

FRANKLY
SPEAKING
ABOUT CANCER

Lung Cancer



People with cancer who actively *participate* in their *care* along with their health care team will *improve* the *quality of their lives* and may enhance the possibility of *recovery*. People with cancer who *actively participate* in their *care* along with *their health care team* will *improve* the *quality of their lives* and may enhance the possibility of *recovery*.

Dedicated to all the people affected by lung cancer who shared their stories, experiences, and wisdom to make this guide possible, as well as health professionals who provided the most recent medical information about lung cancer diagnosis and treatment.

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PROLOGUE

You are not alone. A diagnosis of cancer is stressful, with the three biggest stressors being loss of control, loss of hope, and unwanted aloneness. Learning that you or someone you love has lung cancer can be frightening. You may ask yourself: “Now what?” It is important to know you can become an active participant in your recovery. By becoming more informed and learning skills to help you regain control and maintain hope, we believe that you and your loved ones will be empowered to get the best medical care possible and to enjoy more of life’s precious moments.

For the Fifth Edition, Cancer Support Community (CSC) and Lung Cancer Alliance (LCA) have joined together to update this booklet with helpful information for people with lung cancer and their caregivers. It is our hope that it offers insight into managing a diagnosis of lung cancer, making treatment decisions, and coping with the emotional and practical challenges people with cancer face.

As you read this booklet, you become part of a global cancer support community and you will find you are not alone—*there is a whole community behind you.*

PARTNERS



Cancer Support Community (CSC)
www.cancersupportcommunity.org

Backed by evidence that the best cancer care includes emotional and social support, the Cancer Support Community offers these services to all people affected by cancer. Likely the largest professionally-led network of cancer support worldwide, the organization delivers a comprehensive menu of personalized and essential services. Because no cancer care plan is complete without emotional and social support, the Cancer Support Community has a vibrant network of community-based centers and online services run by trained and licensed professionals. For more information, visit www.cancersupportcommunity.org.

In July 2009, The Wellness Community and Gilda's Club joined forces to become the Cancer Support Community. The combined organization provides high-quality psychological and social support through a network of nearly 50 local affiliates, more than 100 satellite locations and online.



Lung Cancer Alliance
www.lungcanceralliance.org

Lung Cancer Alliance (LCA) is the only national non-profit organization dedicated solely to providing support and advocacy for people living with or at risk for lung cancer. LCA's Community and Support Services include a range of services available free of charge including: A toll free Information Line, a Phone Buddy Program, an online support community, lung cancer-specific support group information, and links to other resources as needed. LCA's advocacy efforts include educating federal & state policy leaders on the need for greater resources for lung cancer research including prevention, early detection, and treatment. Information about all LCA services can be found online at www.lungcanceralliance.org or by phone at 1-800-298-2436.

“People with cancer who actively participate in their care along with their healthcare team will improve the quality of their lives and may enhance the possibility of recovery.”

—Dr. Harold Benjamin, Founder of The Wellness Community



“For about a year, I was having this pain in my chest. Several doctors told me that it was not cause for concern, but I was determined to find out what was causing the pain. Eventually, I was diagnosed with lung cancer, and the tumor was right behind my sternum where I was feeling pain. We caught the cancer early, and my doctors were able to treat it with surgery alone, no chemo. I feel really lucky – I’m the reason for early detection.

— Marilyn

Empower Yourself

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Empower Yourself

Empowerment refers to increasing the knowledge, spirituality, and social or economic strength of individuals and communities. It often involves developing confidence in one's own capacities.

Empowering patients to gain the knowledge and coping skills to find the best treatment and support is one approach that has been effective for thousands of lung cancer survivors. Cancer Support Community's empowerment approach, embraced by LCA for this booklet, is called the Patient Active Concept®:

People with cancer who actively participate in their care along with their health care team will improve the quality of their lives and may enhance the possibility of recovery.

GAIN CONTROL

This booklet, based on the Patient Active Concept, is designed to empower readers to become educated and ask informed questions about lung cancer care and treatment. Being Patient Active is about feeling and acting empowered. Your active participation in the choices you make with your health care team can make a big difference in your cancer experience and the quality of your life. Choosing to be Patient Active is not about making monumental decisions; it is a process of taking small steps that can help you regain a sense of control over your treatment and your life with cancer.

YOU ARE NOT ALONE

It is common for people diagnosed with lung cancer to feel alone at first and even isolated. Many people say they feel like no one understands what they are now going through. It is also common to be scared, confused, and even angry. This is a whole “new normal” and navigating lung cancer can be complicated. However, by learning as much as you can about your lung cancer, you can begin to take back control. You will feel more confident about your next steps if you become an active partner with your health care team, ensure that you have a network of support, and learn how to reduce stress and regain hope. Experiencing a renewed sense of hope, no matter what stage of cancer you have, is invaluable.

Lung cancer-specific challenges

A diagnosis of lung cancer can bring additional challenges because of how this cancer diagnosis is perceived. Often, there is a sense of guilt, anger, and even blame that is associated with a lung cancer diagnosis. The burden of these emotions can hinder your recovery. Being Patient Active can help you understand and cope with these challenges and misperceptions.

- **Individual challenges:** The person with lung cancer who smoked may feel guilty and accept the blame of societal and family reproaches. Unfortunately, some people find this challenge so stressful that they consider not pursuing appropriate treatment due to self-blame.
- **Family challenges:** Family members of people with a history of smoking may blame the patient for developing lung cancer.

- **Society challenges:** Society sees lung cancer as a disease of smokers—people who willfully brought their disease on themselves. Lung cancer patients who never smoked are often assumed to have been smokers and can be particularly upset about being included in this group.

The fact is, 60% of people newly diagnosed with lung cancer either quit smoking many years ago or never smoked. It is important to remember that lung cancer is a disease; it is not tobacco addiction. Everyone diagnosed, regardless of smoking status, is entitled to compassion and the best available treatment. For more information on the emotional impact of a lung cancer diagnosis, please refer to Chapter 7 on Quality of Life.

People with lung cancer and their caregivers can take control back by learning to cope and live with lung cancer. There are steps you can take, and we will help you.

Ten Ways to Become Empowered and Patient Active

Be informed.

Take action.

Connect with others.

You can become a proactive participant in managing your lung cancer. These ten tips can strengthen your sense of control, boost your feelings of hope, and enhance the quality of your life. Ways to implement these suggestions into your life are found throughout this publication.

1. **Stay in the moment.** Try to focus on resolving only today's problems—take a deep breath, and take one step at a time.
2. **Ask for support.** Help others understand what you need. Be as open as you can with your family and friends about how they can support you. Offer them specific examples, such as driving you to appointments, helping with babysitting, or going to the movies to take a break. Take someone with you to medical appointments to take notes and help you remember important information.
3. **Acknowledge and express your feelings.** Take time just to listen to your body and to the things you are saying to yourself. Once you are more aware of your feelings, express them by talking, writing, physical activity, or other creative pursuits. Consider joining a professionally facilitated cancer support group in your area, or online, to address your feelings in a community with others who understand the stressors of lung cancer.
4. **Do what you enjoy.** Continue activities that you enjoy and can do comfortably. Find new activities if you feel tired or have other limitations. Ask friends to join you, or give yourself permission to be alone when you need to be.
5. **Seek relaxation.** “Relaxation” refers to a calm, controlled physical state that will enhance your well-being. Take relaxing breaks in your daily routine: listen to music that makes you happy, read a book, or take a walk. Take time to enjoy the moment. Consider joining a yoga, tai-chi, or meditation class. Perhaps watching your favorite TV show can put you in a relaxed state. Relaxation is something that you might have to learn, but it is easy to do.
6. **Retain as much control of your life as is reasonable.** If you feel that you have lost control to health professionals, loved ones, or even the disease itself, decide what you can realistically take back (probably most things!). Identify the areas in your life in which you could benefit from assistance, and choose what help you want. Even the simplest things can help enhance your sense of control.

7. **Communicate with your health care team.** Prepare a list of questions for each appointment. Ask for clarification of terms you do not understand. Ask for a copy of your medical records, including the pathology reports that confirmed your lung cancer. You might want to see abnormal x-rays or scans to get a better understanding of your status.
8. **Develop a plan.** This plan should coordinate medical and emotional care; support you in managing your illness; link you with needed psychosocial services; and identify support organizations that can assist you with specific needs. Your doctors and caregivers can help. You may choose to consider seeking a second opinion on your diagnosis and treatment plan to best understand your options.
9. **Spend time with other cancer survivors.** People with cancer often find a sense of comfort in communicating with others who share their experiences—either in person, online, or by phone.

Cancer support organizations, such as Cancer Support Community and Lung Cancer Alliance, can help you connect with other lung cancer survivors.

10. **Hope for many things.** Hope is desirable and reasonable. There are millions of people in the world today for whom cancer is just a memory. Even if your own cancer recovery does not seem possible, you can set small goals and enjoy daily pleasures. Get tickets to a concert. Participate in a religious study class. Attend a birthday, anniversary, or other event for someone you love. Redefine how you perceive hope. People who find things that give them hope are often better equipped to handle whatever challenges lie ahead. Talk about what gives you hope and what you hope for — now and in the future. Share these hopes with your family, friends, and the members of your health care team.

*“The Patient Active Concept:
Combining the will of the patient
with the skill of the physician—
a powerful combination.”*

*Harold Benjamin, Ph.D.
Founder, The Wellness Community*

PATIENT ACTIVE COMMUNICATION

Learning that you have cancer is often frightening and overwhelming. Talking (and listening) to your health care team and family can be hard sometimes. Studies show that clear communication can help you regain a sense of control, feel better about your choices, and may even improve the quality of your care.

Communicating with your health care team is a critical part of your treatment and your fight for recovery. One of the most important things you can do is ask questions! There are several other things you can do to make communicating with your health care team easier:

- Make sure you understand what is being discussed. If you do not understand, ask for more detail or a non-technical explanation. If something seems confusing, try repeating it back to your doctor. For example, “You mean I should...”

- Bring a friend or family member to help take notes, ask questions, and provide support. You can also ask if you may record the conversation.
- Ask to see x-rays or scans, or have the doctor draw a diagram if you think pictures will help you understand something better.
- Write down questions you may have as they come up. Take these questions with you to your appointments. Many people have found keeping a notebook with these questions and the answers is a helpful tool.

*Cancer Support Community’s new program, **Frankly Speaking About Cancer: Coping with the Cost of Care**, addresses financial concerns about issues such as employment, insurance, and creditors. This national publication helps to shed light on the psychological impact of incurring debt, sometimes for the first time, while coping with cancer.*

QUESTIONS TO ASK YOUR HEALTH CARE TEAM ABOUT YOUR DIAGNOSIS:

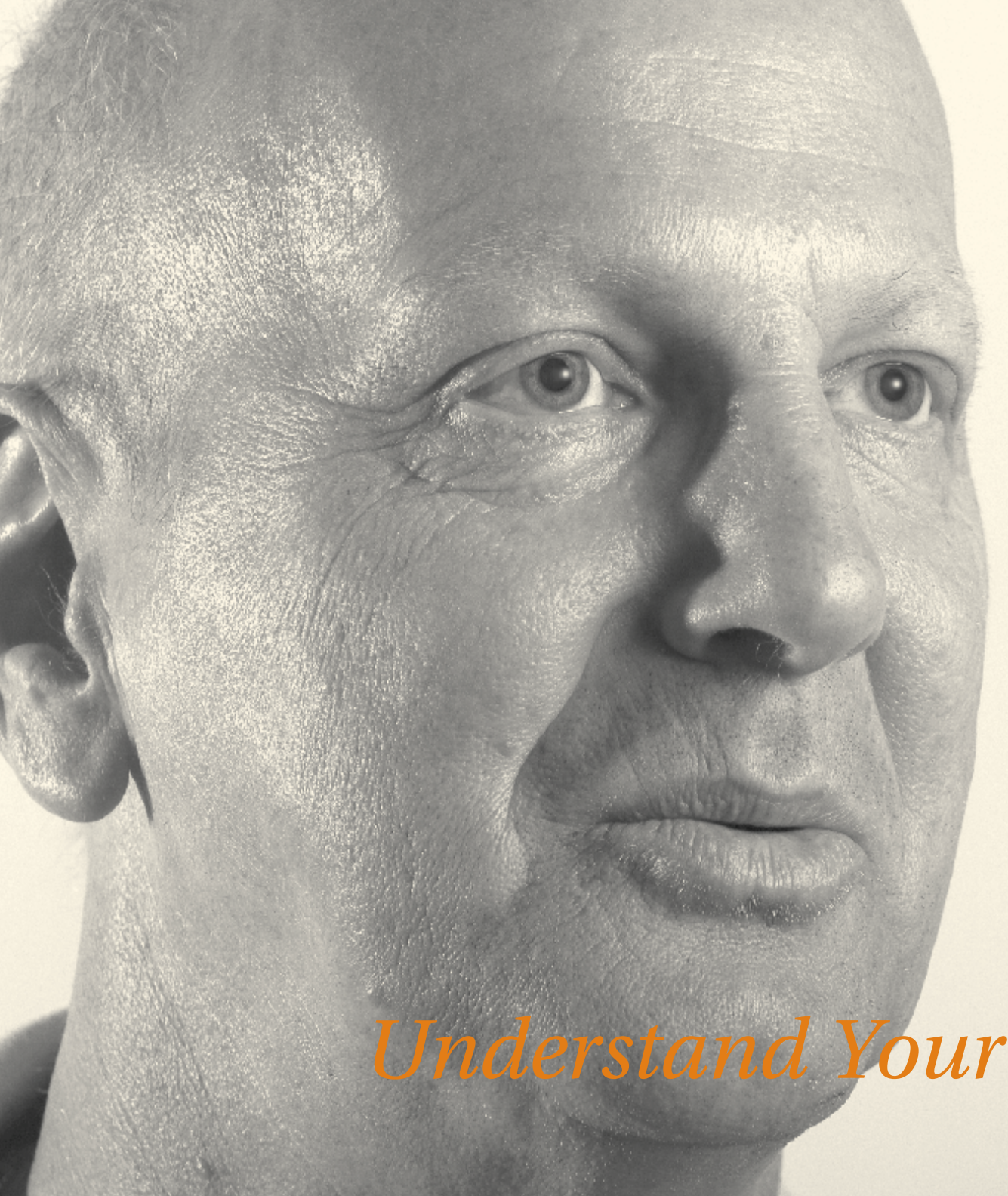
- What type of lung cancer do I have?
- What stage is my lung cancer, and has it spread to other parts of my body?
- What symptoms of lung cancer might I experience?
- What other types of tests will I need?
- Where can I find more information about lung cancer?

QUESTIONS TO ASK YOUR HEALTH CARE TEAM ABOUT YOUR TREATMENT:

- What are my goals for treatment (is it to cure the cancer, control the cancer, or relieve symptoms)?
- What treatment options are available for me?
- Which treatment do you recommend, and why?
- Where can I get a second opinion?
- What are the risks and benefits of each treatment option?
- What side effects might I experience, and how can they be managed or prevented?
- Where will I go to receive my treatment?
- When can I start my treatment, and how long will it last?
- Are there treatment options I should consider if chemotherapy isn't appropriate or has stopped working?
- Which treatments are covered by insurance?
- If insurance doesn't cover this treatment, what options exist to help with finances?
- Are there any clinical trials that might be appropriate for me? Where can I go to get more information about clinical trials?

QUESTIONS TO ASK ABOUT YOUR DOCTOR AND THE CLINIC OR HOSPITAL:

- How much experience do you have in treating my specific type of lung cancer?
- Are you board certified as an oncologist, thoracic surgeon, or are you certified in another specialty?
- How do you stay up-to-date on the latest lung cancer treatments?
- Are you associated with a major medical center, medical school, or comprehensive cancer center?
- Do you and the hospital accept my type of insurance?
- Will I be able to receive all treatments at this facility?
- Are cancer clinical trials offered at this facility?
- Is there an oncology nurse or social worker who will be available during my treatment for education and support?
- What other support services (support groups, housing, transportation, etc.) are available at this facility for patients and families?



“I never want to go to chemo and dealing with side effects from my treatment has been difficult, but I try to remember the importance of taking medications and doing whatever has to be done to beat this disease.”

— Dave

Understand Your Lung Cancer

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Understand Your Lung Cancer

Although lung cancer is the second most common form of cancer diagnosed, it is the number one cause of cancer-related deaths in the United States. According to the American Cancer Society, there are approximately 400,000 people living with lung cancer at any given time.

Cancer is a condition in which cells multiply uncontrollably to form growths (called tumors) that invade and destroy normal tissue. Tumors that are cancerous are called malignant and noncancerous tumors are called benign. Cancer cells can spread from their original site to other parts of the body in a process known as metastasis. Cancers are named for the place in the body where they begin, not where they may spread.

Lung cancer begins in the lungs—two major organs in the chest that are part of the respiratory system. Each lung is contained in a sac called the pleura. The right lung has three sections (lobes), and the left lung has two. Lung cancer is sometimes called bronchogenic cancer because most cases begin in the cells of the bronchi, the breathing tubes of the lungs.

Many people with lung cancer have no symptoms or only vague symptoms until the disease has progressed significantly. The lungs have very few nerve endings, and a tumor may be present without feelings of pain or discomfort. As a result, only 15% of lung cancers are discovered in the earliest stages, when the possibility of cure is greatest.

There are two main categories of lung cancer—non-small cell lung cancer (NSCLC) and small cell lung cancer (SCLC). The difference between NSCLC and SCLC has to do with the cell of origin that becomes cancerous. It also involves the appearance of the cells, how quickly each type spreads to other parts of the body, and how each type responds to treatment.

Symptoms may seem unrelated to the lungs or breathing. Because lung cancer is most likely to be diagnosed at a later stage, it may have spread to the other lung or other parts of the body. Depending upon where the cancer has spread, symptoms can include headaches, coughing up blood (hemoptysis), weakness, poor appetite, weight loss, bone fractures, or blood clots.

The more you know about your particular type of lung cancer and its histology, the better you will be able to make treatment decisions.

Histology is the study of cells and tissues under a microscope. Different types of lung cancer correspond with differences in histology, thus it is important to understand and know the histology of your type of lung cancer in order to select the best treatment.

“It is helpful to know the specific histology of your lung cancer since there are certain drugs which are preferentially used with some histologies, but not others.”

— Dr. Nasser Hanna

NON-SMALL CELL LUNG CANCER (NSCLC)

NSCLC comprises 80-85% of all lung cancers and has three major subtypes:

- Adenocarcinoma
 - Bronchioloalveolar carcinoma
- Squamous cell carcinoma (formerly called epidermoid carcinoma)
- Large cell carcinoma

Adenocarcinoma:

- Accounts for up to 50% of the NSCLC lung cancer cases in the United States
- Is the most common lung cancer diagnosed in women
- Usually starts near the outer edges of the lungs
- May occur in those with a history of smoking but is the type most often found in those who never smoked

Bronchioloalveolar carcinoma:

- Is a rare type of adenocarcinoma that represents only 3% of all lung cancers, but appears to be on the rise
- Initially spreads through tiny sacs in the lungs called alveoli rather than in solid tumors
- May occur in those with a history of smoking or never smokers, but the majority of cases occur in younger women who never smoked

Squamous cell carcinoma:

- Represents about 30% of NSCLC lung cancers in the United States
- Usually starts in one of the bronchi
- Frequently spreads to regional lymph nodes
- Is strongly associated with smoking

Large cell carcinoma:

- Represents about 10% of NSCLC lung cancers in the United States
- May start in any part of the lung
- Is frequently the diagnosis when other types of lung cancer have been ruled out



“I just kept asking questions. I read up on anything I could find, and I asked people so I could learn.”

