

FRANKLY
SPEAKING
ABOUT CANCER

Lung Cancer



Table of Contents

Chapter 1: You Are Not Alone	4
Chapter 2: Understanding Lung Cancer	12
Chapter 3: Planning for Treatment	20
Chapter 4: Treating Lung Cancer	34
Chapter 5: Managing Treatment Side Effects	46
Chapter 6: Coping and Support	52
Chapter 7: Practical Concerns	58
Chapter 8: Moving Forward	64
Glossary	68
Resources	72

IN THIS CHAPTER:

- Becoming an Active Member of Your Health Care Team (Empowering Yourself/Gaining Control)
- Maintaining Hope
- Coping with Stigma
- 10 Tips for Living Well with Lung Cancer

1

You Are Not Alone

You may have recently been given news that you didn't want to hear. You or a loved one has lung cancer. Over the past few days or weeks, you have been asked to participate in decisions that will affect your life moving forward. If you are reading this booklet, there is one thing to know. You are not alone.

Over the course of this year, about 229,000 Americans will hear what you heard: They have lung cancer. Indeed, lung cancer is the most common cancer worldwide, accounting for 2 million new cases in a given year. But help is available. There is a whole community of cancer doctors, nurses, counselors, advocates, and people living with cancer to help you. This is a promising time for cancer research. New ways to treat cancer are improving the outlook for many cancers, including lung. As you start this journey, prepare to listen, learn, ask questions, and accept support.

Empowering Yourself

Being empowered means having a sense of control over your treatment and life with cancer. You gain this through your actions, behaviors, and attitudes.

Gaining Control

Once lung cancer becomes part of your life, you may be faced with many challenging decisions—where to go for treatment, what treatment option is best for you, and how you are going to manage your overall health. During a time of a cancer diagnosis, when people often feel so much is out of their control, you may be wondering “What can I control?” Being active members of your health care team can help you and your caregiver feel more in control and lead to better outcomes.

Learning more about your diagnosis and treatment options lets you be more of an active member of your health care team. Just remember, you can choose who you listen to and what you read. Not all statistics and information found online about lung cancer are correct and up-to-date. Sometimes reading

about lung cancer statistics can be discouraging. In fact, most lung cancer statistics are based on information from studies that were done more than 5 years ago. Today’s newer treatments have not been around long enough to affect the statistics. So your prognosis may be more hopeful than the numbers suggest. In addition, it is important to understand that statistics apply to populations of people, not individuals like you. An individual may do much better than average.

Sometimes neighbors and friends may tell you about someone they know who has lung cancer. At times these stories may be uplifting, but at other times they may focus on the difficulties. For whatever reason, some people provide a sense of hope and others dwell on the negative. You have the control to decide how and when to talk about cancer, and to listen or not listen if what people are saying is not helpful.

Maintaining hope

It can be difficult to stay hopeful when you learn you have cancer, but maintaining hope can be so important. Hope can come from inside yourself, or from talking with family, friends, or members of your health care team.

HOW DO YOU GAIN CONTROL? YOU OR A CAREGIVER CAN DO THIS BY:

- Asking your health care team questions so you understand your treatment options
- Getting a second medical opinion
- Reaching out to other people with lung cancer
- Asking your health care team about clinical trials
- Talking about your preferences and wishes with your health care team and your loved ones
- Taking care of your body by eating healthy foods, exercising as you are able, and getting enough rest

“I learned that it’s okay to ask [your health care team questions]. It’s better than okay. It’s necessary.”

– Elaine, living with lung cancer

There are many ways to hope. You can hope for the big things—that treatment is successful and you can return to your life. Or, depending on your circumstances, you can focus on smaller goals. You might hope for a good result on a scan, or a positive report from your doctor. Or, you might hope that tomorrow will be a sunny day, and you can get out in your garden, or spend time with friends and family doing something you all enjoy. The main thing is not to let go of hope, to keep setting goals, and to keep finding things in your life that matter and bring you happiness.

LEARNING TO SPEAK CANCER

Members of your health care team may use words you don’t understand when they talk about your diagnosis and treatment. Some of these words may sound familiar, and others may be completely new. You may feel like you are learning a new language or back in science class again. Use the glossary at the end of this book to look up words. Ask questions if you don’t understand. Your health care team may not always remember to speak slowly or use simpler words. It’s okay to remind them.

Hope also can be found in scientific research. Now that researchers can see what is going on in a cancer cell at a very basic level, they can find biomarkers—characteristics that may be associated with disease. They are using this information to develop new drugs to stop or slow the growth of the cancer. These drugs are called targeted therapies.

