much experience do you have treating lung cancer?
• How frequently do you treat people with lung cancer?
• Is lung cancer your primary interest?
• How do you stay up-to-date on new lung cancer treatments?
• Do you have patients who participate in clinical trials?
• What hospitals and/or treatment centers do you work with?
• Are you comfortable with me seeking other treatment opinions?
• How quickly will my telephone calls be returned?
• If I want to include complementary therapies in my care plan, will you work with nontraditional practitioners such as naturopaths, herbalists, acupuncturists, and Chinese medicine specialists?

When interviewing a surgeon, consider asking:
• Do you specialize in thoracic surgery?
• Are you board certified in thoracic surgery?
• How often do you perform the procedure I will be having?
• Will you work with my oncologist to coordinate my care?

The initial interview is a good time to discuss issues such as pain management and advance directives. It can be challenging to change your primary cancer provider later if you find you have differences of opinion about these crucial issues.

After you have met with someone you are considering for your cancer care team, you may want to ask yourself some of these questions:
• Are you comfortable with him or her?
• Does he or she seem interested in your needs?
• Did he or she treat you with respect?
• Did he or she answer your questions willingly and completely?
• Did you agree on issues about which you hold strong opinions?
• Does he or she seem knowledgeable about lung cancer staging and treatment?
I already had a primary care doctor, and luckily, I like him a lot. I had been seeing him for several years. During the process of being diagnosed with lung cancer, I was referred on to a pulmonologist, then a surgeon, and so forth. Through that process, I asked who they thought was the best in the lung cancer field. I also did research on my own and found many leads through talking with people, one of them being my Phone Buddy. As I was getting second, third, and fourth opinions from medical oncologists, I found I really needed a doctor that was willing to answer my questions or at least some of them. I also needed a doctor who would answer them in a straightforward manner. Luckily, after having met with five medical oncologists, I have found a doctor who not only does this, but he is also compassionate. I feel he really cares and he certainly takes the time to go over things with me.

– Lovelle, diagnosed with stage IIIA NSCLC in 2002 at age 57

People with lung cancer can live for many years, but some have a more limited survival time. The doctor you choose as your primary cancer doctor will probably be involved your care through the end of your life. When choosing a doctor, think about whether you want him or her to provide your health care throughout your lung cancer experience.

The Rest of Your Cancer Care Team

Quality cancer care requires a team of expert health care professionals. Each member of the team has special training and expertise that he or she contributes to your care. While doctors lead your cancer care team, it is usually the non-physician health care professionals (called allied health professionals) who interact with you and provide the majority of your care on a day-to-day basis. Some of the many functions of the allied health professionals on your cancer care team are presented on the following pages.

Oncology Nurses

Oncology nurses are vital members of the cancer care team. Oncology nurses are usually the providers who administer chemotherapy and counsel you about treatment-related side effects. They are often your primary point of contact with your oncologist. Oncology nurses are the people you will most likely talk with if you call your doctor’s office with a problem. Nurses often coordinate your care with other providers including nutritionists, rehabilitation therapists, oncology social workers, and others. The further you get in your lung cancer journey, the more you will come to appreciate the many contributions of your oncology nurses.
Although my oncologist was great, I spent a LOT more time with Lucy, my oncology nurse. We developed a very special friendship - not outside of the office, she is too professional for that. But she became a very special person during my treatment and I still care for her a great deal. I still get that wonderful smile from her every time I have a check up. I can tell she is genuinely happy for me with each year that passes.
– Patti, diagnosed with limited SCLC in 1998 at age 48

Oncology Advance Practice Nurses (APN, oncology nurse practitioner, or oncology clinical nurse specialists)
Oncology nurse practitioners’ functions on the cancer care team vary but can include physical examinations, diagnosis, prescribing care and treatment, and monitoring of the effects of treatment. APNs work with oncology nurses, doctors, and other health care professionals to promote the best care of people with cancer. The services provided by oncology APNs vary across the United States depending on state laws that govern their work and authority. If you have an oncology nurse practitioner on your cancer care team, talk with him or her about what types of services he or she will be providing. An oncology nurse practitioner can be a very helpful and knowledgeable addition to your cancer care team.

Oncology Social Workers
Oncology social workers are helpful, versatile members of the cancer care team. They act as patient advocates responding to the unique needs of patients, and their families and caregivers. Oncology social workers provide psychosocial counseling to help people cope with a variety of issues related to living with cancer and adjusting to a new lifestyle. They provide expert information and referrals to essential community, state, and national resources. They also coordinate services such as lodging, transportation, home health care, and hospice care that may be needed to support patients throughout their cancer treatment. Social workers often serve as facilitators of lung cancer support groups.

Nutritionists/Dieticians
Nutritionists and dieticians are experts in the nutritional needs and problems associated with a variety of illnesses and conditions. Nutritionists help people deal
with the many challenges to good nutrition that come up during their lung cancer experience.

YOUR PARTNERSHIP WITH YOUR DOCTOR

People with lung cancer are often in the position of making life-changing decisions. The process by which we make such decisions is unique to each one of us. Some people want to learn everything there is to know about their disease and make all their own treatment decisions. Others entrust treatment decisions to their doctors because they feel their doctors have far more knowledge, experience, and expertise on which to base their recommendations. Many people make decisions collaboratively with their doctors.

There is no right or wrong way to approach your treatment choices. You should make your decisions based on what is most comfortable for you. Figure 1 shows that the partnership you choose with your health care providers is a complementary one. As your role in the decision-making process increases, your provider’s role decreases and vice versa. It is important for both you and your providers to feel comfortable with this balance. The far left of the figure represents a doctor/patient partnership in which the patient has entrusted all treatment decisions to the doctor. The far right of the figure shows a doctor/patient partnership in which the patient is making all the final treatment choices. And of course, there is the large area in between these two extremes that shows varying roles in the doctor/patient partnership.

Figure 1: The Doctor/Patient Partnership
It is helpful to put some thought into the kind of doctor/patient partnership that will be most comfortable for you. These questions may help you think through this important aspect of your care.

- Do you want an equal partnership with your doctor wherein you review information and make decisions together?
- Do you want to rely on your doctor’s experience and expertise to choose the treatments he or she judges to be best for you?
- Do you want your doctor to give you facts without interjecting his or her opinions so you can come to your own conclusions and decisions?
- How important is your doctor’s personality to you?
- What is more important to you, your doctor’s personality or his or her experience and expertise in the treatment of lung cancer?
- Are there any personal qualities you are looking for in a doctor?

There are potential advantages and disadvantages to different types of doctor/patient partnerships. People with cancer sometimes feel they have lost control of their lives. Taking a role in the decision-making process can help some people regain a sense of control over the situation. On the other hand, trying to learn all the details of the many different aspects of cancer care can be an overwhelming burden for some people. You may feel you already have enough on your hands trying to deal with the everyday changes having cancer has introduced into your life without taking on the added task of becoming an expert in lung cancer care. In this situation, you may find leaving treatment decisions to your cancer care team frees your mind and time to spend on other things that are more important to you. Keep in mind, the doctor/patient partnership is much like other human relationships in that it changes depending on the circumstances you are facing. In some situations, you may want to make decisions largely on your own. In other circumstances, you may want to defer to your doctor.

Two weeks after I saw my first surgeon, I fired him. I wanted someone who would believe in me and fight for me. My new surgeon was the head of the Thoracic Department. He was very aggressive with my care not only with chemo and radiation, but I have also had four surgeries with him. He was there to fight for me. You need someone who won't give up on you. When I got my brain metastasis and went in for brain surgery, he found out where I was and held my hand through the
Regardless of your personal decision-making approach, your doctors will be part of the process. It is important to establish a relationship with your doctors that compliments your personality and decision-making style. Your relationship with your cancer care team is an important factor in your satisfaction and comfort with your treatment and ongoing care.

**Communicating With Your Doctors**

Clear and open communication between you and your doctor is an important component of quality care. Some key elements of effective communication are:

- the ability to be open and honest with your doctor about any topic that may come up
- feeling free and unembarrassed to ask questions about things you do not understand
- a sense of mutual respect

Effective communication requires the effort of both you and your doctor. It will take some time for you to get to know one another and establish a good working relationship.

Actions that can enhance your working relationship with your doctor include:

- Talk with your doctor about what kind of health care partnership you want to have with him or her.
- Tell your doctor what you already know about lung cancer. Let him or her know if you want to learn more about the disease or prefer not to get involved in the details. Most doctors will look to their patients for guidance about how much detail they want to know.
- Let your doctor know if he or she says something you do not understand. Your doctors think and talk about cancer every day, so they sometimes forget that not everyone is as familiar with cancer-related terms and topics as they are. It is important to understand your doctor correctly. It may be helpful to repeat back
what you hear so your doctor can correct anything that may have been misunderstood. Take the time you need to understand the topic you are discussing.

- Be open with your doctor about fears or concerns you may have about your condition, treatments, or procedures. You may also have concerns about topics such as hospital care, pain management, or end of life issues.

- Discuss topics about which you have strong feelings early in the care process. For example, you may have strong feelings about the use of pain medications, resuscitation, advance directives, the use of blood transfusions, or other forms of treatment. It is best to discuss these topics and come to an agreement about them when you first establish your doctor/patient partnership. This can go a long way toward avoiding miscommunications and possible disruptions of care in the future.

The same principles that apply to communicating effectively with your doctor can also be utilized in communicating with the other members of your cancer care team.

Important conversations with your doctor should take place in a private, quiet area. If you are in a noisy or public setting, suggest moving to some place more private before continuing your conversation. Be sure to tell your doctors and other members of your cancer care team if there is specific information you want kept private. It is best to identify clearly what information can be shared with family members and friends about your condition and treatment. This prevents a possible breach of your privacy and helps your providers respect your wishes.

If you have established someone as your health care agent by granting them medical power of attorney, be sure to provide your doctors with a copy of your advance directive, power of attorney documents, and contact information for your health care agent. People who do not have a health care agent should name someone with whom your doctor can speak if you are unable to communicate on your own behalf. See Chapter 15: Planning for the Future for information about advance directives and medical power of attorney.
Getting Your Questions Answered

Most people come to the experience of having lung cancer with little prior knowledge of the disease, its treatments, and medicine in general. As a result, you are likely to have many questions over the course of your disease. It is important for your peace of mind and comfort with your treatment decisions to get your questions answered satisfactorily. Tips to help ensure your questions are answered include:

- Write down questions as they occur to you between office visits.
- Take someone with you to office visits who can act as a second set of ears to help you remember the answers to your questions.
- Take a pad and pencil to your appointments so you can jot down notes. Some people take a tape recorder to their appointments. They replay the conversations later in a more relaxed environment to help reinforce what was discussed. Ask your doctor if he or she minds you recording the conversation.
- Let your doctor know if he or she uses a word you do not understand. Ask your provider to explain medical terms in language you understand.
- Talk with your oncology nurses about your questions. Oncology nurses are very knowledgeable and may have more time to talk with you than your doctors do. Be aware that if something comes up in a conversation with your oncology nurse that he or she judges to be important to your care, he or she is obliged to share that information with your doctor.
- Do not be embarrassed to ask questions. There are no such things as silly questions. You may need to ask a question more than once before feeling confident you understand the answer.

Working Through Communication Difficulties

All human relationships occasionally have rough spots. Your relationships with your cancer care providers are no different. There will probably be days when you are not feeling very well, or are feeling rather sad or distressed. Your doctor may have days when he or she is feeling rushed or worried. These circumstances and many others can influence the nature and quality of the interaction between you and your doctor on any given day. When you encounter tension in your communication with your doctor or another health care provider,
it is important to work through it so it does not interfere with your peace of mind or treatment.

When interacting with your health care providers, it may be useful to keep the following thoughts in mind.

- Try not to take it personally if your doctor seems more distracted or less friendly on one day than another. It probably has nothing to do with you. Your doctor is a human being just like you with varying moods, energy levels, and outside concerns. Try to treat your doctor with the same consideration and respect with which you want to be treated.

- Doctors can seem emotionally distant at times, which is troubling to some people. The unemotional appearance of a health care provider does not mean he or she does not care about you. Cancer care providers work in a very emotional job. They see people every day who are in potentially life-threatening circumstances. They often must face the loss of people they have come to know and care about in a personal way. In order to provide the best care possible, cancer care providers must learn to keep their emotions in check so they can think clearly and work effectively. An unemotional exterior can be mistakenly perceived as a lack of compassion or empathy.

- Express your appreciation for extra efforts your providers make on your behalf. A word of sincere thanks can be very meaningful to a health care provider.

- Tell your provider if there are things about his or her style of working with you that are particularly helpful. This will let him or her know more about how best to interact with you. It may also help him or her interact more effectively with other people living with cancer.

Sometimes the doctor/patient partnership does not develop as you want it to, or it may get temporarily off track. This can lead to feelings of dissatisfaction and possibly anger. These feelings can disrupt an effective working relationship. Therefore, they must be resolved. If you become angry with your doctor during an appointment, try not to make statements or ask questions in a way that attack your provider in a personal way. It is often best when you
are angry to wait until you have calmed down before discussing the matter that caused your anger to flare. In the heat of the moment, people often say things they later regret. Rather than putting yourself in this situation, you may want to express your feelings to a family member, friend, or a member of your support group. Talking with a trusted confidant allows you to vent your feelings and discuss the situation with someone who can offer objective insight and advice. Releasing your feelings and gaining objectivity about the situation puts you in a much better position to approach your doctor with clear statements and specific requests that can resolve the problem.

It is usually best to talk with your doctor in person if you are bothered by something that has occurred, are uncomfortable with your doctor/patient partnership, or are not satisfied with the care you are receiving. You may need to schedule an appointment for this purpose if you think the problem cannot be resolved during a regular office visit. Be sure to tell the scheduler how much time you want for the appointment so your discussion will not be interrupted or ended prematurely.

Prepare for the meeting by thinking through or writing down your concerns in advance. Be specific about your concerns and specify the changes you would like to see occur. You might:

- Describe specific behaviors that bother you and how you feel in response to them. Try not to use negative words to personally describe your doctor.
- Describe specific incidents you found upsetting as accurately as possible.
- Admit any responsibility you may have had for the problem.
- List specific actions you are requesting to resolve the problem(s).
- Invite your doctor to come up with his or her own ideas about how to resolve the problem(s).

You can present your concerns in a letter if you cannot meet with your doctor personally or are uncomfortable doing so. This approach can be useful because it gives your doctor time to think about things before getting back to you. You may want to follow-up the letter by scheduling a phone call or discussing your concerns at your next appointment. Regardless of
how you present your concerns, it is important for you and your doctor to discuss and resolve your concerns.

Occasionally, well-intentioned efforts to resolve conflicts or concerns fail to bring about an acceptable compromise. In such circumstances, you may want to consider working with another doctor. It is your right to change doctors if you wish to do so. Changing doctors does not mean there is something wrong with you or your doctor. Your doctor should be willing to give you a referral to another physician if you request it. You can also get referrals from other health care professionals or other people living with lung cancer. You may need to repeat some of the same steps you went through in finding your current doctor, including consulting with your health insurance company. Your current doctor will continue to provide care until you find another doctor to take over. You will not be left without care.

Over the course of your illness, you doctor will make many recommendations. While you may be generally satisfied with your doctor and your care, you may not be comfortable with a specific recommendation. In such a situation, you may want to get a second opinion. Your doctor can give you the names of other doctors who can provide a second opinion, or you may want to find a doctor on your own. The resources listed in the previous section Choosing Your Doctor can be used to find someone to provide a second opinion. Some managed care plans require you to pay for a second opinion. You may be able to appeal this provision. The customer service staff at your health insurance company can give you information about how to submit an appeal.

**CHOOSING TREATMENT FACILITIES**

Your choice of treatment facilities is often influenced by outside factors. People are frequently referred to a specific treatment facility because their doctor practices there. Your facility choices may be dictated by your insurance plan, especially if you are enrolled in a managed care plan. People living in rural communities may have a limited number of choices within reasonable traveling distance. Despite outside limitations, finding a quality health care facility can enhance your treatment experience.
Types of Cancer Care Facilities

Cancer care can be provided at a community hospital, university-affiliated teaching hospital, or cancer center. Cancer treatments are also frequently provided in outpatient oncology clinics. Some treatments can even be provided in your home.

Local community hospitals offer many benefits for people undergoing treatment for cancer. Advantages include familiar surroundings, the nearby support of family and friends, a smaller environment that can be more personalized and less overwhelming than larger care centers, and less time, energy, and money spent on travel. There are potential disadvantages to community hospital care, which may or may not be applicable to your local hospital. Local hospitals may not have as much experience with certain procedures because they treat fewer patients than larger facilities. They also may not have all the latest medical equipment. There may or may not be access to clinical trials.

Teaching hospitals or university-affiliated hospitals are facilities associated with a medical school. These facilities are usually quite large and treat many thousands of people each year. They generally offer the advantages of extensive cancer care experience, state-of-the-art equipment, and staff that are up-to-date with the latest medical knowledge. These facilities usually offer excellent cancer care. Nonetheless, there are potential disadvantages to these facilities that may or may not be important to you. The size of these facilities can be overwhelming; it may be hard to find your way around when you first visit. You may need to travel a significant distance to reach your nearest teaching hospital. Friends and family members may not be able to visit as often as they would like because of this distance. Travel can also be costly.

Part of the mission of teaching facilities is to train new doctors, nurses, and other health care professionals. As a result, you may be examined or cared for by many people at different stages of their professional training. Several students or professionals in training may be observing your treatments and procedures, which can feel like an intrusion on your privacy. Some people do not mind this aspect of being cared for at a teaching facility, but others find it can be trying at times.
If you live in a large city, you may be near an NCI supported cancer center. The NCI Cancer Centers Program is comprised of more than 50 NCI-designated cancer centers engaged in research to reduce the occurrence of cancer, and cancer-related illness and death. Two types of cancer centers are supported through NCI Cancer Center Program grants.

- **Comprehensive Cancer Centers** – conduct basic science (laboratory-based), clinical (patient-based), and prevention and control research; these centers also have community outreach and cancer education programs
- **Clinical Cancer Centers** – conduct clinical (patient-based) research and may have other research programs

Facilities designated as NCI cancer centers offer complete cancer care and accessibility to clinical trials. Because NCI cancer centers are involved in research, they are well informed about the most current cancer treatments. You can call NCI at 800-4-CANCER to find the NCI cancer center nearest you.

Community cancer care centers and oncology outpatient facilities offer specialty cancer care in a local setting. The level of care provided by these facilities is often very good. Many of these facilities participate in community-based clinical trial groups. If you are interested in participating in a clinical trial, talk with your doctor or the facility director to find out if they are part of a clinical trial group. The director of the facility can also provide you with information about the qualifications of the staff, quality reports about the facility, and patient satisfaction survey results. Support group members may be able to share their experiences at facilities where they have received care.

The Joint Commission on Accreditation of Healthcare Organizations (JCAHO) is an independent organization that inspects hospitals and other health care facilities to ensure they meet JCAHO quality standards. JCAHO accreditation is not required for a facility to operate. However, JCAHO accreditation provides an indicator of both the facility operator’s interest in quality and the assurance that the facility meets the quality standards outlined by JCAHO. For information about JCAHO accreditation of outpatient care facilities, check the JCAHO Internet site at [www.jcaho.org/accredited+organizations/ambulatory+care/index.htm](http://www.jcaho.org/accredited+organizations/ambulatory+care/index.htm).
Choosing a Hospital

The Agency for Healthcare Research and Quality (AHRQ) in cooperation with the United States Department of Health and Human Services and other private and public health organizations developed a guide to help people choose a hospital that meets their needs. An adaptation of that guide is presented on the following pages.

How can you choose the best quality hospital for the care you need? It is important to consider quality because research shows that some hospitals do a better job than others do. For example, we know hospitals that do a greater number of the same surgeries have better outcomes for their patients.

Quick Check for Hospital Quality

Look for a hospital that:

- is accredited by the JCAHO
- is rated highly by state, consumer, or other groups
- is one where your doctor has privileges (permission to admit patients)
- is covered by your health plan
- has experience with your condition
- has success with your condition
- checks and works to improve its quality of care

Questions to Ask When Considering a Hospital for Your Cancer Care

The following questions can help you make the best hospital choice for your care.

1. *Does the hospital meet national quality standards?*

Hospitals can choose to be surveyed by JCAHO to make sure they meet certain quality standards. The standards address the quality of the staff and equipment, and the hospital’s success in treating and curing patients. If a hospital meets the specified standards, it becomes JCAHO-accredited. Accredited hospitals are reviewed at least once every three years to be sure

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the hospital continues to meet JCAHO standards. Most hospitals participate in this program.

JCAHO prepares a performance report on each hospital it surveys. The report lists:

- accreditation status
  There are six accreditation levels ranging from the lowest (not accredited) to the highest (accredited with commendation).
- date of the survey
- evaluation of the key areas reviewed during the survey
- results of any follow-up activity
- areas needing improvement
- comparison with national results

You can order JCAHO's performance reports free of charge by calling 630-792-5800. Alternatively, check JCAHO's Internet site at www.jcaho.org for a hospital's performance report and accreditation status.

The American College of Surgeons (ACOS) accredits cancer programs at hospitals and other treatment centers. There are over 1,400 ACOS accredited cancer programs in the United States. ACOS provides a searchable database of these programs on their Internet site at web.facs.org/cpm/default.htm. You can also telephone ACOS at 312-202-5000 to find accredited programs near your home.

2. How does the hospital compare with others in my area?

One important way to learn about hospital quality is to look at hospital report cards developed by state and consumer groups. A recent study about such reports found that in addition to helping consumers make informed choices, they also encourage hospitals to improve their quality of care. This is a very good reason to look for and use consumer information about hospitals.
Resources for reports on hospitals include:

- Some states (for example Pennsylvania, California, and Ohio) have laws requiring hospitals to report data on the quality of their care. The information is shared with the public so consumers can compare hospitals.
- Some groups gather information on how well hospitals perform and how satisfied their patients are. An example is the Cleveland Health Quality Choice Program, which is made up of businesses, doctors, and hospitals.
- Consumer groups publish guides to hospitals and other health care choices in various cities. Find out what kind of information is available where you live by calling your state department of health, health care council, or hospital association. Also, ask your doctor what he or she thinks about the hospital.

3. **Does my doctor have privileges (permission to admit patients) at the hospital?**

If your doctor does not have privileges at the hospital, you would need to be under the care of another doctor while at that hospital.

4. **Does my health plan cover care at the hospital?**

If your plan does not normally cover care at a hospital you are interested in, hospital case managers and/or business office personnel may be able to contact your insurance company and negotiate an agreement to pay for your care. If your insurance company refuses to work out a payment agreement, you would need another way to pay for your care at that hospital. This is not an option for many people because hospital care is very expensive.
5. Does the hospital have experience with lung cancer?

General hospitals handle a wide range of routine conditions, such as hernia repairs, gall bladder problems, and pneumonia. Specialty hospitals have a lot of experience with specific conditions (such as cancer) or certain groups of patients (such as children). University-affiliated teaching hospitals usually handle all aspects of medical care. You may want to ask if the hospital you are considering has a special team of cancer care professionals.

6. Has the hospital had success treating lung cancer?

Research shows hospitals that do many of the same types of procedures tend to have better success with them. In other words, ‘practice makes perfect.’ When considering a facility for a specific procedure, ask your doctor or the hospital if there is information on:

- how often the procedure is done there
- how often the doctor does the procedure
- patient outcomes for the procedure (how well the patients do)

Some health departments and other agencies publish reports on patient outcomes for certain procedures. Outcome studies can help you compare which hospitals and surgeons have had the most success with a particular procedure.

7. How well does the hospital check and improve on its own quality of care?

Increasing numbers of hospitals are trying to improve their quality of care. One way to do this is to keep track of patient outcomes for certain procedures. Another way is to keep track of patient injuries and infections that occur in the hospital. By finding out what works and what does not, the hospital can improve the way it treats patients.
Ask the hospital quality management department how it monitors and improves the hospital's quality of care. Also, ask for the results of any patient satisfaction surveys the hospital has done. These will tell you how other patients have rated their quality of care.

YOUR HOSPITAL EXPERIENCE

Most people with lung cancer become familiar with one or more hospitals during their experience with the disease. A hospital is its own little world with unique customs and language. The hospital is just an everyday workplace for the staff. But for you, the hospital is likely to be full of strange objects, words, and routines.

Being in the hospital can be challenging. Hospital staffs can have a tendency to focus on your medical needs rather than responding to your feelings. There may be times when hospital personnel refer to you by your disorder rather than your name, such as “the lung cancer in room 912.” This can leave you feeling as if you are being treated like an object rather than a person. In addition, hospitals have routines they must follow in order to function smoothly. Patients are expected to fit into these routines regardless of their personal preferences. These situations can be very trying and leave you feeling somewhat helpless.

It is important to do what you can to feel a sense of control about your hospital care. It may help to visit the hospital before a planned stay to become familiar with the surroundings and routines. Many hospitals have patient services departments with social workers on staff who can direct you toward a variety of resources. Some hospitals also have case managers (nurses or social workers) who coordinate your care with the various departments that will be involved in your treatment. You may want to meet with one of these professionals to ask any questions you may have before being admitted for treatment. In addition, many hospitals have patient education centers. You may want to visit your local patient education center and utilize some of their services.
Every hospital patient deserves quality care. At the same time, hospital personnel are usually very busy. As a hospital patient, you will have to balance these two realities. It is important to speak up if your needs are not being met. It is also important to be courteous and reasonable in what you ask of the staff. Let the staff members know if something about your care seems amiss. A tone that is polite, respectful, and clear is usually best. Avoid behavior that may appear rude, demanding, or disrespectful. Your goal is to get your needs met. Treating the hospital staff with respect and consideration increases the likelihood that they will respond positively and do what they can to accommodate your requests. You can discuss unresolved concerns or problems with someone in the patient services department.

Tips you may find helpful for making your hospital experience run smoothly include:

• Be sure you understand ahead of time what doctor will be supervising your care. Find out how to reach this person before and during your hospital stay. You may want to ask the supervising doctor who else will be involved in your care (other doctors, residents, medical students, etc.).

• Ask people to visit regularly during your hospital stay. They can help look out for your welfare, bring items from home, and follow-up on any concerns you may encounter.

• Build a positive relationship with hospital staff. Express appreciation for the things they do for you. This fosters a good working relationship. People who feel appreciated are generally receptive to requests for assistance.

• Feel free to ask questions. If you are confused about something, ask for an explanation. If something is upsetting you, talk to someone who can help resolve the problem. It helps if you approach problems in a friendly way. In general, hospital staff will go out of their way to be helpful. Family or friends can follow-up on your concerns or questions if you are not up to handling things on your own.

• Friendly humor can help to reduce tension and build positive connections with hospital staff.
When you are ready to be discharged from the hospital, your doctor and case manager (if you have one) will do discharge planning. This involves:

- making arrangements for any in-home care you may need
- providing you with instructions about how to care for yourself at home
- advising you about activities to avoid and for what length of time
- specific instructions about signs or symptoms to be aware of that may indicate a need for urgent medical attention
- follow-up appointments with your doctor, physical therapists, or other health care professionals
- prescriptions for any medications you will need to take at home

Be sure you understand all your discharge instructions before leaving the hospital. It is often helpful to have someone with you when these instructions are explained so he or she can help you recall them once you get home. A written list of instructions should be provided for your reference. The list should have the name and telephone number of at least one person to contact if you have questions or problems once you get home.

**SUPPLEMENTAL CARE SERVICES**

A variety of health care and other supportive services are available to people with lung cancer. This section briefly reviews some of these services. Your oncology social worker or nurse can help you find additional information about these services if you are interested in pursuing any of them.

**Home Health Care**

Increasing numbers of people with cancer are choosing home health care. Home health care offers many of the service that used to be available only in a hospital or outpatient facility. Services that may be available include:

- intravenous (IV) therapy including chemotherapy infusions, heparin therapy (for blood clots), supplemental fluids, and antibiotics
• blood drawing for laboratory tests
• nursing care
• physical therapy
• respiratory therapy
• medical social work
• home health aides
• personal care assistants
• homemaker and housekeeping services
• home medical equipment such as supplemental oxygen, respiratory equipment, wheelchairs, hospital beds, etc.

Nurses, home health aides, and personal care assistants can be scheduled according to your needs. Homemakers perform such tasks as cooking meals, doing laundry, and grocery shopping.

“It was defiantly nice to have my physical therapist come to my house. When I had knee surgery a while back, I was in a physical rehabilitation clinic for ten days. This time around was much nicer with my therapist coming to the house. If I didn't feel like getting out of my pajamas, I didn't have to. It was just much nicer at home where I am more comfortable [than in a clinic.]
— Judith, diagnosed with stage IIA NSCLC in 2001 at age 60

Coverage for home health care services varies greatly from one health insurance plan to another. Check with your insurance agent or customer service representative to see what coverage you have for these services. Talk with your oncologist or oncology nurse if you are interested in home health care services. He or she can help you make the necessary arrangements.

Some states provide payments to eligible people who are the primary caregivers of someone with a serious illness such as lung cancer. Call your state Department of Health or the Patient Advocate Foundation at 800-532-5274 to find out if financial support is available in your state. You can also search the state resource guide on the Patient Advocate Foundation Internet site at www.patientadvocate.org/report.php.
**Hospice**

Hospice care is similar to home health care, but provides services exclusively to people with terminal illnesses who have made the decision to forego further *curative intent* treatment. Hospice care can be delivered in your home or at a hospice facility. Additional information about hospice care is presented in *Chapter 15: Planning for the Future*.

**Eldercare**

Eldercare is an umbrella term that refers to a variety of coordinated community, social, financial, and medical services available to people over the age of 60 or 65. Eldercare services are very helpful for older people who live alone or live with someone who is also advanced in years. These services can help you meet the challenges of lung cancer that may otherwise make it difficult for you to continue living on your own. Services available through eldercare agencies include:

- personal care services – assistance with bathing, dressing, and grooming
- home health care services
- financial services – applying for social security, disability or pension benefits, keeping track of and paying bills, submitting insurance claims, negotiating with creditors, etc.
- individual and family counseling
- community service referrals
- transportation services

Counselors evaluate your needs and the needs of your caregiver, and arrange for services. They work with your oncologist to be sure all your medical needs are met. Counselors will also review your health insurance coverage and advise you about what services are covered by your plan. Many services available through eldercare agencies are available to qualified persons free-of-charge or on a sliding scale (fees are based on what you can afford). Talk with your oncology nurse or social worker if you are interested in eldercare services. They may be able to give you referrals and recommendations.
Geriatric Care Managers are professionals who charge a fee to provide the same basic services as eldercare agencies. Fees for their services are not reimbursed by most health insurance plans. If you can afford these services, you may want to contact the National Association of Professional Geriatric Care Managers at 520-881-8008, or log onto their Internet site at www.caremanager.org.

Meals On Wheels
Meals On Wheels provides meals for those who want to stay in their homes but are unable to prepare their own meals. This service is available in many communities to people of any income level who are 60 years of age and older. Younger adults may be eligible if they are homebound. Fees for this service vary according to a person’s ability to pay. This service can be used on a long or short-term basis. Ask your social worker, nurse, or doctor for information about this program in your community.

Adult Day Care
Adult day care (ADC) centers are community-based programs that provide non-medical care to people in need of personal care services, supervision, and/or assistance with the tasks of daily living. Most facilities are available to anyone 18 years of age or older. ADC centers provide care during the day. Participants return to their homes or the homes of family members in the evening. The types of services typically provided by ADC centers include:

- therapeutic and recreational activities (exercise, crafts, music, etc.)
- health monitoring (but not health care)
- supervision
- personal care assistance
- nutritional meals and snacks
- caregiver support groups or referral to other programs

ADCs are not medical care facilities. Talk with your oncology doctor or nurse about whether an ADC would be appropriate for your situation.
Assisted Living Facilities

Assisted living facilities may be an option for older adults who want to remain as independent as possible, but who need assistance with many of the tasks of daily living. Assisted living facilities can have from ten to several hundred residents. Different facilities offer their own menu of services that can include:

- basic housing
- meals
- 24-hour emergency monitoring
- supervision and dispensing of medications
- socialization with peers
- assistance with bathing, dressing, grooming, eating, and/or transportation

You can customize the number and type of services you need to fit your particular situation. Cost for this care is variable. Talk with your social worker or oncology nurse about how to obtain additional information about this living arrangement.

SUMMARY

Becoming knowledgeable about lung cancer, the health care system, and your rights as a health care consumer will put you in the best position to find quality health care that suits your needs and preferences. As a health care consumer, you have a right to quality medical care.

Choosing a cancer care team you can work with effectively and comfortably is a key component of quality care. Similarly, a treatment facility that offers services commensurate with your treatment goals and preferences can greatly enhance your sense of satisfaction and comfort.

I hope the information in this chapter contributes to your health and well-being. In addition, I hope your journey through the health care system is smooth and meets your expectations and needs fully.
CHAPTER 14: HEALTH INSURANCE, WORK, AND FINANCIAL MATTERS

INTRODUCTION

A lung cancer diagnosis raises many practical concerns. Health insurance, life insurance, work, disability, and financial matters can cause worry and confusion. This chapter presents information to help you manage these areas of your life and reduce your stress. While this chapter cannot cover every possibility you may encounter, it provides background information and resources to help you get your needs met.

HEALTH INSURANCE

There are several types of health insurance, which vary greatly in terms of rules and payments. It is important to understand the kind of insurance you have, what services are covered, the rules of the policy, and the amounts and conditions of any co-payments you are responsible for paying.