— Cynthia

SMALL CELL LUNG CANCER (SCLC)

- Represents 15-20% of all lung cancers in the United States
- Typically grows and spreads more rapidly than NSCLC
- Is seen predominantly in smokers or former smokers (about 98% of cases are attributed to smoking)
- Usually starts in one of the larger bronchi
- Has often spread beyond the lungs by the time of diagnosis
- Is usually responsive to initial chemotherapy
- Was previously called “oat cell” cancer because the cells are small and oval, like oat grains

For more information about small cell lung cancer, please visit Cancer Support Community’s website at www.cancersupportcommunity.org or call Lung Cancer Alliance at 800.298.2436.

RISK FACTORS FOR LUNG CANCER

While there are cases where people cannot identify the cause of their lung cancer, the following risk factors are directly linked to the disease.

- **History of smoking.** Many people diagnosed with lung cancer have a history of smoking tobacco. For those who have ever smoked, the risk of developing lung cancer is related to their total lifetime exposure to cigarette smoke. This is why many people are diagnosed with lung cancer long after they quit smoking.
- **Secondhand smoke.** It is estimated that every year at least 3,000 people in the United States die of lung cancer caused by secondhand smoke, for example, from living with a smoker or working in a location where smoking is or was permitted.

- **Age and sex.** The median age for cases of lung cancer is around 70 years old. As with most cancers, the risk of developing lung cancer increases as a person ages.
- **Environment.** Increased risk of lung cancer can be attributed to exposure to high levels of certain natural gases and chemicals such as radon, uranium, arsenic, and bischloromethyl ether. Asbestos is also a major risk factor for cancer in the lung.
- **Family history.** In some cases, genetics may play a part in the development of lung cancer. If your family has a history with lung cancer, it is important to talk to your doctor about risk.

More information about the risks for lung cancer may be found through the National Cancer Institute’s website: www.cancer.gov/cancertopics/types/lung.

SCREENING

People who think that they may be at risk for lung cancer because of smoking history, occupation, or family health history should inform their doctor and discuss appropriate diagnostic testing. There are, however, no official screening recommendations for lung cancer at this time. CT (computed tomography) screening remains under investigation. Studies appear to show the ability of CT screening to detect lung cancer at an early stage. Ongoing clinical trials are being conducted to determine if this early detection will lead to a reduction in lung cancer-related deaths.

DIAGNOSIS AND STAGING

Diagnosing and staging lung cancer (determining the extent of disease) provides specific information needed to make decisions about which treatment options are best for your cancer. Staging involves diagnostic tests that identify where the cancer is located and whether it has spread in the body. Treatment decisions are made based on the stage of the lung cancer. (Please refer to Chapters 4 and 5 for staging of NSCLC and SCLC.)

Tools Used to Diagnose and Stage Lung Cancer

Health history

In diagnosing lung cancer, it is critical for a doctor to obtain a detailed history of your health:

- **Your health history** — information about smoking, exposure to environmental risk factors, and any significant symptoms such as nagging cough, shortness of breath, fatigue, back or chest pain.
- **Your family health history** — information that may indicate a genetic predisposition to lung cancer.

“A biopsy is required to definitively diagnose a lung cancer based upon an abnormality detected on an x-ray.”

— Dr. Nasser Hanna

Diagnostic tests

Your doctor may use several diagnostic tests; the most common are described below.

- **Biopsy.** A biopsy is the only reliable way to confirm the presence of cancer and identify its type and stage. In this procedure, a small piece of tissue is examined under a microscope by a pathologist. The tissue is removed either through a thin needle (needle aspiration) or in a surgical procedure with anesthesia as appropriate. Biopsies of the chest lining, lymph nodes, bone, or liver may also be done.
- **CT and MRI scans.** CT (computed tomography) and MRI (magnetic resonance imaging) use computers to produce detailed, three-dimensional images that help diagnose lung cancer and can determine the size, shape, and location of a tumor. If symptoms of lung cancer are present, a contrast-enhanced CT scan (a special contrast agent or medical dye is injected to create clearer images) is recommended. Both CT and MRI scans are useful in determining whether lung cancer has spread. Chest x-rays are also used, but they provide less information.
- **PET scans.** PET (positron emission tomography) scans identify rapidly dividing tumor cells. PET scans may give a more accurate picture of the stage of lung cancer, often as a follow-up to other tests or to diagnose recurrent disease.
- **Sputum cytology.** If cancer cells are in the bronchi, some are likely to be carried up the throat in mucus from the airways called sputum, which can be examined for signs of cancer. Sputum can be coughed up or collected through a tube called a bronchoscope. This test can find cancer cells long before a tumor is evident on other tests, but it may not detect cancers deeper in the lungs and cannot determine a tumor's size or location.

FUTURE DIAGNOSTIC TESTS

Genetic markers. A gene or DNA sequence has a known location on a chromosome and is associated with a particular gene or trait. Genetic markers are associated with certain diseases and cancers. Oncology researchers are trying to find genetic markers detectable in the blood to determine if an individual is at risk for developing a lung cancer. In the future, such markers may make it possible to detect lung cancer earlier.

Follow-up tests

If further clarification about your diagnosis is needed in order to guide the most effective course of treatment, your doctor may request one or more follow-up tests for additional information:

- **Bronchoscopy.** This procedure involves the use of a flexible tube-like instrument called a bronchoscope to view the airways into the lungs and to collect tissue samples. Local anesthesia and mild sedation are generally used. In a newer technique known as auto-fluorescence bronchoscopy, chemical properties of tumor cells cause them to reflect light (fluoresce) differently than normal cells. If the cells do not fluoresce normally, a sample is taken to determine whether they are cancerous.
- **Endoscopic Bronchial Ultrasound (EBUS).** This procedure uses a bronchoscope with ultrasound that can view more distant airways and regional lymph nodes. It allows these areas to be seen and biopsied more easily.
- **Mediastinoscopy.** In this procedure, a rigid instrument called an endoscope is inserted through a small incision in the neck or chest into the area known as the mediastinum. Anesthesia is used. This procedure can show if cancer has spread to lymph nodes near the trachea—one of the first places lung cancer is likely to spread.
- **Thoracentesis.** If fluid is collecting between the lungs and the chest wall, a needle is used to remove some of the fluid to see if cancerous cells are present.
- **Thoracoscopy.** This is a limited surgical procedure, performed under general anesthesia. An instrument called a thoracoscope is inserted through a small incision in the chest wall to allow examination of the lining of the chest wall and the surface of the lungs for tumors.
- **Video-Assisted Thoracic Surgery (VATS)** is sometimes used to diagnose lung cancer (See Chapter 3: Surgical Techniques for more information).

FINDING A LUNG CANCER SPECIALIST

Like most cancers, lung cancer is best treated when it is diagnosed early. Treatment options depend upon careful identification of the type and stage of your lung cancer. Because there are many types of lung cancer, it is crucial that your type be diagnosed and staged accurately and promptly.

A biopsy (tissue sample) is essential to the diagnosis. A specialist called a pathologist (a doctor who identifies disease by studying cells and tissues) should evaluate the tissue sample to determine whether cancer cells are present. Ideally, a thoracic pathologist (a specialist in pathology of chest illnesses) should be involved. You may need to seek out a clinical cancer center or university medical center to find a qualified pathologist, especially if your local doctor or hospital does not see many cases of lung cancer.

Where can I find a lung cancer specialist?

Lung cancer specialists focus on the diagnosis and treatment of this disease. The following tips may provide assistance in locating a lung cancer specialist:

- Your primary doctor or your insurance company can often recommend an oncologist or lung cancer specialist.
- You may consider asking a friend, local cancer support organization, or local hospital referral networks.
- If possible, seek a major cancer center or university hospital for your first, second, or third consultation about your diagnosis. You may also want to seek out an NCI-designated cancer center for the latest available lung cancer treatment.

ADDITIONAL RESOURCES FOR REFERRAL INFORMATION:

- **The National Cancer Institute** (1-800-4CANCER; www.cancer.gov), for information about the nearest cancer center or Specialized Program of Research Excellence (SPORE) in lung cancer.
- **Cancer.net** (www.cancer.net), oncologist-approved cancer information from the American Society of Clinical Oncology, to search for an oncologist in your area.

UNDERSTANDING YOUR HEALTH CARE TEAM

To learn about the variety of treatment options available, you can speak with one or more oncology professionals. It is important to understand each person's role, as they are important members of your care team.

Thoracic surgeon. Some thoracic surgeons are trained specifically in lung surgery; try to talk with a thoracic surgeon who is board-certified and specializes in lung cancer. If no one with this training is available, find a general surgeon who performs the most lung cancer surgeries in your area.

Medical oncologist. A medical oncologist is a doctor who specializes in diagnosing and treating cancer using chemotherapy, and who may coordinate your care with other specialists. It is good to work with a medical oncologist who sees a significant number of lung cancer patients or who specializes in lung cancer.

Radiation oncologist. A radiation oncologist specializes in treating cancer using various forms of radiation to safely and effectively treat cancer by focusing x-rays, gamma rays, and other sources of radiation directly on the tumor site in the body.

Pulmonologist. A pulmonologist specializes in treating diseases and conditions involving the lungs. They may be active in the diagnosis of lung cancer, in follow-up after treatment, and in helping manage your case during treatment.

Rehabilitation specialist. A pulmonary rehabilitation specialist can reduce symptoms and side effects from lung cancer and its treatments. They may work with you to teach proper breathing techniques, the proper way to cough, how to conserve energy, and how to improve your quality of life.

Pathologist. A pathologist specializes in diagnosing lung cancer by studying tissue, fluid, or blood from the patient using a variety of tools. They can also provide information about the cancer that can help the rest of the team make treatment decisions.

“Choosing your doctor is a very personal decision. I emphasize that this is one of the most important relationships you’re going to have. You’d better trust and like whomever you choose. It has to be someone you can work with. Personality is important. Do you want someone who will talk to you about everything, or just tell you what to do?”

— Gloria

Oncology nurse. Oncology nurses specialize in the nursing care of people with cancer. Like physicians, they may specialize in the surgical or medical management of a patient's care. They are often a valuable source of information and support. Some oncology nurses are certified to administer chemotherapy or other treatments for your lung cancer. Some oncology nurses also have advanced training and certification as nurse practitioners or clinical nurse specialists.

Oncology social workers and counselors. Social workers and counselors can help you cope with the emotional impact of cancer and help identify other resources you may need. Do not underestimate the support these individuals provide. Many hospitals, cancer centers, and oncology specialists have specially trained oncology social workers who work with their patients through group or individual counseling.

Patient navigator. Many hospitals and clinics now offer the assistance of a patient navigator. A patient navigator may be an oncology nurse, oncology social worker, or a trained lay person. A navigator is available to assist you on the journey through the health care system, identify members of your health care team, and explain things in terms you can understand.

BE PATIENT ACTIVE:

- Make sure you feel comfortable with your doctor's level of expertise.
- Do not hesitate to ask how many lung surgeries your surgeon performs each year.
- Consider your doctor's communication style and whether it fits well with yours.

SEEKING A SECOND OPINION

Receiving a lung cancer diagnosis is often confusing and frightening. Taking time to discuss your situation with additional experts is very helpful. The bottom line is, you want to feel comfortable and confident that you are receiving the best treatment possible for your cancer.

It is very common to request a second opinion. Some insurance plans actually require an additional medical review for coverage. Even if you have a good relationship with your doctor, you may want to seek a second (and sometimes a third) opinion about your diagnosis and treatment plan. Do not be afraid that your doctor will be offended or treat you differently. A good doctor respects your need to confirm that you are getting the best available treatment, and appreciates that you are gathering vital information that will help you make more informed decisions about your treatment.

IF YOU DO SEEK ANOTHER DOCTOR'S OPINION, REMEMBER:

- It is helpful to seek a second opinion before starting on a course of therapy so all options are open to you, including clinical trials. However, you can seek a second opinion any point during your treatment.
- Call the facility where you plan to go for the second opinion and make sure you understand what they need from you.
- Ask your initial doctor for a complete copy of your medical records: x-rays, scans, medical reports, and pathology slides. To get your medical records in hand: request the documents several days in advance and sign an authorization form for the doctor to release your records.
- While getting a second opinion is an important option, going from doctor to doctor in search of a “magic” cure does not necessarily promise optimal therapy for your disease or support your mental health.
- Be wary of a quick or easy “cure” that does not seem consistent with the information you have heard from other medical professionals.

“It’s not that I sensed that I wasn’t getting good care, but I did always get a second opinion. I don’t care if the doctor says to me, ‘Don’t you trust me?’ No! I want to live. This is my life, and I am in control of it.”

— Cassie



“When I was first diagnosed with lung cancer, I was too overwhelmed and emotional to evaluate the options on my own. So I asked my brother and two other friends (all physicians) to serve as my ‘medical advisory team.’ It was important to have information processed for me in a way that I could deal with.”

— Jerry

Making Treatment Decisions

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Making Treatment Decisions

No one is more qualified than you to make choices about your treatment, your quality of life, and your future. Consider the members of your health care team as consultants who can help you and your family with those decisions. You will feel a greater sense of control over your situation, your treatment plan, and your future as you gain information.

There are many new medical terms to learn and understand when you are diagnosed with lung cancer. The following phrases and terms are used to describe the success or failure rates of various treatments and how your cancer is responding to therapy. In the back of this booklet, you will find a Glossary chapter for additional reference.

LEARNING THE LANGUAGE

Terms for the different types or approaches to treatment:

- **First-line therapy:** Initial cancer treatment. Second-line therapy may follow if the first line is not successful, and so on.
- **Neoadjuvant therapy:** Treatment given before the primary treatment.
- **Adjuvant therapy:** Treatment given after the primary treatment to increase the chances of a cure.
- **Multi-modality or combined modality therapy:** Treatment using a combination of chemotherapy, surgery, radiation therapy, and/or targeted therapy.
- **Palliative therapy:** Treatment that is given to relieve symptoms, provide better quality of life, and perhaps extend life when cure is not probable.

Terms for the different types of responses to treatment:

- **Complete response, apparently cancer-free, or No Evidence of Disease (NED):** On the x-ray or imaging scan, the tumor appears to be completely gone as a result of treatment.
- **Partial response:** The tumor has shrunk in size by at least 30%.
- **Stable disease:** The tumor did not grow or shrink much.
- **Progressive disease:** The tumor is growing in spite of the treatment you received. When this happens, that specific therapy is usually stopped or modified in some way.

“If I learned one thing, it’s that when dealing with any chronic disease (which is how we viewed cancer), you have to be your own best advocate. Doctors aren’t perfect, even the experts. There were several times that we brought a second opinion to the table, and Dan’s doctor accepted it and worked with us. It can be very scary reading all of the medical literature or medication labels, but in the end, we always felt it was better to be armed with information and come with an opinion versus just sitting back and letting someone else make all the decisions. Being proactive with research and questioning allowed us to be more involved and helped remove some of the feelings of being totally out of control.”

— Meg, Caregiver

LEARN ABOUT POTENTIAL SIDE EFFECTS BEFORE YOU MAKE TREATMENT DECISIONS

Although many treatment options have similar potential outcomes, their side effects can vary widely. It is important for you, an active participant in your cancer care, to become informed about side effects before you select your treatment program. This is one of the most important conversations you will have with your doctor. Do not minimize the importance of understanding side effects—your quality of life and ability to tolerate your treatment are important factors to understand.

What to consider about your treatment:

- What is your goal for therapy?
- What does your doctor believe your goal for therapy should be?
- What are the anticipated benefits of each treatment option?
- What side effects and lifestyle changes are likely with each treatment recommended?
- How likely is it that you will have those side effects?
- How mild or severe could they be, and how long could they last?
- How will the potential side effects be prevented or managed so they do not interrupt your treatment schedule or reduce your quality of life?

After you have gathered your facts, then you can consider how these side effects may impact your life and how to prepare for and manage them. Remember, not everyone reacts the same way to treatments, and it is important to not assume you will feel the same as someone else who has undergone cancer treatment. There are tools, resources and medications to assist you in coping with various side effects. For more information about side effects, see Chapter 6.

PREPARING FOR TREATMENT

Smoking. If you smoke, you should consider quitting. Your body may respond more effectively to treatment if you do. It is also helpful if you can avoid secondhand smoke. Ask your doctor or nurse about smoking cessation programs to help you or members of your family quit smoking.

Nutrition. Nutrition can make a difference in how well you recover from the effects of treatment. Consider meeting with a nutritionist or dietitian before you start any treatment—surgery, radiation therapy, or chemotherapy—to help ensure that you are getting the nutrients you need before, during, and after treatment. Be sure to discuss any nutritional supplements you are taking with your doctor to avoid any potential interactions during treatment.

Physical activity. Physical activity is also important in optimizing your cancer treatment. If you are already an active person, maintain your activities as much as possible even if you need to modify your routine. Be sure to discuss your exercise program with your health care providers.

Be sure to tell your doctor about any symptoms you already have, such as shortness of breath and fatigue, as well as any symptoms that may result from your treatment regimen. Some disease symptoms can be managed before you even begin therapy to help you tolerate treatment better. It is important to know that fatigue, pain, and nausea can be managed, and it is critical to let your health care team know how symptoms are affecting you as soon as possible.



“I got all of my tests, reports, and biopsy results, and kept copies so that I could read everything and go back over it. I think that’s very important. No one can remember it all.”

— Cynthia

TREATMENT DECISION-MAKING WORKSHEET

This tool is designed to help you discuss treatment options with your doctor. You are encouraged to tear this page out and take it with you to appointments and use it as a guide to help you with discussions.

PART ONE

Medical Background Questions:

1. What type of lung cancer do I have? (The type of cancer will determine the types of treatment you will receive)

2. What is the stage of my lung cancer? (The stage of cancer will also determine the types of treatment available)

3. Does my current health status affect my treatment options? (age, other medical conditions)

4. What is the goal of my treatment?

5. What side effects might I expect and how can I prepare for them? (By preparing for common side effects before starting treatment, you can improve your quality of life and stay on course throughout your treatment schedule)

TREATMENT DECISION-MAKING WORKSHEET

PART TWO

Treatment Options

1. Potential Side Effects

(e.g., hospitalization, hair loss, fatigue, neuropathy, etc.)

2. Quality of Life/Treatment Convenience

(e.g., required clinic visits to receive treatments, monitoring blood counts, restricted activity, etc.)

3. Effectiveness

(e.g., what are the chances that this treatment will work for me?)

4. Surgery (can the tumor be removed?) _____

5. Pre- or post-surgery chemotherapy _____

6. Pre- or post-surgery radiation _____

7. Radiation _____

8. Chemotherapy _____

9. Targeted therapy _____

10. Investigational therapy in clinical trials _____

11. Combination treatments (from above) _____

12. Best supportive care _____

UNDERSTANDING TREATMENT FOR LUNG CANCER

Treatment for lung cancer depends on the type and stage of the cancer, the extent of symptoms, and the person's general health, age, and preferences. The treatment you receive may involve a combination of therapies that change over time. These changes can be in response to the stage of cancer, your personal circumstances, and the side effects you feel are most acceptable to your lifestyle.

Your treatment team will review your options, and may take a multidisciplinary approach. A multidisciplinary team is a group of health professionals who specialize in different aspects of cancer care. Members of a team may include an oncologist, radiologist, pathologist, surgeon, pulmonologist, radiation oncologist, pulmonary rehabilitation specialist, oncology nurse, and oncology social worker.

For more information about treatments recommended for specific stages of NSCLC or SCLC, see Chapters 4 or 5.

STANDARD THERAPIES

This section provides an overview of the general types of therapy used to treat lung cancer. Standard treatment for NSCLC usually involves surgery, radiation therapy, chemotherapy, or a combination of these approaches. In some cases, it also involves newer targeted therapies. For SCLC, it involves chemotherapy and frequently radiation therapy. (For more specific information: see Chapter 4 for NSCLC, and Chapter 5 for SCLC.)