The immune system is also a source of great hope for treating many cancers, including lung cancer. New treatments push or boost the immune system to work harder to fight the cancer. They have been successful in treating some lung cancers.

Lung cancer clinical trials also provide hope. Clinical trials offer people with cancer the chance to try the latest treatments. A clinical trial is a research study to test a new treatment or learn how to use a current treatment better. More on clinical trials and how to find them can be found on page 42.

Coping with Stigma

There can be blame, shame, and stigma associated with lung cancer. Stigma occurs when a group has negative or unfair beliefs about something. People with lung cancer often are asked, “Did you smoke?” You may find that people are not as sympathetic to you as they are to other people with cancer. The fact is, most new lung cancers are diagnosed in people who do not currently smoke, including

15%-20% in people who never smoked. It does not matter if you smoke or used to smoke. No one deserves to get lung cancer.

You may find that feelings of guilt or shame lead to anger. You may be angry at yourself, angry at people who make insensitive comments, or angry at those who look at you with that “I told you so” gaze. And yes, you may even be angry at the government and corporations for allowing tobacco to exist in the first place. Try to move forward and not focus on blame or the past.

Whether you had a history of smoking or not, you may struggle with a need to explain yourself. Try not to get too caught up in these conversations, and focus on moving forward and taking care of yourself, not answering to others.

A diagnosis of lung cancer can affect your relationships with family and friends in many ways. It may have an impact on your ability to provide or care for your family. It can deepen relationships or add stress to them. Family roles may change as different members spend more time on chores or caregiving, or need to earn money.

If you ever smoked, there may be additional issues related to blame, shame, and stigma. For this reason, some people with lung cancer try to keep their diagnosis a secret, fearing that they will be judged for causing their disease. Others may hold off on seeking medical attention, worrying that insurance won't cover a “self-inflicted” illness. This is a place where people and organizations can help. Use the resources on page 72 to ask for help and find support.

WHAT YOU CAN DO TO COMBAT BLAME, SHAME, AND STIGMA

- If you smoke or smoked, forgive yourself.
- If someone asks whether you smoked, ask them, “Why do you ask?” Often people are just trying to distance themselves from their own risk of the disease and may not realize how they sound.
- If you hear negative remarks, use the opportunity to educate the speaker. If you ever smoked, you might say, “Yes, lung cancer can be caused by smoking, but there are other causes as well.” If you never smoked, use this as a teaching moment and say, “Many people who have never smoked get lung cancer.”
- Find support from other people with lung cancer. This can be very helpful for some people. You might learn ways they have found to cope with the stigma and feelings of guilt and focus on living today.