The best place to start in terms of understanding your health insurance coverage is to read your policy. Contact the customer service department of your insurance carrier if you do not have a current copy of your health insurance policy. Insurance policies can be lengthy and difficult to understand. However, it is important to read your policy carefully. As you review the policy, pay close attention to:

- your yearly deductible (the amount you must pay out-of-pocket before your insurance policy will begin paying for medical expenses)
- coverage for inpatient hospital services; pre-approval may be required for any non-emergency admission to the hospital
- outpatient service coverage including infusion therapy (chemotherapy or intravenous fluids), pulmonary rehabilitation services, home health care, hospice services, mental health care, laboratory testing, and x-rays
• requirements for pre-approval of tests such as CT, MRI, and PET scans
• requirements for specialty care; many policies require a referral from your primary care doctor to cover payments to a specialist
• payment for second opinions; many policies do not cover the cost of second opinions
• prescription drug coverage; some policies have a list of covered drugs called a formulary and will not pay for non-formulary drugs
• co-payments and out-of-pocket expenses
• requirements for submitting claims
• how to appeal a denied claim
• lifetime and per illness policy limits; many policies limit the amount they will pay for each insured person over the course of his or her life and/or for a given illness; these limits are often referred to as policy capitation or policy caps

Talk over questions about your health insurance plan with call your insurance agent, the insurance company’s customer service department, or the human resources department at your work (if your policy was obtained through your employer).

Patient Advocate Foundation is a national non-profit organization that acts as a liaison between patients and their insurers, among other services. They work to safeguard patients by helping them obtain affordable access to medical care. The organization can be reached online at www.patientadvocate.org or toll-free at 800-532-5274.

**Private Health Insurance**

The following is a brief overview of different types of health insurance. This overview will help familiarize you with some of the words commonly used by health insurance companies.

**Individual Health Insurance**

People who are self-employed, retired, or are not eligible for group policies often purchase individual health insurance policies. The coverage offered by individual policies varies widely. These policies are usually sold by independent insurance
agents who must be licensed to sell insurance according the laws of your state.

Individual policies can be expensive.

A *guaranteed renewable or non-cancelable policy* has a stipulation that states the insurer cannot refuse to renew your health insurance policy as long as you pay your premiums on time. A non-cancelable policy also guarantees that your health insurance premiums cannot be increased. It is important to know whether your policy has this feature because without it, some carriers may refuse to renew your policy if you have been diagnosed with cancer.

**Group Health Insurance Policies**

Group health insurance provides coverage for several people under one contract called a master contract. A group policy can cover from less than ten to several thousand people. Group policies are most commonly offered through employers, but can also be offered through political, professional, or other organizations.

Group policies frequently offer more coverage for a lower cost than individual policies because the insuring company has the benefit of gathering premiums from many people under one contract.

**Fee-For-Service (Indemnity) Plans**

Fee-for-service health insurance plans usually offer the broadest choices of doctors and health care facilities. These plans generally allow you to see any doctor of your choosing as long as they accept your health insurance. While these plans offer the greatest freedom of choice, they are usually the most expensive. The insurance company pays on a fee-for-service plan only after they received a bill.

**Health Maintenance Organizations (HMOs)**

An HMO policy is a prepaid health insurance plan. Members (patients) pay a set monthly fee to the HMO in exchange for necessary medical care. If you do not use the services available, the organization and often the doctors affiliated with the
organization benefit. On the other hand, if the cost of your care exceeds the fees you pay, the organization absorbs the cost. Some view the HMO system as an effective way to hold down skyrocketing medical costs. The system removes the financial incentive (profit) that can be made in a fee-for-service system by performing tests or procedures, or prescribing treatments that may not be absolutely necessary. The financial incentive in an HMO is the opposite of a fee-for-service system; there are financial rewards to be gained by decreasing utilization of services. The HMO system promotes disease prevention. From a financial perspective, it is usually more cost effective to prevent disease than it is to treat disease once it has occurred. While some view HMOs positively, others consider the system to be biased in favor of profits over providing optimal patient care.

HMOs are based on two main models. A group model HMO owns and operates its own offices and health care facilities. Doctors who work at these facilities are employees of the HMO. An individual practice association (IPAs) is the other main model of HMOs. IPAs contract with physician groups or individual doctors in private practice to care for a specific number of their HMO members.

All HMOs require you to select a primary care doctor who will coordinate your health care. In most HMOs, you must have a referral from your primary care doctor in order to see a specialist. HMO plans cover only services provided or ordered by a member doctor. If you go to a doctor outside the HMO, you will be responsible for paying all charges associated with that care. Some HMOs require a small co-payment for certain services. There is no yearly deductible for HMO members.

Benefits of participating in an HMO include not having to file insurance claims, and few out-of-pocket expenses. However, HMO plans can be restrictive in terms of limiting your choice of doctors and treatment facilities.

Point of Service (POS) Plans
Many HMOs offer an option known as a point of service plan. Primary care doctors
still make referrals to specialists in the plan. However, with a POS plan, you have the option to refer yourself to a doctor outside the plan. The insurer will pay a percentage of the cost for these services; the member is responsible for paying the remainder of the charges. If your primary care doctor makes a referral to a specialist outside the plan (rather than you referring yourself), the plan pays all or most of the bill.

Preferred Provider Organizations (PPOs)

A PPO is a form of health insurance that has features of both a managed care plan and a fee-for-service plan. A PPO has agreements with doctors, hospitals, and other providers of health care services who have agreed to accept reduced fees from the insurer for their services. These providers are not prepaid as in a traditional HMO, but are paid for the services they actually perform. Members of a PPO plan have the highest rate of coverage when they obtain care from doctors and facilities that are part of the PPO network. However, a reduced percentage of your care is also paid for if you refer yourself to a provider outside the network. PPOs generally require a small co-payment for services and have a yearly deductible. PPO members are responsible for paying the difference between what the provider charges and the plan pays for a given service.

Health/Medical Savings Accounts (HSAs/MSAs)

A medical savings account is a special, tax-sheltered savings account for medical bills. A health savings account (formerly called a medical savings account) is usually coupled with a low-cost health insurance plan with a high deductible. The insurance plan is used for major illnesses associated with high-cost hospitalizations, treatments, surgery, or procedures. The money in the HSA is used to cover lesser medical costs such as doctor visits, prescriptions, and certain tests. HSAs are often limited to the self-employed and employees of small businesses (generally 50 or fewer employees). Money deposited into an HSA account is 100% tax deductible, much like a traditional IRA. Money in the account can be easily accessed by check or debit card to pay medical bills. HSA monies can be used for expenses not normally covered by health insurance such as dental and vision care. Money in the HSA that is not used
for medical bills is yours to keep. It stays in the account and grows on a tax-favored basis to cover future medical bills or supplement retirement. Talk with your tax professional for more information about HSAs.

**Government Health Insurance**

The government provides several types of health insurance for citizens who meet specific eligibility criteria.

**Medicare**

People age 65 or older and those with certain disabilities are eligible for Medicare, a federal health insurance program. In many parts of the country, people covered under Medicare have a choice between managed care and indemnity plans. For information about enrolling in Medicare and benefits, call the Social Security Administration toll-free at 800-772-1213, or log onto the Medicare Internet site at [www.medicare.gov](http://www.medicare.gov).

There are two parts to the Medicare program:

- **Hospital Insurance (Part A)**
  Medicare part A pays for inpatient services at a hospital or skilled nursing facility, and home health and hospice care. You are automatically covered under part A when you enroll for Social Security retirement benefits if you are age 65 or older. Most people do not pay a monthly premium for part A coverage. However, there are deductibles and coinsurance amounts you must pay yourself or through coverage under another insurance plan (Medicare supplemental insurance).

- **Medical Insurance (Part B)**
  Medicare part B insurance pays for doctors’ services, outpatient hospital services, medical equipment, and many other medical services and supplies not covered by part A. Part B coverage has associated monthly premiums, deductibles, and coinsurance amounts that must be paid out-of-pocket or by another insurance plan.
Medicare provides basic coverage for health care, but does not cover all medical expenses. For example, Medicare currently pays for medicines administered by a doctor or nurse such as shots or intravenous chemotherapy, but does not pay for most self-administered medications such as pills. Medicare pays for many hospice and home health care services, but does not pay for long-term nursing home care. You have the right to appeal denied claims or the amount paid on a claim. Contact your local Medicare office for instructions on filing an appeal.

Medicaid
Medicaid covers disabled citizens and eligible people with low incomes, especially children and pregnant women. Medicaid is a joint federal and state health insurance program. Services are operated by state governments under federal guidelines. Insurance plans, benefits, and conditions vary widely from state to state. Some states require people covered under Medicaid to join managed care plans. Check with your state Medicaid office to learn more about your eligibility and options.

Tricare
Tricare is the health care program for active duty and retired U.S. military service personnel, their eligible family members, and survivors. Tricare combines both military and civilian services. Tricare offers eligible beneficiaries three choices for health care:

- Tricare Prime — military treatment facilities (MTFs) are the principal source of health care
- Tricare Extra — a preferred provider option (PPO)
- Tricare Standard — a fee-for-service option (the old Champus program)

The Department of Defense (DoD) and the National Cancer Institute (NCI) established the Clinical Trials Demonstration Project. It provides patients covered by Tricare the opportunity to participate in NCI-sponsored phase II and III cancer treatment clinical trials. DoD covers the cost of these trials. Care may be provided by military medical facilities or participating civilian providers. For more
information about the Clinical Trials Demonstration Project, call the NCI Cancer Information Service at 800-4-CANCER (800-422-6237) or the DoD Cancer Trials Demonstration Coordinator at 800-395-7821 (Regions 6, 11, 9, 10, and 12) or 800-779-3060 (Central and all other regions).

Important Health Insurance Terms
Like the medical community, the insurance industry uses many terms that may not be familiar to you. Some of the most common terms are explained on the following pages.

catastrophic insurance
Catastrophic policies are health insurance plans with very high deductibles (usually $10-50,000) but low premiums. People commonly use these policies as supplemental insurance if their standard policy has a relatively low lifetime cap. Catastrophic insurance is also called excess major medical insurance. Catastrophic policies usually cover 100% of expenses after the deductible has been met. If you are shopping for a catastrophic policy, look for a policy that will apply expenses paid by your other health insurance plan toward your deductible for the catastrophic plan. These policies can be difficult to obtain once you have been diagnosed with cancer; many insurance companies will not sell them to people with cancer. Waiting periods before the policy takes effect are also common with these policies.

claim
A claim is a request for payment under the terms of an insurance policy.

coinsurance
Coinsurance is the amount you are required to pay for medical care in a fee-for-service plan or preferred provider organization (PPO) after you have met your deductible. The coinsurance rate is usually expressed as a percentage of the charges. For example, if the insurance company pays 80 percent of the claim, you pay the remaining 20 percent.
conditionally renewable policy
A conditionally renewable health insurance policy is one that grants an insurer the right to refuse renewal of the policy for reasons specified in the policy.

coopayment
Co-payment is a cost sharing arrangement in which a person pays a preset charge for a specific medical service, for example, $10 for each office visit or $15 for each prescription.

customer service department
The customer service department of a life or health insurance company assists the company's policy owners. Customer service specialists respond to policy owners' requests for information, help interpret policy language, and answer questions about coverage. The customer service department may also be called the client service department, policy administration department, policy owner service department, or service and claim department.

deductible
A deductible is the amount of money you must pay out-of-pocket each year for medical expenses before your insurance policy starts paying for services. Indemnity and PPO health plans usually have a deductible.

election period
An election period is the time (usually 60-days) during which an insured person can opt to continue group health insurance coverage at his or her own expense. This situation is most relevant to people who have recently left a job through which they obtained health insurance.

eligibility period
An eligibility period is the time (usually 31 days) during which a new employee may sign up for group insurance coverage.
fee schedule
A fee schedule is a list of maximum amounts that will be paid under a group medical contract for listed medical procedures.

high-risk pools
A high-risk pool is a state-created, non-profit organization that offers health insurance coverage to people with pre-existing conditions who are otherwise unable to obtain coverage. Over half the states in the U.S. currently operate such pools. The number of programs is expected to grow because the federal 2002 Trade Act made grants available to set up and run high-risk insurance pools. High-risk programs operate similarly to commercial programs in that they charge premiums, co-payments, and deductibles for a defined benefits package. The premiums for this coverage are generally higher than those for standard insurance are. However, the premiums are capped by law as a percentage of the premium charged for comparable coverage in the commercial market. Many state-sponsored programs have waiting periods for pre-existing conditions and limits on enrollment. Check if your state operates a high-risk insurance pool by calling your state Health Department or accessing the Internet site of the National Association of State Comprehensive Health Insurance Plans at www.naschip.org/states_pools.htm.

hospital-surgical expense insurance
Hospital-surgical expense insurance provides benefits related to hospitalization costs and associated medical expenses incurred by a person for treatment of a sickness or injury. Most hospital-surgical expense policies cover:

- hospital charges for room, board, and other inpatient services
- surgeons’ and physicians’ fees during a hospital stay
- specified outpatient expenses
- extended care services such as convalescent or nursing home costs
limited coverage policy
A limited coverage policy is a health insurance plan designed to cover only those medical expenses caused by a specific disease (such as cancer) named in the policy.

Medicare supplement or Medigap insurance
A Medicare supplement is an insurance policy that provides benefits for some expenses not covered under Medicare. This coverage is available only to individuals covered by Medicare. It can be purchased by individuals or employers for their retired workers. This type of policy is also called Medigap insurance.

open enrollment
Open enrollment periods are specific times set up yearly by employers during which employees can change insurance programs. Pre-existing conditions are often waived during open enrollment periods. Open enrollments provide an opportunity to change or obtain health insurance coverage.

preauthorization
Preauthorization is a provision of many health insurance policies requiring authorization by the insurance company before non-emergency hospitalization, surgery, or other services in order to receive coverage.

pre-existing condition
A pre-existing condition is a medical condition diagnosed before joining a new health insurance plan. The Health Insurance Portability and Accountability Act (HIPAA) requires insurers to provide coverage for pre-existing conditions based on specific criteria. Under the law, a pre-existing condition is covered without a waiting period when you join a new group plan if you have been insured for the previous 12 months. Your previous health insurance could have been an individual, group, or government policy. People with a pre-existing condition who have been insured for 12 months or more are able to change to a new group health insurance plan and have their condition covered without a waiting period. Those with a pre-existing
condition who have not been continuously insured for the previous year may have a waiting period of no greater than 12 months before coverage takes effect.

There is one significant exception to HIPAA: it provides no protection if you switch from one individual health plan to another individual plan. This can make it very difficult for people with ongoing medical problems to obtain a new individual health insurance policy.¹

reasonable and customary charge
The reasonable and customary charge is the amount of money commonly charged for a specific medical procedures in a given geographical area. Insurance payments are often based on reasonable and customary charges.

supplemental major medical insurance
A supplemental major medical policy is health insurance that provides benefits over and above those paid by basic hospital-surgical expense insurance.

Maintaining Health Insurance Coverage
It is important for people who have been diagnosed with lung cancer to maintain health insurance coverage. It is often difficult to reestablish health insurance if you drop your coverage after being diagnosed. Those who are able to reestablish coverage find it is usually much more expensive than the previous policy.

People with individual health insurance who are diagnosed with cancer may have their premiums increased and/or their benefits decreased. In some cases, the insurance company is permitted to cancel your policy. Always be sure to pay your premiums on time to avoid being dropped by your insurance company for non-payment.

Two days after my brain surgery, my insurance [was cancelled]. There was a million dollar cap on my plan for the treatment of one disease. Fortunately, by the grace of

God and my little angels, I had a group health plan. They talked with my insurance [company] to get me back on the plan.

– Sue, diagnosed with stage III NSCLC in 1997 at age 48

Before making a decision about changing health insurance or joining a new health plan, review all your options. It may be advantageous to join or change to a plan that has a higher co-payment if it has a higher per illness or lifetime cap. In some cases, it can be advantageous to change jobs if there are immediately accessible health care benefits that would help your situation.

Health Insurance and Job Changes

In recent years, the federal government has enacted new laws to help people maintain health insurance coverage. The Consolidated Omnibus Budget Reconciliation Act (COBRA) is a federal law that requires employers who offer health insurance benefits and employ 20 or more people to give employees and their dependents the option to maintain health, dental, and vision insurance (at the employee’s expense) through the company’s group policy after the employee leaves the company. COBRA also applies to employees whose hours are reduced to the point that they are no longer eligible for insurance benefits.

COBRA entitles you to 18 months of coverage with the same health insurance benefits offered to other employees. If you lose your job due to disability and are eligible for Social Security benefits, you are entitled to COBRA coverage for 29 months. Dependents covered under the plan are entitled to 36 months of coverage. Taking advantage of COBRA allows people time to make long-term plans for continuous health insurance.

The Health Insurance Portability and Accountability Act (HIPAA) of 1996 stipulates protections to help you and your family members when you need to buy, change, or continue your health insurance. HIPAA protections:

- limit the use of pre-existing condition exclusions
- prohibit group health plans from discriminating by denying coverage or charging extra for coverage based on past or present poor health
- guarantee certain small employers and individuals who lose job-related coverage the right to purchase health insurance
• guarantee, in most cases, that employers or individuals who purchase health insurance can renew coverage regardless of the health conditions of those covered under the policy.

For additional information about the health insurance protections offered under HIPAA, see the Department of Health and Human Services Internet site at www.cms.hhs.gov/hipaa/hipaa1/default.asp.

Some health insurance policies can be converted from a group plan to an individual plan when an employee leaves a company. Check with a human resources representative at your company to see if this is an option for you. Individual policies are usually more expensive than group policies and frequently offer less coverage.

**Health Insurance Claims**

Many people do not get the maximum benefits from their health insurance because they are uncertain about their coverage or are overwhelmed by the paperwork involved with submitting and tracking claims. Most doctors’ offices, hospitals, outpatient treatment centers, and home health care agencies file insurance claims for you. However, it is important to ask each provider if an insurance claim will be filed just to be sure. You are responsible for filing claims not filed by your care providers. If you do not file a claim, you will be responsible for payment of bills that might otherwise be covered by your insurance carrier. Call the customer service department of your insurer to obtain information about filing claims.

Health insurance companies sometimes deny claims, meaning they refuse to pay for services for which payment has been requested. There are many possible reasons why a claim may be denied. It can be something as simple as the form being filled out improperly or missing information on the claim. In other instances, the denial is more complicated. Health insurance companies may deny payment for a treatment deemed ‘experimental’ even though your doctor recommended it as the best available treatment. Many companies refuse to pay for treatments that have not been approved by the Food and Drug Administration (FDA).
for the specific condition for which you received it. Under some plans, this exclusion includes clinical trials. This issue is of particular concern to people with lung cancer because there are many diagnostic and therapeutic options that have not been FDA-approved for lung cancer but are commonly used to treat the disease.

The first step to take when a claim is denied is to contact the claims department at your health insurance company to find out the reason for the denial. Often the problem can be resolved by having your provider submit required documentation or missing information. If your insurer denies a claim stating the services are not covered by your policy and you disagree with this determination, you can appeal the decision.

Each insurance company has its own appeal process. The customer service or claims department can tell you their procedure for appealing a denied claim. Your doctor may need to write an explanation about why the treatment in question was necessary. It may help if he or she attaches copies of articles from the medical literature that support use of the treatment for your condition.

There is no way to describe how frightening and scary it is to have your insurer tell you that you are not going to be reimbursed. It is devastating. It takes a huge amount of energy to fight a bureaucracy, let alone while you are dealing with an illness. My insurance won't pay for Celebrex™; it is an expensive drug. They say it is experimental when taken as a cancer treatment. I tried in the beginning to fight this and gave up. It is something I need to start gathering energy to fight again. My insurance owes me thousands.

– Alice, diagnosed with NSCLC (stage unclear) in 2001 at age 58

Insurance companies sometimes challenge a provider’s fee stating it is above the customary amount charged for the service. In this circumstance, check with other local providers to find out if their fees are similar to what you were charged. People who handle patient billing and accounts at your care provider’s office may be able to help you with this process.

Document all correspondence with your insurance company. Take notes when you talk to a company representative. Include the date, the name of the person you spoke with, and what you were told. Keep a copy of any written correspondence between you and your insurance company. These documents can be very important in a disputed claim situation.
If you are convinced an insurance claim has been denied unfairly or incorrectly, do not be afraid to appeal the decision to the top level of the insurance organization. Your state insurance commissioner’s office may be able to assist you in this situation.

**Keeping Accurate Records of Medical Charges, Insurance Claims, and Payments**

It is important to keep track of all medical charges, insurance claims, and payments made by both you and your insurance company. Ask for a receipt for all charges from your doctor’s office, laboratory, or hospital. In some cases, your receipt may not be immediately available but will be mailed later. When you receive a bill or a copy of a claim, review it to make sure the charges are correct. If you find an error, contact the patient account representative at the office that issued the statement to request a correction. When the corrected statement arrives, review it to make sure the necessary corrections have been made.

When your insurance company pays a claim, they will send you a statement showing the amount paid to the care provider. You will be billed if there is a balance due after the insurance payment has been credited. Depending on your coverage and coinsurance responsibilities, your medical bills may exceed your ability to pay them. If you are unable to pay the full amount on one or more bills, call the care provider's accounting office and request a payment plan. Most health care providers are aware of the potential financial burden of medical expenses and are agreeable to a reasonable payment schedule.

Travel expenses for medical appointments and treatments are part of your yearly medical expenses and may be tax-deductible. Keep track of your mileage by noting the date of travel and the odometer readings when you leave for the appointment and return home. Mileage for side trips made for personal reasons are not deductible. You may want to keep a small notebook to record mileage because written documentation may be required by the Internal Revenue Service (IRS). Consult your tax advisor or call the IRS to request a booklet to help determine if these expenses are deductible.

Managing your treatment records and filing insurance claims can take a great deal of time and energy. Many people turn this responsibility over to a family member or friend. Your loved one will probably welcome the opportunity to help you. Private companies and some
community service organizations also offer assistance with these tasks. These organizations check bills, file claims, track deductibles, and advocate for their clients. Your oncology social worker or local cancer organization may be able to help you locate one of these assistance agencies.

MAINTAINING YOUR MEDICAL RECORDS

Many consumer and patient advocacy groups recommend maintaining a personal copy of your medical records. Advantages to this practice include:

- You can easily share important details of your medical history such as recent laboratory test results, previous treatments, and other important details with different members of your cancer care team.
- You have all the relevant background information the doctor needs if you decide to get a second opinion.
- Organized records make it easier to track your experiences and expenses.

Your Personal Medical Record

Essential elements for your personal medical record include:

- your medical history including allergies to medicines or other substances
- laboratory test results
- radiology or other imaging study reports including CT scans, chest x-rays, bone scans, and MRI studies
- medication records
  Include all medicines you are currently taking and have taken in the past for your cancer. Record any side effects from treatment. Note any medication allergies you may have.
- radiology treatment records
- copies of your advance directive and medical power of attorney papers (if you have these documents)
• procedure notes

These are notes written by doctors and nurses when you undergo an invasive medical intervention such as a needle biopsy, drainage of fluid from the lungs or abdomen, placement of a central intravenous line, or other procedures.

While you have a right to obtain a copy of anything in your medical record, it is usually not necessary to have a copy of every page. There are often many pages of doctor’s and nurse’s notes written in medical shorthand. These notes are written to help care providers track your progress, but may not be meaningful to non-medical readers.

You can construct a personal medical record using a 3-ring notebook and a set of dividers. Label the dividers:

- Medical History
- Laboratory Reports
- Radiology Reports
- Medication Records
- Radiation Treatment Records
- Procedure Notes
- Other – doctors’ names, addresses, telephone numbers, appointments, etc.

Place each document in the notebook behind the appropriate divider. Put the most current documents on top so that each section begins with the most recent information. Once you have your notebook assembled, ask for a copy of test records, reports, or other documents as events occur. You may want to include your own notes in each section that record your experiences and reactions with specific treatments or procedures. Ask your oncology nurse or the administrator at your doctor’s offices for copies of past medical documents you need. A request for medical records often must be made in writing.

I wanted to have copies of everything for my own records. I needed to know exactly what all was going on. I am absolutely convinced that you have to take an upper hand in your care. This was just one way to make sure I knew what was going on.

— Sandra, diagnosed with stage II NSCLC in 1998 at age 53
DISABILITY INSURANCE AND SOCIAL SECURITY DISABILITY

Private Disability Insurance Policies
Disability insurance is an insurance plan to provide a percentage of your normal salary should you becomes disabled and unable to work. There are two types of disability insurance, short and long-term. Short-term disability insurance is intended to last for a period of 13-26 weeks. The length of time long-term disability insurance pays benefits depends on the terms of the policy.

Individual short-term disability policies are uncommon and expensive. Long-term individual policies are available, but are usually much more expensive than group policies. Short and long-term group disability policies are offered through employers and other organizations. In general, you cannot purchase a disability insurance policy once you have been diagnosed with cancer.

Cancer is a valid justification to apply for benefits from a disability insurance policy. It is important to notify your insurance company soon after your diagnosis to begin applying for benefits. During the time you are considered disabled (unable to work), your premiums for disability and life insurance policies may be waived. Check your policy or call the customer service department of your insurer to find out if this waiver applies to your policy.

Military Disability Benefits
Military veterans diagnosed with lung cancer may be eligible for medical disability payments if the illness is service-related. To receive benefits, you must file a claim with the Department of Veterans Affairs (VA). Veterans who served in the Asian theater during the Vietnam conflict and later develop lung cancer are usually eligible for VA benefits. Exposure to Agent Orange has been linked to the development of lung and other cancers. According to government policy, all 2.6 million veterans who served in Vietnam and adjacent waters are presumed to have been exposed to Agent Orange.
To apply for benefits, write a letter to the VA Regional Office stating you have lung cancer that you claim it is due to your exposure to Agent Orange while serving in Vietnam. This is called an informal claim. It will set the effective date for your benefit payments if your claim is granted. The VA Regional Office will send you a benefits application form, which must be filled out and returned. To find the address of your VA Regional Office or for questions about filing a claim, call 800-827-1000. Alternatively, you can apply for benefits online at vabenefits.vba.va.gov/vonapp/main.asp.

A veteran’s representative can help you present your claim to the VA. Most veterans service organizations offer free representation. A listing of veterans’ service organizations is available on the Internet at www.va.gov/vso/index.htm. A listing of state veterans’ agencies is also available on the Internet at www.va.gov/partners/stateoffice/index.htm.

**Social Security Disability Programs**

The Social Security Administration operates two disability programs. Social Security Disability Insurance (SSDI) pays benefits to you and certain members of your family if you are insured and become unable to work. To be insured means that you worked and paid Social Security taxes long enough to qualify for benefits. Supplemental Security Income (SSI) is paid to people who are disabled based on their financial need regardless of payment into the Social Security system.

The definition of disability under Social Security is different from other programs. Social Security pays only for **total** disability. No benefits are payable for partial or short-term disability. Disability under Social Security programs is based on an inability to work. Under Social Security rules, you are disabled if you cannot perform the work you did before your illness, and it is determined you cannot adjust to other work because of your medical condition. To receive benefits, the disability must be expected to last for at least one year or to result in death.

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You should apply for Social Security benefits as soon as you become disabled. You will be paid retroactively once your application is approved based on the date you filed your claim. You may file a Social Security disability claim by calling 800-772-1213. The operator will set up a time for your local Social Security office to contact you and take your application over the telephone. Alternatively, you can visit your local Social Security office or file online at the Social Security Internet site at s00dace.ssa.gov/pro/isba3/wwwrmain.shtml.

When you are diagnosed with stage IV lung cancer, the government declares you terminal. When you are considered terminal, you are eligible for social security and disability.* So I applied and retired early.
— Joan, diagnosed with stage IV NSCLC in 1998 at age 56

*Liability is determined on a case-by-case basis. Consult your local Social Security office to determine your eligibility for benefits.

LIFE INSURANCE

It is difficult to obtain life insurance once you have been diagnosed with lung cancer or another potentially life-threatening illness. Life insurance applicants are typically asked if they have been treated for cancer or any other serious illness in the past 1-5 years, and if coverage has been denied in the past. These questions must be answered honestly. A misleading answer generally invalidates the policy on the grounds of fraud. No benefits are paid on an invalid policy.

The following options may provide you with an opportunity to purchase life insurance after you have been diagnosed with lung cancer.

- A guaranteed life insurance policy can be purchased without answering medical questions or undergoing a physical examination. The amount of life insurance you can purchase with a guaranteed policy is generally less than the amount available with a physical exam. Premiums are also often higher. Most guaranteed life insurance policies have a waiting period of 1-5 years before taking effect. If the insured person dies during the waiting period, the policy will not pay the beneficiary.

- A graded life insurance policy can usually be purchased without answering any medical questions. However, the benefits with these policies are graded, which
means the amount of the death benefit is low when you first purchase the policy but gradually increases over time (see the following example).

**$50,000 graded life insurance policy**

<table>
<thead>
<tr>
<th>If insured dies within:</th>
<th>Death benefit would be:</th>
</tr>
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<tbody>
<tr>
<td>6 months</td>
<td>10% or $5000</td>
</tr>
<tr>
<td>12 months</td>
<td>30% or $15,000</td>
</tr>
<tr>
<td>18 months</td>
<td>50% or $25,000</td>
</tr>
<tr>
<td>24 months</td>
<td>75% or $37,500</td>
</tr>
<tr>
<td>After 24 months</td>
<td>100% or $50,000</td>
</tr>
</tbody>
</table>

**Accelerated Death Benefits**

Many life insurance companies offer terminally ill people accelerated death benefits. Accelerated death benefits allow the policy owner to receive a significant portion of the death benefit in advance of his or her death. Often as much as 80% or more of the face value of the policy is available at any time within the last year or two of the insured person’s projected life. The money received from accelerated benefits can be used by the policy owner for any purpose he or she chooses.

Even if your life insurance policy does not mention accelerated death benefits, many companies still offer this option. Practices vary from one company to another in terms of how accelerated death benefits are handled. The benefits paid prior to death sometimes take the form of loans with the balance of the face value amount of the policy to be paid to the insured's estate after death.

Accelerated death benefits are usually tax-free. However, there are exceptions. Discuss your situation with a tax consultant or the IRS to determine if accelerated death benefits would be tax-free in your situation.

**Viatical Settlements**

Viatical settlements are cash payments made to people who sell their life insurance policies for a percentage of the face value of the policy. The percentage offered for a policy is highly
variable. The owner of the policy receives cash when the policy is sold. In exchange, the owner transfers the policy to the person buying the policy. The viatical settlement provider becomes the new owner and/or beneficiary of the life insurance policy and is responsible for paying all future premium payments. The new owner collects the entire death benefit of the policy upon the death of the insured.

The viatical industry is still relatively new. Over half the states in the U.S. have legislation to govern viatical company practices. However, the regulations vary widely. You must be very careful in selecting a company with which to do business if you decide to sell your life insurance policy. Important steps to take when you are considering a viatical settlement include:

- Talk with your doctor about your life expectancy. Most companies will not offer a viatical settlement unless your life expectancy is two years or less.
- Get at least five bids on your policy from competing viatical companies.
- Seek professional, legal, and financial advice from a tax attorney or an accountant. You need to know the tax consequences of a viatical settlement, and how it might affect your eligibility for entitlement programs such as Medicaid.
- Weigh the immediate need for maintaining your standard of living and quality of life against the future needs of your dependents or beneficiaries.

Viatical settlements are usually tax-free if the viatical company is licensed by the state in which you live. Discuss your situation with a tax consultant or the IRS to determine if a viatical settlement would be tax-free in your situation.

Before pursuing a viatical settlement, review all your options to be sure you have not overlooked another possible source of income. For example, are there any government-sponsored financial aid programs for which you may qualify? Does your life insurance policy offer accelerated death benefits? Can you borrow against the value of your life insurance policy? Other options may be available that will ultimately provide more benefits for you and your beneficiaries than a viatical settlement. However, in some cases, a viatical settlement may be your best option.
WORK ISSUES

Work is an important aspect of many peoples’ lives. Work meets many personal and social needs in addition to providing financial security. Many people with lung cancer continue working during treatment or return to work after completing treatment. The decision about how to handle your work situation will depend on many factors including:

- your current state of health
- your treatment plan and how it fits with your work schedule
- your financial needs
- your personal preferences

The decision about how to manage your work situation in light of your recent cancer diagnosis is entirely up to you. You may want to talk with your family and your work supervisor to determine what options are available to you.

Job Discrimination

Many employers are very supportive and accommodating of employees who are diagnosed with cancer. But unfortunately, some people with cancer experience job discrimination. Job discrimination can take many forms including:

- being passed over for a new job or promotion
- being fired or laid off
- being transferred or demoted
- having your hours cut
- unwillingness of your employer to accommodate your needs such as changing your schedule to allow time for your treatments
- being excluded by coworkers

People with cancer may face discrimination for a variety of reasons. Some people believe you can catch cancer by being around someone who has it. This is completely false. Cancer is not a contagious disease like a cold or the flu. In other cases, people with cancer may experience job discrimination because the employer is concerned about the illness affecting the employee’s ability to perform his or her duties. An employer may also be concerned about the liability of the company if the employee gets sick on the job.