Surgery

Surgical removal of the tumor is a common choice when the cancer has not spread to other tissues in the chest or beyond. The following surgical procedures are used to treat lung cancer:

- **Wedge or segmental resection** — removal of a small part of the lung
- **Lobectomy** — removal of an entire section (lobe) of the lung
- **Bilobectomy** — removal of two lobes of the same lung
- **Pneumonectomy** — removal of the entire lung

The types of surgery used to perform these procedures are thoracotomy and VATS (Video-Assisted Thoracic Surgery).

Thoracotomy

- An incision is made across the side of the chest and the ribs are spread apart so that the surgeon can gain access to the lung

VATS

- Uses a tiny video camera to guide the surgeon
- Makes it possible to remove a section of a lung or full lung through a small incision
- May reduce complications, shorten hospital stays and recovery time by avoiding large incisions

There are pros and cons to both types of surgery and you should discuss the options with your doctor to determine which is best for you.

Surgery may be the first type of treatment used, or it may be used after chemotherapy, radiation, or both have been given to shrink the tumor.

In general, surgery is not used as first-line treatment if the lung cancer has:

- Spread from the lung into other parts of the chest (e.g., the heart or the pleural fluid, which is fluid between the lung and chest wall)
- Spread to lymph nodes in the neck, mediastinum (area located in the center of the chest, but outside the lungs) or to other organs (e.g., the liver, adrenal glands, or brain)
- Developed in a part of the lung that can't be removed
- Been diagnosed as SCLC

Surgery is not recommended when the person has other health-related problems that would make surgery risky (e.g., serious heart or vascular problems, severe emphysema, diabetes, and certain other chronic conditions). To find out whether your lungs are healthy enough for surgery, the doctor may give you several tests (e.g., pulmonary function tests).

A pulmonary rehabilitation program may be recommended both before and after surgery, especially for people who do not have a regular exercise program. Sometimes inhalers, like those used to treat asthma, can also help improve breathing function to prepare people for surgery.

Chemotherapy

Chemotherapy uses drugs to destroy or damage cancer cells so they cannot divide and multiply. It can be used to shrink tumors, slow cancer's growth, keep cancer from spreading, relieve disease-related symptoms, or prolong survival. Because chemotherapy attacks all rapidly dividing cells, it not only damages cancer cells but also injures some normal cells. This is what leads to some of the more commonly experienced side effects. (See Chapter 6 for information about managing symptoms and side effects.)

Chemotherapy is given as a single drug or in a combination of drugs; combination chemotherapy may significantly increase the amount of cancer cells that are destroyed. Most chemotherapy drugs are given intravenously (through a vein). Some chemotherapy drugs can also be given orally, as a pill. Because the drugs continue to work for days or weeks after they are taken, a period of rest and recovery follows each dose.

Radiation

Radiation therapy, also called radiotherapy, is another common treatment option for some types of lung cancer. With radiation therapy, high-energy x-rays are used to shrink tumors, relieve pain and pressure, decrease symptoms, and improve quality of life. Radiation can be effective when used alone or in combination with surgery or chemotherapy. Cancer specialists called radiation oncologists provide this specialized treatment.

Radiation treatments are given to a specific area of the body called a radiation field during a series of outpatient hospital visits. The amount of radiation used to treat lung cancer varies, based on the size and location of the tumor and the sensitivity of the normal tissue that surrounds it. Side effects of radiation depend on where the radiation field is located.

NEWER THERAPIES

Targeted Therapies

Cancer treatments are improving constantly. One of the most exciting approaches to cancer today is the expanding area of targeted therapies. Unlike chemotherapy, these drugs target specific cellular pathways that enable cancer cells to grow.

Targeted therapies include agents that:

- interrupt the cell process that leads to an abnormal growth of cells
- cut off the flow of blood to the tumor with the goal of starving it
- target defects in the cancer cells
- make the cancer cells more receptive to the body's immune system
- block the signals that cancer cells receive which cause them to grow
- carry other drugs or substances directly to a tumor
- prevent cell growth

- inhibit the invasive nature of tumor cells to control the spread of cancerous cells and metastases
- cause spontaneous cell death (apoptosis) of cancer cells
- block the growth of new blood vessels and interfere with growth and metastases from solid tumors (angiogenesis inhibitors)

Some of the more common targeted therapy types are defined below:

Epidermal growth factor receptor (EGFR) inhibitors. EGFRs are naturally occurring proteins on the surface of cells that appear to aid in the growth of cancer cells and cause lung tumors to grow. A targeted therapy designed to block EGF receptors is Tarceva® (erlotinib). This drug seems to work best in people who have never smoked or who have certain genetic characteristics. Researchers are studying ways to identify the people who will benefit most from this treatment.

- Tarceva® has been approved by the FDA for the treatment of advanced non-small cell lung cancer as a second-line and third-line therapy (after initial treatment).

Anti-angiogenesis therapy. Cancerous tumors have the ability to create new blood vessels through a process called angiogenesis. These blood vessels help cancer cells grow and spread. Anti-angiogenesis therapy is a new approach to cancer treatment, with the goal of preventing the growth of new blood vessels to tumors. Various clinical trials are evaluating different anti-angiogenesis drugs to assess their impact on the disease.

- Avastin™ (bevacizumab) is an angiogenesis inhibitor, approved by the FDA (in combination with carboplatin and paclitaxel) for the treatment of advanced metastatic NSCLC in patients who have not received prior chemotherapy.

Monoclonal antibodies. Substances produced in a laboratory and tailored to attach themselves to a specific protein (antigen), attacking and destroying only tumor cells.

- Avastin™ is also a monoclonal antibody. Others being investigated in patients with NSCLC are Vectibix (panitumumab) and Erbitux (cetuximab).

Other Emerging Treatments

Ablation therapies. A non-surgical tissue destruction approach used for lung cancer treatment in certain circumstances. The following ablation therapies are available:

- Radiofrequency ablation uses thermal energy to destroy the cancer cells
- Cryotherapy uses an extremely cold energy source to destroy cancer cells and is an option to remove symptoms of airway obstruction

Photodynamic therapy (PDT). A procedure in which a special chemical is injected into the blood stream. The chemical is absorbed by all cells but remains in cancer cells longer. A laser aimed at the cancer activates the chemical to kill the cancer cells. PDT is approved for the relief of symptoms such as breathing problems in non-small cell lung cancer and can also be used to treat small tumors.

Vaccine Therapy

Most people are familiar with vaccines that are used to prevent common illnesses, such as the flu, measles, and polio. The latest in new approaches to cancer treatment involves the use of vaccines to treat lung cancer or decrease risk of recurrence. Vaccines can help the immune system recognize a tumor as foreign and stimulate the body's normal defense mechanisms to destroy tumor cells. Vaccines have many potential advantages, such as greater precision in targeting cancer cells with fewer toxic side effects. Tumor cells (either from the individual or from other sources) are used to develop a vaccine, and then injected into the person. The goal of the vaccine is to stimulate the immune system to recognize and attack the cancer cells.

- MAGE A3 is a vaccine that is being developed for prevention of recurrence after early stage NSCLC. The patient's tumor cells are tested for a tumor-specific antigen using tissue obtained during surgery. If the cells test positive for this specific antigen, the patient is more likely to respond to the vaccine and generate the immune response that would recognize cancer cells in the future.
- Lucanix and Stimuvax are vaccines being developed for treatment of late-stage NSCLC. Living cells are used from the major subtypes of non-small cell lung cancer to develop the vaccines. The goal is for these vaccines to cause the immune system to recognize and attack the proteins from these cancer cells, which will also teach them to attack the cancer cells within the body.

Radiation Techniques

External beam radiation (external beam).

Use of carefully aimed doses of radiation at specific sections of the lungs or surrounding areas (such as the neck or center of the chest).

Brachytherapy (internal or implant radiation therapy). Radioactive material sealed in needles, seeds, wires, or catheters is placed directly into or near a tumor.

Intensity Modulated Radiation Therapy (IMRT). A type of conformal radiation, which means the beams of radiation are shaped to closely match the shape of the tumor. It spares more normal tissue surrounding the tumor than general radiation and allows more radiation to be delivered directly to the tumor, as the intensity of the radiation can be changed throughout treatment. IMRT is only available with linear accelerator based machines; the most well-known is Tomotherapy®.

Stereotactic Radiosurgery (SRS or STRS).

There are three kinds of SRS, and each uses a different kind of machine that operates in a different way, and with a different source of radiation. SRS is a one-day session with a single high dose of radiation, but some machines can also be used for “fractionated” radiation, that which is done over time.

- Particle beam (proton)—only exist in a handful of centers in the U.S.
- Cobalt 60 based (photon)—the most well-known machine is Gamma Knife®, which is designed exclusively for brain tumors. Used for brain metastases from lung cancer.
- Linear accelerator based (linac)—the most well-known machines are Novalis Tx® and CyberKnife®.

Evaluating the Effects of Treatment

There are a number of ways to determine whether your treatment is working. For example, standard diagnostic procedures such as x-rays and CT scans can determine whether a tumor has disappeared, shrunk in size, is unchanged, or has grown. The doctor may request these additional tests after treatment has begun.

Also, most doctors assess performance status—a measure of your ability to do everyday activities—as an indicator of your overall health and physical functioning. If your pain or discomfort is lessened, breathing is easier, and cough diminishes, your performance status may be improved and it can be assumed that treatment is helping.

Considerations After Treatment is Completed

Treatment guidelines suggest that people who have been treated for lung cancer should see their oncologist:

- Every three months for the first two years
- Every six months for two more years
- Annually after four years

Many people continue to see their oncologists or primary care doctor every three months after finishing lung cancer treatment so that any recurrence can be detected as early as possible. At these visits, your doctor will check your general health status, may schedule a CT or other scan, and determine the need for blood work and other tests, depending on your health history.

PALLIATIVE CARE

People are living longer and fuller lives with lung cancer than ever before. With a variety of treatments available, and new ones on the horizon, living with lung cancer is a reality for many people.

According to the Center to Advance Palliative Care, palliative care is “the medical specialty focused on the relief of pain, stress, and other debilitating symptoms of serious disease.” Palliative care may be provided to treat symptoms of the lung cancer or to relieve side effects from treatment.

Palliative care is often provided during active treatment to make the patient more comfortable. However, in some cases, palliative care is given after curative attempts have failed. In those situations, palliative care is provided to prolong survival and to reduce or eliminate symptoms. In either situation, improving the quality of life of the patient is always a primary goal.

Whether the goal of your current treatment is curative, or palliative, there is hope. What you hope for may change, just as the goal of your current treatment has, but there are options to regain control and embrace meaning in your life.

CLINICAL TRIALS

With an overall five-year survival rate that has not improved in 30 years, it is clear that current treatment options for lung cancer still have much room for improvement. Researchers are constantly trying to improve available treatments and are eager to develop new (also called “novel”) therapies. Cancer clinical trials are carefully designed and strictly monitored research studies that determine whether a new treatment option is safe, effective, and better than standard treatments currently in use. The current “standard of care” treatment(s) for lung cancer were originally approved as safe and effective in clinical trials.

During the course of your diagnosis and treatment, you and your doctor may consider exploring your clinical trial options. Participating in a clinical trial does not mean that you will be “experimented on” or treated as a human guinea pig. Clinical trials only explore treatment options that are thought to be as good as or better than the current standard therapies. They are rigorously evaluated by panels of experts, including patient advocates, to ensure that patients enrolled in trials receive the very best care possible and NEVER less than the best available standard of care.

Through a clinical trial, you may be one of the first to receive what may become the new “standard of care.” Clinical trial participation is at the heart of the drug approval process and may help save lives.

If you are eligible for a clinical trial, ask questions until you understand all of the potential benefits and risks so that you can

decide whether the opportunity is right for you. For example:

- Why could this treatment be better for me than other options?
- How is patient safety monitored?
- Who sponsors the study?
- Who reviews the study’s findings, and how often?
- Are additional lab or other tests needed, and if so, who pays for them?
- Is the study done on an outpatient or inpatient basis?
- Do I have to travel to the facility where the study is done, or is treatment available near me?
- What are the possible short-term and long-term effects of the treatment?
- How could the treatment affect my daily life?

- If the treatment has any negative effects, what will be done for me, and who will pay for it?
- How long will the study last?
- Does my medical insurance or the study sponsor cover some or all of the cost of participation in the study? If not, how much will I have to pay?

For more information about lung cancer clinical trials, see the Chapter 9 Resources. For more information about new treatments in general, see Frankly Speaking About New Discoveries in Cancer information online: www.cancersupportcommunity.org.



“I chose to participate in a clinical trial because I wanted to be as aggressive as possible with my treatment. I also know that these trials are an important part in helping us to learn more about lung cancer and help bring us closer to a cure!”
— Jerry



“I think you should be educated as much as you possibly can about your diagnosis. I believe the more you know, the less fear you have. Then you’re not playing ‘what if’ with yourself.”

— Cynthia

Understanding NSCLC and its Treatment

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Understanding Non-Small Cell Lung Cancer and its Treatment

The recommendations from your oncologist and the treatment decisions you make will depend on the stage of your disease, your general health, the potential side effects, and your wishes. Remember, there is no one treatment for non-small cell lung cancer. Your treatment will be as individual as you are and will adapt to your changing needs and side effects.

The stage of cancer is the major factor in determining a treatment plan. It is important to understand the concept of “stage” for lung cancer, because it guides treatment options. The following review of treatments by stage of NSCLC provides only general descriptions of the usual approaches. There are many variations of existing options, and many new treatments are emerging, providing additional treatment options.

STAGING OF NSCLC

The TNM Staging System is one of the most commonly used cancer staging systems, which standardizes cancer staging internationally. It takes into consideration the size of the **tumor (T)**, cancer spread to **lymph nodes (N)**, and how far the cancer has spread beyond the lymph nodes, or **metastasis (M)**. The overall staging of NSCLC is based on the TNM results.

Tumor (T)

How big is the tumor? Where is it located?
Has it spread to nearby tissue?

Lymph Node (N)

Has the cancer spread to the lymph nodes in and around the lungs?

Metastasis (M)

Has the cancer spread to other parts of the body?

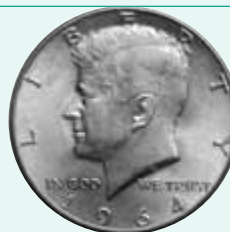
CENTIMETER SIZING

1 CM



THE SIZE OF A CHOCOLATE CHIP

3 CM



THE SIZE OF A 50 CENT PIECE

5 CM



THE HEIGHT OF AN AA BATTERY

STAGES OF NON-SMALL CELL LUNG CANCER

STAGE IA

- The cancer is less than 3 cm, has not spread to the membranes that surround the lungs, and does not affect the main branches of the bronchi.

STAGE IB

- The tumor is larger than 3 cm but less than 5 cm
- **or** it involves the main bronchus (passageway of air to the lung) or the visceral pleura (sac surrounding the lung). However, Stage IB tumors do not involve lymph nodes, do not extend to the center of the chest outside of the lung, and do not involve more than one area of the lung.

STAGE IIA

- The tumor is no larger than 5 cm and has spread to the lymph nodes and bronchus (passageway of air to the lung) entry point within the cancerous lung
- **or** the tumor is larger than 5 cm and less than or equal to 7 cm, with no involvement of the lymph nodes or center of the chest outside the lung and does not involve more than one area of the lung.

STAGE IIB

- The cancer is greater than 5 cm and less than 7 cm but has spread to ipsilateral (same side) lymph nodes or to the area where the bronchus enters the same lung
- **or** the cancer is larger than 7 cm
- **or** the tumor touches an area near the lung, such as the chest wall or diaphragm (muscle below the lungs used for breathing), or pericardium (sac surrounding the heart)
- **or** it has grown into the main bronchus
- **or** the cancer has caused one lung to collapse or caused pneumonia in an entire lung

STAGE IIIA

- Between 3 cm and 7 cm and involves the main bronchus (passageway of air to the lung) or visceral pleura (sac surrounding the lung) and has spread to the ipsilateral (same side) lymph nodes near where the trachea (windpipe) branches into the left and right bronchi or near the mediastinum (area between the lungs)
- **or** the tumor is larger than 7 cm or touches an area near the lung or has grown into the bronchus or caused a lung to collapse or pneumonia in an entire lung or a separate tumor in the same lobe and has spread to ipsilateral lymph nodes which may be near the windpipe (trachea) and the mediastinum
- **or** the tumor is of any size and has spread to the mediastinum, heart, trachea, esophagus, backbone or the place where the trachea branches
- **or** there is a separate tumor in a different lobe of the same lung and cancer may have spread to the ipsilateral lymph nodes near the bronchus entry.

STAGE IIIB

- The tumor may be of any size and has spread to the mediastinum (area between the lungs), heart, trachea, esophagus, backbone or the branch of the trachea (windpipe), or there are separate tumors in a different lobe of the same lung,
- **or** the cancer has spread to lymph nodes on the contralateral (opposite side) lung or to lymph nodes in the neck.

STAGE IV

Stage IV is the most advanced form of cancer

- Cancer has spread beyond a single lung. This spread may be to lobes in the opposite lung, or area surrounding the lung
- **or** the cancer has spread to distant parts of the body such as the brain, liver, adrenal glands, or bone
- **or** there is a separate tumor in the same lobe

TREATMENT OF NSCLC BY STAGE

Stages IA and IB

When cancer is diagnosed in early stages, treatment is more likely to be successful. Some combination of the following treatments may be used:

Surgery. Surgery is the standard of care for patients with stage I NSCLC. (See Chapter 3 for information on types of surgery.)

During lung surgery, it is important for the surgeon to perform a complete examination of the lymph nodes in the chest cavity, including the mediastinum (the area between the lungs). This examination is an important reason to have the surgery done by a qualified thoracic surgeon, as a less knowledgeable one may do an inadequate assessment of the lymph nodes in the mediastinum. Ask your surgeon specifically if he/she plans to check and/or remove these lymph nodes for examination.

Chemotherapy. The need for post-surgery (called adjuvant) therapy is an important topic to discuss with your oncologists. Select patients with stage IB NSCLC may benefit from chemotherapy after surgery. The chemotherapy will usually consist of a platinum-based drug (cisplatin or carboplatin) and one of several other chemotherapy agents.

Targeted therapies. A targeted therapy is a new type of drug that targets specific cellular pathways that enable cells to grow. These treatments are sometimes used in combination with chemotherapy drugs.

Radiation. Sometimes even in early stages of lung cancer the patient may not be able to go through surgery because of other health issues. In this case, radiation is often combined with chemotherapy to treat stage IA and IB NSCLC.

Stages IIA and IIB

If you are diagnosed with stage IIA or IIB NSCLC, it is recommended that you meet with a surgeon, a medical oncologist, and a radiation oncologist to discuss possible treatment options, including clinical trials for your stage of disease.

Surgery. Surgery is the standard of treatment for stage IIA and IIB disease. (See Chapter 3 for information on types of surgery.)

Chemotherapy. Recent studies have shown that chemotherapy with a platinum-based drug regimen after surgery improves survival in people with stage IIA and IIB lung cancer. Under certain circumstances, treatment with chemotherapy before surgery may be beneficial. The goal of that treatment (called neo-adjuvant treatment) is to shrink the tumor to improve the chances that the surgical procedure will be successful in removing the entire tumor.

Targeted therapies. A targeted therapy is a new type of drug that targets specific cellular pathways that enable cells to grow. These treatments are sometimes used in combination with chemotherapy drugs.

Radiation. Under certain circumstances, radiation may be given before and/or after surgery to improve the chances of destroying all the cancer cells.

