

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 with out 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.²⁴ 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

Distracting 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.^{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.⁷

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 Depression¹¹

- 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 than 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 youngster. 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.