Actions can be taken if you suspect you have been discriminated against because of your cancer diagnosis. Your first step might be to sit down with your supervisor and discuss the
situation. Relate your concerns and your desire to resolve them. You may find there are simple misunderstandings that can be easily resolved without further action. When talking the situation over fails to resolve the problem, it may be advisable to consider the following actions.

- Keep written records of all job actions including performance evaluations, promotions, and demotions. Note any comments, conversations, memos, or other exchanges that you think reflect job discrimination.
- Ask your doctor to write a letter to your employer discussing the type of cancer you have and explaining how it does or does not affect your ability to perform your job.
- Discuss work options such as a flexible work schedule, job sharing, and working from home with your supervisor or a human resources representative.

The Americans with Disabilities Act (ADA) is an important law that protects the civil rights of people with disabilities. According to ADA, anyone who has or has had cancer is considered disabled. Caregivers or family members of someone who has or has had cancer may also be covered under ADA provisions. ADA applies to all private employers of 15 or more employees, state and local government agencies, employment agencies, labor organizations, joint labor-management committees, religious bodies that are employers, and Congress. Federal government employees are protected under another law.

Important highlights of ADA that apply to people with cancer include:

- An employer cannot refuse to hire or continue to employ a person with a disability provided the person is otherwise able and qualified to do the job.
- An employee cannot be demoted or fired because of a disability. An employee also cannot be fired because the employer thinks there is or will be a disability.
- An employer cannot refuse insurance or other benefits to an employee with a disability when the same insurance or other benefits are provided to other employees.
An employer must provide reasonable accommodations to an employee with a disability, which would include retraining, special devices, or a change in some other part of the job such as a flexible schedule.

For general information about ADA, consult the U.S. Department of Justice Internet site at www.usdoj.gov/crt/ada/adahom1.htm or call the ADA information line toll-free at 800-514-0301. For information about how ADA applies to people with cancer, access the American Cancer Society (ACS) Web site at www.cancer.org/docroot/MIT/mit_3_1_2.asp. Alternatively, you can call ACS call at 800-227-2345 for information or to order their booklet, Americans With Disabilities Act: Legal Protection For Cancer Patients Against Employment Discrimination.

Your Coworkers

People who work outside the home must decide how to handle the news of their cancer in the workplace. The decision of whom to tell and exactly what you want to say is entirely up to you. Almost certainly, you will need to tell your immediate supervisor about your illness because you are likely to need time off from work during your treatment. If you decide you do not want your coworkers to know about your illness, be sure to tell your supervisor you want to this information kept confidential.

Many people find it is easier to share the news with their coworkers to prevent questions and speculation. Support from others in the workplace can be a source of comfort and assistance during a time of need. However, if you prefer to keep your condition private, that is an equally valid option.

People react differently to hearing news that a colleague has cancer. Possible reactions you may experience include expressions of concern and support, offers of assistance, avoidance of the topic, being told other people’s cancer stories, or being asked questions you might be uncomfortable answering. While most people are well intentioned, their reactions may not be in step with how you want to handle your work situation. Let your colleagues know clearly and kindly what you want from them. If you prefer to focus on work and not discuss
your illness, tell your colleagues this is your preference. Generally, explaining that it is best for you to focus on work while on the job will significantly decrease unwanted talk of your illness. Coworkers often express a desire to help. There may be tasks they can do that would be of assistance. Feel free to accept these well-intentioned offers of support. Chapter 9: Living With Lung Cancer has additional information on talking with others about your diagnosis.

I called my supervisor with the final diagnosis and he passed on the news to my coworkers. That was strange. I am a member of a 6-person support staff for a mid-size engineering and consulting firm. I never heard from one of my team members during the entire time I was off, but several of the engineers kept in touch regularly, which was very comforting. I imagine the others did not really know what to say or do, so they chose to say and do nothing.

— Patti, diagnosed with limited SCLC in 1998 at age 48

Vocational Services

A lung cancer diagnosis leads some people to re-evaluate their goals and values. You may decide to cut back your work schedule. Some people consider retirement. Others decide to pursue a new type of work that appeals to their sense of purpose and commitment. You may find that having lung cancer makes your previous line of work too difficult to continue. This is a frequent occurrence among people involved in physically strenuous work.

Vocational rehabilitation or retraining services are available to help people who are changing careers because of a disability (such as cancer) or a desire to try a new field. Vocational services can include:

- evaluation of job abilities and skills
- employment and educational counseling
- education and training to qualify for suitable employment
- financial assistance while in training
- job placement assistance
- tutorial assistance
- special equipment

Public and private agencies provide vocational services. Each state has a vocational rehabilitation agency that offers services to people with cancer and other life-changing illnesses. The Department of Veterans Affairs also operates vocational rehabilitation
programs for military veterans throughout the country. Your oncology social worker can help you locate vocational services in your area.

**MANAGING YOUR FINANCES**

Living with lung cancer can disrupt your normal financial situation. Circumstances that may disrupt your finances and your ability to manage them include:

- inability to work
- mounting medical expenses
- frequent travel for cancer treatment
- reduced time and/or energy to handle your affairs

This section presents some of the many options available to help manage your finances and alleviate possible financial hardships.

**Durable Power of Attorney for Financial Decisions**

Power of attorney (POA) is a document in which a person authorizes another individual to act on his or her behalf. The authorized person is usually called an agent or attorney-in-fact. Generally, this person is a family member or trusted friend. The most common uses for a POA are financial transactions and health care decisions. In most states, these functions are separate and require two different POA documents. See *Chapter 15: Planning for the Future* for information about medical POAs.

People with serious illnesses such as lung cancer sometimes choose to execute a financial POA in case they lose the capacity to handle their financial affairs. If you lose the capacity to handle your finances and do not have a durable financial POA in place, your family members will have to go to court and have a guardian or conservator appointed to manage your affairs. With a durable financial POA in place, the appointed agent will be able to handle your financial affairs without the time and attorney fees involved in going to court to get a guardian or conservator appointed. A durable financial POA can be designed to give as much or as little authority and decision-making power as you want your agent to have.
The term ‘durable’ in this context means the POA remains in force even if you lose the mental capacity to manage your own affairs. Unless a POA is durable, it becomes void if the authorizing person becomes incompetent.

It is important to clearly define when the POA becomes effective. If you wish to maintain control of your affairs for as long as possible, it is a good idea to specify that the power of attorney only becomes effective after your doctor certifies you have become incapacitated. Talk with your doctor about the circumstances in which he or she would deem you incapacitated.

**Financial Planning**

Many people with lung cancer find it useful to meet with a professional financial planner to help them make decisions about managing their financial affairs during treatment and afterward. The treatment period can bring about an extraordinarily high need for cash to pay for medical, household, and travel expenses.

A good financial planner reviews your finances and makes recommendations designed to preserve your assets. Be sure to check the background and credentials of any financial planner you hire. You may also want to ask for references from some of his or her clients. Many states do not regulate the financial planning industry. Therefore, it is up to you to be sure you are working with someone reliable and reputable.

**Money Shortages**

Medical expenses and time off work can create a financial hardship for many people living with lung cancer. A shortage of needed cash can add a great deal of stress to your personal situation. Several options are available to help alleviate a money shortage in your personal finances.

**Second Mortgages and Equity Lines of Credit**

Homeowners may be able to obtain needed cash by taking out a second mortgage or establishing an equity line of credit. A second mortgage is a loan borrowing against the equity you have built up in your home. Equity is the amount of money you have
paid off on the principal of your mortgage loan. With a second mortgage, you obtain the full lump sum of the loan at the time of dispersement and pay fixed monthly payments on the loan thereafter. The interest on a second mortgage is often lower than the interest on other types of bank loans or credit cards. Interest on a second mortgage is often tax-deductible. Consult with a tax advisor about your specific circumstances to learn how a second mortgage will affect your income tax situation.

An equity line of credit is a source of credit that is secured by the equity your home. Equity line interest is usually tax deductible, but you need to consult a tax advisor to be sure you understand the effects of an equity line on your tax situation. Unlike a second mortgage wherein you obtain a specific amount of money in one lump sum, you access the money available in an equity line as needed up to the maximum of your credit line. Unlike the fixed payments on a second mortgage, payments on an equity line depend on the amount you currently owe.

Consult with your local bank, credit union, or other lending institution to find out if you are eligible for these options. It is usually best to shop around to find the lowest possible interest rate.

**Reverse Mortgages**

A reverse mortgage is a special type of loan that allows eligible homeowners to convert the equity in their home into cash. In a reverse mortgage arrangement, the homeowner is given money borrowed against the equity in his or her home. The money can be paid to the homeowner in a series of payments, as a lump sum, or as a line of credit. Unlike a traditional home equity loan or second mortgage, no repayment is due on the borrowed money until the homeowner dies, the home is sold, or the home is no longer used as a principal residence. When one of these circumstances occurs, the reverse mortgage plus accrued interest must be repaid. Generally, the borrower must be 62 years of age or older to be eligible for a reverse mortgage.
The amount of money you can obtain from a reverse mortgage depends on:

- your age at the time you apply for the loan
- the type of reverse mortgage you choose
- the value of your home and how much equity you have in it
- current interest rates
- where you live

In general, the older you are, the more valuable your home, and the less you owe on your home, the more money you can obtain from a reverse mortgage.

The money received from a reverse mortgage is tax-free. It does not affect regular Social Security or Medicare benefits. However, the funds from a reverse mortgage may affect your eligibility for some government assistance programs such as Medicaid or state-operated assistance programs. Check with the programs you are receiving benefits from to find out if a reverse mortgage would jeopardize your eligibility. People who take out a reverse mortgage continue to own their homes and are responsible for all taxes on the property.

Reverse mortgages are offered by banks, mortgage companies, and other financial institutions. The U.S. Department of Housing and Urban Development (HUD) Internet site lists HUD-approved housing counseling agencies in each state. This list is available at [www.hud.gov/offices/hsg/sfh/hcc/hccprof14.cfm](http://www.hud.gov/offices/hsg/sfh/hcc/hccprof14.cfm). Counselors can advise you about the different types of reverse mortgages, answer questions, and refer you to lenders in your area.

**Personal Loans**

Family members or friend may be willing to lend you money if you are short of cash. While many people avoid these private arrangements for fear of damaging the relationships involved, a notarized promissory note can help establish clear parameters for the loan that will prevent any misunderstandings. You may want to consider including the repayment of any personal loan made to you by a loved one in your will.
Other Options for Obtaining Cash

There are other options available to obtain cash that may be applicable to your situation. A financial planner or consultant can advise you about what options might be best for your particular circumstances. Oncology social workers are also an excellent resource and may have other creative ideas about how to obtain the cash needed to maintain your current living situation.

Options you may want to consider for obtaining cash include:

- withdrawing money from a personal retirement account
- selling stocks or bonds
- selling some of your valuables
- accelerated death benefits and viatical settlement (see the section on Life Insurance in this chapter)
- borrowing against your life insurance policy

Assistance Programs

Many assistance programs are available to people struggling with a financial hardship. Services include access to medications, transportation, lodging, financial help, and other community services. This section reviews some of these programs, but there are many others. Your oncology social worker is an excellent source of information about assistance programs in your community. The Patient Advocate Foundation has a list of financial resources sorted by state on their Internet site at www.patientadvocate.org. You can also contact them toll-free at 800-532-5274.

Patient Assistance Programs

Patient assistance programs are operated by some drug companies to help people obtain medications they could not otherwise afford. Several Internet sites are available to help people find and access patient assistance programs including:

- Medicare site at www.medicare.gov/Prescription/Home.asp
- NeedyMeds, Inc. at www.needymeds.com
- Helping Patients operated by PhRMA at www.helpingpatients.org
- RxAssist at www.rxassist.org
Your doctor and oncology social worker are also good resources for information about patient assistance programs. If you have a specific drug you need to obtain, you can call the manufacturer directly and ask if they have an assistance program. You can locate drug manufacturers’ telephone numbers in The Physician’s Desk Reference, a book available in nearly every doctor’s office. Your public library may also have a copy.

**Drug Discount Cards**

A few drug manufacturers’ offer drug discount cards to Medicare recipients who have no other prescription drug coverage. The eligibility for and terms of these cards vary from one program to another. The Internet sites listed under *Patient Assistance Programs* also have information about drug discount cards. Your doctor or oncology nurse can also advise you about the availability of these programs for your drug therapy.

**Transportation and Lodging**

Several non-profit organizations arrange free or reduced-cost air transportation for cancer patients going to and from treatment. To obtain information about this type of transportation assistance, talk with your social worker or contact:

- Corporate Angel Network Program
  866-328-1313
  [www.corpangelnetwork.org](http://www.corpangelnetwork.org)
- National Patient Air Transport Hotline
  800-296-1217
  [www.patienttravel.org](http://www.patienttravel.org)
- AirLifeLine
  877-AIR-LIFE (877-247-5433)
  [www.airlifeline.org](http://www.airlifeline.org)

Discounted or free lodging is also available in some communities for patients receiving care away from home and their family members. Check into lodging availability by contacting your treatment facility or the National Association of Hospital Hospitality Houses, Inc. at 800-542-9730 or online at [www.nahhh.org](http://www.nahhh.org).
Community Service Organizations

Many agencies and volunteer organizations such as the Salvation Army, Lutheran Social Services, Jewish Social Services, Catholic Charities, the Lions Club, and others may offer financial help to cancer patients suffering a financial hardship. Some churches and synagogues also provide financial help and/or services to their members.

A friend of mine told me about an [organization in my community] that will come in help clean my home. I can't vacuum or mop anymore since I'm on oxygen. I gave them a call and they sent a woman out to see what I needed help with. They can do a number of things to help you, but my daughters do a lot of those things. I just needed them to mop, vacuum, and dust. It's very nice; a woman comes in for an hour on Monday and Tuesday to clean. It's something I don't have to ask my daughters to do. It's hard on them; they have families of their own to take care of.
— Judith, diagnosed with stage IIA NSCLC in 2001 at age 60

In some communities, the American Cancer Society or other cancer organizations offer modest financial aid for out-of-pocket expenses such as transportation to appointments, home or childcare services, groceries, utility bills, or other expenses. Your oncology social worker is an excellent resource to guide you toward organizations in your area that may offer financial assistance.

Government Agencies

Your city or state government may have programs to assist in relieving the financial burdens of individuals with serious illnesses. Again, your social worker is probably the best resource to find out about programs available in your area.

SUMMARY

Practical concerns about health insurance, life insurance, work-related issues, and financial matters can intensify the stress of living with lung cancer. Learning about your options and making use of the many services available to people with cancer can significantly reduce the stress associated with these practical concerns. Effective management of these concerns leaves you free to focus your energy on your health care and enjoying each day in whatever way you choose.
CHAPTER 15: PLANNING FOR THE FUTURE

INTRODUCTION

Each person on this earth will be here for only a limited amount of time. From the moment of our birth, we are on incredible, forward-moving journey that will one day end. The date and hour of our deaths are a mystery to us. In our day-to-day lives that are so full of life, we seldom think of death.

A diagnosis of cancer breaks through our routine and reminds us what we have known all along – that our time here is limited. Tomorrow and the future are suddenly thrown into doubt. Whether the questions are spoken aloud or in the solitude of the mind, everyone with cancer asks them:

What is going to happen to me?
Am I going to die?
What will happen to my loved ones if I die?

The thought of dying is frightening to many people. Yet death is part of every life. We all must face it one day. For some of us, it will be sooner; for others, it will be later. Perhaps you will die of cancer, or perhaps you will not. Nonetheless, having cancer reminds us to prepare for death, whenever it may come.

One of the aspects of death many people find frightening is lack of control over the situation. You have an opportunity now to prepare for death, whether it comes in a month or many years from now. Taking the time to prepare for death allows you to have some control over how that time of your life will unfold. The plans you make now may not be needed for many years. Nevertheless, having plans in place may give you peace of mind that when the time comes, you will be prepared.

Whether you are pursuing curative intent therapy or palliative care, the topics in this chapter are relevant. Unlike people who die unexpectedly of accidental injuries, a heart attack, or a
stroke, many people diagnosed with cancer feel they have been given a reminder about life and death. Now is a good time to consider doing things you may have been postponing. You have time to make preparations and do things you want or need to do.

This chapter reviews information about planning for the end of your life. It is not offered to upset you or diminish your sense of hope, but rather to help you. This book was written to provide you with information that will hopefully contribute to your well-being by bringing a sense of understanding and peace of mind to your journey with lung cancer. You can make many choices and plans now that will have far-reaching consequences for yourself and others. We encourage you to use this information to make the best choices for yourself and your loved ones.

GETTING YOUR PAPERWORK IN ORDER

‘Getting your affairs in order’ is a phrase we have all heard. Yet, when it comes to doing it, many of us have no idea where to start. In general, we are talking about collecting and organizing your personal papers. These would include such things as legal papers, income and investment information, loan papers, credit card information, insurance policies, etc. The reason for doing this is to make things easier for your family in the event of your death.

When I was diagnosed with lung cancer, I had just lost my husband the year before to brain cancer. So everything in the will and all the financial accounts had been put into my name. When the doctors asked me if I wanted to get thing in order, of course it was an awful feeling. I went down to my social worker’s office to talk it over with her. She was wonderful. She helped me understand that it is just a good thing to do, and that no one knows when something may happen. I might get hit by a truck tomorrow. It was just good to have things in place. She helped me realize it wasn't so scary. I had always thought that if you filled out a will that meant you were going to die. But I went to my financial planner who took care of everything with my late husband. I had no idea what all I needed to do until [my financial planner] helped me. He was wonderful. After that, I just felt like I had things taken care of. I was still in the thick of it emotionally, so it was good not to have to spend a lot of time thinking about getting my affairs in order.

– Judy, diagnosed with limited SCLC in 1998 at age 57

You may just need to make sure your files are current if you already have your personal papers organized. If your papers are scattered, it is best to collect them in one location and
organize them. Be sure a trusted family member or friend knows where all your important papers are located. If you keep some of your papers in a safe deposit box and it is in your name only, you may want to grant another person access to the box. Giving a second person access ensures that your family can get to any paperwork they need. Be sure someone you trust has the combination if your papers are kept in a personal safe.

**Personal Papers**

Personal records are documents and information that relate to your history. Important information to gather for your personal records includes:

- full legal name
- any previous legal names you have used including your maiden name if you’re a married woman
- birth certificate; if you do not have a birth certificate, you can request a certified copy from the vital records division in the state of your birth
- social security number
- military records
- names, addresses, and telephone numbers of previous employers and approximate dates of employment
- name, address, and telephone number of your personal attorney, if applicable
- pre-arranged funeral or burial arrangement documents

**Financial Records**

Your financial records include information about bank accounts, investments, real estate, insurance policies, credit cards, loans, deeds, titles, etc.

A list of documents to include in your financial records includes:

- account numbers and recent statements for all your bank accounts including checking accounts, savings accounts, and certificates of deposit (CDs)
  - if you have a personal banker, note his or her name and telephone number
- list and location of savings bonds
• safe deposit box information
• account numbers and recent statements for your investment and retirement accounts including IRAs, 401Ks, pension funds, bond funds, and stock or trading accounts
  – if you have an investment advisor or financial consultant, note his or her name and telephone number
• federal and state income tax returns from the past 2-3 years
• the deed to any property (real estate) you own
• property tax documents
• original insurance policies including house, car, medical, and life insurance
  – include names and telephone numbers of agents or other contacts for each policy
• Medicare information
• Social Security information including any benefits you have received
• credit card policies, account numbers, and recent statements including current balances
• loan papers and account numbers for car loans, mortgage accounts, and personal loans
• titles of vehicles and registration information
• list and location of valuables including jewelry, collections, family heirlooms, etc.

Legal Documents
Any legal documents you have are important even if they are from the distant past.
Examples of legal documents to keep in your personal papers include:
• marriage certificate(s)
• divorce papers
• adoption papers
• your will or trust documents
• durable power of attorney documents
• advance directive or living will
• *health care power of attorney* documents; include contact information for your appointed health care agent

Collecting this information can be a sizable task. You may want to ask a family member or friend to help you collect and organize this information. Whatever you can do now will help make things easier for your family in the future. Working on this task with a family member may also give you an opportunity to talk about things that otherwise might be difficult to bring up in day-to-day conversation.

**Special Considerations for Your Family**

There are a number of things you and your family should be aware of that may take place after your death. Preparing ahead of time can make things easier for everyone involved.

• **joint checking accounts**
  There are different types of joint checking accounts in terms of the rights of the surviving person to access the money in the account. The money in an account that has limited right of survivorship may be frozen for a period of time after the death of one of the joint owners. The bank will not freeze a joint account that has absolute right of survivorship. Check with your bank to see what kind of joint account you have. You may need to change the type of account you have or open a separate account for your spouse to be sure he or she has immediate access to cash after your death.

• **gift taxes**
  The federal government and some states have inheritance taxes. You may be able to avoid some of these taxes for your family members by transferring assets to them before your death. A certified public accountant, tax consultant, or estate-planning lawyer can advise you about such transfers.

• **Social Security and retirement benefits**
  If you are receiving social security benefits, your family needs to be aware that they are *not* entitled to continue receiving these benefits after you die. Your spouse and/or minor children may be eligible to receive their own social security benefits, but they are not entitled to your benefits. If they receive money for you
after your death, this money will have to be returned. The same holds true for most retirement benefits.

• **insurance policies**
  If you are the primary holder of your house, car, and/or health insurance, your spouse will need to arrange to have these accounts changed after your death. You may be able to make changes to your policies now to avoid your spouse having to handle this later. Contact your insurance agents to check what can be done now and what needs to be done later.

• **credit card accounts**
  Any credit card accounts where you are the primary cardholder and your spouse is an authorized user will be closed if you die. Your spouse will not be able to use these accounts. Your spouse may want to consider establishing a credit card account in his or her own name now to avoid being left without a valid credit card.

• **income taxes**
  Special tax rules apply to people who usually file a joint return when one person in the couple dies. Talk with your spouse to be sure he or she knows this. A tax consultant can advise your spouse about what needs to be done.

**ESTATE PLANNING**

*Estate planning* involves making plans for how you want your personal property and money handled after your death. Many people mistakenly believe only very wealthy people need a will. Others do not think a will is necessary because they assume their assets (anything of value) will automatically go to their family members. The truth of the situation is that if you die without a will or other estate-planning document, the state will decide what happens to your property. Each state has its own inheritance laws, which vary considerably. An *intestate estate* is the estate (assets) of a person who died without a will or other estate-planning document. An intestate estate will be distributed according to formulas set out in state law.
This section presents basic information about estate planning. Depending on the size of your estate (the value of your assets) and the complexity of your wishes, you may want to consult with an estate planning lawyer, financial consultant, and/or tax consultant.

**Wills**

A will is a written document that directs how you want your assets distributed after your death. The term will is actually a shortened version of the legal term *last will and testament*. In your will, you can appoint someone as your executor or personal representative. The executor is responsible for distributing your property according to the instructions in your will. It is usually in your best interest to name an executor. If you do not name an executor, the court may require a lawyer or financial officer be hired to serve as the executor of your estate. In this instance, the money to pay the court-appointed executor is taken from the estate. Depending on the complexity of your estate and will, the fees for a hired executor can be substantial.

Many people postpone preparing a will because they are concerned about expensive legal fees. Numerous self-help books and legal software programs are available to help you prepare a simple will if that is something you would like to consider. Preparing your own will may be an option if the distribution of your estate is simple, for example, leaving all your assets to your spouse. If you decide to prepare your own will, it is best to have a lawyer look it over to be certain it is valid.

It is usually best to have a lawyer draft your will if any of the following circumstances apply to your situation:

- you plan to split your estate among several people
- you plan to donate money to charity
- you will be giving gifts to minors
- you want some or all of your assets placed in a trust (see below for information about trusts)
- you own property in more than one state
- you want to forgive debts that others owe you
- you have any other special stipulations for your will
Your local bar association chapter (a professional organization for lawyers) can help you find a lawyer who specializes in estate planning or direct you toward free or low cost legal services in your area. The American Bar Association Internet site has a directory of pro-bono (free) legal services listed by state at www.abanet.org/legalservices/probono/directory.html#. Local senior citizen organizations may also be able to recommend estate-planning specialists. Some community-based programs provide free legal services. Your oncology nurse or social worker may be able to help you find such programs.

If you have a spouse who will survive you, it is very important for him or her to have a will also. This is especially important if you have children or other dependents.

_We already had a will in place before I was diagnosed. However, it was now time to update it. It is just something that had to be done. We have children and we needed to make sure things were in place – just in case. It's not something we continually focused on, but we wanted to make sure that things would be taken care of._

— Janet, diagnosed with stage IV NSCLC in 2000 at age 46

**Guardianship**

You may need to address guardianship in your will if you are the parent or guardian of one or more minors (children less than 18 years of age). Generally, the surviving parent of a minor child will be granted custody unless he or she is unfit or unable to parent. In the event your child’s other parent is deceased, cannot be located, or is unfit to parent, another adult must be named as the minor’s legal guardian. It is in the best interest of your child to name a legal guardian in your will if any of these circumstances apply to your situation. If you do not name a guardian for your child, the court will appoint one.

**Probate**

Probate is the formal court process whereby a judge or other court-appointed official makes a legal decision about whether the will presented to the court requesting that a deceased person’s assets be distributed is valid. A probated will is one in which the court has made a legally binding determination that the document presented is in fact the last will and testament of the deceased person. A will must be probated before the assets of the estate can be distributed.
Some assets are not subject to the probate process, that is, some assets are not considered part of a person’s estate. Life insurance policies, certificates of deposit (CD’s), savings accounts, and annuity accounts are usually not considered part of your estate because they have a named beneficiary (a person to whom the value of the policy or account is paid if you die). You may want to check these policies or accounts to be certain the person you originally named as beneficiary is in fact the person you want to receive the funds.

**Trusts**

A trust can be used as another type of estate planning. A trust is a legal arrangement concerning the ownership and distribution of property. Once you set up a trust, it becomes a legal entity separate from you. If you set up a trust while you are alive, you can transfer any or all your assets to the trust including your home, property, retirement accounts, etc. You can also make the trust the beneficiary of your life insurance policy, annuities, and savings accounts. One of the advantages of a trust is that it is not subject to probate, which means the time and cost of probate can be by-passed. When you set up a trust, you prepare a trust document that outlines the distribution of the assets in the event of your death. You can also specify conditions you want attached to the distribution of the assets. For example, you may want to leave money to your grandchildren, but do not want them to have access to the money until they graduate from college. The manager of the trust will hold the money for your grandchildren until the conditions of distribution are met. Trusts can also be used to distribute money in installments to people or charities.

A trust established while you are alive is called a living trust. A living trust can be set up so that you are able to change the terms or conditions of the trust any time you wish (a revocable trust). Once the owner (the grantor) of a trust dies, the terms and conditions of the trust can no longer be changed, that is, it becomes an irrevocable trust. You can also arrange to have one or more trusts established after your death. This is generally done within a will and is subject to probate.

There are several different kinds of trusts. Although there can be clear advantages to trusts depending on how you want to distribute your estate, trusts can be very complex legal and
financial arrangements. It is usually best to work with a lawyer and financial advisor who are experienced in the use of trusts for estate planning.

All my children have a copy of my will and the trust. I didn't want any surprises. We are and have always been very open in talking with one another. Two of my daughters currently have access to my account. I didn't want to have them try to pay for something if I was unable to write a check. I wanted to make it easy on them. It was a little difficult when my children first saw the trust. My other daughter didn't have access to the account and was offended. But we talked about the situation and she understood. We have been fine since. I know what works for us may not work for everyone, but what I think always works is honesty.

Anita, diagnosed with stage I NSCLC in 1991 at age 60

ADVANCE CARE PLANNING

Advance care planning is working with your health care providers to plan for the kind of medical care you want and do not want at the end of your life. This planning is best done well in advance of your need for end of life care. With advance care planning, you can make your medical care choices known to your doctors now in case you become unable to clearly express your wishes at a later time. An advance directive is a written document that outlines your end of life medical care choices. A living will is an advance directive that applies specifically to a person who has a terminal illness. Many people use the terms living will and advance directive interchangeably.

The Patient Self-Determination Act (PSDA) is a federal law passed in 1990 that requires medical providers to inform all adult patients about their rights to accept or refuse medical or surgical treatment and to execute an advance directive. Every state and the District of Columbia have laws pertaining to the validity of advance directives. Although the details of these laws vary, they all give people the legal right to state in advance what kind of medical care they want and do not want if they come to a point where they cannot make their choices known to others.

In an advance directive, you grant another person permission to make medical choices on your behalf. Granting someone the right to make medical choices for you is called medical
or health care power of attorney. The person you give this right to should be someone you trust to fulfill your wishes and with whom you have discussed your preferences in detail. The legal term for this person varies from one state to another, but common terms are surrogate, proxy, or agent. For simplicity, the term agent is used in this chapter. You may want to consider having a back-up health care agent. The back-up agent would fill in for the primary agent if he or she could not be reached. Keep in mind, your health care agent is consulted only in a situation where you are unable to speak for yourself due to circumstances such as unconsciousness or permanent confusion.

You can grant a family member medical power of attorney. In some cases, it may be difficult for a family member to carry out your wishes if you are near death. This is especially true if your wishes differ from your family member’s personal beliefs about your choices. If you are concerned that carrying out your wishes may place too much stress on a family member, it may be preferable to appoint someone outside your immediate family. A trusted friend may be a practical alternative. It is not necessary to appoint an agent as part of an advance directive unless you live in New York, Michigan, or Massachusetts. The laws of these three states require the appointment of a health care agent to make medical decisions for you if you are unable to make your wishes known, but do not authorize living wills without an agent. Alaska places some limitations of what kinds of decisions your health care agent can make on your behalf. The other 46 states and the District of Columbia authorize advance directives and medical power of attorney.¹

I had three really close friends and a brother whom I had thought [of] for a health care agent. But they all passed away prior to my diagnosis. So instead of assigning someone who I hardly know, I spoke with the woman I had entrusted with my financial affairs. I approached her and we talked everything over. We both felt comfortable with her making decisions if need be. You need to have someone who can make these decisions, and I feel completely confident in her decisions.
— Dorothy, diagnosed with stage IIIA NSCLC in 1998 at age 68

If you live in a state that authorizes both advance directives and medical power of attorney, consider having both. Having both documents provides the assurance of having the advance directive in place if your health care agent cannot be reached.

¹ According to state legislation as of March, 2003.
Executing An Advance Directive

Forms are available from many sources to create an advance directive. Because state laws for advance directives vary, you need to be sure you use an advance directive form that is suited for your state. Many oncologists and oncology social workers have advance care forms or can tell you where to get them. Most hospitals and home health and hospice agencies also have advance directive forms. Your public library is another possible resource; if they do not have the forms, they can help you find out where to get them.

Advance directive forms have directions for how to fill them out. Follow the directions carefully, especially the directions for signing the form and having it witnessed. An advance directive that is not properly witnessed may not be valid.

Advance directive forms may use words that are unfamiliar to you. Terms you need to understand are described below. If you are uncertain about the meaning of any of the terms on an advance directive form, take it to your doctor or nurse and ask about the terms. You need to understand all of the terms on the advance directive form before filling it out and signing it.

- **artificial nutrition and hydration** – food and water fed to a person through a tube when he or she cannot eat or drink enough to sustain life
- **comfort care** – care that helps keep a person comfortable but is not intended to prolong life; bathing, applying lotion to the skin, grooming, and keeping a person's lips moist are examples of comfort care
- **cardiopulmonary resuscitation (CPR)** – medical efforts to restart the heart if it stops beating and artificially breathing for a person if he or she stops breathing
- **death delaying procedure** – another term for life-sustaining treatment; any medical treatment used to keep a person from dying including such things as CPR, breathing machines, artificial nutrition and hydration
- **Do-Not-Resuscitate order (DNR)** – a DNR order is a doctor’s written order instructing health care providers not to attempt cardiopulmonary resuscitation (CPR) if a person stops breathing or if his/her heart stops beating
• **life-sustaining treatment** – any medical treatment used to delay a person’s death; a ventilator (breathing machine), CPR, and artificial nutrition and hydration are examples of life-sustaining treatments

• **persistent vegetative state** – the condition of a person who is unconscious with no hope of regaining consciousness even with medical treatment; the person may have some body movements and at times, his or her eyes may be open, but as far as the doctors can tell, the person can no longer think or respond

• **terminal illness** – an ongoing illness that has no known cure; a disease that doctors expect will lead to a person’s death even with medical treatment; life-sustaining treatments may prolong the life of a person with a terminal illness but they will not prevent death from the illness

• **withdrawing treatment** – discontinuing life-sustaining treatments after they have been used for a certain period of time

• **withholding treatment** – not beginning any life-sustaining treatments

The signed original of your advance directive and/or medical power of attorney document should be stored in a safe place such as a fireproof cabinet or safe deposit box. Give your primary health care agent and his or her back-up copies of these papers. Give another copy to each of your health care providers. You may want to give some of your family members copies, too. Distributing copies of your advance directive to these people helps insure that if a time comes when the advance directive is needed, it will be available. Advance directives and medical power of attorney documents do not have a time limit. They are valid until you destroy them or revoke them in writing.