Stage IIIA

Stage IIIA NSCLC can be a complex stage of lung cancer to manage. Treatment at this stage is determined by whether the tumor is operable (can be surgically removed) or inoperable (cannot be surgically removed) and may involve several of the following treatments:

Operable Stage IIIA NSCLC

Depending on the details of your case, options may include a combination of the following:

Surgery. Surgery without chemotherapy may be possible in some cases if the tumor can be easily removed, especially when the lymph nodes were found to be involved only at the time of surgery.

Chemotherapy. When the lymph nodes in the mediastinum (area between the lungs) are involved, the most common treatment is chemotherapy with or without radiation given before or after surgery.

Targeted therapies. A targeted therapy is a new type of drug that targets specific cellular pathways that enable cells to grow. These treatments are sometimes used in combination with chemotherapy drugs.

Radiation. Radiation is sometimes used for Stage IIIA NSCLC either with chemotherapy or in combination with surgery. Radiation combined with chemotherapy may be used instead of surgery to eliminate the tumor and is probably the most common form of therapy at this stage.

Inoperable Stage IIIA NSCLC

Stage IIIA NSCLC is considered inoperable when the tumor is too large, in a location that is difficult for the surgeon to reach, or the patient has other factors that make surgery impossible. It may also be considered inoperable *even if the patient had surgery*, if during the surgery cancer was found in certain lymph nodes.

Chemotherapy. The standard of care for inoperable Stage IIIA is chemotherapy combined with radiation therapy when the patient is healthy enough to withstand both therapies. Commonly used chemotherapy drugs include a platinum drug in combination with one of several other drugs. Delivery of chemotherapy and radiation therapy concurrently (at the same time) appears to be better than the sequential (one after the other) administration of chemotherapy and radiation treatments.

TREATMENT OF RECURRENT NSCLC

Targeted therapies. A targeted therapy is a new type of drug that targets specific cellular pathways that enable cells to grow. These treatments are sometimes used in combination with chemotherapy drugs.

Radiation. Radiation is often used as part of the treatment for this stage of cancer.

Sometimes lung cancer that was thought to be inoperable due to size or location may become operable after treatment with chemotherapy and/or radiation.

Stage IIIB and Stage IV

The goal of treatment for patients with stage IIIB or IV lung cancer is typically to prolong survival and improve quality of life.

Surgery. Surgery is often not possible for people with stage IIIB, and is rarely used for stage IV.

Chemotherapy. Chemotherapy improves survival and quality of life when compared to best supportive care (to relieve symptoms only) in some people with inoperable stage IIIB and stage IV NSCLC who are healthy enough to tolerate the side effects. Current clinical trials have shown that a combination of different drugs is superior to giving one drug alone.

Targeted therapies. A targeted therapy is a new type of drug that targets specific cellular pathways that enable cells to grow. These treatments are sometimes used in combination with chemotherapy drugs, but in the case of stage IIIB and IV non-small cell lung cancer, they may be used alone following chemotherapy treatment.

Radiation. Radiation is often used as part of the treatment for this stage of lung cancer.

Non-small cell lung cancer can recur (come back after initial treatment) in or near the lungs (local recurrence) or in another part of the body (metastatic recurrence). While this can be a distressing time filled with many emotions, it is important to remember that there are treatment options that can reduce or slow down tumor activity. In the case of metastatic recurrence, the goal of treatment is generally to improve or maintain quality of life and prolong survival. This may include any of the treatments used in other stages of disease. The challenges that impact treatment decision-making for recurrent NSCLC can include:

- General health status — If a person is generally in good health with no other serious conditions, there are more treatment options.
- Potential side effects — Several treatment options may have similar results but vary widely in potential side effects that may impact quality of life.

- Goals and wishes of the patient and family — It is important that the individual's goals of treatment be considered when designing their treatment plan.

These challenges exist at all stages of diagnosis, but may be especially present after having gone through other treatments for lung cancer.

For additional information on specific therapy recommendations, please visit www.cancer.gov/cancertopics/types/lung or 1-800-4CANCER.

If you choose not to take chemotherapy or a targeted therapy, supportive care – treatment that helps relieve symptoms but does not affect the growth of the cancer – may be recommended. Supportive care may include pain-control measures, radiation, or laser therapy to relieve symptoms. Whatever you and your oncologist decide, there is hope. Even if a cure is not possible, there is hope that effective treatment can maintain or improve your quality of life and even slow or control the disease itself. It is now possible to treat advanced lung cancer as a chronic condition in some patients, keeping the disease stable until new drugs and treatments are discovered. As mentioned many times in this booklet, it is important for you to talk with your doctor about all of your treatment options, weighing the potential side effects with the possible benefits.

LUNG CANCER TREATMENT AND YOUR HEART

Surgery, radiation, and common chemotherapy drugs for lung cancer may cause problems with heart function. Before you start treatment, tests such as an echocardiogram and stress electrocardiogram may be done to determine the status of your heart function. Symptoms of heart problems may include:


- Chest tightness or pain
- Difficulty breathing
- Unusually slow or rapid heartbeat
- Numbness in the left arm or shoulder

Be sure your doctor knows about any past problems with your heart, and contact your doctor immediately if you experience any of the symptoms listed above.



“When my cancer came back, I got scared initially and said ‘Oh no! Not again!’ But I was more convinced to enjoy my life. I’ve totally changed my lifestyle. I took the stress out of it, picked up swimming and started taking trips.”

— Mary Ellen



“When I was diagnosed with SCLC, life just became a whirlwind, rushing from one doctor to the next. This cancer spreads fast, even though it reacts well to chemo. Within a week I was diagnosed, met with my oncologist, and was admitted for my first chemo.”

— Lisa

Understanding SCLC and its Treatment

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Understanding Small Cell Lung Cancer and its Treatment

Current treatment for small cell lung cancer involves a combination of chemotherapy drugs with or without radiation therapy. Because new therapies for cancer are always in development, you should discuss the latest treatments with your oncologist, including the possibility of finding a clinical trial that might be a good fit for you.

Treatment is determined by the stage of your disease, your overall health, the possible side effects of specific therapies, and your preferences. Members of your health care team have expertise that can be helpful as you weigh treatment options. No matter what choices you make, it is important that you get the information you need to understand the potential impact of those decisions—for your health and for your future.

STAGING OF SCLC

SCLC tends to be more aggressive than NSCLC. Small cell lung cancer is generally categorized as either limited-stage or extensive-stage disease:

- **Limited-stage** — tumors typically are on one side of the chest in one lung, and within the surrounding area that can be treated by radiation.
- **Extensive-stage** — tumors have spread outside one lung to the other lung or to other areas of the body.

Hearing that your cancer is a more aggressive kind is not easy, and there may be a variety of emotions you experience. However, there are still many opportunities to remain Patient Active and find meaningful ways to experience good quality of life and survival.

TREATMENT OF SCLC BY STAGE

Newly Diagnosed Limited-Stage SCLC

According to the National Cancer Institute (NCI), the current standard treatment for patients with newly diagnosed limited-stage SCLC should be four cycles of combination chemotherapy containing VP16 (etoposide) and cisplatin at the same time as chest radiation.

Newly Diagnosed Extensive-Stage SCLC

Extensive-stage SCLC is treated using the same chemotherapy as in limited-stage SCLC but without additional radiation therapy.

Frequently used first-line chemotherapy drugs for SCLC include:

- VP16 (etoposide) plus a platinum agent like cisplatin or carboplatin

- Camptosar® (irinotecan/CPT11) plus a platinum agent (not FDA approved for SCLC at this time but is often used because it generated promising results in clinical trials)
- Cytosan® (cyclophosphamide) plus doxorubicin plus vincristine (an older regimen – less widely used in the U.S.)

Prophylactic cranial irradiation (PCI) is preventive radiation therapy to the brain. SCLC often spreads to the brain and PCI can help keep this from happening. It is recommended for some people who are in remission after initial chemotherapy.

TREATMENT OF RECURRENT SCLC

If your small cell lung cancer does not respond to initial therapy it is considered to be resistant. If it returns within two years of successful treatment, it is considered to be recurrent. The goal of therapy in these cases is to improve quality of life and prolong survival. Possible chemotherapy drugs for treatment of resistant or recurrent SCLC include:

- Hycamtin® (topotecan) is the only FDA-approved drug for recurrent SCLC. It is also available in pill form.
- VP16 (etoposide)
- For relapses occurring more than six months after the initial treatment, the original chemotherapy can be repeated.

TALK WITH YOUR ONCOLOGIST

If you are newly diagnosed or have recurrent SCLC, it is important to talk with an oncologist about potential treatment options. For some patients with recurrent disease, Phase I or Phase II clinical trials may provide the best treatment options.

“Medical research is being conducted all across the United States, bringing hope for new and more effective treatments for small cell lung cancer.”

*— Maureen Rigney, LICSW, Director of Patient Services,
Lung Cancer Alliance*



Managing Side Effects

“I tell people straight-up ‘I’m sorry, I can’t remember your name!’ I’ve learned not to be embarrassed about chemobrain, but just to admit it and ask people to help. And I’ve found that when you say, ‘This is my problem. Can you help me remember this?’ - that people are really good.”

— Mary Ellen

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Managing Side Effects

Nearly every form of cancer treatment has some side effects, but they vary widely from person to person. Your experience will be unique. You may have many side effects or you may have only a few of the side effects that are associated with your type of therapy.

Discussing possible side effects with your oncologist before you begin treatment helps to reassure you that certain symptoms are expected and inform you about what to do if they occur. If you have any concerns about how you are reacting to either the disease or its treatments, it is always best to contact your doctor.

It is your responsibility to report side effects to your doctor or nurse. Often, side effects can be successfully managed, but your doctor or nurse needs to know you're having them.

IS IT CANCER OR SOMETHING ELSE?

People who have been diagnosed with cancer know that life instantly changed when they heard the words: "You have cancer." Many say that they become very conscious of their body; some think they worry too much about "every ache and pain." More often than not, the symptoms you are experiencing are temporary and related to your treatment and the changes occurring in your body as it works to control or destroy the cancer. It is common to worry even long after treatment is complete.

It is important that you learn to read your body's physical signs, keep track of symptoms and side effects, and maintain regular and open communication with your health care team and family so that you can feel as good as possible throughout and beyond treatment.

MANAGING SIDE EFFECTS

What your body is going through may be related to the symptoms of the disease or they may be effects from treatment. In this chapter, some of the more common side effects and symptoms are discussed:

- Fatigue and difficulty breathing
- Infection, bleeding, and anemia
- Gastro-intestinal system changes
- Changes in appearance
- Pain and discomfort
- Changes in sexual functioning and effects on fertility

Emotional well-being is also affected by cancer and its treatment. Please see Chapter 7 on Quality of Life for more information.

The good news is that there are specific things you can do not only to manage but, in some circumstances, prevent these challenging side effects. Managing your side effects will improve the way you feel during treatment, help you get through treatment as quickly as possible (side effects may delay treatment), and may make a difference in the outcome of your treatment.

Strong evidence shows that exercising helps fight cancer- and treatment-related fatigue. Walking, cycling, and swimming are good examples of activities to try. Ask your doctor about cancer rehabilitation or other specialized exercise programs for people with cancer that might be available in your area.

Fatigue

Of all the side effects associated with treatment, fatigue is the most common and distressing complaint of people with cancer. Fatigue is a lingering feeling of tiredness that gets in the way of daily activities. This is not the same feeling of tiredness caused by activity or overexertion. Feeling fatigued is not an indication that your cancer is worse, but you should tell your doctor if you feel fatigued.

Fatigue during or after cancer treatment may be caused by a low red blood cell count, sleeping problems, diet, breathing difficulties, or emotional distress such as depression and anxiety (see Chapter 6). Generally, fatigue will begin to decrease within a few weeks or months after treatment and your energy will return; however, some patients may have to cope with fatigue for the rest of their lives.

Discuss problems of fatigue with your health care team so strategies can be put into place to help you.

Engage your family and friends to help you accomplish tasks that are important to you. You should view this as taking control of your life and situation, not giving up control.

More comprehensive information about coping with side effects can be found on the websites of Cancer Support Community, www.cancersupportcommunity.org, and the Lung Cancer Alliance, www.lungcanceralliance.org.

Strategies for managing fatigue

- If you have a low red blood cell count, ask your doctor about medications that stimulate red blood cell production and reduce fatigue. (Please see the warning about these medications on page 51).
- Get plenty of rest, and take a short nap during the day. Do not nap after the late afternoon.
- Research shows that moderate daily physical activity can decrease fatigue. Try walking, swimming, biking, or yoga. Start slowly and work up to a comfortable level. Ask your doctor about cancer rehabilitation or other specialized exercise programs for people with cancer that might be available in your area.
- Learn mind-body techniques like t'ai chi or meditation to relax.
- Identify the time of day when you have the most energy, then schedule activities or structure your routine to accomplish tasks and meet reasonable goals at that time.
- Drink enough fluids. Ask your health care team how much fluid is appropriate for you to drink.
- Avoid caffeine after noon and tobacco altogether.
- Ask others to help you; delegate tasks. Don't be shy about accepting gifts of food and help with errands from friends and family. View this as taking control of your life and situation, not giving up control.
- Use shopping lists to shop more quickly, or have someone else shop for you.
- Conserve energy by sitting on a stool to wash dishes, cook, or do other activities for which you might normally stand.

Difficulty breathing

It is also common for people with lung cancer to have breathing problems, which can definitely decrease energy and cause fatigue. Breathing problems can be caused by the cancer, infection, certain chemotherapy drugs, fluid around the lungs or heart, or a condition called radiation fibrosis.

Strategies for managing breathing problems

- Call your doctor right away if you have a feeling of tightness in your chest, pain, fever, or trouble breathing.
- Ask your doctor about oxygen therapy or corticosteroid therapy to relieve breathing problems.
- If you use an inhaler, be sure to do so exactly as your doctor prescribed. If inhalers are not used consistently over time, they will not relieve symptoms.
- Sometimes having a fan in the room or having a cooler room temperature helps if you are having difficulty breathing.

Recognizing radiation fibrosis

Radiation treatment can trigger the immune system to form fibrous scar tissue inside the lung: a condition called radiation fibrosis. It may be temporary, or it could develop months or even years after radiotherapy ends. The symptoms are common for people undergoing treatment for lung cancer and may include dry mouth, sore throat, or problems with swallowing or breathing.

It is a good idea to talk with your radiation oncologist about ways to minimize your risk for developing radiation fibrosis.

Managing low blood counts

Chemotherapy and radiation can destroy healthy cells as well as cancer cells. One of the most common side effects people experience from chemotherapy or radiation is low blood counts (myelosuppression). In cancer treatment, blood counts usually fall to their lowest level seven to ten days after chemotherapy, depending on the type, dose,

and combination of chemotherapy drugs used. Your doctor will watch your blood counts carefully. Low blood counts can lead to infection, anemia, or bleeding.

The following blood counts may drop:

- **White blood cells (WBCs)**—help the body fight off infection. If your WBCs are too low, you are at increased risk for developing an infection. Your doctor may want you to take a medication that stimulates white blood cell production such as Neupogen® or Neulasta®, to prevent your WBC count from dropping too low for a long period of time.
- **Red blood cells (RBCs)**—carry oxygen to your cells. If your RBC count drops too low, you may become anemic—your heart works harder and you may feel fatigued. Your doctor may suggest a blood transfusion or a red cell growth factor like Procrit® or Aranesp® to keep your RBCs from remaining too low for a long period of time.

WARNING ABOUT TREATMENT FOR LOW RBC COUNT

The FDA has issued warnings about the use of medications, such as Procrit or Aranesp (erythropoiesis stimulating agents, or ESAs), in cancer patients. It is important to be aware of possible complications and communicate concerns immediately to your doctor and health care team. Talk to your doctor about the risks and benefits of taking these medications with your particular type of lung cancer.

- **Platelets**—promote blood clotting. If your platelet count drops during therapy, you may notice bruising or bleeding. Your doctor may want you to have a platelet transfusion or take a growth factor to help stimulate platelet production. If you are taking Avastin™ and notice that you are coughing up bright red sputum (1 tsp or more), immediately call your physician or go to the emergency room. In rare cases, Avastin™ has resulted in fatal bleeding in the lungs in patients being treated for NSCLC.

Strategies for managing infection

- Practice good hand-washing techniques: use soap and warm water and rub vigorously for one minute prior to eating and after using the toilet. Make sure others in your home practice good hand washing, too.
- If you learn that your chemotherapy will cause low WBC (white blood cell) counts, keep a record of your temperature. Ask your doctor about the specific level of fever to report.
- If your WBC count is low, avoid crowds or people who might be infected with colds, flu, or other contagious diseases.
- Avoid lung contaminants such as tobacco or wood smoke from a fireplace, since exposure to these substances may increase the risk of infection in people who have a suppressed immune system.
- Avoid fresh or dried flowers as well as plants, due to the risk of fungal or bacterial infections.

- Practice meticulous oral hygiene. Avoid commercial mouthwashes that contain alcohol because they can dry out your mouth. One teaspoon of baking soda in a cup of warm water is a soothing mouthwash that helps to remove bacteria.
- Avoid cleaning cat litter boxes or handling any other animal bodily waste.

Contact your doctor immediately if you have any of the following symptoms:

- A temperature of 100.4° F or higher (ask your doctor for specifics)
- Pain, redness, swelling, or pus at a surgical site
- Severe chills even in the absence of fever
- Pain while urinating
- Trouble breathing
- Mouth sores
- Loose bowel movements or diarrhea for more than 24 hours

No matter what time of the day or night, call your doctor immediately if you have a fever, because this is often a clear indication of infection.

“I liked that the nurses shared anecdotal information when I was trying to cope with side effects. They would say, ‘so-and-so tried this, and it worked for them.’ I really appreciated that little bit of extra information.”

— Lisa

Anemia

- Get plenty of rest. Follow the strategies for coping with fatigue mentioned on page 46.
- Eat a nutritious diet. Ask your doctor or nurse about foods that are important for you to eat if you have anemia.
- Stand up slowly; anemia can cause you to feel dizzy when you get up after lying or sitting.
- Ask your doctor if you need medication to increase your red blood cells. (Please see the warning about these medications on page 49).

Contact your doctor immediately if you have any of the following symptoms:

- Increased shortness of breath
- Pounding or rapidly beating heart
- Confusion or difficulty concentrating
- Dizziness or fainting

Bleeding

- Use a soft toothbrush; ask your doctor about whether you should floss.
- Use an electric shaver instead of a razor.
- Try to avoid injury.
- Don’t use tampons, suppositories, enemas, or rectal thermometers.

Contact your doctor immediately if you have any of the following symptoms:

- Bruising without an injury; tiny red dots on your skin
- Bleeding from your nose or gums; pink or red urine; black or bloody bowel movements
- Headache or any change in your vision

Gastro-intestinal system changes

Problems due to gastro-intestinal system changes associated with cancer treatment are common but very manageable. Depending on the specific drug(s), dosage, and duration of treatment, chemotherapy can cause gastro-intestinal problems, including loss of appetite, changes in the way food tastes and smells, and sores in the mouth and throat. Radiation treatment can cause a condition called esophagitis, which makes swallowing painful and difficult, often described as feeling of food getting stuck in your throat.

Consult a registered dietician or nutritionist to help you maintain good nutrition during cancer treatment and beyond. Ask your doctor for a referral.

Strategies for managing chewing and swallowing difficulties, dry mouth, or mouth sores

- Add gravy, sauces, butter, and salad dressings to make food easier to swallow.
- Eat soft and pureed foods that are easier to swallow.
- Consume food and liquids that are warm rather than very hot or cold (cold foods may be soothing if you have mouth sores).
- Avoid greasy, fatty, or fried foods and strong spices.
- Gargle with one teaspoon of table salt or baking soda added to one cup of warm water to keep your mouth clean and keep mouth sores from becoming infected.
- Keep your lips moist with lip balms.
- Suck on sugar-free hard candy or popsicles, or chew gum to produce more saliva.
- Ask your doctor if sucking on ice cubes or ice chips 10 minutes before chemotherapy and 15 minutes afterward could help prevent mouth sores.
- If you are using oxygen, ask for a humidifier bottle to attach to the oxygen line to decrease dryness.
- If you have mouth or throat pain, tell your doctor or nurse as soon as possible. Medications that reduce pain or numb the area are available.