Ron

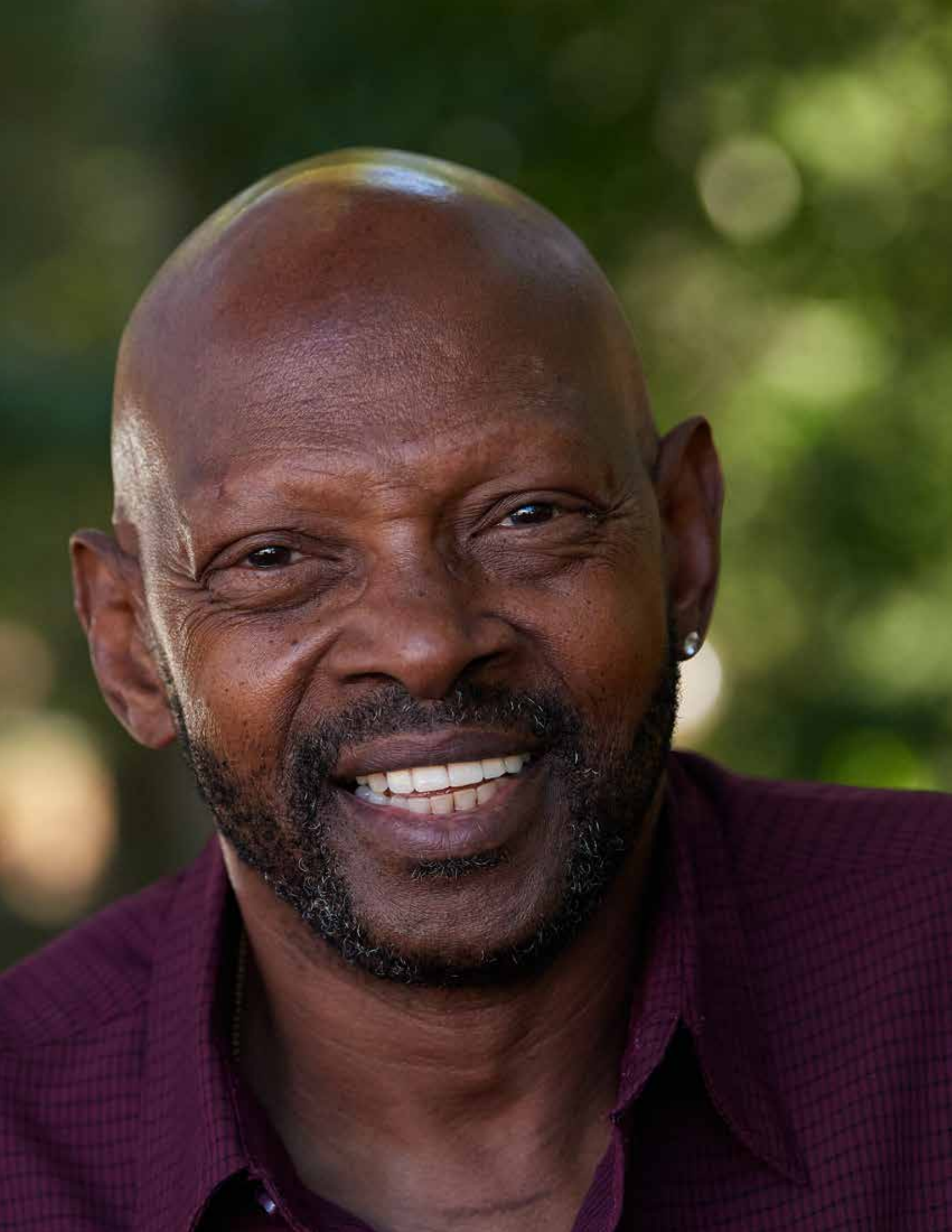
I Listen and I Learn

Ron was at work when he suddenly developed a fever and struggled to breathe. He was sent to a hospital where he passed out. Tests revealed that Ron had small cell lung cancer. Soon after, his right lung was removed. Treatment with radiation and chemotherapy followed. This was 14 years ago.

At the time and since, Gilda's Club (an affiliate of Cancer Support Community) has been a lifeline for Ron. He was looking for a job when someone told him about the cancer support organization. One visit and he was hooked. He connected with the staff, and found community in the support groups.

Since then, Ron has become an active member at Gilda's. He is a consistent face at a weekly support group and has helped many others with lung cancer cope with diagnosis and treatment. He appreciates the opportunity to give back, noting, "this place really gave me hope that I would beat this and be able to talk to other people about it."

Outside of Gilda's Club, Ron focuses on what's most important to him—living, staying healthy, and enjoying his family. Since his diagnosis, he's had the pleasure of seeing his daughter graduate, get married, and have a baby. Reflecting on his life, Ron says that he listens and learns. "I'm still listening and learning."



10 TIPS FOR LIVING WELL

TAKE ONE STEP AT A TIME, AND MAKE ONE DECISION AT A TIME

If life feels overwhelming, take small steps to find your best path. Talk, listen, and learn. In time, you will have the information you need to make the right decisions for you.



PAY ATTENTION TO WHAT YOU NEED

Be aware of your feelings. Focus on activities you enjoy. Try to find humor in each day. Seek out people who help you feel relaxed or happy. Spend time alone if you need to. Take more time to rest. Some days you may not know what you need, and that's okay too. Be kind to yourself. Include mental health in your health care plan. You can ask for help with depression and/or anxiety.



BE YOUR OWN BEST ADVOCATE

You may feel frustrated by changes to your life. Talk with your medical team and your family and friends. Work together to come up with a plan that gives you as much control as possible over your treatment and care.



COMMUNICATE EFFECTIVELY WITH YOUR HEALTH CARE TEAM

Let your health care team know how you feel. Ask questions and ask again if you don't understand the answers. Tell your team about your goals for treatment. Be sure they know how your treatment and symptoms are affecting your everyday life.



GET HELP FROM OTHERS, BESIDES YOUR DOCTOR

Expand your health care team to include a patient advocate or navigator, oncology social worker, and/or specialists. A patient advocate can help you find resources, manage insurance, and prepare legal documents. Other useful specialists include a nutritionist to help with eating, a psychologist for emotional distress, a physical therapist for weakness, and a palliative care specialist for symptom management. See Resources starting on page 72.