An advance directive can bring you peace of mind in knowing that your wishes about your health care will be fulfilled even if you get to a point where you cannot express your choices. Many who have advance directives say it gives them a sense of self-determination. Advance directives can also prevent your family members from having to make very difficult, stressful, and emotional decisions. In this way, many people consider advance directives one way they can take care of their family members.
I am an attorney. I work with people every day to set up advanced directives, and I didn’t even have one for myself until after I was diagnosed. I appointed my mother and fiancé as my health care agents – not that they had to make the decisions cooperatively. Whomever the medical staff could get a hold of first would be fine. I also arranged my wishes for life support. Having done that, I felt so much better. It was a relief to me to know it would relieve the stress of my family.  
– Joanne, diagnosed with stage IIIA NSCLC in 2001 at age 52

END OF LIFE CARE

Where Do You Want to Be?

One of the choices to be made about your end of life care is where you want that care to take place. The three most common choices are a hospital, a hospice facility, or your home. It is often helpful to think about these choices well in advance of when you will need this type of care.

Hospital Care

Hospital care is usually the choice of people who want life-sustaining treatments for as long as possible. This kind of care includes treatments such as intravenous fluids, artificial feeding through a tube, and assisted breathing. While these measures will not prevent death, they may keep you alive longer than if you did not receive them. If you do not want life-sustaining treatments at the end of your life, another choice may be better suited to your wishes.

Hospice Care

The word hospice describes a system of care for dying people and their families. Approximately 80-90% of hospice care takes place in the home of the patient. Hospice facilities are also available in some communities for people who want to receive hospice care outside their home. These facilities offer specially designed inpatient accommodations devoted exclusively to the care of people who are dying. There are no established visiting hours at these facilities, although patients can set limits on who they want to see and when.
The principles that guide hospice care include:

- Hospice care is designed to provide comfort and support to patients and their families when a terminal illness no longer responds to curative or life-prolonging treatments.
- The goal of hospice care is to improve the quality of a person’s last days by offering comfort and dignity.
- Hospice care addresses all symptoms of a disease with special emphasis on controlling pain and discomfort.
- Hospice addresses the emotional, social, and spiritual impact of the disease on the dying person and his or her loved ones.
- Hospice focuses on quality rather than quantity of life.
- Hospice care does not prolong life and does not speed the dying process.
- Hospice offers grief counseling services to families before and after their loved one’s death.

Hospice care is recommended when life expectancy is six months or less. Medicare and most insurance plans cover hospice care if your doctor stipulates this life expectancy. Your doctor needs to make the initial referral to a hospice program for you. Hospice staff meets with your doctor to discuss your medical history, current symptoms, and supportive care treatments. After meeting with your doctor, hospice staff will meet with you and your family to explain hospice care and services, discuss your current symptoms, and answer any questions you may have. The hospice staff will work with a hospice doctor to develop a care plan for you. The care plan will be adjusted as needed over the course of your care. Hospice services include:

- nursing care
- home health aides
- medical equipment and supplies
- nutritional counseling

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2 Adapted from “What Is Hospice?” from the Hospice Foundation of America® at www.hospicefoundation.org.
respite care – staff or volunteers come into the home to give family members free time to do errands or have some quiet time

• grief counseling

• chaplain services

• social services

Since hospice care does not aim to prolong life, when death occurs, there is no attempt to resuscitate the patient (to restart the heart or breathing).

Some resources to help you locate hospice programs in your area include:

• Hospice Foundation of America
  800-854-3402

• American Hospice Foundation
  Internet search at www.americanhospice.org/ahfdb.htm

• National Hospice Foundation
  Internet search at www.nhpco.org
  800-646-6460

We found that the doctors at the hospitals... don't talk about dying.... They just said Janet had 6 to 9 months to live. When we heard this Janet turned to me and said, “I want you to do two things: one, be cheerful around me, and two, keep me out of the hospital.” I did my best to do both. In order to keep Janet out of the hospital, we had a wonderful nurse with hospice, Maureen. She came once a week. Janet always looked forward to Maureen’s visits; she took care of all the medical things for us. She was straightforward and answered my questions. She was always compassionate and cheerful when she came. If Janet was in pain, Maureen would adjust the meds to make her comfortable. Janet died happily in her own home with her children all around her. Because of hospice, she had as good of death as one could have.

– David, husband of Janet who was diagnosed with extensive SCLC in 2001 at age 79

Resuscitation

The term resuscitation describes medical treatments used to restart the heart if it stops beating and restore breathing if it stops. When the heart and breathing stop and resuscitation is not performed, death has occurred. If you are facing death, it is important to consider ahead of time whether you want resuscitation. This can be a difficult decision. You may want to talk with your family and/or a spiritual advisor to help you sort through your thoughts and
feelings about this topic. Whatever you decide, it is important to make your choice about
the use of resuscitation known to your health care providers and family so your wishes can
be carried out.

I was aware [my surgery] was dangerous. I made sure my doctors
understood that I wanted to be a survivor and if that meant resuscitation,
then that's what they should do. I can understand if people don't want to be
resuscitated, but I felt I was in good health in every other way. And I was
going to be a survivor!

– Rita, diagnosed with stage I NSCLC in 2001 at age 58

If You Want Resuscitation

If you are in a hospital, resuscitation is the normal procedure when someone’s heart
and breathing stop. No special requests or forms are needed to insure that
resuscitation will take place.

If you are at home, you need to be sure your family members know that you want
resuscitation. In the event your heart and breathing stop, they need to call 911
immediately to request an ambulance. Emergency medical personnel must perform
CPR on anyone whose heart and breathing has stopped. If your family members
know how to perform CPR, they should begin CPR until the ambulance arrives.

If You Do Not Want Resuscitation

Resuscitation is the standard medical response when someone’s heart and breathing
stop. Therefore, if you do not want resuscitation, you must take actions to make
your wishes known. This is one of the main purposes of an advance directive. Talk
with your family members and health care agent (if you have one) in advance about
what they need to do or not do in specific circumstances to insure that your wishes
are carried out.

If you are admitted to a hospital, a family member or your health care agent must be
certain the hospital staff has a copy of your advance directive in your medical chart.
In addition, you doctor needs to write a Do Not Resuscitate (DNR) order on your
chart. This is very important. If a signed DNR order from a doctor is not on your
chart, resuscitation is legally required even if your advance directive has been provided.

If you are at home, be sure your family members and others who may be caring for you know not to call an ambulance if your heart and breathing stop. Emergency workers are required to perform CPR if they are called. Your doctor or hospice staff will tell your family members what to do if you die at home. This should be discussed well in advance so your family members are not frightened or confused about what to do.

The decision to forego resuscitation can be difficult for family members. Letting go of a loved one can be extremely emotional and painful. Talking about your decision with your loved ones ahead of time can make it easier for them to respect your wishes when the moment of carrying out your choice arrives.

**Talking With Your Doctor About End Of Life Issues**

Death is a very difficult topic for many people to think about. It is even harder for many people to talk about it. Your doctor may be hesitant to bring up end of life issues such as hospice care, advance directives, and resuscitation because he or she:

- does not want to offend you
- does not want to squelch your sense of hope
- is waiting for you to bring up these topics, or to give him or her a cue that you are ready and willing to talk about them
- is not completely comfortable talking about these issues

While it may be difficult to raise these issues with your doctor, it is important to do so if he or she does not. There may be an awkward moment or two when you first raise the topic, but both you and your doctor are likely to feel a sense of relief once these subjects have been discussed openly. If you are having difficulty bringing up end of life issues, tell your
oncology nurse you want to discuss them with your doctor. He or she can let your doctor know. This is often the sort of cue your doctor is waiting for to let him or her know you are ready to talk about these important issues.

**FUNERAL AND MEMORIAL SERVICES**

Since the beginning of recorded history, every culture has had special ceremonies and rituals to honor the dead. Psychologists and grief counselors tell us these ceremonies and rituals are an important part of the grieving and healing process. They allow family members and friends an opportunity to honor the life of their loved one, and to begin the process of saying good-bye to the earthly relationship they shared.

Depending on your cultural background and spiritual or philosophical beliefs, you may have specific preferences about what kind of ceremonies, rituals, and procedures you want following your death. If you so desire, you can make arrangements now to be sure your wishes are fulfilled.

*When I was diagnosed, the doctor said I had a 40% chance to live as long as six months. He told me to get my things in order – so I did. I felt like cancer had taken away my freedom to choose. I had no choice. I had to go through chemotherapy. I had to have radiation in order to live. So at least if I was going to die, I was going to have a say. I went to the funeral home and picked out my casket, bought my burial site, and decided what I wanted on my head stone. I even decided what color my nails were to be painted. I wrote instructions to my daughters. I didn't want any flowers, and I meant it. I wanted contributions to go towards cancer research. Once I made all the arrangements, I felt relieved – not for myself, but to take the burden off my children.*

– Barbara, diagnosed with extensive SCLC in 1997 at age 47

A funeral or memorial service is not required by any agency. It is a matter of personal choice. If you have strong feelings about not having a service, or if you want a service limited to family members, consider putting your request in writing as part of your will. It is usually best to discuss your decision with loved ones in advance.

*In my mind, a funeral and ceremony is something for the loved ones who [are] left behind. So I have left it up to them since it won't bother me a bit; I'm no longer there at that point. My suspicion is they will not do anything being that my husband
Some people prefer to have friends and loved ones make donations to charitable organizations rather than sending flowers for a funeral or memorial service. You may want to write letters to your loved ones to be read at your funeral or memorial service. The choices are yours. Again, you can make your wishes known in your will, by talking with your family, and/or by making arrangements with the institution that will be handling your service.

One consideration is what you want to have happen to your body. Cremation and burial are the two most common options. If you have strong beliefs or wishes about these options, you can include your wishes in your will. You can also prearrange for the services you want. Some people do this to insure that their wishes are honored, and to spare their families from making arrangements when they are going through the immediate pain of losing their loved one.

Many people with cancer wonder about organ donation. People who die of cancer cannot donate their organs to others because the cancer can be transmitted to the recipient through the donated organ. An exception to this rule is the corneas of the eyes, which can be donated in most instances.

While organ donation is not an option for people with cancer, you can donate your body (in whole or in part) for scientific and medical research. Arrangements generally need to be made ahead of time for this type of donation. Medical schools and medical research institutions are the primary recipients of body donations for research purposes. If you live near a medical school, you may want to contact their anatomy department to learn more about their donation program. A list of body donation programs in the United States and contact information is available on the Internet from the University of Florida State...
Anatomical Board at [www.med.ufl.edu/anatbd/usprograms.html](http://www.med.ufl.edu/anatbd/usprograms.html). There is usually a transportation fee charged by the funeral home to take a donated body to the site receiving the body.

You have the time to plan anything you want to have happen in the aftermath of your death. The choices are yours. Planning for your own death can be difficult because it brings up painful feelings of sadness and loss. Your family may resist you making plans because it is painful for them, too. However, planning now can give you the peace of mind of being sure things will be done as you wish. It may also present opportunities for you and your loved ones to talk about emotional but important matters. Sometimes the difficult things we face together bring us closer.

**YOUR LEGACY**

Your legacy is what you leave behind of yourself for your family, friends, and community. We all leave traces of ourselves behind when we pass from this world. We leave behind our love, the effects of love, and the fruits of our work and actions. If you are at a point in your life where you are preparing for death, you may want to think about the legacy that you want to leave behind. Your legacy can take any form you wish. It will be as unique as you are.

Some people keep a journal of their cancer experiences with notes to family and friends about what their efforts meant. Such a journal can be a source of comfort for your loved ones and may help them work through their grief. You may want to have a friend or family member help you make videotaped messages as a way to give special people in your life a permanent visual and auditory message from you. Personal letters are another option. A friend, loved one, or a hospice worker can write what you dictate if writing is difficult for you. Artists may choose to create small works of art for special people in their lives. Musicians may leave a special work or song for loved ones. There are no limits to what you can give as part of your legacy. Whatever you leave to those who love you will be invaluable because it came from your heart.
If you have significant financial assets, you may want to consider charitable donations to further causes that are dear to you. You can set up a scholarship fund or donate to the arts, medical research, or environmental causes. Any way you choose to give will be a special gift you contribute to the world you have shared with others.

Despite the hardships, cancer has changed my life by making it richer in every way and by allowing me the opportunity to help others who are affected by this devastating disease. In March 1999, when I recovered from my lung surgery, I started a Website called Lung Cancer Online for patients and families. At that time, there were few online resources for lung cancer, and those that existed were difficult to locate. Lung Cancer Online was designed as a comprehensive, annotated directory to the best sources of lung cancer information and services on the Internet. My intention was to save patients the time and aggravation of searching for valuable information. As a librarian, I also provide reference and referral services through the website. It is my great privilege to help and get to know so many lung cancer patients and family members in the course of my work.

— Karen, diagnosed with stage IV NSCLC in 1998 at age 38

My legacy is my children.
— Larry, diagnosed with stage II NSCLC in 1991 at age 53

**SUMMARY**

From the time of our birth, we are all moving closer to our death. Death is part of life. While we are busy with the day-to-day tasks and joys of living, we rarely think of death. A cancer diagnosis brings us face-to-face with the inevitable reality of death. While the reality of death can be sad and difficult to accept, it also brings opportunities.

Although your time left may be shorter than that of someone else, you do still have time. Each day brings new challenges and new opportunities. Someone like you once wrote:

Yesterday is history.
Tomorrow is a mystery.
Today is a gift.
That’s why it’s called the present
~ Anonymous

You have today. You can make choices about how you want to live the time you have in the present. You can do many things now that may make things easier for you and your loved ones in the future. Some of these tasks may be hard to think about but may ultimately bring
peace of mind for the future. We encourage you to allow others to help you with your preparations for the future. Those who love you are often looking for opportunities to help you. Allowing them to be of service to you may be one of the most generous gifts you can give them.

Consider what you want to leave behind in this world. It can be as simple and as personal as a letter to your family or as encompassing as funding a foundation. The parts of yourself you leave behind for others will be as unique and precious as you are.

I hope the information provided here will help bring you peace of mind and comfort. I hope it will help relieve you and your loved ones from as much pain, anxiety, and stress as possible. It is my wish that the information presented will contribute to a fulfilling, peaceful journey through the end of your life – whenever that may come to pass.
All chemotherapy drugs can cause side effects. No one can predict ahead of time what side effects you may experience or their severity. Some people experience only a few, mild side effects. Others experience many side effects, some of which can be severe enough to cause changes in the dose of the drug and the treatment schedule.

Every chemotherapy drug has the potential to cause myelosuppression, that is, to reduce the production of bone marrow cells. The severity of this side effect varies widely from one drug to another. Myelosuppression can result in anemia, low white blood cell counts (leukopenia), and low platelet counts (thrombocytopenia).

This appendix contains an alphabetical listing of the most commonly used chemotherapy drugs used to treat lung cancer. The drugs are listed by their generic name followed by their trade name and alternate name(s), if applicable. Each listing shows the known side effects of each drug according to whether they are more common, less common, or rare. It is possible to experience side effects that are not listed.

It is important to discuss with your doctor the possible side effects of any chemotherapy drug you will be taking. Any new symptoms experienced while on chemotherapy should be reported to your cancer doctor even if you are not certain whether the symptom is related to your treatment. Chapter 10: Supportive Care contains information about the management of treatment side effects.

The information contained in this section is based on public data listed on Medline Plus, a service of the U.S. National Library of Medicine and the National Institutes of Health. The Internet site can be accessed at www.nlm.nih.gov/medlineplus/druginformation.html.
**Carboplatin** (Paraplatin®)
Type: alkylating agent

<table>
<thead>
<tr>
<th>More Common</th>
<th>Less Common</th>
<th>Rare</th>
</tr>
</thead>
<tbody>
<tr>
<td>pain at injection site</td>
<td>black, tarry stools</td>
<td>blurred vision</td>
</tr>
<tr>
<td>nausea</td>
<td>blood in urine</td>
<td>ringing in ears</td>
</tr>
<tr>
<td>vomiting</td>
<td>cough or hoarseness</td>
<td>sores in mouth</td>
</tr>
<tr>
<td>tiredness</td>
<td>lower back or side pain</td>
<td>wheezing</td>
</tr>
<tr>
<td>weakness</td>
<td>fever and/or chills</td>
<td></td>
</tr>
<tr>
<td>temporary hair loss</td>
<td>numbness or tingling in fingers/toes</td>
<td></td>
</tr>
<tr>
<td></td>
<td>painful or difficult urination</td>
<td></td>
</tr>
<tr>
<td></td>
<td>pinpoint red spots on the skin</td>
<td></td>
</tr>
<tr>
<td></td>
<td>skin rash or itching</td>
<td></td>
</tr>
<tr>
<td></td>
<td>unusual bleeding or bruising</td>
<td></td>
</tr>
</tbody>
</table>

Medical problems that may affect the use of carboplatin include chickenpox (including recent exposure), shingles (herpes zoster), hearing problems, infection, and kidney disease.

**Cisplatin** (Platinol®)
Type: alkylating agent

<table>
<thead>
<tr>
<th>More Common</th>
<th>Less Common</th>
<th>Rare</th>
</tr>
</thead>
<tbody>
<tr>
<td>joint pain</td>
<td>loss of appetite and/or taste</td>
<td>agitation</td>
</tr>
<tr>
<td>nausea</td>
<td>temporary hair loss</td>
<td>confusion</td>
</tr>
<tr>
<td>vomiting</td>
<td>diarrhea</td>
<td>blurred vision</td>
</tr>
<tr>
<td>loss of balance</td>
<td>black, tarry stools</td>
<td>decreased ability to see colors</td>
</tr>
<tr>
<td>ringing in ears</td>
<td>blood in urine</td>
<td></td>
</tr>
<tr>
<td>swelling of feet/legs</td>
<td>cough or hoarseness</td>
<td></td>
</tr>
<tr>
<td>tiredness</td>
<td>lower back or side pain</td>
<td></td>
</tr>
<tr>
<td>weakness</td>
<td>fever and/or chills</td>
<td></td>
</tr>
<tr>
<td></td>
<td>dizziness or faintness</td>
<td></td>
</tr>
<tr>
<td></td>
<td>fast heartbeat</td>
<td></td>
</tr>
<tr>
<td></td>
<td>painful or difficult urination</td>
<td></td>
</tr>
<tr>
<td></td>
<td>pain at injection site</td>
<td></td>
</tr>
<tr>
<td></td>
<td>pinpoint red spots on the skin</td>
<td></td>
</tr>
<tr>
<td></td>
<td>swelling of the face</td>
<td></td>
</tr>
<tr>
<td></td>
<td>unusual bleeding or bruising</td>
<td></td>
</tr>
<tr>
<td></td>
<td>wheezing</td>
<td></td>
</tr>
<tr>
<td></td>
<td>loss of reflexes</td>
<td></td>
</tr>
<tr>
<td></td>
<td>numbness or tingling in fingers/toes</td>
<td></td>
</tr>
<tr>
<td></td>
<td>trouble walking</td>
<td></td>
</tr>
</tbody>
</table>

385
Medical problems that may affect the use of cisplatin include chickenpox (including recent exposure), shingles (herpes zoster), gout, kidney stones, hearing problems, infection, and kidney disease.

**Cyclophosphamide** (*Cytoxan*®, *Neosar*®)
Type: alkylation agent

<table>
<thead>
<tr>
<th>Side Effects of Cyclophosphamide</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>More Common</strong></td>
</tr>
<tr>
<td>cough or hoarseness</td>
</tr>
<tr>
<td>loss of appetite</td>
</tr>
<tr>
<td>nausea/vomiting</td>
</tr>
<tr>
<td>fever and/or chills</td>
</tr>
<tr>
<td>lower back or side pain</td>
</tr>
<tr>
<td>missed menstrual period</td>
</tr>
<tr>
<td>painful/difficult urination</td>
</tr>
<tr>
<td>blood in urine</td>
</tr>
<tr>
<td>fast heartbeat</td>
</tr>
<tr>
<td>joint pain</td>
</tr>
<tr>
<td>feet/lower leg swelling</td>
</tr>
<tr>
<td>tiredness or weakness</td>
</tr>
<tr>
<td>darkening of skin</td>
</tr>
<tr>
<td>temporary hair loss</td>
</tr>
</tbody>
</table>

Medical problems that may affect the use of cyclophosphamide include chickenpox (including recent exposure), shingles (herpes zoster), gout, kidney stones, infection, kidney disease, liver disease, and prior removal of the adrenal glands.

**Docetaxel** (*Taxotere*®)
Type: taxane

<table>
<thead>
<tr>
<th>Side Effects of Docetaxel</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>More Common</strong></td>
</tr>
<tr>
<td>tiredness</td>
</tr>
<tr>
<td>weakness</td>
</tr>
<tr>
<td>weight gain</td>
</tr>
<tr>
<td>swelling of abdomen</td>
</tr>
<tr>
<td>swelling of face</td>
</tr>
<tr>
<td>swelling of hands/feet</td>
</tr>
<tr>
<td>anemia</td>
</tr>
<tr>
<td>numbness or tingling in</td>
</tr>
<tr>
<td>hands/feet</td>
</tr>
<tr>
<td>diarrhea</td>
</tr>
</tbody>
</table>
### Side Effects of Docetaxel, continued

<table>
<thead>
<tr>
<th>More Common</th>
<th>Less Common</th>
<th>Rare</th>
</tr>
</thead>
<tbody>
<tr>
<td>nausea</td>
<td>red, scaly areas of skin</td>
<td></td>
</tr>
<tr>
<td>skin rash</td>
<td>high or low blood pressure</td>
<td></td>
</tr>
<tr>
<td>sores on lips/mouth</td>
<td>change in color of the nails</td>
<td></td>
</tr>
<tr>
<td>weakness</td>
<td>loosening of the nails</td>
<td></td>
</tr>
<tr>
<td>temporary hair loss</td>
<td>redness/pain at injection site</td>
<td></td>
</tr>
<tr>
<td></td>
<td>headaches</td>
<td></td>
</tr>
<tr>
<td></td>
<td>joint pain</td>
<td></td>
</tr>
<tr>
<td></td>
<td>muscle aches</td>
<td></td>
</tr>
<tr>
<td></td>
<td>vomiting</td>
<td></td>
</tr>
</tbody>
</table>

Medical problems that may affect the use of docetaxel include chickenpox (including recent exposure), shingles (herpes zoster), fluid in the lungs, infection, liver disease, and alcohol abuse.

**Doxorubicin** *(Adriamycin®, Rubex®)*

**Type:** anthracycline antibiotic

### Side Effects of Doxorubicin

<table>
<thead>
<tr>
<th>More Common</th>
<th>Less Common</th>
<th>Rare</th>
</tr>
</thead>
<tbody>
<tr>
<td>sores on lips/mouth</td>
<td>fast/irregular heartbeat</td>
<td>skin rash or itching</td>
</tr>
<tr>
<td>nausea</td>
<td>pain at injection site</td>
<td>irregular heartbeat</td>
</tr>
<tr>
<td>vomiting</td>
<td>shortness of breath</td>
<td>heart damage</td>
</tr>
<tr>
<td>loss of appetite</td>
<td>swelling of feet/legs</td>
<td></td>
</tr>
<tr>
<td>temporary hair loss</td>
<td>cough or hoarseness</td>
<td></td>
</tr>
<tr>
<td></td>
<td>fever and/or chills</td>
<td></td>
</tr>
<tr>
<td></td>
<td>joint pain</td>
<td></td>
</tr>
<tr>
<td></td>
<td>lower back or side pain</td>
<td></td>
</tr>
<tr>
<td></td>
<td>difficult or painful urination</td>
<td></td>
</tr>
<tr>
<td></td>
<td>red streaks along injection site</td>
<td></td>
</tr>
<tr>
<td></td>
<td>stomach pain</td>
<td></td>
</tr>
<tr>
<td></td>
<td>darkening of soles and palms</td>
<td></td>
</tr>
<tr>
<td></td>
<td>darkening of the nails</td>
<td></td>
</tr>
<tr>
<td></td>
<td>diarrhea</td>
<td></td>
</tr>
</tbody>
</table>

Medical problems that may affect the use of doxorubicin include chickenpox (including recent exposure), shingles (herpes zoster), gout, kidney stones, liver disease, and heart disease.
**Etoposide** (Etopophos®, VePesid®, Toposar®, VP-16)

Type: plant alkaloid

<table>
<thead>
<tr>
<th>More Common</th>
<th>Less Common</th>
<th>Rare</th>
</tr>
</thead>
<tbody>
<tr>
<td>tiredness</td>
<td>black, tarry stools</td>
<td>fast heartbeat</td>
</tr>
<tr>
<td>weakness</td>
<td>blood in urine</td>
<td>shortness of breath</td>
</tr>
<tr>
<td>loss of appetite</td>
<td>cough or hoarseness</td>
<td>sweating</td>
</tr>
<tr>
<td>nausea</td>
<td>fever and/or chills</td>
<td>swelling of face/tongue</td>
</tr>
<tr>
<td>vomiting</td>
<td>difficult or painful urination</td>
<td>tightness in throat</td>
</tr>
<tr>
<td>change in taste</td>
<td>pinpoint red spots on skin</td>
<td>wheezing</td>
</tr>
<tr>
<td>temporary hair loss</td>
<td>sores on mouth or lips</td>
<td>back pain</td>
</tr>
<tr>
<td></td>
<td>unusual bleeding or bruising</td>
<td>difficulty walking</td>
</tr>
<tr>
<td></td>
<td>diarrhea</td>
<td>numbness/tingling in extremities</td>
</tr>
<tr>
<td></td>
<td>constipation</td>
<td>pain at injection site</td>
</tr>
<tr>
<td></td>
<td>stomach pain</td>
<td>skin rash or itching</td>
</tr>
</tbody>
</table>

Medical problems that may affect the use of etoposide include chickenpox (including recent exposure), shingles (herpes zoster), infection, kidney disease, and liver disease.

**Fluorouracil** (Adrucil®, 5-FU)

Type: anti-metabolite

<table>
<thead>
<tr>
<th>More Common</th>
<th>Less Common</th>
<th>Rare</th>
</tr>
</thead>
<tbody>
<tr>
<td>diarrhea</td>
<td>black, tarry stools</td>
<td>blood in urine</td>
</tr>
<tr>
<td>heartburn</td>
<td>cough or hoarseness</td>
<td>pinpoint red spots on skin</td>
</tr>
<tr>
<td>sores on mouth/lips</td>
<td>fever and/or chills</td>
<td>skin</td>
</tr>
<tr>
<td>loss of appetite</td>
<td>lower back or side pain</td>
<td>unusual</td>
</tr>
<tr>
<td>nausea</td>
<td>painful or difficult urination</td>
<td>bleeding/bruising</td>
</tr>
<tr>
<td>vomiting</td>
<td>stomach cramps</td>
<td>chest pain</td>
</tr>
<tr>
<td>skin rash or itching</td>
<td>dry or cracked skin</td>
<td>cough</td>
</tr>
<tr>
<td>weakness</td>
<td></td>
<td>shortness of breath</td>
</tr>
<tr>
<td>temporary hair loss</td>
<td></td>
<td>tingling in extremities</td>
</tr>
</tbody>
</table>

Medical problems that may affect the use of fluorouracil include chickenpox (including recent exposure), shingles (herpes zoster), infection, kidney disease, and liver disease.
**Gefitinib** (Iressa®)

Type: tyrosine kinase inhibitor

<table>
<thead>
<tr>
<th>More Common</th>
<th>Less Common</th>
<th>Rare</th>
</tr>
</thead>
<tbody>
<tr>
<td>diarrhea</td>
<td>dry skin</td>
<td>swelling of extremities</td>
</tr>
<tr>
<td>skin rash</td>
<td>itching</td>
<td>vision changes</td>
</tr>
<tr>
<td>acne</td>
<td>nausea</td>
<td>shortness of breath</td>
</tr>
<tr>
<td></td>
<td>vomiting</td>
<td>cough</td>
</tr>
<tr>
<td></td>
<td>loss of appetite</td>
<td>eye irritation</td>
</tr>
<tr>
<td></td>
<td>weight loss</td>
<td>sores on mouth/lips</td>
</tr>
<tr>
<td></td>
<td>weakness</td>
<td>unusual</td>
</tr>
</tbody>
</table>

Medical problems that may affect the use of gefitinib include chickenpox (including recent exposure), shingles (herpes zoster), infection, and liver disease.

**Gemcitabine** (Gemzar®)

Type: anti-metabolite

<table>
<thead>
<tr>
<th>More Common</th>
<th>Less Common</th>
<th>Rare</th>
</tr>
</thead>
<tbody>
<tr>
<td>shortness of breath</td>
<td>cough or hoarseness</td>
<td>change in color of skin</td>
</tr>
<tr>
<td>black, tarry stools</td>
<td>fever and/or chills</td>
<td>skin rash</td>
</tr>
<tr>
<td>constipation</td>
<td>headache</td>
<td>hives or itching</td>
</tr>
<tr>
<td>diarrhea</td>
<td>lower back or side pain</td>
<td>swelling of face/eyelids</td>
</tr>
<tr>
<td>blood in urine</td>
<td>painful or difficult urination</td>
<td>increased urination</td>
</tr>
<tr>
<td>cloudy urine</td>
<td>pain in chest, arm or back</td>
<td>decreased urination</td>
</tr>
<tr>
<td>pinpoint red spots on skin</td>
<td>pressure in chest</td>
<td>yellow skin (jaundice)</td>
</tr>
<tr>
<td>swelling of the hands/feet</td>
<td>slurred speech</td>
<td></td>
</tr>
<tr>
<td>unusual</td>
<td>breathing difficulty</td>
<td></td>
</tr>
<tr>
<td>bleeding/bruising</td>
<td>wheezing</td>
<td></td>
</tr>
<tr>
<td>tiredness</td>
<td>weakness</td>
<td></td>
</tr>
<tr>
<td>weakness</td>
<td></td>
<td></td>
</tr>
<tr>
<td>loss of appetite</td>
<td>fast or irregular heartbeat</td>
<td></td>
</tr>
<tr>
<td>muscle pain</td>
<td>high blood pressure</td>
<td></td>
</tr>
<tr>
<td>nausea</td>
<td>drowsiness</td>
<td></td>
</tr>
<tr>
<td>vomiting</td>
<td></td>
<td></td>
</tr>
<tr>
<td>runny nose</td>
<td>pain or redness at injection site</td>
<td></td>
</tr>
<tr>
<td>sweating</td>
<td>numbness/tingling of extremities</td>
<td></td>
</tr>
<tr>
<td>trouble sleeping</td>
<td>sores on mouth/lips</td>
<td></td>
</tr>
<tr>
<td></td>
<td>flu-like symptoms</td>
<td></td>
</tr>
<tr>
<td></td>
<td>hair thinning</td>
<td></td>
</tr>
</tbody>
</table>

Medical problems that may affect the use of gemcitabine include chickenpox (including recent exposure), shingles (herpes zoster), infection, kidney disease, and liver disease.
**Ifosfamide (Ifex®)**
Type: alkylating agent

<table>
<thead>
<tr>
<th>Side Effects of Ifosfamide</th>
<th>More Common</th>
<th>Less Common</th>
<th>Rare</th>
</tr>
</thead>
<tbody>
<tr>
<td>blood in urine</td>
<td>cough or hoarseness</td>
<td>black, tarry stools</td>
<td></td>
</tr>
<tr>
<td>frequent urination</td>
<td>fever and/or chills</td>
<td>pinpoint red spots on skin</td>
<td></td>
</tr>
<tr>
<td>painful urination</td>
<td>lower back or side pain</td>
<td>unusual</td>
<td></td>
</tr>
<tr>
<td>nausea</td>
<td>agitation</td>
<td>bleeding/bruising</td>
<td></td>
</tr>
<tr>
<td>vomiting</td>
<td>confusion</td>
<td>convulsions</td>
<td></td>
</tr>
<tr>
<td>temporary hair loss</td>
<td>hallucinations</td>
<td>cough</td>
<td></td>
</tr>
<tr>
<td></td>
<td>tiredness</td>
<td>shortness of breath</td>
<td></td>
</tr>
<tr>
<td></td>
<td>dizziness</td>
<td>sores on mouth/lips</td>
<td></td>
</tr>
<tr>
<td></td>
<td>redness, swelling, pain at injection site</td>
<td>sleepiness</td>
<td></td>
</tr>
</tbody>
</table>

Medical problems that may affect the use of ifosfamide include chickenpox (including recent exposure), shingles (herpes zoster), infection, kidney disease, and liver disease.