Strategies for managing loss of appetite

- If you aren't hungry at dinnertime, make breakfast or lunch your main meal. Similarly, if you aren't hungry first thing in the morning, eat more later in the day.
- Eat several small meals or snacks rather than three large meals per day.
- Keep nutritious snacks on hand.
- Vary your diet—try new recipes and foods.
- Add olive oil to increase the caloric intake of foods you do eat.
- Consider taking a walk before meals to spur your appetite.
- Drink protein-fortified beverages or add milk, powdered milk, or yogurt to increase protein and calories.
- Try some of the commercially prepared food supplements; for variety, add fresh berries or juice.
- Arrange to eat with family and friends, or watch TV while you eat if you are alone.

Strategies for managing nausea or vomiting

- Prevention works best, so ask your doctor about anti-nausea medications and take them on time and according to instructions.
- Eat and drink slowly.
- Try beverages such as peppermint tea, ginger ale, or ginger tea.
- Eat small, frequent meals.
- Eat food served at room temperature.
- Suck on ice cubes, mints, or candies.
- Rest in a chair after meals. Do not lie flat for at least two hours after you have finished eating.
- Eat crackers, toast, soft or bland fruits and vegetables, oatmeal, clear liquids, and ice.
- Eat foods prepared with moist heat, such as soups, stews, and casseroles.
- Avoid alcohol and smoking.

- Avoid greasy, fatty, fried, spicy, and very sweet foods.
- Avoid highly seasoned, spicy, tart, or acidic foods (no citrus foods or tomatoes).
- Keep your caloric intake high by using supplemental types of drinks, such as Ensure® or Boost®.
- If cooking odors make you feel nauseated, try to (1) microwave your meals, (2) use a strong venting fan while cooking, and (3) use frozen or chilled foods, which give off fewer odors.
- Talk with your doctor about complementary treatments like acupuncture and acupressure to relieve nausea.
- Mind-body techniques such as music therapy or guided imagery may also ease nausea.

MORE ABOUT MEDICATIONS FOR NAUSEA AND VOMITING

Nausea and vomiting should no longer be a serious concern for most people undergoing cancer treatment since these symptoms can usually be controlled effectively by medications.

Medications for nausea and vomiting allow patients to feel better and tolerate more aggressive treatments for their disease.

Treatments for **nausea and vomiting** differ according to when they are likely to occur and their probable cause. Chemotherapy-induced vomiting can be divided into three types:

- Acute nausea or vomiting usually occurs within 24 hours of the chemotherapy treatment.
- Delayed nausea or vomiting generally begins 24 hours after the administration of chemotherapy and can persist for six to seven days.
- Anticipatory nausea or vomiting, which is thought to be a learned response, occurs prior to administration of chemotherapy and usually happens when the person has experienced nausea or vomiting in previous chemotherapy treatment sessions.

Surgery and radiation—for example, radiation therapy to the esophagus or upper body—also can cause nausea and vomiting. However, radiation therapy for lung cancer does not typically cause nausea and vomiting.

Anti-emetic (anti-nausea) medications are often used along with a steroid-like dexamethasone before chemotherapy to prevent the uncomfortable feelings of nausea and vomiting. Depending upon the nature of your nausea and vomiting, your doctor may prescribe one or more of these medications:

- Aloxi® (palonosetron) is given as a single IV dose to prevent both acute and delayed chemotherapy-induced nausea and vomiting.
- Zofran® (ondansetron) and Kytril® (granisetron) are used for prevention of nausea and vomiting associated with chemotherapy and radiation. They are available as an intravenous solution or oral tablet.

- Anzemet® (dolasetron) is used for the prevention of nausea and vomiting associated with chemotherapy and surgery, but it should be used with caution in those who have, or are at risk for, certain heart problems. It is available as an intravenous solution and as an oral tablet.
- Emend® (aprepitant) is an oral capsule used with other medicines for the prevention and the control of acute and delayed nausea and vomiting associated with chemotherapy. It is available in an oral and intravenous form and not used to treat nausea and vomiting that you already have.
- Phenergan® (promethazine) and Compazine® (prochlorperazine) are also used to control nausea and are administered at the earliest onset of mild nausea. There are additional medications that can be used to control nausea and vomiting like Reglan® (metoclopramide), Ativan® (lorazepam), Marinol® (dronabinol), and others. If the medicine your doctor first prescribed does not work for you, be sure to let him or her know. You can always try other medicines so that you do not have to deal with nausea and vomiting.

Strategies for managing constipation

- Drink plenty of non-caffeinated fluids. Caffeine can cause or worsen constipation since it is a diuretic, meaning that it increases urine output.
- Eat high-fiber foods, such as whole-grain breads and cereals, fresh and dried fruits, raw vegetables, and beans. If you eat fresh, raw fruits and vegetables, make sure they are washed thoroughly.
- Walk or do some form of physical exercise every day.
- Eat/drink warm or hot fluids, such as soup (but not caffeinated tea or coffee) to help stimulate the bowel.
- Consult your doctor before you use an enema. An enema could cause bleeding if your platelet counts are low, or lead to an infection if your WBC count is low.

- Ask your doctor before you use a laxative, stool softener, or suppository.
- If you've been constipated for more than three days, call your doctor immediately. Prolonged constipation can cause a serious condition called fecal impaction.

A WORD ABOUT BLOATING, CRAMPING, OR GAS

Dairy products are an excellent source of calories and protein, but after chemotherapy or abdominal radiation, some people develop lactose intolerance, difficulty in digesting or absorbing the lactose milk sugar. If you experience bloating, cramping, or gas several hours after eating milk products, lactose intolerance may be the problem.

Talk to your doctor about adding enzyme tablets or liquid drops (available at drug stores) to break down the lactose, or use lactose-reduced dairy products to decrease or eliminate your discomfort.

Strategies for managing diarrhea

- Avoid high-fiber foods that contain roughage, such as whole-grain breads, raw fruits and vegetables, and dried beans.
- For a short period eat low-fiber, nutritious foods, like the BRAT diet: bananas, rice, plain applesauce, and toast. Also try yogurt, cottage cheese, smooth peanut butter, and white bread.
- Drink plenty of water between meals—at least eight glasses of clear fluids—but not with meals.
- Eat foods and liquids high in salt and potassium (minerals often lost during diarrhea), such as bouillon, bananas, mashed potatoes, and apricot nectar.
- Avoid milk and milk products.
- Eat frequent, small snacks rather than three large meals per day.

- Ask your doctor before you take any over-the-counter medicines for diarrhea.
- For severe diarrhea, restrict your diet to clear, warm liquids such as broth, or flat ginger ale for one day.

If diarrhea lasts for more than a day, or if you also have fever and/or pain, contact your doctor immediately.

Changes in appearance

Hair loss

Radiation to the head and some chemotherapy drugs cause people to lose some or all of their hair (a condition called alopecia), including scalp hair, body hair, eyebrows, and eyelashes. When alopecia occurs, it usually happens 10 to 21 days after the first chemotherapy treatment. Talk to your doctor about whether hair loss occurs with your specific treatment regimen. Not everyone who undergoes cancer treatment will lose their hair; it varies depending on the

person and the treatment. Do not make any assumptions about how you are responding to treatment based on your hair loss.

Strategies for managing hair loss

- Use mild shampoos and soft hairbrushes.
- Use low heat when drying your hair.
- If you are thinking about buying a wig (sometimes called a scalp prosthesis), try to do so before you lose your hair so the hair stylist can more easily match your color and preference. Some insurance policies will cover a “hair prosthesis” with a doctor’s prescription. You may want to explore this with your social worker or doctor’s office.
- Do not dye your hair or get a permanent or body wave.
- Use sunscreen and wear a hat or scarf to protect your scalp from the sun.

- Call your local American Cancer Society to see if a *Look Good...Feel Better* program is available in your area. This program is for women undergoing cancer treatment.
- Sometimes cutting your hair short or buzzing it off completely gives you a sense of control over the situation and is easier to deal with than having your hair fall out in large clumps.

Skin

A variety of skin problems, including pain, redness, scaling, dryness, sun sensitivity, hives, and sometimes hyperpigmentation (darkening) of the skin may be side effects of radiation, photodynamic therapy, and certain chemotherapies.

The newer targeted therapies, such as Tarceva®, tend to cause skin rash, some forms of acne, and sometimes hyperpigmentation of the skin and nails. If a rash from a targeted therapy becomes severe enough that painful pustules develop, or if you are concerned about your appearance, please consult your doctor or nurse immediately. Some rashes can become severe if infected and must be managed carefully by your doctor.

Strategies for managing skin problems

- Use skin care products, especially ones that contain lanolin or aloe, to relieve and prevent chapped and hardened skin.
- Do not use lotion or any skin products on your skin immediately before radiation treatment.
- Protect your skin from the sun, both during and after treatment.
- If you have a rash, keep the affected area clean and dry; do not use over-the-counter acne medications unless approved by your doctor.

- If you are receiving Avastin™, it can cause delays in your body’s ability to heal from a surgical wound. If you are scheduled for a surgical procedure, you will be taken off of Avastin™ for a period of time until your oncologist feels it is safe to restart the medication.
- Call your doctor if your skin reaction gets worse.

Pain and discomfort

For many people, the most frightening part of a cancer diagnosis is the prospect of being in pain. Cancer itself can cause pain in several different ways. Some cancer treatments may also cause pain. After surgery for lung cancer, there is typically pain at the incision site. Women may have an especially difficult time as the incision line is often at or near the brassiere line. If you do have pain, you should know that pain can almost always be relieved. Always remember, you have the right to relief from pain.

Strategies for managing pain and discomfort

- Always report pain to your doctor. You are the expert on your pain. Communication about pain is the first step toward controlling it.
- Be honest about your pain. Keep a journal to track when you are in pain—use a scale of 0 to 10 to rate your pain with 10 as the worst pain you can imagine.
- Note how much medication you are taking and the time you take it. It is important to take your pain medicine on the schedule as prescribed so you don’t get into “peaks and valleys” with your pain control.
- Consider consulting a pain or symptom management specialist if you continue to have problems managing your pain. (Your doctor can give you a referral.)
- Ask about mind-body and relaxation techniques. (See page 66)

- Avoid snug clothing that can irritate the incision site. Women may find camisoles and other loose undergarments more comfortable.
- Always tell your physician about any abdominal pain, especially if you are taking Avastin™.
- Do not hesitate to discuss any concerns about taking pain medications with your health care team.
- Do NOT wait until the pain is unbearable to take pain medication. It is easier to prevent pain or relieve it when it starts than it is to treat pain once it becomes severe.

Many patients who are prescribed pain medications express concerns about becoming addicted to them. Research has shown that less than 1% of people taking pain medications become addicted. Pain can be well managed with virtually no risk of addiction if you communicate regularly with your health care team about your

pain, allowing your pain medicine to be adjusted accordingly. Your doctor and nurse will carefully watch the amount of pain medication you are taking.

Pain from nervous system changes (peripheral neuropathy)

Certain chemotherapy drugs such as the platinum-based drugs (carboplatin, cisplatin) and taxanes (Taxol and Taxotere) can cause peripheral neuropathy, which is a tingling or burning sensation, weakness, or numbness in the hands or feet that can make it difficult to handle objects or even to move your fingers. Let your physician know if you are experiencing any of these types of sensations or notice difficulties with opening jars, buttoning your clothes, or picking up small objects from flat surfaces.

For safety measures:

- Be careful when grasping sharp or hot objects.
- Use handrails when going up and down stairs.
- Be careful driving, as it may be difficult to feel your brakes or accelerator.
- Always wear shoes or house slippers with rubber soles to prevent falls.
- Remove throw rugs or other objects in your home that make it easy for you to trip.
- Avoid exposing your fingers and toes to very hot or very cold temperatures.

Hypertension

Increasing blood pressure (hypertension) is one side effect from Avastin™. Your physician will monitor your blood pressure carefully. It is important for you to let your physician know if you are having headaches or any unusual symptoms that may be caused by hypertension.

RARE TOXICITIES

Platinum-based chemotherapy agents can also cause muscle weakness, hearing loss, ringing in the ears, and difficulty walking. In addition, these same drugs can affect the levels of certain chemicals in your blood called electrolytes, which can lead to more severe side effects. Your physician will check your electrolyte levels prior to any chemotherapy and provide supplementation if your level is low so these side effects can be controlled.

Please report any of these symptoms to your physician immediately:

- **Visual changes.** Avastin™ can cause a rare condition called leukoencephalopathy. The first symptom of this condition is visual changes, so it is very important to let your physician know if you notice any such changes. Leukoencephalopathy usually reverses when Avastin™ is no longer used.
- **Worsening cough, chest pain, or shortness of breath.** Tarceva® can cause interstitial lung disease, an inflammation of the lungs. This is a rare side effect but can be fatal. Notify your doctor immediately if you experience a worsening cough, chest pain, or shortness of breath while taking Tarceva®. The problem can reverse itself with discontinuation of Tarceva®, or steroids are used to reverse the inflammation.

Changes in sexual functioning and effects on fertility

Many people have said that after being diagnosed with cancer, they experience a change in their interest and desire for sexual activity. They also often have concerns about the effect of treatment on their ability to have children. If you think you may want to have children in the future, talk to your doctor prior to treatment.

Strategies for managing changes in sexual functioning and fertility

Give yourself and your partner some time to adjust to the many changes in your body and your life. It is normal not to be interested in sexual activity because of the emotional stress of cancer, fatigue, or pain. Mood swings and sadness are common. Counseling can sometimes be helpful if you continue to have anxiety about intimacy and sexuality issues.

If you are concerned about becoming a parent in the future, consider asking your doctor about harvesting sperm or eggs before beginning treatment. For more information, please refer to Chapter 7 on Intimacy.

“If my husband has headaches, bone pain, or nausea, I try to find out if these are side effects of his medications and learn about ways to alleviate his anxiety. We try to think of side effects as the chemo working to fight off cancer cells.”

— Annie, Caregiver

THE IMPORTANCE OF PHYSICAL ACTIVITY

The Patient Active Concept® extends to all aspects of your cancer experience, including being active physically.

No matter how fit you were before your diagnosis, you may lose strength and physical conditioning as a result of treatment for lung cancer. Fatigue, pain, and emotional adjustments are common, and you may begin to need assistance with your regular daily tasks.

Improving your physical fitness after cancer treatments can provide many benefits to your overall health and well-being:

- Physical activity helps prevent problems associated with immobility such as stiff joints, breathing problems, constipation, skin sores, poor appetite, and depression.
- Many people find that exercise helps them gradually increase their energy, reduce fatigue, and increase their ability to function more independently.

- Participation in low-impact activities such as yoga, t'ai chi, walking, or chair exercises can help to focus the mind, alleviate tension and anxiety, reduce stress, and give you a renewed sense of physical well-being.

Strategies for staying active

- Make an effort to get out of bed each day if possible. Even simple activities like walking to another room or taking a shower is a form of healthy activity.
- Engage in activities you enjoyed before cancer! They may have to be modified, but you can begin to rediscover the activities that are important to you.
- Set an activity goal for yourself; take a walk every day, if you can—even if a short one out to get the mail.
- Keep track of your exercise in an exercise log.

- Physical therapy can help you regain strength. Consult with your doctor about a referral to a trained physical therapist who is under the direction of your oncologist. This therapy may take place in a hospital-based program, at an outpatient facility, or in your home.

- An occupational therapist can evaluate your ability to return to your daily activities and help increase your strength and coordination.

When you are exercising, remember not to confuse *active* with *overactive*. You need rest and relaxation during and after cancer treatments. Exhaustion can weaken your physical and emotional defenses, and fatigue can make you feel depressed and discouraged.

CONTACT YOUR DOCTOR IF YOU EXPERIENCE ANY OF THE FOLLOWING CONDITIONS:

- You become progressively weaker
- Your pain increases
- You have headaches, blurred vision, numbness, or tingling
- Your fatigue is so great that you cannot do the things you need or want to do

“CHEMOBRAIN”—COGNITIVE DYSFUNCTION

It is estimated that one in five people who undergo chemotherapy will experience what many survivors refer to as “chemobrain.” Symptoms like forgetfulness, lack of concentration, difficulty finding the right word, and difficulty multi-tasking have all been described by cancer survivors. Though no one knows why this occurs, some theories include: toxic effects of chemotherapy, severe stress, hormone shifts, or the effects of cancer itself on the body.

“Finding peace is possible at any moment by anyone, regardless of living with lung cancer or any other disease.”

— Gabriel Rocco, M.A., Mind-Body Health Coordinator, TWC Philadelphia

If you feel that you may have chemobrain, talk with your doctor about the problems you are experiencing so other causes (medicine reactions, depression, and sleep disturbances) can be ruled out. Some people have found the following to be helpful:

- Make lists
- Carry a personal diary or calendar
- Do puzzles to “exercise your brain”
- Reduce stress with relaxation or meditation practices
- Take notes during conversations and consider having a support person join you at important appointments to take notes as well.

COMPLEMENTARY, INTEGRATIVE, OR ALTERNATIVE MEDICINE (CAM)

Today, many medical centers and cancer treatment centers combine standard therapy with a broad range of other treatments. No matter what options you explore, it is essential to discuss any new treatments or practices you may be considering with your oncologist. A variety of complementary activities may fall under this category (e.g., meditation). However, you need to be aware that some alternative therapies promise cure; be cautious about unproven treatments.

- Complementary therapy refers to supportive methods (e.g., meditation for stress reduction, peppermint tea for nausea, acupuncture for back pain) that are used to complement, or add to, conventional treatments.
- Alternative therapy refers to treatments that are promoted for use instead of conventional therapy (such as chemotherapy or surgery). *These therapies have not been scientifically tested.*

- Integrative therapy refers to the combined offering of conventional and complementary therapies.

The combined approach of integrative medicine may be used to control pain, relieve anxiety, and improve quality of life. To date, however, there is no scientific data to prove that complementary or alternative therapy alone can cure cancer. It is important not to view alternative or complementary cancer treatments as substitutes for proven standard therapies.

Are these CAM therapies safe to use with standard cancer treatment?

Many complementary methods can be used safely along with standard treatment to help relieve symptoms or side effects, ease pain, and enhance daily life. However, in some cases, herbal supplements have been found to actually interfere with the success of chemotherapy agents. Thus, it is critical to discuss any CAM therapies you may be

considering with your doctor and health care team. The American Cancer Society (ACS) suggests that you consider answers to the following questions before you decide to use methods outside of standard medical treatment.

Questions to ask

- Will the therapy counteract the effectiveness of my current treatment?
- Is the therapy used to cure the cancer or allow standard treatment to work better?
- Is it to relieve symptoms or side effects?
- Are those who offer the treatment recognized experts in cancer treatment?
- Has research about the therapy been published in scientific journals?
- Is the therapy promoted only through mass media, or also in scientific journals?
- Is the therapy expensive? Will insurance cover the cost?

SIGNS OF TREATMENT TO AVOID

A “yes” answer to any item on the checklist below is a reason for caution and concern. If you are not sure, talk to your doctor or nurse before moving ahead:

- Is the treatment based on an unproven theory, rather than a carefully controlled scientific study?
- Does the treatment promise a cure for cancer?
- Are you counseled to avoid conventional medical treatment?
- Is the treatment or drug a “secret” that only certain providers can offer?