LL WITH LUNG CANCER

REMEMBER THAT HOPE IS POSSIBLE

Even if cure is unlikely, many treatment options exist, and it is possible to live well with lung cancer. Hope can make each day a little better. Accept that some days will be better than others, but try to enjoy small moments and do things that make you smile.



FOCUS ON NUTRITION AND EXERCISE

Healthy food provides nutrients to help your body. Exercise can lift your spirits, boost your energy, and reduce stress. Talk with your health care team before you make major changes to diet or exercise. Even minor efforts can help you feel better.



REACH OUT TO OTHERS WITH LUNG CANCER

It's comforting to talk with people who understand what you're going through. Try to connect with others online or in a local support group.



ASK FOR SUPPORT AND ACCEPT HELP WHEN IT IS OFFERED

Talk to your caregiver or loved ones if you need help making decisions. Let your family and friends know how they can support you. Be specific if you can. Consider using an online schedule such as **MyLifeLine.org** to stay organized and let friends know what's needed.



KEEP A NOTEBOOK NEARBY

Use a notebook or online planner to keep track of side effects, take notes when you talk with your health care team, and remember financial or insurance details.



IN THIS CHAPTER:

- Risk Factors & Screening
- Types of Lung Cancer
- Diagnosis – Staging
- Diagnosis – Tools for Diagnosis
- Diagnosis – Biomarker Testing

2

Understanding Lung Cancer

The lungs are organs in the chest that move oxygen from the air into the blood and carbon dioxide from the blood out of the body into the air. The lungs are divided into sections called lobes, with three lobes in the right lung and two lobes in the left lung. They are surrounded by a thin lining called the pleura. Air flows through your windpipe to the lungs' many tubes to get air in and out of the lungs.

Cancer is a condition in which cells grow out of control to form masses called tumors. The cancer cells invade and destroy normal, healthy tissue. Cancer cells can spread from their original site to other parts of the body in a process known as metastasis. The word metastatic is often used to describe cancer that has spread to other parts of the body. Cancer that

has spread only to nearby tissues or lymph nodes may be called locally advanced. Cancers are named for the place in the body where they begin (known as the “primary site” or “primary cancer”), not where they spread.

Many people with lung cancer have no symptoms or only vague symptoms until the disease has progressed outside of the lungs or to other parts of the body. The lungs have very few nerve endings, so the first symptoms are often those from metastases rather than the primary tumor in the lung. Even a large tumor may be present without any feelings of pain or discomfort. As a result, only 16% of lung cancers are discovered in the earliest stages.

Risk Factors

A risk factor is something that increases your chances of developing a disease. Research has found several risk factors for lung cancer.

HISTORY OF SMOKING OR EXPOSURE TO SECONDHAND SMOKE

A history of smoking is a major risk factor for lung cancer. For people who have smoked, the risk of developing lung cancer is related to their total lifetime exposure to cigarette smoke. The increased risk decreases after quitting smoking, but never goes completely away. Secondhand smoke is exposure that comes from living with someone who smokes or working in a location where smoking is or was allowed.

ENVIRONMENT

An increased risk of lung cancer can be tied to exposure to high levels of certain natural gases and chemicals in your home or workplace, such as radon, uranium, diesel exhaust, arsenic, and bischloromethyl ether. In fact, radon is the second leading cause of lung cancer in the United States. Asbestos exposure has also been

linked to increased risk of lung cancer. Asbestos is more commonly associated with another type of cancer that can affect the lungs called mesothelioma. Other occupational exposures like Agent Orange or being a firefighter may also increase risk.

PERSONAL AND FAMILY HISTORY

If you have had lung cancer and were successfully treated for that cancer, you are at increased risk of developing a second lung cancer. Radiation therapy to the chest for another type of cancer also increases your risk of lung cancer. Your risk may also be higher if your parents, siblings, or children have had lung cancer. This could be related to genetics. It could also be because they also smoke, or they live or work in the same place where there is radon or other substances that can cause lung cancer. If members of your family have had lung cancer, it is important to talk to your doctor about your possible risk.

AGE

As with most cancers, the risk of developing lung cancer increases as a person ages.

SCREENING FOR LUNG CANCER

The goal of screening is to look for disease in people who do not yet have symptoms. Screening is recommended for people who are at high risk for lung cancer including:

- Those between the ages of 55 and 80 years with a history of heavy smoking (at least “30 pack-years”), which would include people who smoked one pack of cigarettes per day for 30 years or people who smoked two packs per day for 15 years, or three packs per day for 10 years, and so on. This includes those who currently smoke, as well as those who quit within the last 15 years.
- People who have had lung cancer already: If you survived one lung cancer, you have a high risk of getting a second lung cancer. It is a good idea to have yearly low-dose screening CT scans after you have completed treatment.