**Irinotecan (Camptosar®, CPT-11)**
Type: topoisomerase inhibitor

<table>
<thead>
<tr>
<th>Side Effects of Irinotecan</th>
<th>More Common</th>
<th>Less Common</th>
<th>Rare</th>
</tr>
</thead>
<tbody>
<tr>
<td>diarrhea</td>
<td>cough or hoarseness</td>
<td>fast heartbeat</td>
<td></td>
</tr>
<tr>
<td>constipation</td>
<td>dizziness, lightheadedness, fainting</td>
<td>irregular heartbeat</td>
<td></td>
</tr>
<tr>
<td>stomach cramps or pain</td>
<td>fever and/or chills</td>
<td>puffiness of eyelids</td>
<td></td>
</tr>
<tr>
<td>loss of appetite</td>
<td>lower back or side pain</td>
<td>hives or itching</td>
<td></td>
</tr>
<tr>
<td>nausea</td>
<td>painful or difficult urination</td>
<td>tightness in chest</td>
<td></td>
</tr>
<tr>
<td>vomiting</td>
<td>runny or stuffy nose</td>
<td>wheezing</td>
<td></td>
</tr>
<tr>
<td>black, tarry stools</td>
<td>sore throat</td>
<td></td>
<td></td>
</tr>
<tr>
<td>blood in urine</td>
<td>abdominal bloating or gas</td>
<td></td>
<td></td>
</tr>
<tr>
<td>pinpoint red spots on skin</td>
<td>swelling of face, fingers, feet, lower legs</td>
<td></td>
<td></td>
</tr>
<tr>
<td>unusual bleeding or</td>
<td>decreased urination</td>
<td></td>
<td></td>
</tr>
<tr>
<td>bruising</td>
<td>dry mouth</td>
<td></td>
<td></td>
</tr>
<tr>
<td>weakness</td>
<td>increased thirst</td>
<td></td>
<td></td>
</tr>
<tr>
<td>weight loss</td>
<td>sores on mouth/lips</td>
<td></td>
<td></td>
</tr>
<tr>
<td>temporary hair loss</td>
<td>wrinkled skin</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>headache</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>increased sweating</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>indigestion</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>skin rash</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Medical problems that may affect the use of irinotecan include chickenpox (including recent exposure), shingles (herpes zoster), infection, liver disease, and lung disease.
**Methotrexate** (Amethopterin®, Folex®, Mexate®, MTX)

Type: anti-metabolite

<table>
<thead>
<tr>
<th>More Common</th>
<th>Less Common</th>
<th>Rare</th>
</tr>
</thead>
<tbody>
<tr>
<td>black, tarry stools</td>
<td>cough</td>
<td>confusion</td>
</tr>
<tr>
<td>blood in urine</td>
<td>pinpoint red spots on skin</td>
<td>seizures</td>
</tr>
<tr>
<td>diarrhea</td>
<td>shortness of breath</td>
<td>dizziness</td>
</tr>
<tr>
<td>stomach pain</td>
<td>unusual bleeding or bruising</td>
<td>blurred vision</td>
</tr>
<tr>
<td>joint pain</td>
<td>cough or hoarseness</td>
<td></td>
</tr>
<tr>
<td>reddening of skin</td>
<td>fever and/or chills</td>
<td></td>
</tr>
<tr>
<td>swelling of feet/legs</td>
<td>lower back or side pain</td>
<td></td>
</tr>
<tr>
<td>sores on mouth/lips</td>
<td>painful or difficult urination</td>
<td></td>
</tr>
<tr>
<td>tiredness/weakness</td>
<td>drowsiness</td>
<td></td>
</tr>
<tr>
<td>loss of appetite</td>
<td>yellow skin or eyes (jaundice)</td>
<td></td>
</tr>
<tr>
<td>nausea/vomiting</td>
<td>skin rash or itching</td>
<td></td>
</tr>
<tr>
<td>increased sun sensitivity</td>
<td>temporary hair loss</td>
<td></td>
</tr>
</tbody>
</table>

Medical problems that may affect the use of methotrexate include chickenpox (including recent exposure), shingles (herpes zoster), infection, immune system disease, colitis, intestinal blockage, gout, kidney stones, kidney disease, liver disease, stomach ulcers, and alcohol abuse.

**Mitomycin** (Mitomycin C®, Mutamycin®)

Type: antibiotic

<table>
<thead>
<tr>
<th>More Common</th>
<th>Less Common</th>
<th>Rare</th>
</tr>
</thead>
<tbody>
<tr>
<td>loss of appetite</td>
<td>black, tarry stools</td>
<td>pain/redness at injection site</td>
</tr>
<tr>
<td>nausea</td>
<td>decreased urine output</td>
<td>bloody vomiting</td>
</tr>
<tr>
<td>vomiting</td>
<td>cough or hoarseness or shortness of breath</td>
<td></td>
</tr>
<tr>
<td>temporary hair loss</td>
<td>fever and/or chills</td>
<td></td>
</tr>
<tr>
<td></td>
<td>lower back or side pain</td>
<td></td>
</tr>
<tr>
<td></td>
<td>painful, difficult or bloody urination</td>
<td></td>
</tr>
<tr>
<td></td>
<td>pinpoint red spots on skin or skin rash</td>
<td></td>
</tr>
<tr>
<td></td>
<td>unusual bleeding or bruising</td>
<td></td>
</tr>
<tr>
<td></td>
<td>sores on mouth/lips</td>
<td></td>
</tr>
<tr>
<td></td>
<td>swelling of feet/legs</td>
<td></td>
</tr>
<tr>
<td></td>
<td>numbness/tingling in extremities</td>
<td></td>
</tr>
<tr>
<td></td>
<td>purple bands on the nails</td>
<td></td>
</tr>
<tr>
<td></td>
<td>tiredness or weakness</td>
<td></td>
</tr>
</tbody>
</table>

Medical problems that may affect the use of mitomycin include chickenpox (including recent exposure), shingles (herpes zoster), infection, bleeding problems, and kidney disease.
**Paclitaxel** *(Taxol®)*  
Type: taxane

<table>
<thead>
<tr>
<th>Side Effects of Paclitaxel</th>
<th>More Common</th>
<th>Less Common</th>
<th>Rare</th>
</tr>
</thead>
<tbody>
<tr>
<td>facial flushing</td>
<td></td>
<td>black, tarry stools</td>
<td>shortness of breath</td>
</tr>
<tr>
<td>skin rash or itching</td>
<td></td>
<td>blood in urine</td>
<td>severe skin reaction</td>
</tr>
<tr>
<td>anemia</td>
<td></td>
<td>unusual bleeding or bruising</td>
<td>pain/redness at injection site</td>
</tr>
<tr>
<td>diarrhea</td>
<td></td>
<td>fever and/or chills</td>
<td>sores on mouth/lips</td>
</tr>
<tr>
<td>nausea</td>
<td></td>
<td>cough or hoarseness</td>
<td>swelling of face</td>
</tr>
<tr>
<td>vomiting</td>
<td></td>
<td>lower back or side pain</td>
<td>wheezing</td>
</tr>
<tr>
<td>burning/tingling in extremities</td>
<td></td>
<td>painful or difficult urination</td>
<td></td>
</tr>
<tr>
<td>joint pain</td>
<td></td>
<td>low blood pressure</td>
<td></td>
</tr>
<tr>
<td>muscle pain</td>
<td></td>
<td>slow heartbeat</td>
<td></td>
</tr>
<tr>
<td>bone pain</td>
<td>temporary, total hair loss</td>
<td>fatigue</td>
<td></td>
</tr>
<tr>
<td>fatigue</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Medical problems that may affect the use of paclitaxel include chickenpox (including recent exposure), shingles (herpes zoster), infection, and heart rhythm problems.

**Teniposide** *(Vumon®, VM-26)*  
Type: plant alkaloid

<table>
<thead>
<tr>
<th>Side Effects of Teniposide</th>
<th>More Common</th>
<th>Less Common</th>
<th>Rare</th>
</tr>
</thead>
<tbody>
<tr>
<td>facial flushing</td>
<td></td>
<td>black, tarry stools</td>
<td>decreased urine output</td>
</tr>
<tr>
<td>sores on mouth/lips</td>
<td></td>
<td>blood in urine</td>
<td>swelling of face</td>
</tr>
<tr>
<td>fast heartbeat</td>
<td></td>
<td>chills or fever</td>
<td>swelling of extremities</td>
</tr>
<tr>
<td>tiredness</td>
<td></td>
<td>hives or skin rash</td>
<td>yellow skin (jaundice)</td>
</tr>
<tr>
<td>diarrhea</td>
<td></td>
<td>cough or hoarseness</td>
<td></td>
</tr>
<tr>
<td>nausea</td>
<td></td>
<td>lower back or side pain</td>
<td></td>
</tr>
<tr>
<td>vomiting</td>
<td></td>
<td>painful or difficult urination</td>
<td></td>
</tr>
<tr>
<td>temporary hair loss</td>
<td></td>
<td>pinpoint red spots on skin</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>shortness of breath</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>tightness in chest</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>wheezing or troubled breathing</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>unusual bleeding or bruising</td>
<td></td>
</tr>
</tbody>
</table>

Medical problems that may affect the use of teniposide include chickenpox (including recent exposure), shingles (herpes zoster), infection, bone marrow disorders, Down syndrome, kidney disease, and liver disease.
**Topotecan (Hycamtin®)**

Type: topoisomerase inhibitor

<table>
<thead>
<tr>
<th><strong>More Common</strong></th>
<th><strong>Less Common</strong></th>
<th><strong>Rare</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>tiredness/weakness</td>
<td>black, tarry stools</td>
<td>fast heartbeat</td>
</tr>
<tr>
<td>stomach pain</td>
<td>blood in urine</td>
<td>irregular heartbeat</td>
</tr>
<tr>
<td>burning/tingling in</td>
<td>cough or hoarseness</td>
<td>hives on face</td>
</tr>
<tr>
<td>extremities</td>
<td>fever and/or chills</td>
<td>tightness in chest</td>
</tr>
<tr>
<td>constipation</td>
<td>lower back or side pain</td>
<td>wheezing</td>
</tr>
<tr>
<td>diarrhea</td>
<td>painful or difficult urination</td>
<td>skin color change</td>
</tr>
<tr>
<td>fatigue</td>
<td>pinpoint red spots on skin</td>
<td>skin rash or itching</td>
</tr>
<tr>
<td>headache</td>
<td>shortness of breath</td>
<td></td>
</tr>
<tr>
<td>loss of appetite</td>
<td>troubled breathing</td>
<td></td>
</tr>
<tr>
<td>muscle weakness</td>
<td>unusual bleeding or bruising</td>
<td></td>
</tr>
<tr>
<td>nausea/vomiting</td>
<td>bruising/redness at injection site</td>
<td></td>
</tr>
<tr>
<td>sores on mouth/lips</td>
<td></td>
<td></td>
</tr>
<tr>
<td>temporary hair loss</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Medical problems that may affect the use of topotecan include chickenpox (including recent exposure), shingles (herpes zoster), infection, and kidney disease.

**UFT (Uracil + Ftorafur, Uracil + Tegafur®)**

Type: anti-metabolites

Note: Ftorafur is metabolized by the body into fluorouracil.

<table>
<thead>
<tr>
<th><strong>More Common</strong></th>
<th><strong>Less Common</strong></th>
<th><strong>Rare</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>diarrhea</td>
<td>black, tarry stools</td>
<td>chest pain</td>
</tr>
<tr>
<td>nausea</td>
<td>cough or hoarseness</td>
<td>trouble with balance</td>
</tr>
<tr>
<td>vomiting</td>
<td>fever and/or chills</td>
<td></td>
</tr>
<tr>
<td>loss of appetite</td>
<td>lower back or side pain</td>
<td></td>
</tr>
<tr>
<td>temporary hair loss</td>
<td>painful, difficult, or bloody urination</td>
<td></td>
</tr>
<tr>
<td>sores on mouth/lips</td>
<td>pinpoint red spots on skin</td>
<td></td>
</tr>
<tr>
<td></td>
<td>unusual bleeding/bruising</td>
<td></td>
</tr>
<tr>
<td></td>
<td>stomach cramps</td>
<td></td>
</tr>
<tr>
<td></td>
<td>dry or cracked skin</td>
<td></td>
</tr>
<tr>
<td></td>
<td>joint pain</td>
<td></td>
</tr>
<tr>
<td></td>
<td>swelling of feet/legs</td>
<td></td>
</tr>
<tr>
<td></td>
<td>darkening of the skin</td>
<td></td>
</tr>
<tr>
<td></td>
<td>skin rash and itching</td>
<td></td>
</tr>
<tr>
<td></td>
<td>irritability/mental depression/nervousness</td>
<td></td>
</tr>
<tr>
<td></td>
<td>headaches</td>
<td></td>
</tr>
<tr>
<td></td>
<td>numbness/tingling in extremities</td>
<td></td>
</tr>
</tbody>
</table>

Medical problems that may affect the use of UFT include chickenpox (including recent exposure), shingles (herpes zoster), infection, kidney disease, and liver disease.
**Vinblastine** *(Velban®)*
Type: plant alkaloid

<table>
<thead>
<tr>
<th>Side Effects of Vinblastine</th>
<th>Side Effects of Vincristine</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>More Common</strong></td>
<td><strong>Less Common</strong></td>
</tr>
<tr>
<td>cough or hoarseness</td>
<td>blood in urine</td>
</tr>
<tr>
<td>temporary hair loss</td>
<td>fever and/or chills</td>
</tr>
<tr>
<td></td>
<td>lower back or side pain</td>
</tr>
<tr>
<td></td>
<td>painful or difficult urination</td>
</tr>
<tr>
<td></td>
<td>redness/pain at injection site</td>
</tr>
<tr>
<td></td>
<td>pinpoint red spots on skin</td>
</tr>
<tr>
<td></td>
<td>unusual bleeding or bruising</td>
</tr>
<tr>
<td></td>
<td>joint pain</td>
</tr>
<tr>
<td></td>
<td>sores on mouth/lips</td>
</tr>
<tr>
<td></td>
<td>swelling of feet/legs</td>
</tr>
<tr>
<td></td>
<td>bone pain</td>
</tr>
<tr>
<td></td>
<td>muscle pain</td>
</tr>
<tr>
<td></td>
<td>nausea/vomiting</td>
</tr>
<tr>
<td></td>
<td>constipation</td>
</tr>
</tbody>
</table>

Medical problems that may affect the use of vinblastine include chickenpox (including recent exposure), shingles (herpes zoster), infection, gout, kidney stones, and liver disease.

**Vincristine** *(Oncovin®, Vincasar PFS®, Vincrex®)*
Type: plant alkaloid

<table>
<thead>
<tr>
<th>Side Effects of Vincristine</th>
<th>Side Effects of Vinblastine</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>More Common</strong></td>
<td><strong>Less Common</strong></td>
</tr>
<tr>
<td>weakness</td>
<td>pain/redness at site of injection</td>
</tr>
<tr>
<td>temporary hair loss</td>
<td>diarrhea and/or bloating</td>
</tr>
<tr>
<td>numbness/tingling in</td>
<td>loss of appetite or weight loss</td>
</tr>
<tr>
<td>extremities</td>
<td>nausea/vomiting/stomach cramps</td>
</tr>
<tr>
<td>constipation</td>
<td>difficulty walking</td>
</tr>
<tr>
<td></td>
<td>drooping eyelids</td>
</tr>
<tr>
<td></td>
<td>joint pain</td>
</tr>
<tr>
<td></td>
<td>lower back or side pain</td>
</tr>
<tr>
<td></td>
<td>testicular pain</td>
</tr>
<tr>
<td></td>
<td>swelling of feet/legs</td>
</tr>
<tr>
<td></td>
<td>agitation, confusion, depression</td>
</tr>
<tr>
<td></td>
<td>bed-wetting</td>
</tr>
<tr>
<td></td>
<td>painful or difficult urination</td>
</tr>
<tr>
<td></td>
<td>dizziness or lightheadedness</td>
</tr>
<tr>
<td></td>
<td>lack of sweating</td>
</tr>
<tr>
<td></td>
<td>trouble sleeping</td>
</tr>
<tr>
<td></td>
<td>skin rash</td>
</tr>
</tbody>
</table>

Medical problems that may affect the use of vincristine include chickenpox (including recent exposure), shingles (herpes zoster), infection, gout, kidney stones, liver disease, nerve disease, and muscle disease.
Vindesine (Eldisine®)
Type: plant alkaloid

<table>
<thead>
<tr>
<th>Side Effects of Vindesine</th>
<th>More Common</th>
<th>Less Common</th>
<th>Rare</th>
</tr>
</thead>
<tbody>
<tr>
<td>temporary hair loss</td>
<td>black, tarry stools</td>
<td></td>
<td>double vision</td>
</tr>
<tr>
<td>numbness/tingling in</td>
<td>diarrhea</td>
<td></td>
<td>blurred vision</td>
</tr>
<tr>
<td>extremities</td>
<td>chest pain</td>
<td></td>
<td>blindness</td>
</tr>
<tr>
<td>constipation</td>
<td>cough</td>
<td></td>
<td>seizures</td>
</tr>
<tr>
<td></td>
<td>shortness of breath</td>
<td></td>
<td>difficulty walking</td>
</tr>
<tr>
<td></td>
<td>fever and/or chills</td>
<td></td>
<td>drooping eyelids</td>
</tr>
<tr>
<td></td>
<td>difficult or painful urination</td>
<td></td>
<td>headache</td>
</tr>
<tr>
<td></td>
<td>sore throat</td>
<td></td>
<td>jaw pain</td>
</tr>
<tr>
<td></td>
<td>sores on mouth/lips</td>
<td></td>
<td>testicular pain</td>
</tr>
<tr>
<td></td>
<td>swollen lymph glands</td>
<td></td>
<td>unusual bleeding/bruising</td>
</tr>
<tr>
<td></td>
<td>tiredness or weakness</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>loss of appetite and/or weight loss</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>nausea and/or vomiting</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>stomach pain</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>muscle or bone pain</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Medical problems that may affect the use of vindesine include chickenpox (including recent exposure), shingles (herpes zoster), infection, Charcot-Marie-Tooth syndrome, blood disorders, liver disease, nerve disease, and muscle disease.

Vinorelbine (Navelbine®)
Type: plant alkaloid

<table>
<thead>
<tr>
<th>Side Effects of Vinorelbine</th>
<th>More Common</th>
<th>Less Common</th>
<th>Rare</th>
</tr>
</thead>
<tbody>
<tr>
<td>tiredness</td>
<td>cough or hoarseness</td>
<td></td>
<td>chest pain</td>
</tr>
<tr>
<td>weakness</td>
<td>fever and/or chills</td>
<td></td>
<td>shortness of breath</td>
</tr>
<tr>
<td>constipation</td>
<td>lower back or side pain</td>
<td></td>
<td>sores on mouth/lips</td>
</tr>
<tr>
<td>loss of appetite</td>
<td>redness or pain at injection site</td>
<td></td>
<td>black, tarry stools</td>
</tr>
<tr>
<td>nausea</td>
<td>sore throat</td>
<td></td>
<td>dark or bloody urine</td>
</tr>
<tr>
<td>vomiting</td>
<td>numbness/tingling in extremities</td>
<td></td>
<td>chill</td>
</tr>
<tr>
<td></td>
<td>diarrhea</td>
<td></td>
<td>fast heartbeat</td>
</tr>
<tr>
<td></td>
<td>jaw pain</td>
<td></td>
<td>indigestion/loss of appetite</td>
</tr>
<tr>
<td></td>
<td>joint pain</td>
<td></td>
<td>painful or difficult urination</td>
</tr>
<tr>
<td></td>
<td>muscle pain</td>
<td></td>
<td>stomach pain or bloating</td>
</tr>
<tr>
<td></td>
<td>temporary hair loss</td>
<td></td>
<td>pinpoint red spots on skin</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>unusual bleeding/bruising</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>skin rash</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>yellow skin (jaundice)</td>
</tr>
</tbody>
</table>

Medical problems that may affect the use of vincristine include chickenpox (including recent exposure), shingles (herpes zoster), and infection.
LUNG CANCER RESOURCE DIRECTORY

The Lung Cancer Resource Directory provides information about organizations, Internet sites, books, and other materials that may be useful to people living with lung cancer. Resources included in this section offer materials and services people affected by lung cancer have found useful. However, the author is not responsible for your personal experience with the organizations or materials included.

Certainly, other local and national resources are available that may be useful to people living with lung cancer beyond those included here. The exclusion of a particular resource should not be interpreted as a lack of endorsement. Use your judgment and consult with family members, friends, and professionals to determine the authenticity and legitimacy of all organizations that are new to you.

The resources are organized in the following sections:
- Organizations
- Useful Internet Sites
- Pharmaceutical Companies' Prescription Assistance Programs
- National Cancer Institute (NCI) Designated Comprehensive Cancer Centers and Clinical Cancer Centers
- Books
- Magazines and Newsletters
- Audio, Video, and DVD Recordings

All contact information was verified at the time of publication. However, contact information may change over time.
ORGANIZATIONS

Acupuncture and Oriental Medicine Alliance
Telephone:  253-851-6896
Internet:  www.aomalliance.org

The Acupuncture and Oriental Medicine Alliance (AOMA) works to support the development of acupuncture and oriental medicine. AOMA maintains an active patient referral service of over 10,000 state-licensed and nationally certified acupuncture and oriental medicine practitioners via fax, telephone, and the Internet.

Alternative Medicine Foundation
Telephone:  301-581-0116
Internet:  www.amfoundation.org

The Alternative Medicine Foundation is a nonprofit organization formed to provide evidence-based research resources for health care professionals, and responsible and reliable information for patients and consumers about the integration of alternative and conventional medicine.

American Art Therapy Association
Telephone:  888-290-0878
Internet:  www.arttherapy.org

The American Art Therapy Association (AATA) is a national, nonprofit association dedicated to the use of art for healing and life enhancement. AATA was founded in 1969, and includes approximately 4,750 art therapy professionals and students.

American Association of Naturopathic Physicians
Telephone:  886-538-2267 or 202-895-1392
Internet:  www.naturopathic.org

The American Association of Naturopathic Physicians (AANP) is an organization of practitioners trained as specialists in natural medicine. Members are licensed or are eligible for licensure in states that license naturopathic physicians as medical providers. AANP distributes information about naturopathic medicine, and offers a locator service to help interested parties find a naturopathic practitioner in their area.

American Association of Oriental Medicine
(formerly American Association of Acupuncture and Oriental Medicine)
Telephone:  888-500-7999
Internet:  www.aaom.org

The American Association of Oriental Medicine (AAOM) was formed to be the unifying force for American acupuncturists committed to ethical and educational standards to ensure the safety of the public.
American Association of Professional Hypnotherapists
Telephone: 650-323-3224
Internet: www.aaph.org

The American Association of Professional Hypnotherapists is a worldwide organization that promotes communication between professionals for the promotion and development of ethical methods, techniques, and standards in the field of hypnotherapy.

American Bar Association
Telephone: 800-285-2221
Internet: www.abanet.org

The American Bar Association is a professional organization of more than 400,000 lawyers. The ABA provides law school accreditation, continuing legal education, information about the law, programs to assist lawyers and judges in their work, and initiatives to improve the legal system for the public. The Center for ProBono work (free legal services) can be found at www.abanet.org/legalservices/probono/directory.html#.

American Board of Medical Specialties
Telephone: 866-275–2267 (866–ASK–ABMS)
Internet: www.abms.org

The American Board of Medical Specialties (ABMS) is an organization of 24 approved medical specialty boards. The intent of certification is to provide assurance to the public that those certified by an ABMS Member Board have successfully completed an approved training program and an evaluation process assessing their ability to provide quality patient care in the specialty. The Official ABMS Directory of Board Certified Medical Specialists is a directory of ABMS specialists and is available at most public libraries. You can find out a doctor’s board certification status by calling ABMS or checking the online Internet site at www.abms.org/login.asp. This is a free service but requires registration.

American Brain Tumor Association (ABTA)
Telephone: 800-886-ABTA (800-886-2282) or 847-827-9910
Internet: www.abta.org

ABTA collects current information about brain tumor research and provides it to patients to help them make educated decisions about their health care. ABTA offers print materials about research and treatment of brain tumors, and provides listings of doctors, treatment facilities, and support groups throughout the country.

American Cancer Society (ACS)
Telephone: 800-ACS-2345 (800-227-2345) or 404-320-3333
Internet: www.cancer.org

ACS is a nationwide organization with chartered divisions in every state, the District of Columbia, and Puerto Rico. ACS focuses on research and education but also provides patient and community services including public and professional education and community resource referrals. Local chapters provide various support services.
American Chiropractic Association
Telephone: 800-986-4636
Internet: www.amerchiro.org

The American Chiropractic Association (ACA) improves the public's awareness and utilization of chiropractic medicine, and conducts chiropractic surveys and statistical studies. ACA also provides a chiropractic physician locator service.

The American College of Surgeons (ACOS)
Telephone: 312-202-5000
Internet: http://www.facs.org/

The American College of Surgeons (ACOS) is a professional organization of surgeons dedicated to improving the care of surgical patients and to safeguarding standards of care in an optimal and ethical practice environment. ACOS accredits over 1,400 cancer programs at hospitals and other treatment centers in the United States. The ACOS Internet site provides a searchable database of these programs at http://www.facs.org/.

American Council of Hypnotist Examiners
Telephone: 818-242-1159
Internet: www.hypnotistexaminers.org

The American Council of Hypnotist Examiners (ACHE) was founded in 1973 as a nonprofit professional organization engaging in self-regulation of all who utilize hypnosis/hypnotherapy as an integral part of a professional practice. ACHE now certifies more than nine thousand hypnotherapists including numerous physicians, psychiatrists, psychologists, and representatives of the healing arts, counseling, and allied professions.

American Dance Therapy Association
Telephone: 410-997-4040
Internet: www.adta.org

The American Dance Therapy Association (ADTA) works to establish and maintain high standards of professional education and competence in the field of dance/movement therapy. ADTA maintains a registry of dance/movement therapists who have met stringent standards of education and experience, and sets and monitors standards for the masters level programs that prepare people to become dance/movement therapists.

American Institute of Homeopathy
Telephone: 703-246-9501
Internet: www.homeopathyusa.org

The American Institute of Homeopathy (AIH) is a nonprofit organization working to promote and improve homeopathic medicine and the dissemination of medical knowledge pertaining to homeopathy. The Internet site has a listing of AIH members by state and level of membership at www.homeopathyusa.org/onlinedirectory.
American Institute for Cancer Research (AICR)
Telephone: 800-843-8114 or 202-328-7744
Internet: www.aicr.org

AICR is a charitable cancer organization that fosters research on diet and cancer prevention and educates the public about the results of such research.

American Lung Association (ALA)
Telephone: 800-LUNG-USA (800-586-4872)
Internet: www.lungusa.org

ALA is a nonprofit organization dedicated to the promotion of lung health and the eradication of lung disease.

American Massage Therapy Association (AMTA)
Telephone: 847-864-0123
Internet: www.amtamassage.org

AMTA is a professional organization of over 46,000 massage therapists. The AMTA Internet site has a searchable database of massage therapists in the U.S. and Canada at www.amtamassage.org/findamassage/locator.htm.

American Medical Association (AMA)
Telephone: 312-464-5000
Internet: www.ama-assn.org

The (AMA) is a voluntary membership organization of physicians in the U.S. The AMA offers a free physician locator on their Internet site at www.ama-assn.org/aps/amahg.htm. The AMA database of physicians contains basic professional information on nearly all licensed physicians in the U.S.

American Music Therapy Association (AMTA)
Telephone: 301-589-3300
Internet: www.musictherapy.org

AMTA's purpose is the progressive development of the therapeutic use of music in rehabilitation, special education, and community settings. Call AMTA or send them an e-mail at findMT@musictherapy.org if you would like help finding a music therapist in your area.

American Psychosocial Oncology Society (APOS)
Telephone: 434-293-5350; referral line 866-276-7443 (toll-free)
Internet: www.apos-society.org

The mission of American Psychosocial Oncology Society is to advance the science and practice of psychosocial care for people with cancer. APOS operates a referral service for cancer patients and patient advocates in need of psychological services.
American Psychotherapy and Medical Hypnosis Association
Telephone: 817-594-7003
Internet: www.apmha.com

The American Psychotherapy and Medical Hypnosis Association (APMHA) exists to provide competent, professional, and caring treatment and referrals for treatment to the clients and patients we serve. Call APMHA or click on the Find Treatment link on the Internet site for assistance finding a hypnotherapist.

American Society of Clinical Oncology (ASCO)
Telephone: 703-299-0150
Internet: www.asco.org

ASCO is a professional organization representing health care professionals who treat people with cancer. ASCO’s membership is comprised of clinical oncologists, oncology nurses, and other health care practitioners with a predominant interest in oncology. ASCO’s members specialize in all fields of oncology. The ASCO Internet site offers a free searchable list of members at www.asco.org/ac/1,1003,,12-002215,00.asp. ASCO also operates an Internet site for people living with cancer at www.peoplelivingwithcancer.org/plwc/Home/1,1743,,00.html.

Angel Flight America
Telephone: 800-446-1231
Internet: www.angelflightamerica.org

Angel Flight America—a national network of seven autonomous regional members—arranges free flights of hope and healing by transporting patients and their families in private planes to hospitals for medical treatment.

Associated Bodywork and Massage Professionals
Telephone: 800-458-2267
Internet: www.abmp.com

Associated Bodywork and Massage Professionals (ABMP) is a membership organization serving the massage, bodywork, somatic, and esthetic professions. The Internet site has information about various forms of bodywork and a locator for ABMP members under the link ABMP MassageFinder.

Association for Applied Psychophysiology and Biofeedback (AAPB)
Telephone: 800-477-8892
Internet: www.aapb.org

AAPB is a nonprofit, membership organization founded in 1969. The goals of AAPB are to promote a new understanding of biofeedback and advance the methods used in this practice. The Internet site offers assistance finding a biofeedback practitioner at www.aapb.org/public/articles/index.cfm?Cat=7.
Association of Cancer Online Resources (ACOR)
Telephone:  212-226-5525
Internet:  www.acor.org

ACOR creates, produces, hosts, and manages a large number of online resources for cancer patients, caregivers, health care professionals, and basic research scientists. The Oncology Support Mailing Lists Center keeps professionals and patients abreast of breaking news stories, treatment protocols, and the psychosocial effects of specific types of cancer. ACOR offers disease-specific online discussion groups free of charge.

Ayurvedic Institute
Telephone:  505-291-9698
Internet:  www.ayurveda.com

The Ayurvedic Institute was established in 1984 to promote the traditional knowledge of ayurveda. The online Resource page has information about ayurvedic medicine and practices.

Biofeedback Certification Institute of America
Telephone:  303-420-2902
Internet:  www.bcia.org

The Biofeedback Certification Institute of America (BCIA) was formed in 1981 to establish and maintain professional standards for the provision of biofeedback services and to certify those who meet these standards. The Internet site offers a practitioner locator at www.bcia.org/directory.

Cancer Care
Telephone:  800-813-HOPE (800-813-4673)
Internet:  www.cancercare.org

Cancer Care is a national, nonprofit organization whose mission is to provide free professional help to people with all cancers through counseling, education, information, referral, and direct financial assistance. Cancer Care provides online social workers to answer questions, and offers guidance, educational materials, telephone support groups, and other services. In-person support groups are available for people in the greater New York City area.

Cancer Hope Network
Telephone:  877-HOPENET (877-467-3638) or 908-879-4039
Internet:  www.cancerhopenetwork.org

Cancer Hope Network is a nonprofit organization that offers one-on-one support for people living with cancer and their families by matching those seeking support with trained volunteers who been through similar experiences.
Cancer Information Service (CIS)
Telephone: 800-4-CANCER (800-422-6237)
CancerFax: 301-402-5874
Internet: cis.nci.nih.gov/index.html

The National Cancer Institute (NCI) operates the Cancer Information Service (CIS) for people with cancer, their families, and health care professionals. CIS allows you to speak directly to a Cancer Information Specialist who will answer your questions by telephone Monday through Friday from 9:00 AM to 4:30 PM local time. You can also access an information specialist online by clicking on the LiveHelp link; check the Internet site for hours of availability. The Internet site also has downloadable Fact Sheets and ordering information for NCI publications.

Cancervive
Telephone: 800-4-TO-CURE (800-486-2873) or 310-203-9232
Internet: www.cancervive.org

Cancervive is a nonprofit organization dedicated to helping cancer survivors reclaim their lives after cancer.

Caring Connections
Telephone: 800-658-8898
Internet: www.caringinfo.org

Caring Connections, a program of the National Hospice and Palliative Care Organization (NHPCO), is a national consumer engagement initiative to improve care at the end of life, supported by a grant from The Robert Wood Johnson Foundation. Caring Connections
• Provides free resources, information, and motivation for actively learning about end-of-life resources.
• Promotes awareness of and engagement in efforts to increase access to quality end-of-life care.
• Helps people connect with the resources they need, when they need them.
• Brings together community, state and national partners working to improve end-of-life care.

Council on Chiropractic Education (CCE)
Telephone: 480-443-8877
Internet: www.cce-usa.org

CCE is recognized by the U.S. Secretary of Education as the accrediting body for programs and institutions offering the doctor of chiropractic degree. CCE responds to inquiries, distributes publications, and makes referrals to other sources of information.

Corporate Angel Network (CAN)
Telephone: 866-328-1313 or 914-328-1313
Internet: www.corpangelnetwork.org

CAN is a charitable organization whose mission is to arrange free flights for people with cancer to treatment centers using the empty seats on corporate aircraft. The program is
open to all cancer patients who are able to get around on their own and are not in need of medical support while traveling. Eligibility is not based on financial need, and patients may travel as often as necessary.

**Department of Health and Human Services (HHS), Inspector General Hotline**  
**Telephone:** 800-HHS-TIPS (800-447-8477)  
**Internet:** [www.oig.hhs.gov](http://www.oig.hhs.gov)  

The Office of Inspector General (OIG) protects the integrity of HHS programs as well as the health and welfare of the beneficiaries of the programs. HHS programs and institutions under OIG oversight include Medicare, Medicaid, the Food and Drug Administration, the National Institutes of Health, and many others. The purpose of the OIG hotline is to allow consumers to report fraud, overcharging, or other abuses.

**Department of Veterans Affairs**  
**Telephone:** 800-827-1000 (VA Benefits), 877-222-8387 (Health Care Benefits), 800-669-8477 (Life Insurance)  
**Internet:** [www.va.gov](http://www.va.gov)  

The Department of Veterans Affairs (VA) offers many benefits to military veterans. The Internet site is comprehensive and allows you to submit online applications for most VA benefits. The site also has contact information for regional VA offices and medical centers. There is also a listing of veterans' service organizations at [www.va.gov/vso/index.htm](http://www.va.gov/vso/index.htm).