Organizations that provide credible information about CAM practices and the role they may play in cancer treatment (in addition to ACS) include the National Center for Complementary and Alternative Medicine (NCCAM) and the National Cancer Institute’s Office of Cancer Complementary and Alternative Medicine (OCCAM). Please refer to the Resources Chapter for additional information.

THE MIND-BODY CONNECTION

The medical community is increasingly aware of how the mind and body work together in our overall health and recovery from illness. Making the mind-body connection can make a significant difference for people with cancer; managing your thoughts, feelings, beliefs, and attitudes may affect your overall quality of life during and after treatment.

Research has linked stressful events to the development of certain health conditions such as heart disease or a reduced immune response. The same link has not been found between stress and cancer. It is important that you do not blame yourself for the onset of cancer or the course of the illness itself. It is equally important that you find ways to actively cope with cancer and the stress that it brings, not only to improve your quality of life, but also to possibly enhance your immune functioning and your ability to manage treatment and treatment side effects.

Mind-body techniques

Mind-body techniques can help reduce stress caused by cancer. Practices such as guided imagery, relaxation, meditation, yoga, etc., have been found to help people better manage side effects and lifestyle changes during and after cancer treatment.

There are many types of mind-body techniques available for you to try. Mind-body techniques work best when done as a regular practice in your life. You can experience the most benefit from them if you learn how to incorporate them into your daily life by doing them at a particular time each day for a certain amount of time, or by doing them in moments of opportunity throughout the day (e.g., while you are on-hold on the phone, waiting in line in the grocery store, or stuck in traffic).

Here are some examples of mind-body practices:

- **Guided imagery**—a simple, effective way to transform your emotional state of mind while incorporating deep breathing and meditation. The feelings you experience are governed by the thoughts and images on which you focus. Think of something positive, and your emotions will be led in that direction.
- **Yoga**—a mindful movement practice that includes stretching and strengthening poses, breathing exercises, and meditation practices.
- **Qigong and t'ai chi**—both are Chinese practices using physical movements that are believed to promote the flow of “qi,” or life force, and support internal harmony, good health, and vitality.

- **Mindfulness meditation**—a self-directed practice for relaxing the body and calming the mind. Meditation can be done while sitting quietly or while moving mindfully, such as a walking meditation.

For practice exercises in breathing and relaxation, visit Cancer Support Community Online at www.cancersupportcommunity.org.



“We always tried to keep things as normal as possible, even in the most abnormal situations. We made sure to always celebrate birthdays and anniversaries in any way, shape, or form that we could.”

— Meg, Caregiver

Quality of Life

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Quality of Life

Dealing with a cancer diagnosis and treatment can be emotionally challenging. You may experience a wide range of feelings that include fear, shock, and isolation. It can be difficult to maintain a sense of control in your life as you embark on a whirlwind of doctor appointments, medical tests, and treatment.

DISTRESS AND THE EMOTIONAL IMPACT OF LUNG CANCER

Emotional distress is a common and normal experience for people who recently have been diagnosed with lung cancer, who are undergoing treatment, or who are living with lung cancer. Caregivers and family members also experience emotional distress.

Remember that you have experienced difficult situations in the past and have managed them successfully. Turn to the coping mechanisms that you used in the past or learn others to try now. Cancer support groups or individual counseling will introduce you to new coping strategies that may help you to reduce anxiety, depression, or distress in general. Being Patient Active with your emotional—as well as physical—well-being can help improve your quality of life throughout your cancer experience.

DISTRESS

Distress is the most underreported and common side effect of cancer. Distress extends along a continuum ranging from common feelings of vulnerability, sadness, and anger, to problems that can become disabling such as severe depression, anxiety, and panic. It is important to know that these feelings can be managed successfully in a variety of ways. Be sure to discuss your feelings with your health care providers at each office visit.

The emotional impact of a lung cancer diagnosis on an individual or family can vary greatly, depending on the extent of the disease, its treatment, and each person's situation and personality. At Cancer Support Community, LCA and other cancer support organizations, people with cancer learn that by sharing their experiences and supporting each other, they can begin to cope with the emotional distress associated with cancer. Learning you are not alone can be an important tool in the fight for recovery for both patients and caregivers. It is important to find people with whom you can share and express your feelings. Some people are able to do this with close friends and family; others benefit from talking one-on-one with a therapist or counselor, or by participating in a cancer support group.

Living with cancer can often affect a person's emotional and mental health. Depression, shock, anxiety, extreme fearfulness, and even panic are some possible reactions to a cancer diagnosis. There may also be changes in family roles, financial resources, and issues related to self-esteem. Understanding what the diagnosis will mean for the person with lung cancer and their caregivers is a process, and reactions will change over time.

Emotional distress can range from feelings of vulnerability, sadness, and fear of recurrence or death, to problems that are more debilitating such as clinical depression, intense anxiety, or panic.

The energy it takes to stifle normal negative emotions can make coping with the illness much more difficult. It is important to acknowledge emotional distress when it affects your ability to carry out daily activities, affects your relationships with caregivers, makes physical symptoms seem more severe, and impacts your ability to cope with your treatment.

Mourning the loss of "normal" and of certainty about the future is to be expected. When these feelings are acknowledged, it is much easier to have a positive approach to the challenges ahead.

The Resources section in the back of this booklet provides you with a list of places where you can locate cancer support groups.

ANGER

Anger is a normal response to being diagnosed with lung cancer. It is an emotion that may arise at any point as you navigate lung cancer treatment and the health care system. Your first reaction may have been, “Why me?” If you were a smoker and quit or you never smoked and still got lung cancer, you may feel angry at the tobacco industry, your doctor, or the sight of others smoking. If you still smoke, you may feel angry or guilty when others mention quitting while you feel as though smoking is your only “comfort” left. Some people feel angry when they are not communicating well with their doctor or family. This lack of communication may be a temporary reaction, or it may indicate a deeper concern that needs to be addressed.

Denial and anger sometimes play an important part in coping with difficult news, like a diagnosis of cancer. Our hearts and heads can’t take everything in at once, and sometimes our emotions help protect us until we can get a grasp on what this diagnosis means in our life. For some, anger is an affirmation of life and their desire to fight for recovery.

It is healthy to express your emotions—including anger—in a healthy and appropriate manner. Holding onto or repressing emotions, especially anger, can hinder your fight for recovery and can deplete energy and resources that could be better used in embracing your treatment and recovery.

It takes time to accept a diagnosis of cancer and to understand what it will mean for both patient and family. People’s reactions differ and vary over time, and feelings of denial, anger, or guilt may come and go. Remember that you are not alone. Many other people with cancer share the same feelings and concerns, and it sometimes helps to talk with other people going through treatment. By becoming Patient Active, you can regain a sense of control about your treatment, your life, and even your anger.

DEPRESSION AND ANXIETY

Sometimes emotional, social, or spiritual distress can feel unmanageable; you may feel as though you have lost interest in things that used to make you happy. You should discuss these feelings with your health care team; they may be able to help. Your doctor may prescribe a change in your medications or recommend that you speak to an oncology social worker or therapist.

If you or your loved one has serious thoughts of suicide, help is just a phone call away. Call the National Suicide Hotline at 1-800-SUICIDE (784-2433) to be connected with a crisis center in your local area. This service is available 24 hours a day, seven days a week.

Signs of depression

- Persistent sad or “empty” feelings most of the day
- Loss of interest or pleasure in ordinary activities
- Difficulty sleeping
- Change in appetite
- Change in body weight (loss or gain)
- Difficulty concentrating or making decisions
- Fatigue or restlessness
- Thoughts of suicide or death

Tips to cope with depression and anxiety

- Talk to friends and family about your feelings and fears.
- Make an appointment with a counselor, therapist, or psychiatrist to help deal with your thoughts and feelings.
- Join a support group.
- Ask your doctor about medications that can help.

Overall, people cope with their fears in different ways. Individuals need to identify solutions that match their natural temperament and personality. In many cases, learning to express a wide range of emotions within a support group or individual therapy can:

- Decrease feelings of hostility
- Improve self-confidence and assertiveness
- Improve an individual’s expression of support, empathy, interest, and humor
- Improve physical functioning
- Improve your overall quality of life

STRESS AND ITS IMPACT ON THE IMMUNE SYSTEM

Emotions affect hormones and the way the immune system functions. Emotions can also interfere with your active participation in treatment decisions and sense of well-being.

As previously mentioned, stress alone has not been proven to be a direct cause of cancer. The diagnosis and treatment of cancer brings a great deal of stress into our lives. You do have some control over how you respond to that stress and the magnitude and duration of the other stressors in your life. Patient Active behaviors, attitudes, and actions give you even more control over how you react to the stress of diagnosis and treatment. Stress management techniques can become valuable allies in the treatment of cancer as you learn ways to take charge of your reaction to the challenges that cancer brings.

The three most significant psychosocial stressors for people with cancer can be overcome. They are:

- **Unwanted aloneness.** Many cancer support organizations, such as Cancer Support Community and Lung Cancer Alliance, are available to connect people in similar situations throughout the cancer experience. This connection can reduce a person's fear that they are alone and increase their access to support.
- **Loss of control.** When you participate actively in decisions that affect your treatment and your daily life with cancer, you take back some control over your life.
- **Loss of hope.** There are many forms of hope. What is hoped for may change, however. For example: when physical cure does not seem possible, the focus shifts to hope for physical comfort and emotional and spiritual healing.



“I make sure I go to bed early and get a lot of sleep. I can’t keep a positive attitude if I’m tired and cranky.”

— Jerry

DEALING WITH STRESS

Stress-management techniques can become valuable allies in the treatment of cancer. Part of being empowered to manage a cancer diagnosis is learning to deal with the challenges of stress that accompany this disease.

There are many ways to cope actively with cancer to increase your sense of well-being. For example:

- Express your emotions. Do not keep feelings inside—they will only become more overwhelming.
- Be mindful and allow for reflection. Use prayer, meditation, and/or deep breathing and relaxation exercises.

“I’d say, as a person who was raised to be independent, that I wasn’t accustomed to leaning on anyone. With cancer, you have to let go. You have to rely on the strength and love of other people.”

— Terri

- Talk with your health care team about the possible need for medication such as antidepressants.
- Recognize that cancer is a challenging experience and that asking for professional help or medication to relieve distress symptoms is not a sign of weakness. It takes courage and strength to ask for help.
- Seek help through individual or family counseling and support groups.

Family members also experience distress and emotional challenges when caring for a loved one with cancer; they may at times feel even more helpless and frustrated in their inability to “fix it” for their loved one. Tips for caregivers and family members include:

- Provide reassurance that it is normal to feel sad, frustrated, and afraid.
- Listen to what the person is saying. Do not feel like you have to have an answer or “fix it.” Sometimes just being able to talk through feelings can relieve the symptoms of depression or anxiety.
- Recognize you may have your own emotional challenges as you support your loved one with cancer, and seek support for yourself as well.
- Seek help for you and your loved one through counseling and support groups.

GETTING THE SUPPORT YOU NEED

There are many ways to get the support you need. Part of the challenge is accepting that you'd like support, and that it's okay. If you already have an existing network of support through family, friends, your work, or place of worship, use it; learn with whom you feel comfortable sharing the positive and negative emotions you experience.

Seeking support can diminish feelings of isolation, despair, and loss of control, and should be as integral to your cancer treatment as chemotherapy, radiation, or surgery. People who are able to connect with others in a safe, constructive way, such as at Cancer Support Community and through Lung Cancer Alliance, report an improvement in their quality of life during cancer and beyond.

Support groups

"I know how you feel..."

No one understands the experience of someone affected by cancer more completely

than somebody else in the same situation. That is the basis of support groups. Some groups consist of cancer patients and their family members together; others hold separate groups for patients and support persons.

Support groups may be:

- Open-ended, where participants attend as many meetings as they find helpful.
- Time-limited, for a fixed number of sessions.
- Diagnosis-specific, where all members have the same kind of cancer.
- Age-related, such as those for young adults.
- Professionally facilitated or led by a fellow survivor.
- Face-to-face, online (through bulletin boards or real-time chats), or via the telephone.

If you seek a support group, here are some things to keep in mind:

- Think about your personality. Would you prefer the individualized attention of personal therapy or the collective dynamic of support groups?
- What type of support group would work best for you? There are both face-to-face and online support groups.

No matter how the group is organized, the basic goal is to provide opportunities for people to share concerns and coping strategies and find they aren't alone. Effective support groups are usually offered free of charge and run by a counselor or therapist experienced in working with people with cancer and their families. Group facilitators are not necessarily experts in cancer treatments; their job is to try to make sure that the needs of everyone in the group are addressed. The participants become the experts in helping each other through similar situations.

You can decide whether a support group would be helpful for you or not. You may be surprised by the difference the right group can make in your experience. Ask your doctor, nurse, or social worker about groups, and see the Resources section for additional information. You may have to attend a few meetings before you can tell if the group is the right experience for you and you may have to try support groups offered by different organizations before you decide where you want to continue. You may find you prefer an online support group instead of a face-to-face group. For more information on support groups, visit Cancer Support Community at www.cancersupportcommunity.org. Lung Cancer Alliance also maintains a list of lung cancer-specific support groups in the U.S. Call 1-800-298-2436 to find out what may be available in your area.

Counseling

A diagnosis of lung cancer may prompt a decision to seek counseling or psychotherapy, or sometimes a person or family member with cancer may cope well during the acute treatment phase but find that after treatment they feel more vulnerable to emotional distress. These are excellent times to pursue any type of counseling, whether it is individual, family, or group support.

Counseling will teach you effective ways to communicate about the illness to:

- Find new ways to cope with the normal feelings and reactions to lung cancer.
- Address changes in roles and family routines that may result from a chronic illness in the family.
- Relieve some of the emotional side effects of cancer and treatments and help you cope with changes in your physical abilities after treatment (e.g., body image changes or mobility issues).

How to find counseling services

- The hospital or treatment center where you receive care may provide counseling services.
- Ask the doctor, nurse, or social worker for a referral to a counselor experienced in dealing with the challenges of cancer.
- Talk to your minister, priest, rabbi, or other spiritual leader about counseling resources.
- Contact Cancer Support Community, Lung Cancer Alliance, or other cancer support organizations (see Resources).

Support for living with a long-term illness

As a result of improvements in early diagnosis and treatment, management of some forms of lung cancer is similar to treating a chronic condition. That means that a person might have recurrent cycles of disease, treatment, and then recovery.

Many people fear recurrence, especially when treatment ends. The challenge is to learn how to live in the moment and balance the fear of recurrence with the desire to enjoy health and wellness. It is during this period that people often find support groups or individual counseling to be of great value.

If you experience a relapse, you may feel even more distress than when you were first diagnosed. However, you may find you have more tools at your disposal to help you cope than you did initially. Many people cope surprisingly well with subsequent recurrences because they:

- Know what to expect
- Are more knowledgeable about treatment options and how to find support
- Have learned to employ Patient Active strategies that help them retain control and hope

Supporting Yourself

Physical self-image

Treatment for lung cancer almost always involves some combination of surgery, chemotherapy, and radiation treatments. Cancer surgery can leave scars and may cause neurological damage and a temporary or permanent physical impairment. Radiation or chemotherapy may cause side effects such as fatigue and hair loss, which can create more illness or discomfort than the disease itself.

Although it may seem superficial, improving your appearance can promote self-esteem under any circumstances and may, in fact, help a person with cancer actually feel better. This is not about vanity, it is about self-care. Engage with family and friends in finding ways to promote self-care and feel good about yourself.

Strategies to help promote self-image

- Resume grooming habits practiced before the diagnosis—hairstyles, makeup, manicures, etc. Many people have even found they are inspired to try new styles and have embraced this new opportunity.
- Recognize that weight loss or gain often accompanies chemotherapy treatments and have clothing altered accordingly.
- Exercise daily whenever possible.
- Participate in activities outside the home that you enjoyed before your illness.
- Participate in workshops such as *Look Good...Feel Better*, sponsored by the American Cancer Society and offered at many of Cancer Support Community's locations.
- Join a support group with other people who have cancer, where feelings can be shared openly.

PARTNERSHIP WITH ALA

AMERICAN LUNG ASSOCIATION.

Cancer Support Community has partnered with the American Lung Association to bring this resource to areas where a Cancer Support Community affiliate does not exist. This valuable partnership increases the mobility of this program and ensures that it is delivered to more populations in need. To learn more about the American Lung Association, please visit: <http://www.lungusa.org/>.

“I was so enlightened by the number of resources available to me as a caregiver and to my sister as a lung cancer patient/survivor. Thank-you!”

— CSC Participant

Education Workshops

This *Frankly Speaking About Cancer: Lung Cancer* booklet is part of a complete psychosocial educational program that includes free patient education workshops. The purpose of these workshops is to educate people affected by lung cancer about the most current lung cancer treatments, symptom/side effect management, and survivorship. The seminars include a slide presentation by a medical oncologist, a presentation by an oncology social worker and/or lung cancer survivor, and a question-and-answer period.

Attending a workshop will help you be more Patient Active by:

- **Being Informed.** Learn about your cancer, the most current treatments available and how to better manage side effects experienced from treatments

- **Taking Action.** Work closely with your medical team to determine what available treatment options will work best for you and identify the need for additional support to overcome the social and emotional challenges of a lung cancer diagnosis
- **Connecting with Others.** Ask the speakers any questions you may have about your cancer and connect with other participants who may be going through similar experiences

How to Find a Workshop Near Me

Workshops are scheduled throughout the year at affiliates of the Cancer Support Community, partnership organizations, and cancer centers. To find out if a workshop is being held near you, please visit: www.cancersupportcommunity.org/events.

RELATIONSHIPS

Your friends and family may want to help, but sometimes don't know how. In an effort to be supportive, they might say or do things that aren't entirely helpful to you. Although family and friends can be the greatest source of support following a lung cancer diagnosis, they can also add to the stress of the experience.

It is not uncommon for a cancer diagnosis to produce changes in personal relationships. Relatives and friends may struggle to find a balance between supporting someone they care about who has cancer and taking care of themselves. Rather than risk saying or doing the wrong thing because of their own fears about the future, they may say nothing or avoid contact. People with lung cancer may worry about who will be there if they need help.

Although some people feel that their marriage or relationship is strengthened through the process of dealing with a crisis together, being the primary provider of physical and emotional care to a person with cancer can also be highly stressful. Often, caregivers find it difficult to ask for and receive help. Attending support groups, couples workshops, family counseling, educational programs, and retreats may show people in crisis new ways of coping with life-threatening illness.

It can be useful to put together a list of tasks for family and friends who offer to help. For example, friends can accompany the person to medical appointments, shop for food and prepare meals, drive children to activities, mow the lawn, or assist with household tasks. Be specific about what you need when people offer their assistance. Keep in mind that people offering help are eager to be able to do something—and you will be allowing them this opportunity to be supportive.

TALKING WITH CHILDREN

Why children should be told

Cancer is an impossible secret to keep. Children sense and know more than adults often give them credit for. Children will overhear telephone conversations, pick up their parents' anxiety, blame themselves, and fear the worst if they are given no information. When a parent has cancer, the natural desire to protect the children through silence usually backfires and makes things worse.

“Our strategy was two-fold with our kids. One was to always be honest with them — that didn't mean telling them everything, but it meant always telling them the truth. Two was to try and keep their lives as normal as possible.”

— Jerry

If parents do not explain the situation with age appropriate facts, their children may:

- Hear about a parent's cancer from someone else and have trouble trusting their parents afterward.
- Think their parents are trying to conceal something and have trouble believing the truth when they are told.
- Decide that whatever is happening is too terrible to be discussed and become even more fearful.
- Believe that they are to blame for the cancer because they have been angry with their mom or dad or misbehaved. (Parents should openly discuss this fear and reassure children that this is not how cancer is caused.)
- Worry that cancer is contagious, that everyone dies from it, or that they or the other parent will become ill.