If you think you may be at risk for lung cancer, find a screening program that follows the recommendations for lung cancer screening and uses low-dose CT scans. Remember, the ultimate goal of lung cancer screening is to find lung cancer earlier. Even if you have never smoked or have smoked less than the criteria above, you can still get lung cancer, but current screening guidelines do not recommend routine screening in these situations. Talk to your doctor if you are concerned that you have an increased risk for lung cancer and are not eligible for screening under current guidelines.

Types of Lung Cancer— NSCLC & SCLC

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

There are two main types of lung cancer—non-small cell lung cancer (NSCLC) and small cell lung cancer (SCLC). NSCLC is more common. It accounts for 85% of all lung cancer cases. NSCLC has many basic subtypes. The three most common ones are adenocarcinoma,

squamous cell carcinoma, and large cell carcinoma. Even within a subtype, every person’s lung cancer has different features from every other.

SCLC is found in fewer than 15% of people with lung cancer. As the name suggests, it is defined by smaller size of the cancer cells. It is sometimes called oat cell cancer.

NSCLC and SCLC cells look different under a microscope. They also spread to other parts of the body at different rates, respond to different treatments, and contain different molecular abnormalities.

Diagnosis

HEALTH HISTORY

Your health care team will want a detailed medical history if they suspect lung cancer. They will ask about any key symptoms, such as nagging cough, shortness of breath, fatigue, and back or chest pain. They will ask whether you have ever had any other types of cancer or other diseases. They also will ask if you ever smoked and whether you have been exposed to secondhand smoke or chemicals. In addition, they may ask about your family history of lung or other cancers.

The team also will evaluate your “performance status.” This status describes how well you can function, including your ability to take care of yourself and do usual daily activities. It will also help determine initial treatment and next steps in treatment along the way.

Your doctor may use several different tests to determine if you have lung cancer, what type it is, and where it has spread. (See the “Tools for Diagnosis” box for more about these tests.) This is called diagnosis and staging. Your health care team will need this information in order to provide the best treatment.

Staging

Staging is a vital part of treatment planning. Doctors match what they learn about your cancer into one of several distinct groups, also known as stages, to help guide treatment. Staging may happen at diagnosis or before or after surgery or biopsy. Sometimes, your health care team may restage a cancer based on how well a treatment is working. They also may restage to get more information about a cancer

that has come back after treatment. Most often when restaging, some of the same tests that were done when the cancer was first diagnosed are repeated. After this, your health care team can determine if your cancer is in remission.

Many different tests are used to diagnose and stage lung cancer. Common ones are listed on page 16. No single plan for diagnosis and staging is right for every patient. Talk with your health care team about the tests you will need.

STAGING OF NSCLC

The results of these tests allow cancers to be grouped into stages using the “TNM” system (short for Tumor, Nodes, Metastasis). The TNM Staging System is one of the most commonly used cancer staging systems and is particularly useful if surgery is being considered.

It takes into consideration:

TUMOR (T): How big is the tumor? Where is it located? Has it directly invaded nearby tissue?

LYMPH NODES (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?

This information is used to assign a numerical stage for NSCLC. There are five numerical stages associated with NSCLC. Roman numerals 0 to IV (4) are used.

In general, cure rates are better for cancers diagnosed at lower (earlier) stages than higher (more advanced) ones. Keep in mind, though, that other factors are tied to outcome besides staging. They include your overall health and the type of lung cancer.

TOOLS FOR DIAGNOSIS

Imaging scans provide a picture of the lungs and other areas to determine the extent of spread of the cancer. Major types include:

- **CHEST X-RAY.** A simple radiographic picture of your lungs. A chest x-ray is likely one of the first tests used to see where your tumor is located. It is fast and inexpensive but does not give as clear a picture as CT or MRI scans. Some lung cancer diagnoses can be missed if this is the only test used to detect lung cancer. That is why a low-dose CT scan is recommended for screening.
- **CT AND MRI SCANS.** CT (computed tomography) and MRI (magnetic resonance imaging) use computers to produce detailed, 3-D images that help diagnose lung cancer and can determine the size, shape, and location of a tumor. A CT scan is more likely to show lung tumors than routine chest x-rays. Both CT and MRI scans are useful in determining whether lung cancer has spread.
- **PET SCANS.** PET (positron emission tomography) takes advantage of the fact that cancers take up more sugar than most normal tissues. For this scan a labeled sugar is injected and a special camera makes images of where it goes. They may give a more accurate picture of the stage of lung cancer and help determine if the cancer has spread outside of the lungs. PET scans are also useful if your health care team thinks the cancer may have spread but aren't sure where. They do not provide as detailed an image, so they are often used as a follow-up to other tests or to diagnose cancer that has come back after treatment. PET scans are more expensive, more time-consuming, and involve more radiation exposure than other types of scans. So they are not recommended for routine follow-up while on treatment.