**Dream Foundation**  
**Telephone:** 805-564-2131  
**Internet:** [www.dreamfoundation.com](http://www.dreamfoundation.com)  

The Dream Foundation is a nonprofit organization whose mission is to grant the last wishes of terminally ill adults.

**Food and Drug Administration (FDA)**  
**Telephone:** 888-INFO-FDA (888-463-6332) or 301-827-4460  
**Internet:** [www.fda.gov](http://www.fda.gov)  

The Food and Drug Administration (FDA) is the government agency responsible for ensuring that foods are safe, wholesome, and sanitary; human and veterinary drugs, biological products, and medical devices are safe and effective; cosmetics are safe; and electronic products that emit radiation are safe. FDA also ensures that these products are honestly, accurately, and informatively represented to the public. The Cancer Liaison Program answers questions directed to FDA by cancer patients, their loved ones, and patient advocates about therapies for cancer. The Cancer Liaison Program can be accessed online at [www.fda.gov/oashi/cancer/cancer.html](http://www.fda.gov/oashi/cancer/cancer.html) or by telephone at 888-INFO-FDA (888-463-6332) or 301-827-4460. The program provides information about cancer drug approval processes, links to clinical trial Internet sites, and FDA-related articles and information.
Hope Air
Telephone: 1-877-346-HOPE (4673)
Internet: www.hopeair.org

Hope Air helps Canadians in financial need fly to necessary medical treatment.

Hospice Education Institute
Telephone: 800-331-1620 or 207-255-8800
Internet: www.hospiceworld.org

The Hospice Education Institute is an independent, nonprofit organization serving the public and health care professionals with information and education about the many facets of caring for the dying and the bereaved. The Institute helps people obtain information about good hospice and palliative care, gives referrals to hospices and palliative care organizations, and provides counsel regarding care for the dying and the bereaved.

Joint Commission on Accreditation of Healthcare Organizations (JCAHO)
Telephone: 630-792-5800
Internet: www.jcaho.org

JCAHO is an independent organization that inspects hospitals and other health care facilities to ensure they meet specific quality standards defined by JCAHO. Participation in JCAHO is voluntary, but most large health care institutions participate in this quality assurance program. Access lists of JCAHO-accredited organizations at www.jcaho.org/accredited+organizations/ambulatory+care/index.htm.

LifeLine Pilots
Telephone: 800-822-7972
Internet: www.lifelinepilots.org/index2.htm

LifeLine Pilots is a private, non-profit organization that provides people in medical and financial distress with access to free air transportation on small (4-6 seat), private aircraft for health care and other compelling human needs.

Lung Cancer Alliance
Telephone: 800-298-2436
E-mail: info@lungcanceralliance.org
Internet: www.lungcanceralliance.org

LCA offers many services specifically designed to meet the needs of people living with lung cancer and their loved ones. Services include the Phone Buddies Program, Spirit and Breath, a quarterly newsletter, patient education materials, and lung cancer awareness materials.

Mercy Medical Airlift
Telephone: 888-675-1405
Internet: www.mercymedical.org

Mercy Medical Airlift (MMA) is a non-profit organization dedicated to serving people in situations of compelling human need through the provision of charitable air transportation.
National Asian Women’s Health Organization (NAWHO)
Telephone: 415-989-9747
Internet: www.nawho.org

NAWHO was founded in 1993 to achieve health equity for Asian Americans. NAWHO is working to improve the health status of Asian American women and families through research, education, leadership, and public policy programs. Resources are available in English, Cantonese, Laotian, Vietnamese, and Korean.

National Association for Drama Therapy
Telephone: 202-966-7409
Internet: www.nadt.org

The National Association for Drama Therapy (NADT) is a nonprofit association established in 1979 to uphold high standards of professional competence and ethics among drama therapists, and to promote the profession of drama therapy through information and advocacy.

National Association of Professional Geriatric Care Managers
Telephone: 520-881-8008
Internet: www.caremanager.org

The National Association of Professional Geriatric Care Managers (GCM) is a nonprofit, professional organization of practitioners whose goal is the advancement of dignified care for the elderly and their families. GCM has more than 1,500 members who provide the same basic services as eldercare agencies, but charge fees for their services that are not reimbursed by most health insurance providers.

National Association for Home Care and Hospice
Telephone: 202-547-7424
Internet: www.nahc.org

The National Association for Home Care and Hospice (NAHC) is a national trade association representing the interests and concerns of home care agencies, hospices, home care aide organizations, and medical equipment suppliers. The Consumer Information section of the Internet site at www.nahc.org/Consumer/coninfo.html has information about home care services and finding a provider for these services.

National Association of Hospital Hospitality Houses
Telephone: 800-542-9730 or 301-961-5264
Internet: www.nahhh.org

The National Association of Hospital Hospitality Houses (NAHHH) is a nonprofit corporation serving facilities that provide lodging and other supportive services to patients and their families who are confronted with medical emergencies. Each facility assures that a homelike environment is provided to persons who must travel to be with a patient or to receive necessary outpatient care. Reduced cost or free temporary housing may be available on a case-by-case basis.
National Association of State Comprehensive Health Insurance Plans
Telephone: 952-851-7245
Internet: www.naschip.org

The National Association of State Comprehensive Health Insurance Plans (NASCHIP) was created in 1993 to provide educational opportunities and information for state high-risk health insurance pools that have been, or are yet to be, established by state governments to serve the medically 'uninsurable' population. The NASCHIP Internet site has a list of states plans and contact information at www.naschip.org/states_pools.htm.

National Board for Certified Clinical Hypnotherapists (NBCCH)
Telephone: 800-449-8144
Internet: www.natboard.com

NBCCH was organized in 1991 as an educational, scientific, and professional organization dedicated to professionalizing the mental health specialty/subspecialty of hypnotherapy. You can find a NBCCH-certified hypnotherapist in your area from the Internet site at www.natboard.com/consumer.html.

National Brain Tumor Foundation
Telephone: 800-934-CURE (800-934-2873) or 510-839-9777
Internet: www.braintumor.org

The National Brain Tumor Foundation (NBTF) is a national, nonprofit organization dedicated to providing information and support for people with brain tumors, their family members, and health care professionals. NBTF publishes printed materials for patients and family members, provides access to a national network of patient support groups, and assists in answering patient inquiries.

National Cancer Institute (NCI)
Telephone: 800-4-CANCER (800-422-6237) or 301-496-5583
CancerFax: 800-624-2511
Internet: www.nci.nih.gov

NCI is a component of the National Institutes of Health (NIH). NCI is the federal government's principal agency for cancer research and training. NCI coordinates the National Cancer Program, which conducts and supports research, training, health information dissemination, and other programs with respect to the cause, diagnosis, prevention, and treatment of cancer, rehabilitation from cancer, and the continuing care of cancer patients and the families of cancer patients. NCI sponsors the Physicians Data Query (PDQ), a computerized listing of up-to-date information for health professionals and patients concerning the latest information on cancer treatments and clinical trials. PDQ information can be obtained through a fax machine with a telephone handset by calling CancerFax. See the listing for the Cancer Information Service for additional information about obtaining NCI products and services by telephone.
National Center for Homeopathy (NCH)
Telephone: 877-624-0613 or 703-548-7790
Internet: www.homeopathic.org

NCH is a national, nonprofit, membership organization. The mission of NCH is to promote health through homeopathy. The Internet site allows you to search for a homeopathic practitioner at homeopathic.org/NCHSearchNew.htm.

National Certification Board for Therapeutic Massage and Bodywork (NCBTMB)
Telephone: 800-296-0664 or 703-610-9015
Internet: www.ncbtmb.com

NCBTMB is an independent, private, nonprofit organization that certifies professionals in the massage therapy and bodywork industry through a recognized credentialing program. A practitioner locator is available at www.ncbtmb.com/database/query.asp.

National Certification Commission for Acupuncture & Oriental Medicine (NCCAOM)
Telephone: 703-548-9004
Internet: www.nccaom.org

NCCAOM is a nonprofit organization established in 1982. Its mission is to establish, assess, and promote recognized standards of competence and safety in acupuncture and oriental medicine for the protection and benefit of the public. The directory of diplomates (practitioners) is available at www.nccaom.org/find.htm to help you find a practitioner in your area.

National Coalition for Cancer Survivorship
Telephone: 888-650-9127 or 310-650-8868
Internet: www.canceradvocacy.org

The National Coalition for Cancer Survivorship (NCCS) is a survivor-led advocacy organization working exclusively on behalf of the over 9 million cancer survivors in the U.S. and the millions more touched by this disease. By educating all those affected by cancer and speaking out on issues related to quality cancer care, NCCS is empowering every cancer survivor.

National Coalition of Creative Arts Therapies Associations
Telephone: 201-224-9146
Internet: www.ncata.com

The National Coalition of Creative Arts Therapies Associations (NCCATA) is an alliance of professional associations dedicated to the advancement of the arts as therapeutic modalities. NCCATA represents over 8,000 individual members of six creative arts therapies associations.
National Consumers League (NCL)
Telephone: 202-835-3323
Internet: www.nclnet.org

NCL works to protect and promote the economic and social interests of American consumers. NCL offers brochures on various health care topics.

National Family Caregivers Association (NFCA)
Telephone: 800-896-3650 or 301-942-6430
Internet: www.nfcacares.org

NFCA provides education, support, respite care, and advocacy for caregivers. Support groups are available.

National Guild of Hypnotists
Telephone: 603-429-9438
Internet: www.ngh.net

The National Guild of Hypnotists (NGH) is a nonprofit, professional organization of individuals committed to advancing the field of hypnotism. The Internet site has a listing of local chapters at www.ngh.net/chapter.shtml. Your local chapter may be able to assist you in finding a practitioner in your area.

National Hospice & Palliative Care Organization (formerly National Hospice Organization)
Telephone: 800-658-8898 or 703-243-5900
Internet: www.nho.org

The National Hospice and Palliative Care Organization (NHPCO) provides information about hospice and palliative care. The Internet site allows you to search for providers online, or will give referrals via the toll-free information line.

National Patient Air Transport Helpline (NPATH)
Telephone: 800-296-1217 or 703-361-1191
Internet: www.patienttravel.org

NPATH provides information about all forms of charitable, long-distance medical air transportation and provides referrals to available sources of help in the national charitable medical air transportation network. The Internet site and Helpline are provided by Mercy Medical Airlift, a national, nonprofit organization.

National Center for Complementary and Alternative Medicine (NCCAM)
Telephone: 888-644-6226
TTY (for deaf or hard-of-hearing callers): 866-464-3615
Fax-on-Demand Service: 888-644-6226
Internet: www.nccam.nih.gov

NCCAM is part of the National Institutes of Health (NIH). NCCAM's mission is to support rigorous research on complementary and alternative medicine (CAM), to train
researchers in CAM, and to disseminate information to the public and professionals on which CAM modalities work, which do not, and why. The NCCAM Clearinghouse disseminates publications and other information about CAM to the public and the health care community. The clearinghouse does not make referrals to CAM practitioners or provide medical advice.

**Patient Advocate Foundation (PAF)**

Telephone: 800-532-5274 or 757-873-6668

Internet: [www.patientadvocate.org](http://www.patientadvocate.org)

PAF is a national non-profit organization. PAF provides education, counseling, and referrals to health care consumers concerning managed care, insurance, financial issues, job discrimination, and debt crisis matters. The Internet site has a state listing of financial resources at [www.patientadvocate.org/report.php](http://www.patientadvocate.org/report.php).

**The Viatical and Life Settlement Association of America**

Telephone: 407-894-3797

Internet: [www.viatical.org](http://www.viatical.org)

The Viatical and Life Settlement Association of America (VLSAA) was founded in 1995 as a nonprofit trade association for members of the viatical and life settlement industry, associated businesses, and consumers. The Internet site has state-by-state information about member organizations and state regulations governing viatical settlements.

**Visiting Nurse Association of America**

Telephone: 617-737-3200

Internet: [www.vnaa.org](http://www.vnaa.org)

The Visiting Nurse Associations of America (VNAA) is a national, nonprofit association for community-based home health organizations known as visiting nurse associations (VNAs). VNAA provides information on all aspects of home health care including general nursing, physical, occupational, and speech therapy, social services, home health aide and homemaker services, nutritional counseling; and hospice care. The VNAA Internet site allows users to search for VNAs in their area at [www.vnaa.org/vnaa/Searches/SearchByMap.aspx](http://www.vnaa.org/vnaa/Searches/SearchByMap.aspx).

**Vital Options® International TeleSupport® Cancer Network**

Telephone: 818-508-5657

Internet: [www.vitaloptions.org](http://www.vitaloptions.org)

Vital Options® International TeleSupport® Cancer Network is a nonprofit cancer communications, support, and advocacy organization whose mission is to facilitate a global cancer dialogue by using communications technology to reach every person touched by cancer. Vital Options sponsors The Group Room®, a weekly syndicated cancer radio talk show that is simulcast on the Internet and XM Satellite. The Group Room® can be reached by telephone at 800-GRP-ROOM (800-477-7666). The program is broadcast on Sundays 4-6 PM (ET), 3-5 PM (CT), 1-3 PM (PT). The Internet site has a listing of local radio stations that carry The Group Room®.
Well Spouse Foundation
Telephone: 800-838-0879 or 212-644-1241
Internet: www.wellspouse.org

Well Spouse is a national, nonprofit organization that gives support to wives, husbands, and partners of the chronically ill and/or disabled. Well Spouse also works to make health care professionals and the general public aware of the great difficulties caregivers face every day. The foundation operates support groups throughout the U.S. Check the Internet site at www.wellspouse.org/support.html to check for a Well Spouse support group in your area.

Wellness Community
Telephone: 888-793-WELL (888-793-9355) or 513-421-7111
Internet: www.thewellnesscommunity.org

The Wellness Community (TWC) is a national, nonprofit organization dedicated to providing free emotional support, education, and hope for people with cancer and their loved ones. Through participation in professionally led support groups, educational workshops, and mind/body programs, people affected by cancer can learn vital skills to regain control, reduce feelings of isolation, and restore hope—regardless of the stage of disease. There are 20 Wellness Community facilities nationwide in addition to online support groups.
USEFUL INTERNET SITES*
(*not listed under Organizations)

The author is not responsible for information found on these or other Internet sites.

The Internet is a valuable tool. However, you are urged to consult your health care provider or another appropriate professional before acting on the information found on these or other Internet sites.

Agency for Healthcare Research and Quality, Lung Cancer Screening Recommendation
Internet: [www.ahcpr.gov/clinic/cpsix.htm#neoplastic](http://www.ahcpr.gov/clinic/cpsix.htm#neoplastic)
(click on Lung Cancer under Neoplastic Diseases)
summary of the lung cancer screening recommendations from The Guide to Clinical Preventive Services, a report from the U.S. Preventive Services Task Force

American Association for Respiratory Care
Internet: [www.aarc.org/index.html](http://www.aarc.org/index.html)
information on respiratory care and related issues
includes health tips for patients with respiratory problems

American Cancer Society/Lung Cancer Section
Internet: [www.cancer.org/docroot/HOME/pff/pff_0.asp?level=0](http://www.cancer.org/docroot/HOME/pff/pff_0.asp?level=0)
provides information about lung cancer, preparing for treatment, coping with treatment, and aftercare

Americans With Disabilities Act Home Page
Internet: [www.usdoj.gov/crt/ada/adahom1.htm](http://www.usdoj.gov/crt/ada/adahom1.htm)
information about the rights of people affected by cancer and other diseases

Cancer News: Lung Cancer Information
Internet: [www.cancernews.com/lung.htm](http://www.cancernews.com/lung.htm)
articles, video news clips, book lists, treatment options, and other information on lung cancer

Cancer WEB
Internet: [cancerweb.ncl.ac.uk](http://cancerweb.ncl.ac.uk)
information on many different aspects of cancer, investigation and treatment, provided for patients and families, clinicians, researchers, and supporters

City of Hope Medical Center
Internet: [www.cityofhope.org](http://www.cityofhope.org)
an NCI-designated Comprehensive Cancer Center
information on clinical trials, supportive care, and cancer treatments

Cuneo Lung Cancer Study Group (CuLCaSG)
Internet: [www.culcasg.org](http://www.culcasg.org)
site of an Italian Lung Cancer Study Group (CuLCaSG)
information is available in Italian and English
Department of Housing and Urban Development (HUD), Housing Counseling Agencies
Internet: www.hud.gov/offices/hsg/sfh/hcc/hccprof14.cfm
This section of the HUD Internet site lists approved housing counseling agencies that can provide you with information on defaults, foreclosures, credit issues, and reverse mortgages.

Steve Dunn’s Cancer Guide
Internet: cancerguide.org
Cancer resource compiled by a cancer survivor; the site contains many links to other resources available on the Internet.

HelpingPatients.org
Internet: www.helpingpatients.org
Site sponsored by member pharmaceutical companies to help patients gain access to prescription assistance programs.

iAround.org
Internet: www.iaround.org
Non-profit organization working to create a lung cancer resource guide so patients and caregivers can get the critical yet sufficient resources quickly, easily, and achieve the best possible outcome.

KIDSCOPE
Internet: http://www.kidscope.org/
Site dedicated to helping children understand and cope with the effects from cancer and chemotherapy in a parent; request the book Kemo Shark to help children understand chemotherapy.

Lung Cancer Information Center
Internet: www.meds.com/lung/lunginfo.html
An electronic library of educational materials on lung cancer for health care professionals and patients; links to many Internet sites containing useful information about lung cancer.

Lung Cancer Online
Internet: www.lungcanceronline.org
Internet clearinghouse of information about lung cancer created by a lung cancer survivor. Site is a gateway to lung cancer resources that is intended to facilitate the time consuming and often-frustrating process of learning about lung cancer, treatment options, and support services.

Medicaid
Internet: cms.hhs.gov/medicaid/default.asp
Government site for Medicaid information.
Medicare
Internet: www.medicare.gov
Government site for Medicare information. Information about prescription drug assistance programs at www.medicare.gov/Prescription/Home.asp.

Mt. Zion Medical Center, Department of Thoracic Surgery
Internet: www.ucsf.edu/thoracic/patient-ed.html
Basic information lung structure and function and lung surgery part of the University of California at San Francisco Medical Center Internet site information about clinical trials, lung cancer awareness, and smoking cessation.

National Cancer Institute (NCI) Cancer.gov
Internet: cancer.gov/cancerinformation
Comprehensive information about cancer including types of cancer, prevention, treatment, clinical trials, supportive care, terminology resources, and cancer literature.

National Comprehensive Cancer Network Lung Cancer Treatment Guidelines
Internet: www.nccn.org/patient_gls/_english/_lung/index.htm
Information about the function of the lungs, types of lung cancer, lung cancer stages, and a glossary of medical terms. Site allows you to go through an interactive treatment decision tree based on your stage of disease and other specific circumstances.

National Institute of Mental Health
Internet: www.nimh.nih.gov
Federal government’s agency for information on mental health. online information, ordering of publication, and useful links to other resources

NeedyMeds.com
Internet: www.needymeds.com
Information source for patient assistance programs and prescription assistance programs.

New York Times, Women’s Health: Lung Cancer
Information on lung cancer and women’s health including links to other useful sites.

OncoLink
Internet: www.oncolink.upenn.edu
Extensive cancer resource site from the University of Pennsylvania Abramson Cancer Center. Includes information on types of cancer, treatment options, clinical trials, and coping with cancer.

Quackwatch
Internet: www.quackwatch.com
Independent site operated by Stephen Barrett, MD, “Your Guide to Health Fraud, Quackery, and Intelligent Decisions.”
**Reuters Health Information Services**  
Internet: [www.reutershealth.com](http://www.reutershealth.com)  
Source of general health and medical news on the Internet.

**RxAssist**  
Internet: [www.rxassist.org](http://www.rxassist.org)  
Site sponsored by the Robert Wood Johnson Foundation to help people locate prescription assistance programs.

**Social Security Administration**  
Internet: [www.ssa.gov](http://www.ssa.gov)  
Government site for information on Social Security benefits and disability programs.

**University of Florida State Anatomical Board**  
Internet: [www.med.ufl.edu/anatbd/usprograms.html](http://www.med.ufl.edu/anatbd/usprograms.html)  
National referral list of body donation programs in the United States.

**Viatical Settlement Guide**  
Internet: [www.viatical-settlement.net](http://www.viatical-settlement.net)  
Independent site with extensive information about viatical settlements.
Some pharmaceutical companies offer prescription drug programs to make specific drugs available to people who could not otherwise afford them. Generally, your doctor must apply to these programs on your behalf. However, you can call and obtain the applications and information to help speed the process. Eligibility requirements and program operations vary greatly from one program to another.

The Pharmaceutical Research and Manufacturers of America (PhRMA) is an organization of pharmaceutical and biotechnology companies. PhRMA publishes a book called The Directory of Prescription Drug Indigent Programs that lists programs through which drug manufacturers offer medications to people who are unable to pay for them. The book is available to doctors, other health care professionals, and health care agencies free of charge. Eligible parties can request a copy by writing to PhRMA at 1100 15th Street NW, Washington, DC 20005 or calling 202-835-3400.

RxHope.com is a patient assistance Internet initiative financially supported by PhRMA and participating pharmaceutical companies. RxHope.com began as a grassroots effort of the Patient Assistance Managers and Directors of the PhRMA-member companies. The Internet site is located at www.rxhope.com. Patients can fill out an Assistance Finder request form, which matches patients with federal, state, and charitable assistance programs that may be useful for meeting their needs and circumstances. The site also permits doctors to make assistance requests on a patient’s behalf. RxHope.com does not approve or deny requests nor do they take delivery or ship any products.

RxAssist.org, NeedyMeds.com, and HelpingPatients.org are independent Internet sites that also help people locate prescription drug assistance programs. See each listing under Useful Internet Sites for additional information about these organizations.

Following are listings of pharmaceutical company patient assistance programs for some of the drugs commonly used by people with lung cancer.
Amgen, Inc.
Safety Net Programs
PO Box 13185
La Jolla, CA 92039-3185
Telephone: 800-272-9376

products include Aranesp\textsuperscript{TM} (darbepoetin), Neulasta\textsuperscript{TM} (pegfilgrastim), Epogen\textsuperscript{TM} (epoetin alfa), Neupogen\textsuperscript{TM} (filgrastim)

Patient must meet certain insurance and financial criteria.

Aventis Pharmaceuticals
Aventis Oncology PACT+ Program
100 Grandview Rd., Suite 210
Braintree, MA 02184
Telephone: 800-996-6626

products include Anzemet\textsuperscript{TM} (dolasetron), Taxotere\textsuperscript{TM} (docetaxel)

Program based on grounds that patient does not have any insurance. However, there are exceptions. Please call company to determine eligibility.

Bayer Corporation Pharmaceutical Division
Bayer Indigent Patient Program
PO Box 29209
Phoenix, AZ 85038-9209
Telephone: 800-998-9180

products include Cipro\textsuperscript{TM} (ciprofloxacin)

Patient must be a US citizen, have no prescription drug coverage, and taking the drug for an FDA-approved indication.

Income must be at or below federal poverty level.

Bristol-Myers Squibb Company
Bristol-Myers Squibb and AmeriCares Oncology/Virology Access Program
6900 College Blvd. Suite 1000
Overland Park, KS 66211-9840
Telephone: 800-272-4878

products include BiCNU\textsuperscript{TM} (carmustine), Blenoxane\textsuperscript{TM} (bleomycin), Ceenu\textsuperscript{TM} (lomustine), Cytoxan\textsuperscript{TM} (cyclophosphamide), Etopophos\textsuperscript{TM} (etoposide), Hydea\textsuperscript{TM} (hydroxyurea), Ifex\textsuperscript{TM} (ifosfamide), Megace\textsuperscript{TM} (megestrol), Mesnex\textsuperscript{TM} (mesna), Mutamycin\textsuperscript{TM} (mitomycin), Paraplatin\textsuperscript{TM} (carboplatin), Platinol\textsuperscript{TM} (cisplatin), Taxol\textsuperscript{TM} (paclitaxel), Vepesid\textsuperscript{TM} (etoposide), and Vumon\textsuperscript{TM} (teniposide)

Patient must be residing in the United States (its territories, possessions) and receiving the product on an outpatient basis.

Patient must have no assistance from third-party private or public sources.

Patient must meet program income/asset criteria.
Eli Lilly and Company
Gemzar Patient Assistance Program
PO Box 9105
McLean, VA 22102-0105
Telephone: 888-443-6927
products include Gemzar™ (gemcitabine)
Patient must have no medical coverage and be ineligible for any programs with a
drug benefit provision, including Medicaid, third-party insurance, Medicare, and
all other programs have denied coverage for Gemzar in writing, and all appeals
have been exhausted.

Food and Drug Administration (FDA), Single Patient Investigational New Drug
Program
Patients who are not eligible for a clinical trial and who are in an immediate medical crisis
may be able to receive drugs that are not yet FDA-approved. Your doctor would have to
apply to the FDA for permission to use the drug, an approval known as a Single Patient
IND for Compassionate or Emergency Use. Contact information appears below. The FDA
usually responds to an application within 24 to 48 hours.
CDER Oncology Drug Products (most cancer drugs): 301-594-2473
CBER Oncology Branch (for biologicals): 301-827-5093
Internet information: www.fda.gov/cder/cancer/singleIND.htm

Genentech, Inc.
Access to Care
Health Care Affairs Dept.
PO Box 2586
South San Francisco, CA 94083-2586
Telephone: 800-530-3083
products include Activase™ (alteplase), Herceptin™ (trastuzumab), Nutropin™
(somatropin), Protropin™ (somatrem), TNKase™ (tenecteplase)
Patient must not be eligible for public or private insurance reimbursement and meet
income restrictions.

Glaxo Smith Kline
Bridges to Access (non-cancer drugs)
PO Box 29038
Phoenix, AZ 85038-9038
Telephone: 866-728-4368

Commitment to Access (cancer drugs)
PO Box 29038
Phoenix, AZ 85038-9038
Telephone: 866-265-6491
Glaxo Smith Kline, continued

products include Ceftin™ (cefoxime), Compazine™ (prochlorperazine), Fortaz™ (ceftazidime), Hycamtin™ (topotecan), Navelbine™ (vinorelbine), Paxil™ (paroxetine), Wellbutrin™ (bupropion), Zofran™ (ondansetron), and Zyban (bupropion)

Patient must be a resident of the United States.
Patient must not be eligible for prescription drug benefits through any private or public insurer/payer/program.
Income eligibility varies according to the drug being sought; call for additional information.

Janssen Pharmaceutica

Janssen Patient Assistance Program
PO Box 221857
Charlotte, NC 28222-1857
Telephone: 800-652-6227
products include Duragesic™ (fentanyl), and Nizoral™ (ketoconazole)
Patients are eligible who lack access to prescription drug coverage and meet specific financial criteria.

Medimmune, Inc.

Ethyol Protect Program
PO Box 222197
Charlotte, NC 28222-2197
Telephone: 800-887-2467
products include Ethylol™ (amifostine)
Patient must have no insurance including Medicare and meet program income guidelines.

Merck & Company, Inc.

The Merck Patient Assistance Program
PO Box 1985
Horsham, PA 19044-9848
Telephone: 800 994-2111
products include Vioxx™ (rofecoxib)
The program is for patients who do not have pharmaceutical insurance coverage and cannot afford to pay for their medicine.
Patients are eligible if there is medical and financial need as identified by their physician and they are unable to get help from any other insurers, including private insurance, Medicare, Medicaid, HMOs, state pharmacy assistance programs, Veterans' assistance programs, or any other social service agencies.
Patients must reside in the United States and have a prescription from a US-licensed physician. The patient does not have to be a US citizen.
Applications are reviewed on a case-by-case basis.
Novartis Pharmaceuticals
Novartis Oncology Reimbursement Program
1250 Bayhill Dr.
San Bruno, CA 94066
Telephone: 800-282-7630
products include Gleevec™ (imatinib) and Zometa™ (zoledronic acid)
Patients must not have prescription drug coverage and meet programs income requirements.

Ortho Biotech Products
PROCRITline Patient Assistance Program
1250 Bayhill Dr., Suite 300
San Bruno, CA 94066
Telephone: 800-553-3851
products include Procrit™ (epoetin alfa),
Patients should not have any insurance that would cover the medication.
In the case of Medicare, medications are covered if given in the physician's office and diagnosis meets state-by-state Medicare guidelines.

Ortho-McNeil Pharmaceutical
Ortho-McNeil Patient Assistance Program
1250 Bayhill Dr., Suite 300
San Bruno, CA 94066
Telephone: 800-577-3788
products include Ultram™ (tramadol)

Pfizer, Inc.
Sharing the Care
PO Box 6057
E. Brunswick, NY 08816-9721
Telephone: 800-984-1500
products include Zoloft™ (sertraline)
The program, a joint effort of Pfizer, the National Governors' Association, and the National Association of Community Health Centers, works through community, migrant, and homeless health centers. The program includes the participation of more than 350 health centers throughout the United States.
To be eligible to participate in Sharing the Care, the patient must be registered at a participating health center, must not be covered by any private insurance or public assistance covering pharmaceuticals, must not be Medicaid-enrolled, and must have family income that is equal to or below the federal poverty level.
**Pharmacia Corporation**

First Resource (Camptosar™ only; no mailing address available)
Telephone: 877-744-5675

Patients In Need (products other than Camptosar™)
PO Box 52059
Phoenix, AZ 85072
Telephone: 800-242-7014

- products include Camptosar™ (irinotecan), Celebrex™ (celecoxib), and Ellence™ (epirubicin)
- Patients must be financially disadvantaged.
- Program assists uninsured and underinsured patients.

**Purdue Pharma**

Patient Assistance Program
c/o Express Scripts SDS
PO Box 66547
St. Louis, MO 63166-6547
Telephone: 800-599-6070

- products include MS Contin™ (morphine), MSIR™ (morphine), Oxycontin™ (oxycodeone), OxyFast™ (oxycodeone), and OxyIR™ (oxycodeone)
- Patients must not have insurance coverage and do not qualify for Medicaid.

**Roche Pharmaceuticals**

Roche Medical Needs Program
JoAnn Hanly, Medical Needs
340 Kingsland St.
Nutley, NJ 07110
Telephone: 800-285-4484

- products include Kytril™ (granisetron), Valium™ (diazepam), Vesanoid™ (tretinoin), and Xeloda™ (capcitabine)
- Patient must be an outpatient to qualify.
- Patient cannot be eligible for any federal assistance such as Medicaid or Medicare.