How and what to tell children

Young children up to the age of eight will not need a great deal of detailed information; older children and adolescents will need and deserve to know more. In a two-parent household, it is advisable for parents to talk to their children together. If single parents are feeling a bit anxious about the conversation, they may want to ask a relative or friend to be present.

Parents should set aside a quiet time dedicated for this conversation. Although no one wants to alarm children, there is nothing wrong with crying when a crisis happens. Crying is normal and healthy, and by explaining that everyone needs to cry sometimes because they are sad, parents give children permission to express their own feelings.

If other family members have died of cancer, children may assume the worst possible outcome. What people tell their children depends largely on how they understand their own cancer and its prognosis.

The National Cancer Institute's free booklet, *When Someone in Your Family Has Cancer*, can help families start difficult discussions. Call 1-800-4-CANCER.

INTIMACY

Many people struggle with regaining an intimate relationship after a lung cancer diagnosis. Treatments can make you feel alone even if there are loving and supportive people at your side. Some of that loneliness may come from a change in the intimacy of your relationships and a change in your self-confidence. Sharing your fears and concerns with your partner or loved one may allow them the opportunity to provide emotional or physical closeness.

CANCER CAN ACTUALLY IMPROVE THE INTIMATE RELATIONSHIPS IN YOUR LIFE.

About 30-50% of men or women already in a committed relationship when diagnosed say they feel closer to their partner after dealing with cancer. They stop taking each other for granted and are less likely to argue about the small hassles of daily life. They are grateful for each other's support.

Sexual Intimacy

Physical survival is usually uppermost in the mind of a person diagnosed with cancer, and sex may seem relatively unimportant. Once treatment is completed, people usually experience a return of sexual desire, but it is often complicated by worries related to body image changes or effects of treatment.

Here are some suggestions that might help:

- Talk with your sexual partner about concerns, fears, and feelings of embarrassment.
- Depression can cause a decrease in sexual desire; your doctor can help.
- Exercise and healthy nutrition can give you more energy for sexual contact.
- If you have distracting thoughts about cancer that interfere with relaxation and good physical feelings, try to focus on your own sensations during sexual contact or think about a particularly romantic experience.
- If you feel comfortable with self-touch, relax in private. It may take some patience and practice to feel sexual pleasure again.
- If you are a man with an erection problem, your primary care physician (or possibly a urologist) can help.
- If you are a woman who has pain during sexual touching or intercourse, it is crucial to get some help. Use a vaginal moisturizer regularly and use a water or silicone-based vaginal lubricant during sex. If pain persists, your gynecologist can help.
- If the problem is a loss of attraction between you and your partner, couples or individual counseling can help pinpoint what is going on.

SPIRITUALITY

People are often reluctant to discuss sexuality. Health care professionals rarely ask whether their patients have questions about sex, leaving it to the person with lung cancer to raise the subject, yet this is an important concern to discuss.

Remember that sexuality is more than intercourse. It comprises all the feelings and actions associated with loving someone, including a gentle touch, holding hands, kissing, hugging, warmth, caring, physical closeness, and emotional intimacy.

Being diagnosed with a potentially life-threatening disease often challenges people to take a reflective look at their life. The crisis of cancer can serve to help people gain insight into their beliefs and experiences, and thereby promote personal growth.

Each of us holds beliefs about life, its meaning, and its value, whether or not we participate in a religious tradition. If you or a loved one is diagnosed with lung cancer, you may find comfort in your spiritual beliefs or you may question your faith. Despite current understanding about the causes of cancer, families sometimes feel distressed by the idea that the illness might be a punishment for some past sin or lack of faith.

If you find that you want to explore the impact of this experience on your faith, you may find it helpful to talk to your pastor, rabbi, or a pastoral counselor in your community about the difficult questions that arise and receive reassurance that having doubts and being angry are normal responses to a cancer diagnosis. Members of religious and spiritual communities also may provide practical help, such as assistance with transportation, meals, and visitation services.

“I’ve tried to surround myself with positive, pleasant people to keep fun and laughter in my life. I’ve used visualization, meditation and prayer – and just refused to believe things were hopeless, even when professionals told me this. These things all helped me to survive 17 years since I was first diagnosed at Stage IV.”

— CSC Participant

CAREGIVERS

Living with someone who has a serious disease is not easy. People with cancer and the people who care about them face many problems and challenges. Coping with these issues can be easier with information and support.

If you are a family member or friend of someone with lung cancer, you may find the following suggestions helpful:

- Learn about lung cancer and how it's treated.
- Support your loved one by allowing them to express their feelings and concerns when they want to; do not push them to communicate when they don't.
- Understand that side effects from the cancer or its treatment may impact your loved one's ability to do the things they used to.

- Consider support services offered through the patient's insurance plan. Insurance case managers can help you learn how to take advantage of the various benefits offered.
- Try to maintain some of your normal activities. It can be difficult, but it's crucial for both your well-being and that of your loved one.
- You are doing an important and sometimes difficult job. Remember that you need time to take care of yourself and your own physical and emotional health.

Caregivers often identify stress as their biggest problem. Coping with stress can be difficult, but stress management is essential to maintain your caretaking responsibilities.



“I guess the hardest part about being a caregiver to my wife was feeling helpless. Sometimes there’s nothing you can do but just hold her hand.”

— Ken, Caregiver

RESOURCES FOR CAREGIVERS

National Family Caregivers Association

www.nfcacares.org

1-800-896-3650

Family Caregiver Alliance

www.caregiver.org

1-800-445-8106

Cancer Support Community

www.cancersupportcommunity.org/mm/caring/caregive-support.aspx

1-888-793-WELL

*There is always a way to find meaning
and a sense of quality in your life.*



“What I found most important for my wife was simply to be present for her and be positive, encouraging, helpful and upbeat. She was anxious enough having to face all the questions in her mind and the decisions regarding treatment and follow-up. She needed to be able to count on me to be strong for her, and that’s what I tried to do despite all my own concerns.”

— Harry, Caregiver

Practical Concerns

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Practical Concerns

While your initial concerns will focus primarily on health and recovery, issues such as finances, insurance, legal matters, and employment will follow closely behind. There are some steps you can take now to address these practical issues, from keeping careful records of all expenses to working with an experienced attorney to draft a will, a living will, and medical power of attorney. You may want to discuss these types of decisions with close family members, friends, health care providers, and spiritual advisors.

EMPLOYMENT ISSUES

Although many people with lung cancer feel unable to work during treatment, some find it valuable to maintain as much of their “normal” lifestyle as possible. There is no reason why a person with lung cancer who feels able to work, even part time, should not be able to do so. Three federal laws provide some protections and benefits for people with cancer and their caregivers:

Americans with Disabilities Act (ADA)

Under the ADA, anyone who has had cancer is considered disabled and may be entitled to reasonable accommodation at the workplace. Reasonable accommodation is any modification or adjustment to a job or the work environment that will enable a qualified employee with a disability to perform essential job functions. You are responsible for notifying your employer of the disability. The employer is not obligated to provide accommodation if the employee does not ask. The ADA only applies to employers with 15 or more employees. The ADA does not apply if you are no longer able to perform the essential functions of your job.

Family and Medical Leave Act (FMLA)

This law allows an ill person or a family member caring for an ill person to take up to 12 weeks off from work without pay with no loss of benefits. It gives cancer survivors time for physical rehabilitation or counseling they may need before they return to their old job or start a new one. Under this law, the employee is required to provide the employer 30 days notice before the FMLA is scheduled to begin, unless there is a medical emergency. FMLA applies to employers of 50 or more employees as well as to public agencies.

Vocational Rehabilitation Act of 1973

Under this law, people with cancer may be eligible for job training if they seek a different kind of work than they did before cancer. State government employment agencies can help with this process.

INSURANCE AND FINANCIAL CONCERNS

Lung cancer can impose heavy economic burdens on patients and families. For some people, most or all of the medical expenses are paid by health insurance. For others, insurance may only partially cover the costs, and some people may not be insured at all.

Some of the financial burden for many people is caused by job and career changes that can happen during lung cancer treatment and recovery. Concerns about insurance coverage also come up for lung cancer survivors who are considering a career change.

Whatever your financial situation, there are government programs and nonprofit organizations offering advice and help. (See Resources, on page 89, for more information). Additionally, there may be a member of your health care team who could answer some questions about insurance choices.

Health insurance

If you have health insurance and have questions about what treatments it covers, call your insurance provider and ask about your coverage. You can also talk with your human resources department or manager at work. If you don't have health insurance or need financial assistance to cover health care costs, there are some organizations and programs that offer help. Talk to the social worker or business officer of your hospital or clinic about any financial concerns you may have.

Disability insurance

Whether or not you have health insurance, short- and long-term disability insurance may provide financial assistance while you're being treated for lung cancer. Some employers carry disability insurance for their employees, and policies can also be purchased directly from private insurance carriers.

Social Security pays disability benefits under two programs:

- Social Security Disability Insurance (SSDI) for insured workers, their disabled surviving spouses, and children of disabled, retired, or deceased workers.
- Supplemental Security Income (SSI) for people with little or no income and resources, or those who have not worked to the point of being eligible for SSDI. Most people who get SSI are also eligible for Medicaid.

If you and your doctor anticipate that you will be out of work for at least one year due to lung cancer treatment, you should apply for SSDI as soon as possible. The sooner you apply, the sooner you will possibly receive assistance. You can apply for benefits by calling the toll free Social Security number, 1-800-772-1213, or online at www.socialsecurity.gov.

LEGAL ISSUES

It is a good idea for all adults, regardless of their current health status, to prepare for the future by having their affairs in order. The following legal documents are tools to help you do that.

Will

A legal document that designates who will receive your money and belongings and who will be responsible for your young children (in the absence of the other parent) when you die. In many states, an agent of the state will make these decisions if there is no will.

Advance directives

A term that refers to instructions about your future medical care if you become unable to speak for yourself. Each state regulates advance directives differently, so you should check with your health care provider about what is needed where you live.

There are two types of advance directives: a living will and medical power of attorney.

Living will

A document that details your wishes about medical treatment if you can no longer express those wishes. Most states honor a living will prepared in advance, but laws vary by state.

Medical power of attorney (POA)

A document that allows you to appoint a trusted person to make decisions about your medical care if you cannot make decisions yourself. Also known as a healthcare agent. In many states, the person you appoint is authorized to speak for you any time you are unable to make your own medical decisions, not only at the end of life.

Before designating a medical POA, think carefully about who is most likely to follow your wishes. It is often difficult for a parent to make these decisions; people often choose a sibling or spouse instead. Having conversations with your family members and

loved ones about the contents of your living will can make these decisions much easier and reduce stress on your family. Be sure your medical POA and health care provider have copies of the signed directives.

DO NOT RESUSCITATE (DNR) ORDER

An order that your doctor writes on your chart if you determine you do not want “heroic measures” taken in the event of cardiac or respiratory arrest. Your specific desires should be stated in the previously described documents. This is a medical order which states that if you stop breathing or your heart stops beating, you do not want to be hooked up to machines that will keep your body alive. It is very important to think about this issue and discuss it with your family and doctor before you get seriously ill. Your decisions about resuscitation should be documented in your living will and should be discussed with your medical power of attorney (POA).

“I don’t think it’s difficult to talk about end-of-life, but it’s difficult to get people to listen—it’s not something that people want to talk about. We celebrate survivors, and we don’t want to talk about when bad things happen. But I’m always very open with my experience because he was. It’s a matter of how he lived his life, and that’s kind of how I live mine.”

— Meg, Caregiver

PRACTICAL END-OF-LIFE PLANS

When you are diagnosed with a life-threatening illness such as lung cancer, it can be the first time you and your family have thought about death. People often anticipate what they might need and want to achieve in the weeks, months, or years ahead. It is normal for people with cancer to want to discuss the possibility of death. Family members often have a harder time with these discussions and think this means the person who has cancer is giving up. This is not always the case. These discussions can be important and powerful parts of the coping process.

When active treatment is stopped, it is normal to experience a wide range of emotions such as anger, denial, fear, sadness, and even acceptance. Open and honest communications with your doctor and your family can help you to maintain control over this time and provide you the opportunity to accomplish certain goals, or put closure to things that might give you a sense of peace.

Hospice

Hospice care is a useful resource for you and your family to explore when you and your doctor decide that it might be helpful. Hospice care can be provided in the comfort of your home, with specially trained nurses available by phone 24 hours a day. A hospice team is available to meet your physical and emotional needs, as well as the emotional needs of your family. To get more information about hospice care, ask your insurance provider or doctor.

KEEPING A HOPEFUL ATTITUDE

Your sense of “hope” can change over time. You may hope for many things in your life. Perhaps you hope for recovery of your physical and emotional health; for peace in your relationships; for good communication with your doctor; for a way to come to terms with lung cancer and its place in your life. By doing important things — like taking steps to improve your level of physical activity, your diet, your relationships, and your emotional health — you are improving the quality of your life. Never be afraid to hope; just remember what you hope for may change.

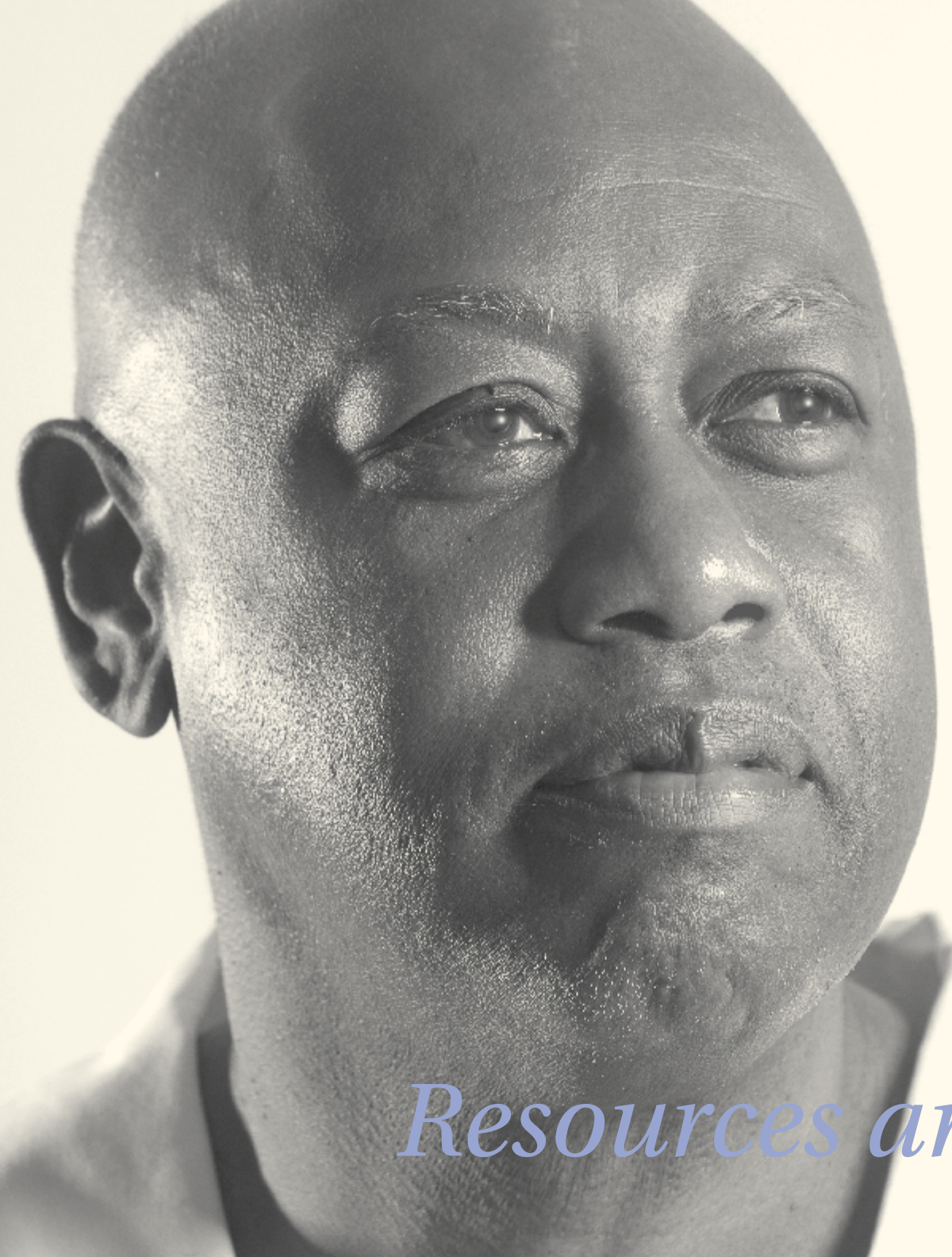
People affected by cancer sometimes hear that they need to have a positive attitude in order to beat their cancer. You should not expect to be positive all of the time. Trying to view things from a positive perspective as much as possible, however, can improve your general well-being. Finding productive ways to express your feelings—positively or negatively—is always helpful.

“I think the simple pleasures of life are just so wonderful...on a summer night, we’ll go out for a walk and its just really nice. It doesn’t have to be a great trip or a dinner out. Sometimes, just spending time together in a very quiet way is really important.”

— Marc, Caregiver

“Cancer is no simple disease, and effective treatment is not just about killing rogue cells with radiation and chemotherapy. It’s about healing the human being.”

— Institute of Medicine (IOM), 2008 *Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs*. Nancy Adler and Ann E.K. Page, eds. Washington, D.C.: The National Academies Press



“My wife and I were so surprised to learn of the many and varied types of resources available to both the lung cancer patient and their caregivers. Everyone should take advantage of resources available to them.”

— Ken, Caregiver

Resources and Glossary

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Resources & Glossary

RESOURCES

American College of Chest Physicians

1-800-343-2227

www.chestnet.org

Offers suggestions for lung cancer specialists and second opinions.

American Cancer Society (ACS)

1-800-ACS-2345

www.cancer.org

Provides local support, resources, and information for all cancer types, including lung cancer.

American Lung Association (ALA)

1-800-LUNG-USA (586-4872)

www.lungusa.org

Provides free interactive decision support tools provides personalized treatment options, reports tailored to each diagnosis.

Focus on Lung Cancer

1-877-646-LUNG

www.lungcancer.org

Call the lung cancer toll free information line for lung cancer support.

Lung Cancer Alliance (LCA)

1-800-298-2436

www.lungcanceralliance.org

Provides patient support and advocacy to people affected by lung cancer.

The National Cancer Institute (NCI)

1-800-4-CANCER

www.cancer.gov

Provides comprehensive and up-to-date information about lung cancer, treatment options, and more.

Cancer.net

1-888-651-3038

www.cancer.net

Cancer.net is an award-winning patient information website of the American Society of Clinical Oncology (ASCO). Provides timely, oncologist-approved information to help patients and families make informed health care decisions.

Clinical trials

Cancer Support Community

1-888-793-9355

www.cancersupportcommunity.org/clinical.trials/vwc.asp

In collaboration with Emergingmed.com, provides general information about cancer trials and an online search engine to find a clinical trial for your cancer.

Lung Cancer Alliance

Clinical Trial Matching Service

1-800-698-0931

www.lungcanceralliance.org/facing/trials.html

In collaboration with Emergingmed.com and other lung cancer organizations, LCA offers a free, confidential, personalized service to match lung cancer patients with relevant clinical trials as well as general information about clinical trials.

National Cancer Institute (NCI)

1-800-4-CANCER

www.cancer.gov/clinicaltrials

Provides comprehensive information about cancer clinical trials. Information about clinical trials is available in Spanish or English.

National Library of Medicine, National Institutes of Health

1-888-346-3656

www.clinicaltrials.gov

Provides a thorough and searchable listing of federally sponsored clinical trials and general information.