A sample of tissue or fluid will be needed to confirm whether tumors seen on scans are cancer and identify its type and stage. There are many ways to obtain a sample. Common ones include:

- **NEEDLE BIOPSY.** A small piece of tissue is removed and looked at under a microscope. This may be taken from the lung or a part of the body where the cancer has spread.
- **SPUTUM CYTOLOGY.** A sample of sputum (mucus produced by a cough) is collected and looked at under a microscope.
- **THORACENTESIS.** If there is fluid build-up around the lungs (called pleural effusion), a doctor can use a needle to remove some of the fluid. This can help you breathe better by expanding your lungs. A sample of the fluid can be sent to a lab to be tested for cancer cells.
- **BRONCHOSCOPY.** A bronchoscope (a flexible tube-like instrument) is used to directly view the airways into the lungs and to collect tissue samples. Local anesthesia and mild sedation are generally used.
- **NAVIGATIONAL BRONCHOSCOPY.** This new technology uses a bronchoscope to provide a 3-D virtual "roadmap" that enables a doctor to biopsy hard-to-reach parts of the lungs.
- **LIQUID BIOPSY.** A new technology that allows the detection of tumor DNA in your blood for biomarker analysis. It is best not used alone (without other types of biopsy), doesn't identify stage, and currently is not as sensitive as other types of biopsies.

Doctors look at the TNM numbers as a group. Because of this, it is hard to describe the stages in just a few words. In general, though, the stages of NSCLC are as follows:

STAGE 0 (Carcinoma in situ)

This is a very early stage, marked by abnormal cells only in the air passages.

STAGES IA & IB (1A & 1B)

At these stages, the tumor is small and cancer has not spread to the lymph nodes. In Stage IA, the tumor is 3 cm or less. In Stage IB, the tumor is between 3 and 4 cm.

STAGES IIA & IIB (2A & 2B)

In Stage IIA, the tumor is between 4 and 5 cm. It has not spread to the lymph nodes. In IIB, the tumor is smaller than 5 cm and cancer has spread to the lymph nodes on the same side of the chest as the tumor.

STAGES IIIA, IIIB, & IIIC (3A, 3B, & 3C)

In these stages, the cancer has spread to the lymph nodes. It has not spread to other parts of the body. The tumor may be bigger or the cancer may be in an area that is harder to reach than cancers in earlier stages. Stages IIIB and IIIC are often treated more like Stage IV cancers.

STAGE IV (4)

In these cases, the cancer has spread beyond one lung. It is in the other lung, the fluid near the lung or heart, or another part of the body. When it spreads, lung cancer can go anywhere, but often spreads to the brain, bones, liver, kidneys, or adrenal glands.

STAGING OF SCLC

The TNM Staging System may also be used to describe small cell lung cancer. Most often, though, a 2-stage system is used:

LIMITED STAGE

The cancer is in a part of the chest that allows the whole tumor to be treated with radiation therapy. About 1 out of 3 people with SCLC have limited stage disease when first diagnosed, and it is often curable.

EXTENSIVE STAGE

The cancer has spread to parts of the body—such as the other lung, bone, brain, or bone marrow—that don't allow the entire tumor to be treated safely with radiation. However, radiation may still be used to treat symptomatic areas. SCLC that has spread to the fluid around the lung is extensive stage as well. About 2 out of 3 people with SCLC have extensive disease when their cancer is first diagnosed.

RECURRENT LUNG CANCER

Recurrent lung cancer is when the cancer returns after treatment. The cancer may come back in the brain, lungs, or other parts of the body. The cancer may need to be restaged in this case. New treatment may be recommended. Many people with lung cancer experience great improvement with additional treatment, even after their cancer has recurred.