**Solvay Pharmaceuticals**

Solvay Patient Assistance Program (Androgel, Marinol, Anadrol)
PO Box 66550
St. Louis, MO 63166-6550
Telephone: 800-256-8918

- products include Androgel™ (testosterone gel), Marinol™ (dronabinol), and Anadrol™ (oxymetholone)
- Patients must be US residents.
- Patients must meet income requirements and must not have insurance coverage for the requested product.
NATIONAL CANCER INSTITUTE (NCI) DESIGNATED
COMPREHENSIVE CANCER CENTERS AND CLINICAL CANCER CENTERS

Following is an alphabetical listing by state of NCI designated cancer centers. These centers provide state of the art medical treatment for cancer. Comprehensive cancer centers also provide cancer-related community outreach and education services. Cancer centers are designated with a single star (*). Clinical cancer centers are designated with two stars (**). Comprehensive cancer centers are designated with three stars (***)

Alabama

University of Alabama at Birmingham Comprehensive Cancer Center***
1824 Sixth Avenue South
Birmingham, AL 35293-3300
Telephone: 800-822-0933 or 205-934-5077
Internet: www.ccc.uab.edu

Arizona

University of Arizona, Arizona Cancer Center***
1515 North Campbell Avenue
Tucson, AZ 85724
Telephone: 800-622-2673 or 520-626-6044
E-mail: copeline@azcc.arizona.edu
Internet: www.azcc.arizona.edu

California

Burnham Institute Cancer Research Center*
10901 North Torrey Pines Road
La Jolla, CA 92037
Telephone: 858-646-3100
E-mail: info@burnham.org
Internet: www.burnham institute.org

City of Hope National Medical Center & Beckman Research Institute***
1500 East Duarte Road
Duarte, CA 91010
Telephone: 800-826-4673 or 626-359-8111
E-mail: becomingapatient@coh.org
Internet: www.cityofhope.org
Salk Institute Cancer Center*
Post Office Box 85800
San Diego, CA 92186-5800
Telephone: 858-453-4100
Internet: www.salk.edu

University of California Davis Cancer Center**
4501 X Street, Suite 3003
Sacramento, California 95817
Telephone: 800-362-5566 or 916-734-5900
Internet: cancer.ucdmc.ucdavis.edu

University of California Irvine, Chao Family Comprehensive Cancer Center***
101 The City Drive South
Orange, CA 92868
Telephone: 877-824-3627
E-mail: physpecref@msx.ndc.mc.uci.edu
Internet: www.ucihealth.com/cancer

University of California Los Angeles, Jonsson Comprehensive Cancer Center***
10833 Le Conte Avenue
Los Angeles, CA 90095-1781
Telephone: 800-825-2631 or 310-206-6909 or 310-794-1648
E-mail: JcccInfo@mednet.ucla.edu
Internet: www.cancer.mednet.ucla.edu

University of California San Diego Rebecca and John Moores Cancer Center***
9500 Gilman Drive
La Jolla, CA 92093-0658
Telephone: 866-558-7933 or 619-543-3456
E-mail: dedavis@ucsd.edu
Internet: http://cancer.ucsd.edu/

University of California San Francisco Cancer Center and Cancer Research Institute***
2340 Sutter Street, Box 0128
San Francisco, CA 94115-0128
Telephone: 800-888-8664 or 415-885-7777
E-mail: cceditor@cc.ucsf.edu
Internet: cc.ucsf.edu

University of Southern California Kenneth Norris Jr. Cancer Hospital and Center***
1441 East Lake Avenue
Los Angeles, CA 90033-0800
Telephone: 800-872-2273 or 323-865-0816
E-mail: cainfo@ccnt.hsc.usc.edu
Internet: ccnt.hsc.usc.edu
Colorado

University of Colorado Cancer Center***
1665 N. Ursula St.
Aurora, CO 80010
Telephone: 800-473-2288 or 303-372-1550
E-mail: CancerCenter.Webmaster@uchsc.edu
Internet: www.uccc.info

Connecticut

Yale Cancer Center***
333 Cedar Street, Box 208028
New Haven, CT 06520-8028
Telephone: 203-785-4095
Fax: 203-785-4116
Internet: www.med.yale.edu/ycc

District of Columbia

Georgetown University Medical Center, Lombardi Cancer Center***
3800 Reservoir Road, NW
Washington, DC 20007
Telephone: 202-784-4000 or 202-687-2110
E-mail: lccis@georgetown.edu
Internet: lombardi.georgetown.edu

Florida

University of South Florida, H. Lee Moffitt Cancer Center & Research Institute***
12902 Magnolia Drive
Tampa, FL 33612-9497
Telephone: 800-663-3488 or 813-979-7265
Internet: www.moffitt.usf.edu

Hawaii

University of Hawaii, Cancer Research Center of Hawaii**
1236 Lauhala Street
Honolulu, HI 96813
Telephone: 808-586-3013
Internet: www.hawaii.edu/crch
Illinois

Northwestern University Robert H. Lurie Cancer Center***
Olson 8250
303 East Chicago Ave.
Chicago, IL 60611
Telephone: 800-554-4570 or 312-908-5250
E-mail: cancer@northwestern.edu
Internet: www.cancer.northwestern.edu

University of Chicago Cancer Research Center**
5841 South Maryland Ave. MC 1140
Chicago, IL 60637-1470
Telephone: 773-702-6149 or 773-834-0783
Internet: uccrc.uchicago.edu

Indiana

Indiana University Cancer Center**
535 Barnhill Drive, Room 455
Indianapolis, IN 46202-5289
Telephone: 888-600-4822 or 317-278-4822
Internet: iucc.iu.edu

Purdue University Cancer Center*
South University Street
West Lafayette, IN 47907-1524
Telephone: 765-494-9129
E-mail: mkhines@purdue.edu
Internet: www.cancer.purdue.edu

Iowa

University of Iowa, Holden Comprehensive Cancer Center***
200 Hawkins Drive
Iowa City, IA 52242
Telephone: 800-777-8442 or 319-353-8620
Internet: www.uihealthcare.com/depts/cancercenter/index.html

Maine

The Jackson Laboratory*
600 Main Street
Bar Harbor, ME 04609-0800
Telephone: 207-288-6000
E-mail: pubinfo@jax.org
Internet: www.jax.org
Maryland

Johns Hopkins Sidney Kimmel Comprehensive Cancer Center***
600 North Wolfe Street
Baltimore, MD 21287-8943
Telephone: 410-955-8964
E-mail: jhis@jhmi.edu
Internet: www.hopkinskimmelcancercenter.org/index.cfm

Massachusetts

Dana-Farber/Harvard Cancer Institute***
44 Binney Street
Boston, MA 02115
Telephone: 866-408-3324 or 617-632-6366
E-mail: Dana-FarberContactUs@dfci.harvard.edu
Internet: http://www.dfci.harvard.edu/

Massachusetts Institute of Technology Center for Cancer Research*
40 Ames St, E17-110
Cambridge, MA 02139
Telephone: 617-253-6403
E-mail: hollyc@mit.edu
Internet: web.mit.edu/ccr/index.html

Michigan

University of Michigan Comprehensive Cancer Center***
1500 East Medical Center Drive
Ann Arbor, MI 48109-0942
Telephone: 800-865-1125 or 313-936-1831
Internet: www.cancer.med.umich.edu

Meyer L. Prentis Comprehensive Cancer Center of Metropolitan Detroit***
(part of the Barbara Ann Karmanos Cancer Institute of Wayne State University)
4100 John R. Street
Detroit, MI 48201-1379
Telephone: 800-527-6266 or 313-833-0710
E-mail: prentis@karmanos.org
Internet: www.meyerlprentiscccmd.org
Minnesota

University of Minnesota Cancer Center***
Box 806, 420 Delaware St. SE
Minneapolis, MN 55455
Telephone: 888-226-2376 or 612-624-2620
E-mail: info@cancer.umn.edu
Internet: www.cancer.umn.edu

Mayo Clinic Cancer Center***
200 First St. SW
Rochester, MN 55905
Telephone: 507-284-2511
Internet: http://www.mayoclinic.org/cancercenter

Missouri

Washington University School of Medicine Siteman Cancer Center**
660 South Euclid Avenue
St. Louis, MO 63110
Telephone: 800-600-3606 or 314-747-7222
E-mail: info@ccadmin.wustl.edu
Internet: www.siteman.wustl.edu

Nebraska

University of Nebraska Medical Center Eppley Cancer Center**
600 South 42nd Street
Omaha, NE 68198-6805
Telephone: 800-999-5465 or 402-559-9999
Internet: www.unmc.edu/cancercenter

New Hampshire

Dartmouth-Hitchcock Medical Center Norris Cotton Cancer Center***
One Medical Center Drive
Lebanon, NH 03756-0001
Telephone: 800-639-6918 or 603-650-5527
E-mail: cancerhelp@dartmouth.edu
Internet: cancer.dartmouth.edu/index.shtml
New Jersey

Robert Wood Johnson University, The Cancer Institute of New Jersey***
195 Little Albany Street
New Brunswick, NJ 08901
Telephone: 732-235-2465
Internet: www.cinj.org

New York

Albert Einstein College of Medicine Cancer Research Center**
1300 Morris Park Ave
Bronx, NY 10461
Telephone: 718-430-2302
E-mail: aecr@aecc.aecom.yu.edu
Internet: www.aecom.yu.edu/cancer/new/default.htm

Cold Spring Harbor Laboratory*
P.O. Box 100
Cold Spring Harbor, NY 11724
Telephone: 516-367-8397
Internet: www.cshl.org

Columbia University Herbert Irving Comprehensive Cancer Center***
177 Fort Washington Ave.
New York, NY 10032
Telephone: 212-305-8602
Internet: www.ccc.columbia.edu

Memorial Sloan-Kettering Cancer Center***
1275 York Ave.
New York, NY 10021
Telephone: 800-525-2225 or 212-639-2000
Internet: www.mskcc.org/mskcc/html/44.cfm

New York University Cancer Institute***
550 First Ave.
New York, NY 10016
Telephone: 888-769-8633 or 212-263-3551
Internet: www.nyucancerinstitute.org
Roswell Park Cancer Institute***
Elm & Carlton Streets
Buffalo, NY 14263-0001
Telephone: 877-275-7724 or 716-845-2300
E-mail: askrpci@roswellpark.org
Internet: www.roswellpark.org

North Carolina

Duke University Comprehensive Cancer Center***
301 MSRB, DUMC Box 3843
Durham, NC 27710
Telephone: 888-275-3853 or 919-416-3853 or 919-684-3377
Internet: cancer.duke.edu

University of North Carolina Lineberger Comprehensive Cancer Center***
School of Medicine CB# 7295, UNC at Chapel Hill
Chapel Hill, NC 27599-7295
Telephone: 919-966-3036
E-mail: dgs@med.unc.edu
Internet: cancer.med.unc.edu

Wake Forest University Comprehensive Cancer Center***
Medical Center Boulevard
Winston-Salem, NC 27157-1082
Telephone: 800-446-2255 or 336-716-2255
E-mail: jthornbu@wfubmc.edu
Internet: www.wfubmc.edu/cancer

Ohio

Case Western Reserve University Ireland Cancer Center***
11100 Euclid Ave
Cleveland, OH 44106-5065
Telephone: 800-641-2422
E-mail: info@irelandcancercenter.org
Internet: www.irelandcancercenter.org

Ohio State University Comprehensive Cancer Center***
300 West 10th Ave.
Columbus, OH 43210-1240
Telephone: 800-293-5066 or 614-293-2678
E-mail: cancerinfo@jamesline.com
Internet: www.jamesline.com
Oregon

Oregon Health Sciences University Oregon Cancer Institute**
3181 SW Sam Jackson Park Road
Portland, OR 97201-3098
Telephone: 503-494-1617
E-mail: cancer@ohsu.edu
Internet: www.ohsu.edu/oci

Pennsylvania

Fox Chase Cancer Center***
7701 Burholme Ave.
Philadelphia, PA 19111
Telephone: 888-369-2427 or 215-728-2570
Internet: www.fccc.edu

Thomas Jefferson University Kimmel Cancer Center**
233 South 10th Street
Philadelphia, PA 19107-5799
Telephone: 215-503-4500
Internet: www.kcc.tju.edu

University of Pennsylvania Abramson Cancer Center***
3400 Spruce Street
Philadelphia, PA 19104-4283
Telephone: 800-789-7366
Internet: pennhealth.com/hup/cancer

University of Pittsburgh Cancer Institute***
3471 Fifth Ave.
Pittsburgh, PA 15213-3305
Telephone: 800-237-4724
E-mail: PCI-INFO@msx.upmc.edu
Internet: www.upci.upmc.edu

Wistar Institute*
3601 Spruce Street
Philadelphia, PA 19104
Telephone: 215-898-3700
Internet: www.wistar.upenn.edu
Tennessee

St. Jude Children’s Research Hospital**
332 N. Lauderdale
Memphis, TN 38105-2794
Telephone: 901-495-3300
E-mail: info@stjude.org
Internet: www.stjude.org

Vanderbilt-Ingram Cancer Center***
691 Preston Building
Nashville, TN 37232
Telephone: 800-811-8480 (615) 936-1782
Internet: www.vicc.org

Texas

San Antonio Cancer Institute**
7979 Wurbach Road, Urschel Tower, 5th Floor
San Antonio, TX 78229
Telephone: 210-616-5590
Internet: www.ccc.saci.org/

University of Texas M.D. Anderson Cancer Center***
1515 Holcombe Boulevard
Houston, TX 77030
Telephone: 800-392-1611 or 713-792-6161
Internet: www.mdanderson.org

Utah

University of Utah Huntsman Cancer Institute**
2000 Circle of Hope
Salt Lake City, UT 84112
Telephone: 877-585-0303 or 801-585-0303
Internet: www.hci.utah.edu

Vermont

University of Vermont, Vermont Cancer Center***
149 Beaumont Avenue
Burlington, VT 05405
Telephone: 802-656-4414
E-mail: vcc@uvm.edu
Internet: www.vermontcancer.org
Virginia

University of Virginia Cancer Center**
PO Box 800334
Charlottesville, VA 22908
Telephone: 800-223-9173 or 434-924-9333
Internet: http://www.healthsystem.virginia.edu/internet/cancer

Virginia Commonwealth University Massey Cancer Center**
401 College Street
P.O. Box 980037
Richmond, VA 23298-0037
Telephone: 804-828-0450
Internet: www.vcu.edu/mcc

Washington

Fred Hutchinson Cancer Research Center***
1100 Fairview Ave. North
PO Box 19024
Seattle, WA 98109
Telephone: 800-804-8824 or 206-667-5000
Internet: www.fhcrc.org

Wisconsin

University of Wisconsin Comprehensive Cancer Center***
600 Highland Ave.
Madison, WI 53792
Telephone: 608-263-8600
Internet: www.cancer.wisc.edu
BOOKS

100 Questions and Answers about Lung Cancer
Karen Parles and J.H. Schiller
Jones & Bartlett Publishers, 2002
a patient-oriented guide to dealing with lung cancer written by a lung cancer survivor and a practicing oncologist

The Activist Cancer Patient: How to Take Charge of Your Treatment
Beverly Zakarian and Ezra M. Greenspan
John Wiley and Sons, 1996
step-by-step guidelines written by a cancer survivor to help empower cancer patients to work with their doctors and the medical system to find the most effective treatment options

The Alpha Book on Cancer and Living: For Patients, Family, and Friends
Brent G. Ryder
Alpha Books, Inc., 1997
guide to living with cancer, including getting quality care and support

American Cancer Society Consumer's Guide to Cancer Drugs
Gail M. Wilkes and Terri B. Ades
information about cancer drugs for patients and their loved ones

American Cancer Society Guide to Complementary and Alternative Cancer Methods
American Cancer Society, 2000
an overview of complementary and alternative therapies commonly used to treat cancer

American Cancer Society's Guide to Pain Control: From the Experts at the American Cancer Society
American Cancer Society, 2001
guide for cancer patients and loved ones; topics includes describing and measuring pain, drug tolerance, managing side effects, complementary non-drug treatments, and government sources of financial assistance
**Be Prepared: Complete Financial, Legal, and Practical Guide for Living with Cancer, HIV, and Other Life-Challenging Conditions**

David S. Landay  
Griffin Trade Paperback, 2000  
review of the many issues facing people living with life-challenging conditions includes accessing medical care, maximizing income entitlements, reducing expenses and debts, investment strategies, work-related issues, using existing assets, and legal rights

**Beyond Miracles: Living with Cancer**

Stephen P. Hersch  
Seven Locks Press, 2000  
guides people through the emotional roller coaster of being diagnosed with cancer and going through treatment

**Can I Still Kiss You?: Answering Your Children's Questions About Cancer**

Neil Russell  
Health Communications, 2001  
a chapter-by-chapter series of questions and answers dealing with diagnosis, surgery, radiation, and chemotherapy written by a cancer survivor reflecting his personal experiences

**Cancer and Natural Medicine: A Textbook of Basic Science and Clinical Research**

John C. Boik  
Oregon Medical Press, 1996  
reference book that reviews the science of cancer and complementary therapies includes research data

**Cancer Has Its Privileges: Stories of Hope and Laughter**

Christine Clifford and Jack Lindstrom (Illustrator)  
Berkley Publishing Group, 2002  
written by a cancer survivor and the founder of The Cancer Club®; a humorous outlook on living with cancer told through a collection of battlefield stories and anecdotes from her fellow survivors that go from funny to moving

**A Cancer Survivor's Almanac: Charting Your Journey**

Barbara Hoffman and the National Coalition for Cancer Survivorship (Editors)  
John Wiley and Sons, 1998 (second edition)  
- information and resources for legal concerns including insurance and employment, medical treatment, emotional support, self-help, and family issues
Cancer...There’s Hope
Richard A. Bloch
R.A. Bloch Cancer Foundation, Inc., 1982
- story of one man’s survival story after being diagnosed with lung cancer
  Note: This Book is available free of charge by calling The Cancer Hotline at 800-433-0464, or can be downloaded from the Internet at www.blochcancer.org/hope/hope1.htm.

Cancervive: The Challenge of Life after Cancer
Susan Nessim and Judith Ellis
Gale Group, 1993
- cancer survivor discusses the challenges of life after a diagnosis of cancer

Caring for Loved Ones at Home
Harry van Bommel
BookWorld Press, Inc., 1997
- step-by-step instructions on practical skills and challenges of caring for a sick loved one at home

Judith McKay and Nancee Hirano
- explanation of chemotherapy, radiotherapy, and self-help suggestions for making treatments more tolerable

Choices in Healing: Integrating the Best of Conventional and Complementary Approaches to Cancer
Michael A. Lerner
MIT Press, 1996
- a review of conventional and alternative approaches to cancer therapy
- explanations and evaluations of a wide range of complementary therapies including spiritual and psychological approaches, nutritional therapies, physical therapies, psychotherapy, support groups, visual imagery, hypnosis, massage, therapeutic touch, yoga, qi gong, macrobiotic diets and other cancer diets, acupuncture, Chinese herbal medicines, and others

Comfort of Home: An Illustrated Step-by-Step Guide for Caregivers
Maria M. Meyer and, Paula Derr
CareTrust Publications, LLC, 2002
- a guide to care giving in the home
- defines preparation for care giving, the day-to-day expectations, and a listing of numerous resources
Couples Confronting Cancer: Keeping Your Relationship Strong
Joy L. Fincannon and Katherine V. Bruss
American Cancer Society, 2002
addresses the challenges and problems cancer can cause in a relationship; offers advice to help couples communicate more easily and truthfully with one another, and to cope with the demands that cancer can unexpectedly put on relationships

Malin Dollinger, Ernest H. Rosenbaum and Margaret Tempero, Editors.
Andrews & McMeel Publishing, 2002
information on cancer diagnosis and treatment, supportive care, risk factors, genetics, and causes written by an oncologist for lay readers includes diagnosis and treatment of common cancers

The Healing Journey
M. D. Simonton, Reid Henson, Barbara Hogenson
iUniverse, Incorporated, 2002
a doctor and one of his patients offer healing ideas to anyone touched by life-threatening illness outlines the program currently in use at the Simonton Cancer Center in California; the program is based on the guiding principle that beliefs, attitudes, and emotions play a major role in determining the quality of our lives and health

How to Help Children through a Parent's Serious Illness
Kathleen McCue and Ron Bonn
St. Martin’s Press, 1996
practical advice from a child-life specialist; includes information such as what to tell a child about the illness, how to recognize early-warning signs in a child's drawings, sleep patterns, schoolwork and eating habits, and when and where to get professional help

Human Side of Cancer: Living with Hope, Coping with Uncertainty
Jimmie C. Holland and Sheldon Lewis
written by a psycho-oncologist, the book shares her thoughts and insights about facing cancer and what truly helps along the cancer journey; includes inspiring stories of the simple courage of ordinary people confronting cancer

Imperatives for Quality Cancer Care: Access, Advocacy, Action and Accountability
National Coalition for Cancer Survivorship, 1996
• consensus of the First National Congress on Cancer Survivorship, which focused on quality cancer care, physiologic long-term and late effects of cancer treatment, and psychosocial issues of cancer survivorship [Note: Book is online at www.canceradvocacy.org/advocacy/intro/imperatives.aspx.]
**It's Always Something**  
Gilda Radner  
William Morrow & Company, 2000  
the story of Gilda Radner's life and her battle with cancer - told with the spunk and irreverence that made her America's favorite late-night comedienne

**Keeping Them Healthy, Keeping Them Home: How to Care for Your Loved Ones at Home**  
Ellen M. Caruso  
Practice Management Information Corporation, 1998  
- a comprehensive handbook to help lay caregivers take care of their sick loved ones at home

**Living Beyond Limits: New Hope and Help for Facing Life-Threatening Illnesses**  
David Spiegel  
Random House, 1994  
- discusses how people with serious or life-threatening illnesses can live fuller lives by addressing their quality of life

**Living With Lung Cancer: A Guide for Patients and Their Families, 4th Edition**  
Barbara G. Cox, Robert E. Lee, David T. Carr, Eloise Harman  
Triad Publishing Company, 1999  
- guidebook for living with lung cancer written by doctors for patients and their families  
- divided into three main areas: an overview of the lungs and lung cancer; chapters on the three main treatment modalities of surgery, radiation therapy, and chemotherapy; and a section on nutrition, stress, and alternative therapies

**Love, Medicine and Miracles: Lessons Learned about Self-Healing from a Surgeon's Experience with Exceptional Patients**  
Bernie S. Siegel  
HarperCollins Publishers, 1988  
a former surgeon shares inspirational stories of self-healing and characteristics shared by survivors drawn from his experience with cancer patients and support groups

**Lung Cancer: A Comprehensive Guide for Patients and Families**  
Lorraine Johnston  
O'Reilly & Associates, Incorporated, 2001  
guidebook written by an author who has also written books on colorectal cancer and non-Hodgkin's lymphoma
Lung Cancer: A Guide to Diagnosis and Treatment
Walter J. Scott
Addicus Books, 2000
guidebook for patients and their loved ones written by a cardiothoracic surgeon who specializes in lung cancer surgery

Lung Cancer Chronicles
John A. Meyer
Rutgers University Press, 1990
stories about a surgeon and the men and women he treats for lung cancer are interwoven with discussions of the disease and the controversies surrounding tobacco addiction and lung cancer

Lung Cancer: Myths, Facts, Choices--and Hope
Claudia I. Henschke, Peggy McCarthy, and Sarah Wernicke
guidebook written for lay readers by a radiation oncologist who specializes in early lung cancer detection, a lung cancer advocate, and a freelance writer

Natural Compounds in Cancer Therapy
John C. Boik
Oregon Medical Press, 2001
reviews the effects of three dozen carefully selected natural botanical compounds on the biological processes involved in cancer progression

New Cancer Survivors: Living with Grace, Fighting with Spirit
Natalie Davis Spingarn
Johns Hopkins University Press, 1999
a collection of personal experiences of cancer survivors, including the author; addresses issues faced by people living with a serious illness and their caregivers; the author’s goals are to offer education and hope, and assist the reader in finding peace and acceptance in what can be a tumultuous experience

Spontaneous Healing: How to Discover and Enhance Your Body's Natural Ability to Maintain and Heal Itself
Andrew Weil
Random House, 2000
an examination of the body’s ability to heal itself written by a doctor who promotes integrated medicine
Soul Medicine: Medical Challenges on Life's Uncertain Journey
John E. Postley
Love and Logic Press Institute, 1996

guide for patients with serious illnesses and their loved ones; addresses developing
and maintaining a framework of personal values in the face of often
overwhelming medical situations

Wellness Community Guide to Fighting for Recovery from Cancer
Harold H. Benjamin
Putnam Publishing Group, 1995

guide devoted exclusively to providing psychological and social support for people
with cancer; the methods proposed in this book are intended to empower
patients so they can actively participate in their recovery

When a Parent Has Cancer: A Guide to Caring for Your Children
Wendy Schlessel Harpham

written by a physician, mother, and cancer survivor; describes how parents can
manage their cancer while raising a family and how to explain the disease to their
children

When Life Becomes Precious: A Guide for Loved Ones and Friends of Cancer Patients
Elise NeeDell Babcock
Bantam Books, 1996

a handbook that offers simple, straightforward guidelines designed to assist family
members and friends of cancer patients as they travel the cancer journey with a
person they love
MAGAZINES AND NEWSLETTERS

Cancer Breakthrough Newsletter
quarterly newsletter produced by the International Cancer Alliance (ICARE)
available in print or electronic format, for a suggested contribution of $25
to subscribe, call 301-654-7933 or 1-800-ICARE-61 or sign up online at
www.icare.org/registry/index.htm

Cancer Care News
newsletter published three times per year by Cancer Care
includes listings of support groups, educational workshops, teleconferences, and
professional education programs, as well as informative articles, book reviews,
and updates on Cancer Care initiatives
available in print or electronic format, free of charge
to subscribe, call 800-813-4673 or sign up online at
www.cancercare.org/team/teamList.cfm?c=83

The Cancer Letter
is an independent, weekly newsletter; it keeps oncologists, cancer researchers, and
patient advocates current with government grant opportunities and research
plans, industry news, and advocacy activities
the cost of a yearly subscription is $295
to subscribe, call 800-513-7042, e-mail info@cancerletter.com, or logon to
www.cancerletter.com/archives

The Clinical Cancer Letter
an independent, monthly newsletter on cancer clinical trials and clinical research
the cost of a yearly subscription is $95
to subscribe, call 800-513-7042, e-mail info@cancerletter.com, or logon to
www.cancerletter.com/archives

Coping With Cancer
a bimonthly magazine for people whose lives have been touched by cancer
a yearly subscription (six issues) is $19
to subscribe, call 615-791-3859 or logon to
www.copingmag.com/CopPages/CgHome.html

Cure Today
Independent quarterly magazine developed for individuals coping with cancer and
blood disorders; it is published by physicians committed to providing quality
care to their patients.
CURE stands for Cancer Updates, Research & Education; the magazine provides
scientific information in an easy-to-understand format.
free subscriptions are available by calling 800-210-2873, e-mailing
subs@curetoday.com, or logging on to
www.curetoday.com/freesubscriptions/index.html
**Interactions**
quarterly newsletter for members of the National Coalition for Cancer Survivorship (NCCS)
to subscribe to NCCS, call 301-650-8868 or logon to
[www.canceradvocacy.org/about/support/join.aspx](http://www.canceradvocacy.org/about/support/join.aspx)

**Spirit and Breath**
- quarterly newsletter for people living with lung cancer from the Lung Cancer Alliance
- available to members of LCA; to subscribe, call LCA at 800-298-2436


**Audio, Video, and DVD Recordings**

These items are available for purchase from your local bookstore, online bookstore, or another resource for multi-media. Special orders may be required for some items. You may also be able to borrow or rent items from your cancer clinic, library, bookstore, or video store.

**A Bend In The Road: Finding God When Your World Caves In (audio)**
David Jeremiah  
Thomas Nelson, 2000  
Drawing from his sermons and his experience with cancer, pastor Jeremiah shares the comfort and hope of the Psalms and how these truths can guide believers through life's greatest challenges.

**AM/PM Yoga for Beginners (video)**
Living Arts, 1998  
Instructors Rodney Yee and Patricia Walden lead viewers in gentle yoga positions; set in Maui, Hawaii.

**Cancer Clinical Trials: An Introduction for Patients and Their Families (video)**
National Cancer Institute, 2001  
Free of charge  
Call 800-4-CANCER, or logon to cissecure.nci.nih.gov/ncipubs to order.

**Cancer Schmancer (audio)**
Fran Drescher  
Time Warner Audiobooks, 2002  
Star of the TV sitcom *The Nanny*, Fran Drescher shares her experience with uterine cancer to reveal that even in life's darkest moments, there's unexpected comedy.

**Chemotherapy and Radiation for Cancer Treatment (video and DVD)**
Dartmouth-Hitchcock Medical Center Production  
Films for the Humanities and Sciences, 2000  
People with Hodgkin's disease and breast, lung, prostate, and ovarian cancer describe the treatments—what they are like, how they incorporate them into their daily routines, and how they deal with the side-effects—and the emotional ups and downs that accompany them; information is also provided on new treatments that are extending the life expectancies of lung cancer patients.

**Controlling Cancer Pain, A Video for Patients and Families (video)**
National Cancer Institute, 2000  
Free of charge  
Call 800-4-CANCER, or logon to cissecure.nci.nih.gov/ncipubs to order.

**Dissolving & Destroying Cancer Cells: A Guided Imagery Program (video)**
2002  
A series of guided imagery sessions with soothing music.
**Feel the Qi: A Beginner's Guide to Qigong** (video)
1998

instruction by a qi gong master

**Gentle Tai Chi: Meditation in Motion** (video)
Ageless Fitness, 2001

instructor Dagmar Munn guides viewers through a series of easy movements adapted from traditional tai chi; her target audience is those who find strenuous exercise difficult

**Healing Imagery for People Facing Cancer: Four Guided Imagery Audiotapes** (audio)
Patricia B. Palmer
Touch Star Productions, 1998

a series of four tapes focusing on the immune system, chemotherapy, radiotherapy, and mobilizing your healing energy

**Health Talks at The Cleveland Clinic Presents - When Cancer Touches Your Life: Meeting the Needs of Patients and Families** (video)
Cleveland Clinic, 2000

documentary that addresses the needs of the entire family when one member is facing cancer

**Humor and Healing** (audio)
Bernie S. Siegel
Sounds True, 1994

Siegel talks about how positive thinking and the healing power of laughter

**Inner Art of Meditation** (video)
Jack Kornfield
Sounds True Video, 1997

instruction in meditation by a widely published author on eastern philosophy

**It’s Not About the Bike: My Journey Back to Life** (audio)
Lance Armstrong with Sally Jenkins; Narrated by Oliver Wyman
High Bridge Company, 2000

the personal story of Lance Armstrong's life from childhood through early success, nearly fatal cancer, recovery, survivorship, more triumph, marriage, and first-time fatherhood

**Lessons from the School of Suffering: A Young Priest with Cancer Teaches Us How to Live** (audio)
Jim Willig, read by Brian Patrick
Saint Anthony Messenger Press and Franciscan, 2002

inspirational messages from a priest who faced cancer
Letting Go: A Hospice Journey (video and DVD)  
HBO Productions  
Films for the Humanities and Sciences, 1996  
A documentary takes an intimate look at three patients – an eight year-old boy with an incurable brain disease, a 46 year-old woman with lung cancer, and a 62 year-old man with an inoperable brain tumor – this program shows how hospice care helps them cope with fear and pain in the final stages of their lives, and prepares loved ones for their imminent loss.

To Live Until I Die (video)  
Fanlight Productions, 1999  
A documentary that follows the lives of several people facing a terminal illness.

Living Fully Until Death (video and DVD)  
Dartmouth-Hitchcock Medical Center Production  
Films for the Humanities and Sciences, 1995  
The inspirational tales of three people who find new meaning in life and the courage to deal with the challenge of living fully after learning they have a terminal illness; featured in the program are the late Morrie Schwartz of the best-seller Tuesdays with Morrie, who was diagnosed with Lou Gehrig’s disease (ALS); Shirley Waring, a mother of four adult children, who has leukemia; and William Meyer, who has lung cancer; each person has struggled in his or her own unique way to try to find personal control, to plan for the unknown, and to find a place for spirituality; as Morrie Schwartz notes, "Learning to die is also learning how to live."

Living & Laughing With Cancer (video)  
Tapeworm, 1998  
The story of one man’s experience with facing cancer; told with humor and honesty.

Living with Cancer: A Message of Hope (video)  
Wellspring Media, 1998  
A documentary that aims to provide comfort and solace in its portrayal of a few ordinary people's successful battle over the disease; focuses on the idea of treating cancer as a challenge instead of a death sentence.

Lung Cancer (video and DVD)  
Films for the Humanities and Sciences  
Explains what we know about the causes of lung cancer, presents evidence linking smoking to lung cancer and discusses other known and suspected causes including asbestos, radon, and other environmental factors.