Complementary and alternative medicine

National Center for Complementary and Alternative Medicine (NCCAM)

1-888-644-6226

<http://nccam.nih.gov>

Provides information about and conducts research and training on complementary and alternative medicine.

National Cancer Institute's Office of Cancer Complementary and Alternative Medicine (OCCAM)

1-800-4-CANCER

www.cancer.gov

OCCAM's goal is to increase the amount of quality information and cancer research conducted about the use of CAM therapies.

American Cancer Society (ACS)

1-800-ACS-2345

www.cancer.org

The "ACS Guide to Complementary and Alternative Cancer Methods" and the booklet "Making Treatment Decisions: Complementary and Alternative Therapy" can be ordered on the group's website or by calling.

Further information on treatment

American Society for Therapeutic Radiology & Oncology

1-800-962-7876

www.astro.org

Answers radiation therapy and cancer pain questions.

Food and Drug Administration

1-888-463-6332

www.fda.gov

Provides a list of FDA-approved drugs.

Also, some drugs approved by the FDA for a disease other than lung cancer may be in clinical trials for lung cancer.

National Cancer Institute

1-800-4-CANCER

www.cancer.gov

Provides a wide variety of publications on cancer and treatment.

Culturally specific information

Intercultural Cancer Council

713-798-4617

www.iccnetwork.org

Promotes policies, programs, partnerships, and research to support cultural competence.

Asian American Cancer Support Network

650-967-2305

www.aacsn.org

An organization aiming to provide an educational, supportive, and diverse network of resources for Asian Americans affected by cancer.

Native American Cancer Research

303-838-9359

natamcancer.org

A community-based American Indian resource seeking to help reduce cancer incidence and mortality in Native Americans.

The Mautner Project

1-866-628-8637

www.mautnerproject.org

A support organization for lesbians with cancer and their loved ones.

Disability and life insurance

U.S. Social Security Administration

1-800-772-1213

www.socialsecurity.gov

For the SSA's Disability Planner:

www.ssa.gov/dibplan/

American Council of Life Insurers

202-624-2000

www.acli.org

Provides information about brokers who specialize in high-risk life insurance.

Equal Employment Opportunity

Commission

1-800-669-4000

www.eeoc.gov

Federal agency that provides information about protections against discrimination due to illness.

Employment, medical insurance, and legal issues

American Cancer Society

1-800-ACS-2345

www.cancer.org

ACS has the following publication:

“Americans with Disabilities Act: Legal Protection for Cancer Patients Against Employment Discrimination.”

Cancer Legal Resource Center

1-866-843-2572

<http://disabilityrightslegalcenter.org/about/cancerlegalresource.cfm>

Provides free and confidential information and resources on cancer-related legal issues to cancer survivors, their families, friends, employers, health care professionals, and others coping with cancer.

Centers for Medicare and Medicaid Services (CMS)

1-800-MEDICARE

www.cms.hhs.gov

Contact the CMS and SSA to find out if you are eligible for government health insurance programs.

National Coalition for Cancer Survivorship

1-888-650-9127

www.canceradvocacy.org

Information and resources including publications on health insurance and employment rights for survivors.

Patient Advocate Foundation (PAF)

1-800-532-5274

www.patientadvocate.org

Offers assistance to patients who need specific help with insurance, insurance coverage, job retention, debt crisis matters, and other practical matters affecting people with cancer. PAF also offers a co-pay relief program for pharmaceutical products: www.copays.org.

Support groups and information about life with cancer

American Cancer Society

1-800-ACS-2345

www.cancer.org

Provides listings of support groups by location.

CancerCare

1-800-813-4673

www.cancercare.org

Offers toll free telephone and online support groups, excellent literature, and resources for cancer patients.

Lance Armstrong Foundation

1-866-673-7205

www.livestrong.org

Provides survivor support and education regarding emotional, financial, and treatment issues as well as clinical trials information.

Lung Cancer Alliance (LCA)

1-800-298-2436

www.lungcanceralliance.org

Maintains a list of all lung cancer-specific support groups across the country, maintains an online support community, and offers the Phone Buddy Program, peer-to-peer support by phone for people with lung cancer and their caregivers.

National Coalition for Cancer Survivorship

1-888-650-9127

www.canceradvocacy.org

Provides information, programs, and resources on cancer survivorship.

Cancer Support Community

1-888-793-WELL

www.cancersupportcommunity.org

Offers free support groups at Cancer Support Communities around the country or online in Cancer Support Community Online; offers free educational programs, literature, and resources.

Recommended reading

Lung Cancer: Myths, Facts, Choices And Hope. Henschke CI, McCarthy P, with Wernick S. WW Norton & Company, 2002.

Lung Cancer: Making Sense of Diagnosis, Treatment and Options. Johnston, L. Patient Centered Guides. O'Reilly, 2001.

100 Questions & Answers About Lung Cancer. Parles K, Schiller JH. Jones & Bartlett, 2002.

The Human Side of Cancer: Living with Hope, Coping with Uncertainty. Holland JC, Lewis S. Harper Collins, 2001.

The Alternative Medicine Handbook: The Complete Reference Guide to Alternative and Complementary Therapies. Cassileth BR. WW Norton & Company, 1999.

Comprehensive Cancer Care: Integrating Alternative, Complementary, and Alternative Therapies. Gordon JS. Persus Publishing, 2001.

You can find many more suggested reading materials on:

www.cancersupportcommunity.org

GLOSSARY

Ablation — The removal or destruction of a body part or tissue or its function. Ablation may be performed by surgery, hormones, drugs, radiofrequency, heat, or other methods.

Ablation therapies — Radiofrequency Ablation (RFA) uses radio waves to heat up and destroy tumors. Cryoablation uses liquid nitrogen or argon gas to freeze tumors.

Acute nausea — Usually occurs within 24 hours of chemotherapy treatment.

Adenocarcinoma — A subtype of non-small cell lung cancer.

Adenosquamous carcinoma — A subtype of non-small cell cancer.

Adjuvant therapy — Anti-cancer therapy given after another initial therapy such as surgery.

Advanced directive — Instructions about your future medical care if you become unable to speak for yourself.

Alopecia — Hair loss during cancer treatment that is almost always temporary and grows back when therapy is finished.

Alternative therapy — Nontraditional methods of diagnosing, preventing, or treating cancer.

Anemia — A shortage of red blood cells that can cause weakness and fatigue.

Angiogenesis — The process of developing new blood cells.

Antiangiogenesis therapy — Therapy to prevent development of new blood vessels that supply blood to the tumor, thereby stopping or limiting tumor growth.

Anticipatory nausea — Occurs prior to administration of chemotherapy and usually happens when the person has experienced nausea or vomiting in previous chemotherapy treatment sessions.

Antiemetic — A drug that reduces or prevents nausea and vomiting.

Apparently cancer free — The tumor has disappeared after treatment.

Bilobectomy — Removal of two lobes of the same lung.

Biopsy — Surgical removal of a small piece of tissue for evaluation under a microscope.

Brachytherapy — Radiation treatment that uses radioactive pellets inserted into a flexible tube placed inside the breathing passage to directly treat lung cancer.

Bronchial basal epithelial cells —

Cells that line the breathing passages and a common site where cancers develop.

Bronchogenic carcinoma — A general name for all types of lung cancer.

Bronchioloalveolar carcinoma (BAC) — A subtype of non-small cell lung cancer that can sometimes grow slowly.

Bronchodilators — Typically used to treat asthma, can also be used in pulmonary rehabilitation programs and to help improve breathing before surgery.

Bronchorrhea — A cough producing large amounts of phlegm.

Bronchoscopy — Viewing and biopsy of the bronchial tubes with a type of endoscope called a bronchoscope.

Bronchus — Either of two tubes that are the main airways into the lungs that branch from the trachea and enter the lungs.

Cachexia — Loss of body weight and muscle mass, and weakness that may occur in patients with cancer, AIDS, or other chronic diseases.

Cancer — An abnormal cell that cannot be controlled by the body's natural defenses. Cancerous cells can grow and eventually form tumors.

Carcinoma in situ — A tumor that is still confined to the innermost layer of the lung where it first started.

Catheter (intravenous) — A device that is temporarily or permanently put into a vein that makes it easier to give medications.

Chemobrain — A common term used to describe thinking and memory problems experienced after cancer treatments.

Chemotherapy — Treatment with drugs to stop the growth of rapidly dividing cancer cells.

Chemotherapy cycle — The term used to describe the process in which chemotherapy is given, followed by a period of rest in which the body is allowed to recover.

Chemotherapy regimen — Combinations of anti-cancer drugs given at a certain dose in a specific sequence according to a strict schedule.

Clinical trial — A research study in which a new treatment is given to patients to determine whether it is safe, more effective, or less toxic than a current standard of care.

Complete Response (CR)/No Evidence of Disease (NED) — The term used when all signs of cancer have disappeared.

Contralateral — Opposite side.

Computed axial tomography scan (CT/CAT scan) — Imaging test that provides a series of detailed pictures of the inside of the body using an x-ray machine linked to a computer.

Diaphragm — The thin muscle below the lungs and heart that separates the abdomen from the chest that is integral to the push-pull mechanism of breathing.

Delayed nausea — Generally begins 24 hours after administration of chemotherapy.

Disease progression — Term used if the disease worsens despite treatment.

Distal — The portion of the lung that is farthest from the mouth.

Dose intensity — A term used to describe giving the highest possible doses of drug over a specific period of time with acceptable side effects. This approach has been shown to be very effective in curing some cancers.

Do not resuscitate (DNR) order — An order that your doctor writes on your chart if you determine you do not want heroic measures taken in the event of a cardiac or respiratory event.

Dysphagia — Difficulty swallowing.

Dyspnea — Difficult, painful breathing or shortness of breath.

Epidermal growth factor receptor (EGFR) inhibitors — Naturally occurring proteins on the surface of cells that appear to aid in the growth of cancer cells and cause lung tumors to grow.

Esophagitis — A condition caused by radiation treatment that results in the symptoms of painful and difficult swallowing. Often described as a feeling of food getting stuck in your throat.

Etiology — The study of the cause of disease. In cancer there are often multiple causes.

Fatigue — A decreased capacity for activity that is often accompanied by feelings of weariness, sleepiness, or irritability.

First-line therapy — A medical therapy recommended for the initial treatment.

Genes — The basic building blocks of heredity that are present in all cells.

Genetic markers — A gene or DNA sequence has a known location on a chromosome and is associated with a particular gene or trait. They are associated with certain diseases and cancers.

Grade — A method of classifying a tumor on the basis of how aggressively it is growing.

Hemoptysis — Coughing blood.

Histology — The study of tissues to determine their specific characteristics, which may lead to identifying a specific type of lung cancer.

Imagery — Also known as guided imagery, a simple yet effective tool for transforming emotional states of mind. The feelings you evoke are governed by the thoughts and images on which you focus.

Immune system — The body's important defense mechanisms against infection and fighting disease.

Interstitial lung disease — A group of disorders, most of which cause progressive scarring of lung tissue, that create difficulty breathing and getting enough oxygen into the bloodstream.

Ipsilateral — On the same side.

Laparoscopy — Passing a tube through the abdominal wall to obtain a small sample of tissue for examination under a microscope.

Large Cell Carcinoma — Destruction of the myelin sheaths that cover nerve fibers.

Living will — A document that details your wishes about medical treatment if a time should come when you can no longer express those wishes.

Lobe — One major section of one lung. The right lung has three lobes, but the left has just two to make room for the heart and other organs.

Lobectomy — Removal of one lobe of either lung.

Lymph — The watery fluid in the lymph system that contains white blood cells (lymphocytes).

Lymph nodes — Small bean-shaped glands located along the small vessels of the lymphatic system. There are thousands of lymph nodes located throughout the body, with clusters of them in the neck, under the arms, and in the chest between the lungs, abdomen, and groin. Lymph nodes filter lymph fluid, trapping and destroying potentially harmful bacteria and viruses. Lymph nodes may be enlarged as a result of benign as well as malignant causes.

Malignant — A malignant tumor is a cancerous tumor.

Mediastinal pleura — The lining of the inner chest between the lungs.

Mesothelioma — A type of cancer that grows on the outer surface of the lung that is often mistaken for lung cancer and usually linked to inhalation of fibers like asbestos.

Metastasis — The spread of cancer to other tissues.

Mediastinoscopy — A surgical procedure to examine the inside of the upper chest between and in front of the lungs.

Mediastinum — Sac that contains all chest organs except the lungs.

Medical power of attorney — A document that allows you to appoint a trusted person to make decisions about your medical care if you cannot make decisions yourself.

Monoclonal antibodies — Substances produced in a laboratory and tailored to attach themselves to a specific protein (antigen), attacking and destroying only tumor cells.

MRI scan — A scan that uses magnets and radio frequency waves to produce images of the inside of the body.

Multimodality/combined modality therapy — Therapy that combines more than one method of treatment.

Myelosuppression — A reduction in the bone marrow's ability to make red blood cells, white blood cells, and platelets.

Non-small cell lung cancer (NSCLC) — Non-small cell lung cancer.

Neoadjuvant therapy — Chemotherapy or radiotherapy used before surgery to shrink a tumor.

Oxygen therapy — Therapy used to relieve breathing problems.

Palliative therapy — A therapy used to relieve pain and other symptoms without the intent to cure the disease.

Partial remission — The term used when a cancer has shrunk in size but has not totally disappeared. The cancer can still be detected, and other treatments may be recommended.

Peripheral neuropathy — Damage to the nervous system. Some chemotherapy drugs can cause this condition. Symptoms include weakness or tingling in the hands and/or feet.

PET scan (positron emission tomography) — A scan used to identify areas in the body that are affected by cancer. This test measures metabolic activity in different parts of the body using a radioisotope.

PFT (pulmonary function test) — Determines how well the lungs are functioning.

Photodynamic therapy (PDT) — An intravenous injection of a tumor specific photosensitizing agent (Photofrin) followed by a laser light exposure that results in a photochemical reaction to destroy the tumor cells.

Pleural effusion — An abnormal collection of fluid between the thin layers of tissue (pleura) lining the lung and the wall of the chest cavity.

Pleurodesis — A medical procedure that uses chemicals or drugs to cause inflammation and adhesion between the layers of the pleura. This prevents the buildup of fluid in the pleural cavity. It is used as a treatment for severe pleural effusion.

Pleura — The sac that contains the lungs.

Pneumonectomy — Surgery to remove one lung.

Primary cancer — The place in the body where the cancer started. If a primary lung cancer spreads to other parts of the body, it has metastasized. For example, a brain tumor from lung cancer is still lung cancer and not brain cancer. It is a metastasis of lung cancer.

Primary therapy — The first therapy given after a diagnosis of cancer.

Prognosis — The likely outcome of a disease, including the chance of recovery.

Progressive disease — The tumor is growing in spite of the treatment you received. When this happens, that specific therapy is usually stopped or modified in some way.

Psychotherapy — Treatment of mental, emotional, personality, and behavioral issues and disorders using methods such as discussion, listening, and counseling. Also called talk therapy.

Pulmonary rehabilitation — Education about behavior and lifestyle changes to help patients with chronic lung disease decrease breathing problems, return to daily activities, and improve quality of life. Education may include instruction about breathing exercises, nutrition, use of medicines, and ways for the patient to reduce stress and save energy.

Radiation therapy — The use of radiation beams (x-rays) to treat cancer. High doses of high-energy radiation beams, carefully focused on a tumor, will kill cancer cells.

Radiation fibrosis — When radiation treatment triggers the immune system to form fibrous scar tissue inside the lung. It may be temporary, or it could develop months or even years after radiotherapy ends. Symptoms can include dry mouth, sore throat, or problems with swallowing or breathing.

Radiofrequency/laser therapy — The use of thermal energy to destroy the cancer cells.

Refractory disease — A cancer that is resistant to treatment.

Regimen — A specific combination of drugs, their doses, and their schedules of administration.

Relapse — The return of cancer after it has been treated and the patient has been in remission.

Remission — The absence of disease. A patient is in remission when the lung cancer has been treated and tumors have diminished by at least 50% (partial) or have disappeared (complete). Remission does not necessarily mean cure.

Resection — Surgery that removes all or part of an organ.

Small cell lung cancer (SCLC) — Small cell lung cancer. It is categorized as either limited stage or extensive stage.

Sputum — Mucus brought from the airway usually by coughing.

Sputum cytology — A test that can find cancer cells long before a tumor is evident on other tests, but it may not detect cancers that are deeper in the lungs and cannot determine a tumor's size or location.

Squamous cell carcinoma — A subtype of non-small cell lung cancer.

Stable disease — The disease does not get better or worse following therapy.

Stage (lung cancer) — The extent of cancer in the body, including whether the disease has spread from the original site to other body sites.

Standard therapy — A current primary therapy that has shown to be safe and effective over time.

Stereotactic radio-surgery — Uses high-energy x-rays to destroy cancer.

Systemic symptoms — Symptoms that affect the entire body. Examples of these include fever, night sweats, and weight loss.

Targeted therapies — Drugs that target specific cellular pathways that enables cancer cells to grow.

Thoracentesis — Inserting a narrow needle with a larger reservoir through the chest wall for one-time drainage via suction aspiration.

Thoracic pathologist — A specialist in pathology of chest illnesses.

Thoracoscopy — A limited surgical procedure, performed under general anesthesia. An instrument called a thoracoscope is inserted through a small incision in the chest wall to allow examination of the lining of the chest wall and the surface of the lungs for tumors.

TNM staging system — Three measures of tumor spread, tumor size, lymph nodes affected, and metastatic (distant) sites involved that are used to stage lung cancer and many other cancers at Levels I through IV.

Trachea — The windpipe.

Tumor — An abnormal mass or swelling of tissue. Tumors may occur anywhere in the body. It may be benign (harmless) or malignant (cancerous).

Video-Assisted Thoracic Surgery (VATS) — This technique uses a camera to guide surgical tools into the lungs and is less invasive than traditional surgery.

Vaccine — Cancer vaccines combine malignant cancer cells with a patient's own natural defenses to fight the disease. These vaccines are custom-made, using a sample of the tumor that is obtained from each patient's lymph nodes.

Wedge/Segmental resection — Surgery to remove a wedge of tissue from one lobe of one lung that is usually done only for early-stage disease or isolated tumors.

X-ray — High-energy radiation that is used in low doses to provide images of the inside of the body and in high doses to treat cancer.

Cancer Support Community and Lung Cancer Alliance would like to recognize and thank all of those who make *Frankly Speaking About Cancer: Lung Cancer* a success.

FIFTH EDITION

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CANCER SUPPORT COMMUNITY'S FRANKLY SPEAKING ABOUT CANCER SERIES

Cancer Support Community's *Frankly Speaking About Cancer: Lung Cancer* program is part of a national education program that provides support, education and hope to people affected by cancer and their loved ones. The programs consist of educational booklets, clinically facilitated workshops and online content at www.cancersupportcommunity.org.

Frankly Speaking About Cancer booklets feature information about treatment options, how to manage side effects, the social and emotional challenges of the diagnosis and survivorship issues.

All publications are FREE and are available ONLINE. Copies of this booklet are available by request.

Frankly Speaking About Cancer workshops are dedicated to empowering patients, caregivers and loved ones to gain knowledge as it relates to each person's unique situation with cancer. Our unique format offers participants an opportunity to connect with a medical professional outside of an oncologist's office in a comfortable and relaxed environment.

For more information about this program, the *Frankly Speaking About Cancer* series or Cancer Support Community, please visit our website or call us toll-free at 888.793.9355.



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People with cancer who actively *participate* in their care along with their health care team will *improve* the quality of *their lives* and may enhance the possibility of *recovery*. People with cancer who *actively* participate in their care along with *their health* care team will improve the *quality* of their lives and may *enhance* the possibility of *recovery*.