Biomarkers for Diagnosis and Treatment

Biomarkers are features of your tumor that can be measured to help guide your therapy. They are sometimes called molecular markers or cancer markers. All patients with advanced or recurrent non-small cell lung cancer (NSCLC) should ask their health care team to test their cancer for biomarkers. Biomarker testing can be done using tumor tissue, blood, or sputum. Ideally, comprehensive next generation sequencing (NGS) will be used to test for many

biomarkers at once. Biomarker testing is also called tumor marker testing, genomic testing, mutation testing, and molecular testing. Not every hospital has a lab capable of testing for all biomarkers. If this is not an option where you are receiving care, ask if your doctor can send your samples out for testing. Ask your doctor if you have been tested for these biomarkers: EGFR, ALK, BRAF, ROS1, NTRK, and PD-L1. There are approved treatments targeting those. Other biomarkers that may be relevant to lung cancer include HER2, KRAS, MET, MEK1, and RET. Drugs targeting these may be available through clinical trials. If your tumor was tested using NGS, the test may have included these markers and many others. This information can also be used to look for clinical trials focusing on other biomarkers.

You should get tested when you are first diagnosed with advanced NSCLC. As additional targeted therapies become available, biomarker

testing may be recommended for small cell lung cancer (SCLC) and early-stage NSCLC. Today, the main reason to get biomarker testing if you have SCLC or early-stage NSCLC is to see if you can join certain clinical trials.

Comprehensive biomarker testing should be done before starting treatment. Patients who test positive for certain biomarkers may not respond as well to standard chemotherapy or immunotherapy. For this reason, it can be better to wait a few weeks for the results of all biomarker tests, even if this means delaying start of therapy.

Testing may also be useful when your targeted therapy stops working, or when your cancer comes back. More information about biomarker testing for lung cancer can be found at www.CancerSupportCommunity.org/TargetedLung.

QUESTIONS TO ASK ABOUT BIOMARKER TESTING:

- Was my tissue sent for biomarker (molecular) testing?
- Have you tested my tumor for EGFR, ALK, BRAF, ROS1, NTRK, PD-L1, HER2, KRAS, MET, MEK1, and RET?
- Was comprehensive NGS used for my biomarker testing?
- How long will it take for all results to be returned?
- How will you use the information to recommend a treatment plan?
- Will my insurance pay for the biomarker testing? If not, is there any financial assistance available for paying for biomarker testing?
- What do my results mean for my treatment?



IN THIS CHAPTER:

- Find the Right Team
- Key Members of Your Health Care Team
- Communicating with Your Team
- Understand the Goals for Your Treatment
- Treatment Decision Making
- Taking Care of Your Body

3

Planning for Treatment

The process of learning about treatment options and choosing one is called treatment planning. Treatment planning is a big part of the cancer experience. You will be asked to make choices at the beginning of treatment and again along the way.

As you consider your options, talk with family, friends, and members of your health care team. Try to learn as much as you can about each treatment. Your treatment plan depends on the type and stage of the cancer. Factors like where the cancer is located, if or where it has spread, and whether it is affecting other parts of the body will affect your choices. Here are some steps you can take to feel more in control and better able to make decisions that are right for you.

Tips for Taking Charge of Your Care

STEP 1: FIND THE RIGHT HEALTH CARE TEAM FOR YOU

Your health care team includes the doctors, nurses, and other professionals who will provide you with medical care and support. Living with lung cancer typically means a lot of doctors' visits. You need a health care team you can trust. This team probably will be led by a medical oncologist (a cancer doctor). Specialists in lung cancer are called thoracic oncologists.

You may have already met with a medical oncologist. You may know that this doctor is the right person to treat your lung cancer. If you are not sure, it's important to talk to another doctor—preferably at a major medical center—to get a second opinion. If your doctor is a medical oncologist and doesn't see many lung cancer patients, it might be helpful to talk to a thoracic oncologist to get a second opinion.

Even if you like your doctor, it's a good idea to review the questions in the pages that follow. You want to make sure that you have the right doctor to treat your cancer.

Where you go for treatment is a very personal choice. Here are some important questions to ask yourself when choosing your health care team:

Recommendations. Is there a doctor or nurse you trust who can recommend a medical oncologist for you? Do you have a friend, co-worker, or relative you trust who has had a good experience with a doctor they can recommend?

FIND A LUNG CANCER SPECIALIST

Here are some tips for how to find a lung cancer specialist:

- Ask your doctor or insurance company.
- Ask a friend or someone you know who has had lung cancer.
- Call a local cancer support organization, lung cancer advocacy group, or hospital referral network.
- If possible, go to a major cancer center or university hospital for a first, second, or third consultation about your diagnosis.
- Try seeing a doctor at a National Cancer Institute (NCI)-designated cancer center. They are likely to have the latest treatments.