Lung Cancer in Women (video and DVD)  
Films for the Humanities and Sciences, 1997  
Information about how diet, exercise, and healthy living can help prevent lung cancer, and discusses cutting-edge treatments that are benefiting lung cancer patients.
Meditation For Beginners (video)
Gaiam Americas, 2001
beginning instruction on meditation

Meditations for Enhancing Your Immune System: Strengthen Your Body's Ability to Heal (audio)
Bernie S. Siegel
Hay House, 1992
a series of meditations designed to affirm vibrant health

No Hair Day: Laughing (and Crying) Our Way Through Cancer (video & DVD)
WBGH Boston, 1999
three women undergoing treatment for breast cancer challenge society's image of beauty in this unconventional film; the women share their attitudes, both positive and negative, about life with cancer; although the women have breast cancer, most of the documentary is appropriate for any woman facing cancer

Preparing Mentally & Emotionally for Cancer Chemotherapy: A Guided Imagery Program (video)
2002
a series of guided imagery sessions with soothing music

Preparing Mentally & Emotionally for Cancer Radiation: A Guided Imagery Program (video)
2002
a series of guided imagery sessions with soothing music

Preparing Mentally & Emotionally for Cancer Recovery: A Guided Imagery Program (video)
2002
a series of guided imagery sessions with soothing music

Preparing Mentally & Emotionally for Cancer Surgery: A Guided Imagery Program (video)
2002
a series of guided imagery sessions with soothing music

Return to Wholeness (audio)
David Simon
John Wiley & Sons, 2000
written by a medical doctor, the author applies the principles of Ayurvedic and Chinese medicine to the management of cancer; cancer is framed by the author in a way that respects its physiological realities while offering patients another plane of existence from which to cope with their disease; his message is that you exist apart from what's happening to your body and with this awareness, you can experience life in a more complete and satisfying way, whether you recover or not
Seasons in Cancer (audio)
George S.J. Anderson, Read by Alan Zimmerman
Americana Publishing, 2002
a series of short stories describing the author’s experiences as a man dealing with loss and grief; stories share lessons learned and can be helpful to anyone confronting a life-changing experience

See Yourself Well: For People with Cancer: Guided Visualizations & Relaxation Techniques (audio)
Ann Beattie
Equinox Press, 1994
guided visualizations and relaxation techniques designed to enhance mind/body healing for the person with cancer

Tai Chi for Older Adults (video)
Wellspring Media, 1998
gentle tai chi for older adults who are new to this form of exercise; instructed by Dr. Paul Lam

Therapeutic Qigong Video (video)
2002
instruction for beginng qigong

Treating Lung Cancer (video and DVD)
Films for the Humanities and Sciences, 1990
contributions from a pathologist, a radiographer, a thoracic specialist, a surgeon, and a radiologist, this program covers the incidence, etiology, histology and natural history, clinical features, investigation and diagnosis, treatments, and palliation of lung cancer

Yoga Practice for Meditation (video)
Living Arts, 1997
renowned yoga instructor Rodney Yee leads viewers through five yoga practices that release bodily tension, improve posture, and open up breathing; setting is Yosemite National Park
GLOSSARY

NOTE TO THE READER

Many of the words listed in the Glossary have more than one definition. The definitions presented here are limited to how the words are used in the context of discussing lung cancer.

abdomen – the trunk of the body below the ribs; the area of the body containing the stomach, liver, spleen, intestines, and other organs

accelerated hyperfractionation – a radiation treatment schedule that involves two to three treatments per day over a shorter timeframe than routine radiotherapy

adjuvant – a secondary treatment added to enhance the effects of a primary treatment

adjuvant therapy – treatment given after the primary treatment to increase the chance of cure

adrenocorticotropic hormone (ACTH) – a hormone normally produced by a small structure in the brain called the pituitary gland; ACTH acts on the adrenal glands stimulating them to produce and release steroid hormones called glucocorticoids; elevated in paraneoplastic Cushing syndrome

advance care planning – working with your health care providers to plan for the kind of medical care you want and do not want at the end of your life

advance directive – legal document that outlines end-of-life medical care choices

allied health professionals – non-physician members of the health care team including nurses, respiratory therapists, pharmacists, radiology technicians, laboratory technicians, and others

allopathic physician – a medical doctor; doctor who holds an MD degree

alopecia – hair loss

alternative therapy – CAM treatment used instead of conventional treatment

alveoli – tiny air sacs at the end of the airways in the lungs

analgesic – pain relieving medicine
anecdotal reports – reports on experience with a particular medicine or treatment outside of a controlled, clinical trial

anemia – a condition in which the number of red blood cells or the amount of hemoglobin in the blood is abnormally low

angiogenesis – the process of growing new blood vessels

anorexia – loss of appetite

antiangiogenic compounds – substances that slow or inhibit the growth of new blood vessels (angiogenesis)

antibodies – proteins manufactured by immune cells that attach to specific sites on cells marking them for destruction by the immune system

anticoagulant – a medicine used to prevent the formation or growth of blood clots

antidiuretic hormone (ADH) – a hormone normally released into the body by a small gland in the brain called the pituitary gland; ADH acts on the kidneys to help limit the loss of fluid from the body by decreasing urine volume; elevated in the paraneoplastic syndrome of inappropriate antidiuretic hormone (SIADH)

antineoplastons – small protein molecules (called peptides) that were first described by Dr. Stanislaw R. Burzynski in 1976; Dr. Burzynski reports these peptides act to “normalize” cancer cells

antioxidants – any of several different chemicals used by the body to neutralize free radicals and keep them from causing cell damage

aorta – the large artery that carries oxygen-rich blood away from the heart where it will be distributed throughout the body by smaller blood vessels of the circulatory system

apex (of the lung) – the top part of the lung in the upper chest under the collar bone

apoptosis – a series of reactions inside a cell that lead to normal cell death

arteriole – an intermediate-sized blood vessel that carries oxygen-rich blood to body tissues

artery – a large blood vessel that carries oxygen-rich blood to body tissues

atelectasis – poor inflation of an area of the lung

atria (airway atria) – the smallest airways of the lungs; the atria lead to the alveoli
asthenia – weakness

autofluorescence bronchoscopy – a modified bronchoscopy procedure that uses fluorescent light to detect potentially cancerous areas of the airways

base (of the lung) – the broad, lower end of the lung that sits on the diaphragm

benign – in oncology, a tumor or condition that is non-cancerous

biological response modifiers – drugs used to stimulate or induce one or more of the body’s functions, especially immune functions

biopsy – the process of obtaining a tissue sample for diagnostic purposes

blinded trial – a clinical trial in which the participants are unaware of what specific drug or treatment they are receiving; in a double-blind trial, neither the participants nor their doctors are aware of what specific drug or treatment each patient is receiving

bone scan – a nuclear medicine test in which a radioactively labeled substance is injected into the bloodstream where it is taken up by actively dividing cells; areas that have taken up large amounts of the test substance show up as hot spots on the scan; hot spots in the bones may indicate metastatic cancer

brachytherapy – radiotherapy delivered within the body

bronchial tree – the branching system of airways in the lungs

bronchial washings – liquid that is introduced and then removed from the airways during a bronchoscopy procedure; the liquid can be sent to the laboratory and checked for the presence of cancer cells

bronchiogenic cancer – another term for lung cancer; term referring to lung cancers that arise from the epithelial cells that line the airways of the lungs; also known as bronchiogenic carcinoma

bronchiogenic carcinoma – another term for lung cancer; term referring to lung cancers that arise from the epithelial cells that line the airways of the lungs; also known as bronchiogenic cancer

bronchiole – small airways of the lungs; part of the bronchial tree

bronchopulmonary segment resection – a lung sparing operation that involves removal of only the section or segment of the lung lobe that contains the cancerous tumor; also known as segmentectomy
bronchoscopy – a procedure that involves putting a small, flexible tube called a bronchoscope into the larger airways of the lungs; the bronchoscope allows the doctor to see the inside the airways and take tissue samples

cachexia – substantial weight loss that involves not only fat but non-fatty tissues of the body such as muscle and bone; cachexia is usually accompanied by loss of appetite and weakness

calorie – a measurement of the energy content of food

capillary – the smallest blood vessels of the circulatory system

carcinoembryonic antigen (CEA) – a substance present in elevated amounts in the blood of smokers and people with lung, colon, bladder, and stomach cancer; a non-specific epithelial cell tumor marker

carcinogen – a substance capable of causing cancer

carcinoma – cancer that arises from epithelial cells (skin cells or the cells that line or cover internal organs of the body)

cardiopulmonary system – the joint work of the heart and lungs that brings oxygen to cells and rids them of excess carbon dioxide

carina – the area where the trachea splits into the right and left main bronchi

cell – the tiny structure that is the smallest unit of all plant and animal life; all the tissues of the human body are made up of cells

cell differentiation – the maturation process of cells in which they become specialized to perform specific functions; as cells differentiate, they take on the appearance of mature cells

cell proliferation – the processes of cell growth and division that lead to new cells; uncontrolled cell proliferation is one of the characteristics of cancer cells

cemonaive – term referring to people who have not had previous chemotherapy for their cancer

chemoprevention – the use of specific substances to reverse, suppress, or prevent cancer

chromosomes – the part of the cell that contains its genetic information; human cells have 46 chromosomes (23 pairs)

chronic bronchitis – a condition of persistent inflammation of the airways; associated with long-term smoking and decreased pulmonary function
chronic obstructive pulmonary disease (COPD) – persistent, progressive lung disorder characterized by inflammation of the airways, loss of air sacs, and decreased lung function; often associated with long-term smoking

complementary therapy – a treatment that is used in addition to rather than in place of conventional treatment

complete response – the disappearance of all signs of cancer in response to treatment

complex carbohydrates – food matter made up of chemically linked sugars (carbohydrates); includes breads, pasta, grains, beans, and other foods

computer assisted diagnosis (CAD) – the process of using computer programs to aid in the reading of digital radiographic images with the intention of improving accuracy and reproducibility

concurrent – when two treatments such as chemotherapy and radiotherapy are given at the same time rather than one followed by the other

confidence interval – a statistical term; a range of values that is reasonably certain to contain the true value

contralateral lymph nodes – in lung cancer, lymph nodes on the side of the chest opposite the primary tumor

control arm – the group of people in a clinical trial that receive standard treatment or a placebo

cortisol – a hormone produced by the adrenal glands; elevated in paraneoplastic Cushing syndrome

cryoablation – the use of very cold temperatures to kill cancerous tissue with little damage to surrounding healthy tissues

CT scan – an imaging study which utilizes an x-ray beam that moves in circles around the length of the body to create three-dimensional images

cupping – an acupuncture-related treatment that involves stimulating acupuncture points by applying suction using a metal, wood, or glass jar in which a partial vacuum has been created; the technique causes blood to pool at the cupped site stimulating the acupuncture point

curative intent – cancer therapy used to try to cure the disease

Cushing syndrome – in oncology, a paraneoplastic syndrome caused by an ACTH-like hormone produced by cancer cells that stimulates abnormally high cortisol production
cytokines – naturally occurring proteins that act as messengers and regulators of the immune system

cytotoxic drug – a medication that is detrimental or destructive to cells; sometimes used interchangeably with the word chemotherapy

daughter cells – two cells that result when a single cell divides; normally, the daughter cells are exact copies of the original cell

deep venous thrombosis – a blood clot in the deep veins of the legs, and less frequently, the arms

deoxyribonucleic acid (DNA) – the chemical substance that chromosomes and genes are made of; DNA is the substance the carries genetic information in humans

digestive system – the body system that functions to breakdown food into its essential nutrients to be used for energy and tissue building; the digestive system includes the stomach, small intestine, and large intestine; the liver and pancreas are also involved in digestive processes

digital chest x-ray – a chest x-ray that collects an image of the chest with a computerized detector instead on a piece of film as is done with a conventional chest x-ray; the use of the detector instead of film allows for sharper, clearer images

digital clubbing – rounding of the ends of the fingers, and sometimes the toes; can be a symptom of lung cancer, but is also associated with other conditions

diplomate – designation given to doctors by a certifying or professional organization to indicate having met specific educational and/or training criteria

dose-limiting side effects – severe physical side effects that can be potentially life-threatening and may make it necessary to alter the treatment dose and/or schedule; in extreme cases, treatment may need to be stopped altogether

dysphagia – difficult or painful swallowing

dyspnea – difficult or painful breathing

early micrometastasis – process in which cancer cells break off from the original tumor early in the growth process and travel to distant sites in the body; often not seen on routine x-rays and scans because the cancer has not yet grown to a detectable size

edema – swelling of the soft tissue caused by an abnormal accumulation of fluid

embolization – blockage of an artery by a clot or foreign material; intentional embolization can be done as treatment to block the flow of blood to a tumor
**embolus** – a plug blocking a blood vessel; may be a piece of a blood clot, bacteria, or another foreign substance

**emphysema** – a disease in which the air sacs of the lungs lose their elasticity resulting in a loss of breathing capacity

**endoscope** – a rigid instrument that is surgically introduced into the body to visualize the internal organs

**epidermoid carcinoma** – another name for squamous cell carcinoma; one form of non-small cell lung cancer

**epithelial cells** – the cell type found in skin, and the linings and coverings of organs in the body; the cell type that lines the airways of the lungs and gives rise to small cell and non-small cell lung cancer

**erythropoietin** – a hormone produced by the kidneys that stimulates red blood cell production

**esophagitis** – inflammation of the esophagus; a possible side effect of radiation therapy to the chest; can cause difficulty swallowing and eating

**esophagus** – the tube-like structure that carries food from the mouth to the stomach

**estate planning** – making plans for how you want your personal property and money distributed after your death

**executor** – the person named in your will who is responsible for distributing your property according to the instructions of the will after your death; also known as a personal representative

**exhale** – to breathe out

**experimental treatment arm** – the group of people in a clinical trial that receive one of the experimental treatments being tested

**exploratory surgery** – in cancer, a surgical procedure during which the surgeon examines the tissues and lymph nodes around a tumor to determine the extent of disease

**external beam radiation** – radiotherapy delivered from outside the body

**fatigue** – a persistent or overwhelming feeling of tiredness

**fine needle aspiration biopsy (FNA)** – tissue sampling technique in which a needle is introduced from outside the body into the tissue in question; the tissue sample is pulled out through the needle
**first line treatment** – the first therapy used to treat cancer

**fluoroscopy** – an x-ray technique in which images are projected on a fluorescent screen

**fraction** – the dose of radiation given in each treatment as part of the total dose of radiation given to treat cancer

**gene** – a piece of DNA that encodes for a specific hereditary trait

**gene therapy** – cancer treatment that aims to interrupt the cancerous process by replacing lost or damaged genes, or blocking the expression of damaged genes

**glucocorticoids** – hormones produced by the adrenal glands; elevated in paraneoplastic Cushing syndrome

**granulocyte** – term referring to a white blood cell with a granular appearance; important in fighting bacterial infections

**granulocytopenia** – an abnormally low number of granulocytes in the blood stream; one of the problems associated with myelosuppression caused by chemotherapy

**group model health maintenance organization (HMO)** – a type of HMO in which the organization owns and operates its own offices and health care facilities; doctors working at these facilities are employees of the HMO

**guaranteed renewable policy** – a health insurance policy that has a stipulation stating the insurer cannot refuse to renew your policy as long as you pay your premiums on time; also called a noncancellable policy

**health care power of attorney** – granting someone the right to make medical choices for you if you are unable to speak for yourself; also known as medical power of attorney

**helical CT scan** – a newer CT scanner capable of x-raying the entire chest in 20-30 seconds while the patient holds his or her breath; the continuous nature of the data collection by the computer and the reduced effects of movement make CT scans performed with helical/spiral machines clearer, and better able to detect small tumors

**hematopoietic growth factors** – substances that stimulate bone marrow production of blood elements including red blood cells, white blood cells, and platelets

**hemoptysis** – the condition of coughing up blood or blood-streaked phlegm

**hilar lymph nodes** – lymph nodes in the area of the lung where the main bronchus enters

**hilum** – the area of the lung where the mainstem bronchus and the large pulmonary arteries and veins enter and exit the lung
**holistic medicine** – a philosophy in certain medical disciplines, especially complementary and alternative medicine, that states one must treat the whole person rather than just the symptoms he or she is experiencing

**homeostatic mechanism** – any of a number of processes that keep the substances of the body in normal balance

**Horner's syndrome** – a triad of symptoms including a drooping eyelid, a small pupil in the affected eye, and lack of sweating on the affected side of the face; this syndrome can accompany a Pancoast tumor

**hospice** – a system of care for terminally ill people and their families

**hypercalcemia** – high blood calcium

**hyperfractionation** – radiation therapy that is given two to three times per day over a period of days to weeks

**hypertrophic osteoarthropathy** – a condition in which the outer layer of the long bones of the arms and/or legs are inflamed causing pain and swelling in the ankles, wrists, and knees; may be associated with digital clubbing; may be a sign of lung cancer but is also associated with other conditions

**immunoconjugates** – monoclonal antibodies that have chemotherapy drugs attached to them

**immunotherapy** – a broad term that refers to a variety of ways the immune system might be used to treat cancer

**immunotoxins** – monoclonal antibodies that have a toxin (a cell destroying substance) attached to them; immunotherapeutic agents used to treat cancer

**individual practice association (IPA)** – a health maintenance organization in which physician groups or individual doctors in private practice have contracts with the HMO to care for a specific number of HMO members

**induction therapy** – treatment designed to be used as a first step toward shrinking the cancer; induction therapy is usually followed by additional therapy to eliminate whatever cancer remains

**inhale** – to breathe in

**initial work-up** – in cancer treatment, the tests and procedures done before treatment begins to determine a person’s overall health status and begin the staging process
integrated medicine – the combined use of western medicine and complementary and alternative medicine

interventional radiologist – doctor who has special training to diagnose and treat illnesses and conditions using miniaturized tools while watching the procedure on X-ray or other imaging equipment

intestate estate – the estate (assets) of a person who died without a will or other estate planning document; the person’s assets will be distributed according to state law

intraoperative brachytherapy – placing small radioactive pellets in specific sites in the chest during lung cancer surgery

intrathoracic – within the chest cavity

ionizing radiation – high energy waves that can disrupt the atoms and molecules of the body; the form of radiation used in radiation therapy for cancer

ipsilateral lymph nodes – in lung cancer, regional lymph nodes on the same side of the chest as the primary tumor

keratin – a substance produced by some epithelial cells; the main substance that makes up hair and nails

lactase – the digestive enzyme that breaks down milk sugar

last will and testament – see will

lean body mass – the non-fatty tissues of the body including the muscles and bones

left atrium – the chamber of the human heart that receives oxygenated blood from the lungs

left ventricle – the chamber of the human heart that sends oxygenated blood from the lungs to the body

leukocytosis – condition of an abnormally high level of white blood cells

leukopenia (leucopenia) – condition of an abnormally low level of white blood cells; one of the myelosuppressive effects of some chemotherapy drugs

living will – an advance directive that applies specifically to a person who has a terminal illness

lobar bronchi – large airways that transport air to the individual lobes of the lungs
lobe (of the lung) – sections of the lungs; the right lung has three lobes and the left lung has two lobes

lobectomy – surgical removal of a single lobe of a lung; a surgical procedure used to treat localized lung cancer

local recurrence – the return of a tumor at the original site

lymph – the fluid that circulates through the lymphatic vessels; made up of excess tissue fluid, proteins, and cells of the immune system

lymph node – a compact collection of immune cells, primarily lymphocytes; structures in the lymphatic system that filter out foreign particles such as viruses, bacteria, and cancer cells

lymphatics/lymphatic vessels – thin walled structures that carry lymph fluid throughout the body

malignant – a term used to refer to cancerous cells or tumors; malignant cells have uncontrolled growth processes, and can invade neighboring tissues or spread to distant sites in the body

margins (surgical) – in cancer, the edges of tissues removed at surgery; the surgical margins are examined in the laboratory to determine if there are cancer cells present

matrix metalloproteases (MMPs) – a group of naturally occurring enzymes that help break down the structures between cells to make room for new, healthy tissue to grow

matrix metalloprotease inhibitors (MMPIs) – drugs that block the actions of matrix metalloproteases (MMPs)

mean – the average value in a set of measurements

median – the middle value in a set of measurements

medical oncologist – a doctor who specializes in the treatment of cancer using non-surgical techniques

mediastinal lymph node dissection – removal of nearly all lymph nodes in the mediastinum during surgical resection of lung cancer

mediastinal lymph nodes – lymph nodes in the mediastinum in the center of the chest

mediastinal lymph node sampling – removal of multiple lymph nodes in the mediastinum during surgical resection of lung cancer
mediastinoscopy – a surgical procedure in which an endoscope is inserted into the mediastinum to visualize the structures and sample the lymph nodes; a common procedure used to stage lung cancer

mediastinum – the area in the center of the chest between the lungs; contains the heart and the large blood vessels entering and leaving the heart, the trachea, the esophagus, and several lymph nodes; the lymph nodes of the mediastinum are often checked for cancer in the lung cancer staging process

meridians – in Chinese medicine, the pathways through which the qi flows

metabolism – the total of all chemical changes that take place in a cell or an organism; changes that use and produce energy; includes the break down and build up of basic materials needed for life-sustaining processes

metastasis/metastasize – the process whereby cancer cells break off from the original tumor and travel to distant areas of the body where they begin to grow into new tumors

micrometastasis – small numbers of cancer cells that have spread from the original tumor to other parts of the body but are too few to be detected by currently available tests

mind/body medicine – the study of the interactions between the mind and body in health and disease

moxibustion – the use of heat produced by burning an herb over acupuncture points to stimulate the points or an entire meridian

MRI scan (magnetic resonance imaging scan) – an imaging technique that uses a large magnet to produce three dimensional images of the internal structures of the body

mucin – a thick, slippery fluid secreted by some glandular epithelial cells

mucositis – inflammation of the lining of the mouth, throat, and/or esophagus; a side effect of some chemotherapy and/or radiation therapy

multimodality therapy – two or more forms of cancer treatment used together or in succession; usually refers to the use of both chemotherapy and radiation therapy; also called combined modality therapy

mutation – any change in the DNA of a cell; certain mutations can lead to cancer

myelosuppression – a reduced ability of the bone marrow to produce cellular blood elements including red blood cells, white blood cells, and platelets; a common side effect of chemotherapy
negative energy balance – a condition in which the body is using more energy than it is taking in; unintentional weight loss is a symptom of negative energy balance

neoadjuvant therapy – treatment given before the primary treatment to increase the chance of cure

neuroendocrine cells – specialized nerve cells located throughout the body that secrete hormones into the blood stream where they are delivered to distant target cells and exert their effects; the cells that give rise to carcinoid tumors

neutropenia – an abnormally low level of the granulocytes called neutrophils in the blood; a common side effect of chemotherapy

neutrophils – one type of the white blood cell group called granulocytes; important in fighting bacterial infections

oat cell carcinoma – another name for small cell carcinoma or small cell lung cancer

off-label use – the use of a drug for an indication other than those for which it has been approved by the Food and Drug Administration; also known as unapproved indications usage

oncogene – a gene that allows or promotes uncontrolled cell growth

p-value – a statistical term; a numeric representation of how certain researchers are that their findings are true

palliative care – see palliative therapy

palliative therapy – treatment given to relieve symptoms caused by advanced cancer; it is not curative and does not alter the course of the disease but can significantly improve quality of life

Pancoast syndrome – symptoms caused by a Pancoast tumor, which can include pain in the shoulder and/or arm, loss of muscle mass in the arm of the affected side, and/or a drooping eyelid, small pupil, and lack of facial sweating on the affected side

Pancoast tumor – non-small cell lung cancer that originates in the upper portion of the lung and extends to other nearby tissues such as the ribs and back bones; also called a pulmonary sulcus tumor

paraneoplastic syndrome – signs and symptoms of cancer that are not caused by the tumors themselves, but by substances produced by the tumors; these syndromes can affect various organs of the body and cause a wide variety of signs and symptoms
parietal pleura – part of the sac enclosing the lung that is in contact with the inside of the chest wall

partial response – a decrease in the size of a tumor or in the extent of cancer in the body in response to treatment

partial thromboplastin time (PTT) – a blood test that measures the amount of time it takes for blood to clot; often used to monitor people on heparin anticoagulant therapy

pathological bone fracture – a bone break that is not associated with an injury or fall, but is caused by an abnormality in the bone; metastatic bone disease is a common cause of these fractures

pelvis – the area of the trunk of the body surrounded by the hips containing the sex organs, bladder, and the end of the intestines

performance status – a measure of how well a person is able to perform ordinary tasks and carry out daily activities

peripheral nerves – the part of the nervous system beyond the brain and spinal cord

peripheral neuropathy – a condition of the nervous system that causes numbness, tingling, burning or weakness; usually begins in the hands or feet and can be caused by certain anticancer drugs

petechiae – pinpoint, flat, round, red spots under the skin caused by bleeding from tiny blood vessels in the skin; may be seen if the platelet count drops to a very low level

pharynx – the area behind the nose and mouth that leads to the trachea (for air) and the esophagus (for food); commonly thought of as the throat area

photodynamic therapy – treatment with drugs that become active when exposed to light; used to kill cancerous and precancerous cells

pleura – a thin layer of tissue covering the lungs and lining the interior wall of the chest cavity

pleural effusion – an abnormal collection of fluid in the sac around the lung; can be infectious, benign, or malignant

pleuritic pain – sharp pain that occurs with breathing; occurs when a lung cancer involves the outer covering of the lung called the pleura; also occurs with other conditions
pleurodesis – a procedure for treating pleural effusion that involves draining the pleural fluid and placing a substance called a sclerosing agent in the pleural space to create irritation; the irritation causes the two sides of the pleural sac to stick together leaving no room for a reaccumulation of fluid

pneumonectomy – surgical removal of an entire lung

policy capitation (policy caps) – a stipulation in a health insurance policy stating the maximum amount of money to be paid over the course of the policy (lifetime cap) or for an illness (per illness cap)

post-marketing surveillance study – another term for a phase IV clinical trial

preclinical testing – the testing of a new drug or treatment that takes place before testing in people begins; testing that takes place before clinical trials begin; can involve testing in cancer cells grown in the laboratory, animal testing, and other forms of testing

pre-existing condition – a medical condition diagnosed before joining a new health insurance plan

presentation – the combination of symptoms reported and the physical findings of a patient

presenting symptoms – the symptoms a person experiences that cause him or her to seek medical attention

presumptive stage – the apparent stage of a person’s cancer based on the test results available; a presumptive stage may change as additional tests and/or procedures are performed

primary tumor – the original cancerous tumor; the source of cancerous cells that lead to secondary or metastatic tumors

prognosis – the likely outcome or course of a disease; the chance of recovery or recurrence

progressive disease – cancer that is growing and/or spreading

prothrombin time (PT) – a blood test that measures the amount of time it takes for blood to clot; often used to monitor people on warfarin (coumadin) anticoagulant therapy

protocol – a treatment action plan; in a clinical trial, the plan which states what the study will do, how, and why

psycho-oncology – psychology specialty concerned with the psychological, social, behavioral, and ethical impacts of cancer
**pulmonary artery** – the large blood vessel that carries oxygen-poor blood from the right side of the heart to the lungs

**pulmonary edema** – accumulation of fluid in the lung

**pulmonary vein** – the large blood vessel that carries oxygen-rich blood from the lungs to the left side of the heart

**qi** – in Chinese and eastern medicine, the vital energy that travels through body along internal pathways called meridians

**quality of life** – a person’s overall enjoyment of life and sense of well-being; includes the ability to carry on the activities of daily living and to derive enjoyment

**radiation fibrosis** – the formation of scar tissue as a result of radiation therapy

**radiation oncologist** – a doctor who specializes in the use of radiotherapy to treat cancer

**radiation pneumonitis** – inflammation of lung tissue as a result of radiation therapy; can cause coughing, shortness of breath, fever, and pain; may progress to radiation fibrosis

**radiofrequency ablation** – a technique involving the placement of a small wire or electrode into a target tissue and transmitting radio waves to destroy the cells in the area around the electrode

**radioprotectant** – substance that protects healthy tissues from radiation damage without reducing the effectiveness of radiotherapy against cancerous cells

**radiosensitizer** – substances that make cancer cells more susceptible to the effects of radiation

**radiotherapy** – the use of high-energy beams from x-rays, gamma rays, neutrons, and other sources to kill cancer cells and shrink tumors; radiation may come from a machine outside the body (external-beam radiation therapy) or from materials placed inside the body (internal radiation therapy); also called radiation therapy, irradiation, and x-ray therapy

**randomization** – the process in which people enrolled in a clinical trial are assigned by chance to a treatment group

**randomized controlled trial** – a clinical trial in which participants are assigned by chance to receive either an experimental treatment or a standard treatment; a type of clinical trial that is designed to compare the effectiveness and safety of a specific treatment to other treatments or a placebo

**reactive depression** – short-term depression (usually lasting two weeks or less) a person experiences as a reaction to a serious, life-altering event; a normal response to a life-changing event
**red blood cells** – microscopic structures in the blood that carry oxygen and carbon dioxide between the body tissues and the lungs; the component of blood that gives it its characteristic red color

**regional lymph nodes** – term referring to the lymph nodes that receive lymph fluid from a specific area or region of the body; each area of the body has its own regional lymph nodes

**resection** – surgical removal of a diseased tissue or organ

**respiration** – the process whereby cells take up oxygen and give off carbon dioxide; the breathing process

**resuscitation** – medical treatments used to restart the heart if it stops beating and restore breathing if it stops

**right atrium** – the chamber of the human heart that first receives oxygen-poor blood from the body

**right ventricle** – the chamber of the human heart that sends oxygen-poor blood from the heart to the lungs

**route of administration** – how a drug or other substance is given such as by mouth or through an intravenous line

**sclerosing agent** – an irritating substance used in pleurodesis (and other procedures) to cause an inflammatory reaction

**salvage therapy** – treatment given when cancer recurs after an initial response to therapy or when cancer fails to respond to initial therapy

**satellite lesion** – a separate tumor nodule in the same lobe of the lung as a primary tumor; considered stage IIIIB disease

**second line treatment** – any form of therapy used after first line cancer therapy

**secondary tumors** – metastatic tumors

**segmental bronchi** – intermediate size airways that transport air in and out of the various segments of each lobe of the lung

**segmentectomy** – a lung sparing operation that involves removal of only the section or segment of the lung lobe that contains the cancerous tumor; also known as bronchopulmonary segment resection

**side effect profile** – the list of possible side effects associated with a specific drug

**signs** – distinct physical findings that can be seen, felt, or measured during an examination
**simulation** — process used to prepare for radiation therapy; the process whereby the target area is precisely located and marked

**sleeve resection** — surgical procedure used to remove tumors in the main airways (the right and left main bronchus); the area with the tumor is removed and the ends on either side are sewn together to re-establish air flow to the affected lung

**sorbitol** — a sugar found naturally in certain fruits such as prunes, pears, peaches, and apples; a natural laxative; used as a sweetener in some reduced calorie foods

**spinal cord compression** — any condition that causes pressure on the spinal cord; in cancer, there is usually damage to one or more of the back bones from metastatic cancer that causes deformity or collapse of the bone which then presses on the spinal cord

**spiral CT scan** — a newer CT scanner capable of x-raying the entire chest in 20-30 seconds while the patient holds his or her breath; the continuous nature of the data collection by the computer and the reduced effects of movement make CT scans performed with helical/spiral machines clearer, and better able to detect small tumors

**sputum** — the thick, slippery fluid secreted by the airways; also known as phlegm

**sputum cytology** — examination of the sputum to look for abnormal cells from the airways

**staging** — in cancer, the process of determining if the cancer has spread beyond the original tumor, and if it has spread, the extent of spread

**stereotactic radiosurgery (SRS)** — a radiation therapy technique for brain tumors that uses a rigid head frame attached to the skull; the frame is used to help aim high-dose radiation beams directly at the tumors while sparing normal brain tissue; also called stereotactic external-beam radiation, stereotactic radiation therapy, and stereotaxic radiosurgery

**stomatitis** — inflammation or irritation of the mucous membranes in the mouth; can be caused by chemotherapy or radiation therapy to the head

**superior vena cava** — the large vein that carries blood from the head, neck, arms, and chest to the heart; may be compressed by a lung tumor causing swelling of the face

**supportive care** — treatments or interventions used to eliminate or reduce symptoms that interfere with quality of life while you are receiving therapy for lung cancer

**supraclavicular lymph nodes** — lymph nodes just above the collarbones

**symptoms** — feelings, pains, or other perceived abnormalities experienced by a patient but that are not measurable or detectable on physical examination

**systemic therapy** — treatment that affects the entire body, usually a medicine that is taken orally or given through an intravenous line
**Thoracic surgeon** – a doctor who specializes in surgery of the chest

**Thoracoscopy** – surgical procedure in which an endoscope is inserted into the chest space to visualize the structures; tissue samples can be collected during the procedure

**Thoracotomy** – major surgical procedure in which the chest is opened and the ribs are spread to expose the heart and lungs

**Thrombocytopenia purpura** – condition of abnormally low blood platelets; can cause bruising and/or uncontrolled bleeding

**Thrombocytosis** – condition of abnormally high blood platelets; can lead to blood clots

**Thrombolytic** – a medication that breaks down blood clots

**Thrush** – an overgrowth of yeast, especially in the mouth or throat; can occur in people on chemotherapy or radiation therapy that involves the head

**Time to progression** – the length of time a treatment is able to keep a cancer from growing and/or spreading

**TNM classification system** – system that uses characteristics of the tumor (T), regional lymph node involvement (N), and the presence or absence of distant metastasis (M) to divide NSCLC into clinical stages

**Tolerance** – in drug treatment, when an effect (desired or undesired) decreases over time while taking the drug as in becoming tolerant to the sedating effects of morphine; can also refer to a situation in which increasing quantities of a drug are needed over time to produce the same effect

**Trachea** – the tube-like structure that carries air between the mouth and nose and the lungs

**Transthoracic needle biopsy** – procedure in which a needle is inserted through the chest wall into a lung tumor (or other structure) to obtain tissue samples via the needle

**Treatment cycle** – in chemotherapy, the length of time over which a drug(s) is given; often involves a period of time off the drug such as taking chemotherapy on day one and three and then having three weeks off (without taking the treatment drug)

**Treatment field** – in radiation therapy, the area of the body that will be receiving radiation beams; normal tissues may be included in the treatment field in order to get the radiation to the diseased tissue; also called the treatment port

**Treatment naïve** – term referring to people who have not had any previous treatment for their cancer

**Tui na** – Chinese therapeutic massage
tumor – an abnormal growth in the body; can be benign or malignant

tumor marker – substance in the blood that is present only when cancer is present, or is present in highly elevated amounts when cancer is present

tumor suppressor gene – a gene that can prevent or block the development of cancer

ultrasonography – imaging technique that uses special frequency sound waves to visualize internal organs

unapproved indications use – the use of a drug for an indication other than those for which it has been approved by the Food and Drug Administration; also known as off-label use

vaccine – a substance that is given to stimulate the immune system to act against a specific target

vasculitis – inflammation of the blood vessel, especially the arteries

vein – a large vessel of the circulatory system that carries oxygen-poor blood from the tissues toward the heart

vertebral subluxation – in chiropractic medicine, the abnormal position of the backbones that lead to malfunctions in the body

video-assisted thoracoscopy (VATS) – a thoracoscopy technique in which a tiny video camera is inserted into the chest by a small incision, in addition to the thoroscope; pictures of the chest cavity are projected onto a screen during the procedure to give surgeons a better view of the area

visceral pleura – part of the sac enclosing the lung that is in contact with the outer surface of the lung; the most common site of malignant mesotheliomas

wedge resection – removal of a wedge-shaped section of tissue surrounding a cancerous lung tumor; performed on growths near the surface of the lung when a more extensive procedure cannot be tolerated

western medicine – the standard form of medical treatment practiced by MDs and DOs in the U.S. and Canada

whole brain radiation therapy (WBRT) – radiation therapy that involves the whole brain; used to try to prevent metastatic brain tumors or to treat multiple or large established brain tumors

will – a written document that directs how your assets (property and money) are to be distributed after your death
Chapter 2: Understanding Cancer


Chapter 3: Lung Cancer Overview


Chapter 4: Lung Cancer Diagnosis and Staging


Chapter 5: Lung Cancer Treatment Overview


Chapter 6: Treatment of Small Cell Lung Cancer


Chapter 7: Treatment for Non-Small Cell Lung Cancer


Chapter 9: Living With Lung Cancer

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Chapter 10: Supportive Care


**Chapter 11: Complementary Healing**


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**Chapter 12: Nutrition and Lung Cancer**


**Chapter 13: Managing Your Health Care**


