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.

<u>Point of Service (POS) Plans</u>

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.

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.

co-payment

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

[1] Agency for Health Care Research and Quality (AHRQ), "Choosing and Using a Health Plan." AHRQ Internet site at www.ahcpr.gov/consumer/hlthpln1.htm.

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[2]

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.

[2] Social Security Online at www.ssa.gov/disability.

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**
>
> ***Eligibility 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

If insured dies within:	Death benefit would be:
6 months	10% or $5000
12 months	30% or $15,000
18 months	50% or $25,000
24 months	75% or $37,500
After 24 months	100% or $50,000

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 you 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.

<u>Second Mortgages and Equity Lines of Credit</u>

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 that 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. 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
- National Patient Air Transport Hotline
  800-296-1217
  www.patienttravel.org
- AirLifeLine
  877-AIR-LIFE (877-247-5433)
  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.

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.