Additional Resources for Referral Information

American College of Surgeons, Commission on Cancer (CoC)
www.facs.org/cancerprogram

American Lung Association Lung HelpLine
800-586-4872
www.Lung.org

American Society of Clinical Oncology's (ASCO's) Cancer.Net
www.cancer.net/find-cancer-doctor

GO₂ Foundation for Lung Cancer
800-298-2436
www.go2foundation.org

The National Cancer Institute
800-422-6237
www.cancer.gov/cancer-centers

Expertise. Is your doctor a lung cancer specialist? Lung cancer therapy is increasingly complicated, and some oncologists treat many different kinds of cancer. If possible, try to find one who focuses on lung cancer, so is more likely to be up-to-date on the latest treatments. This means that at least half of their practice is dedicated to lung cancer. You can:

- Ask how they stay current. Do they attend medical conferences and keep up with lung cancer research? Are they a member of the International Association for the Study of Lung Cancer (IASLC)? Advances in treatment happen quickly. You want a doctor who is up-to-date on the latest research.
- Ask about their experience treating lung cancers like yours. Try to find a doctor who treats lung cancer with the same stage, type, and subtype as yours.

You may have more options at a hospital with an active research program, such as an NCI-designated comprehensive cancer center. If there are none near you, consider visiting one for a second opinion before you start or change treatment. Refer to the next page for information on how to find one.

Past relationships. If you had lung cancer before, would you like to see the same doctors? Do they listen and take your needs and concerns into account? Do you trust them? If you aren't sure, it's a good idea to meet with someone else, or more than one doctor, as a comparison. Even after meeting with other doctors, you can choose to continue with your original doctor.

Communication style. Do you want a doctor who tells you all of your options and leaves the final decision up to you? Or do you want

someone who doesn't go into detail and just tells you what they think is the best thing to do? Think about which approach works better for you. Once you have chosen a doctor, let them know when they are explaining things well. Tell them if you would like them to explain things differently.

Approach to treatment. Some doctors recommend many tests and combined treatments. Others prefer a less aggressive approach. The decision is yours, but it is important for you to understand the choices. Be sure to:

- Ask each doctor you meet about all your options for treatment, including taking part in a clinical trial.
- Ask about the goal of each treatment option.
- Be clear about your goals. Let them know what is important to you and what helps you feel good about life. Ask if the treatment they are recommending will be the best to meet your goals.

Getting a second opinion. If you have any doubts, get a second opinion. You may be unsure of your diagnosis, your doctors, or the treatments they suggest. Talking to another doctor can help you learn more about your disease and how to treat it. Other doctors may offer different treatments, different support services, or be a better fit in other ways. Do not worry about hurt feelings. If your doctor discourages you from getting a second opinion, this may be more of a reason to get one. Many people seek second opinions. Some doctors even encourage it. Your first concern is your own health.

WHEN YOU DON'T HAVE MANY OPTIONS FOR HEALTH CARE

It may be hard to find a doctor. You may be limited by geography, insurance, or finances. As a first step, make sure that you have done a thorough search. There may be a doctor or hospital you haven't heard about. Use the resources in the box on page 21 to find a doctor.

If you can't find a doctor nearby or have chosen a doctor who does not treat your type of lung cancer very often, here are some things you can do to ensure that you receive the best possible care:

- **Learn about lung cancer.** Read this book. Use the resources at the end of this book. Ask questions. Your doctor may not be able to answer them on the spot. Try to find a doctor who will learn as much as possible about your disease and how to treat it.
- **Ask your doctor where to go for a second opinion.** Does your doctor know another doctor at an NCI-designated cancer center? Maybe there is someone you could see once who could consult on your case? Look into the possibility of getting a remote second opinion, which would not require travel.
- **Call or email the closest NCI-designated cancer center.** Ask if they have a visiting oncologist who comes to your area occasionally. Ask how you can get to see this doctor. Some hospitals have telemedicine services that could be useful to you or your doctor.
- **Find out if you are eligible for any clinical trials.** More information about getting treatment through a clinical trial is in Chapter 4 of this book.
- **Build your own health care team.** Work with your doctor to find other resources and care team members. (See the next few pages for who might be on your team.)
- **Join an online support group for your specific type of lung cancer** to learn from other patients going through similar experiences.

Availability of clinical trials. Some treatments with the best chance of success may be available only through clinical trials. But not all treatment centers offer clinical trials. And not all centers have the same clinical trials. Be sure to ask:

- About local clinical trials that might be right for you.
- If they are willing to refer you to other clinical trials. This information may help you choose your treatment team.

(Refer to the Clinical Trials section in Chapter 4 of this book for more information on clinical trials.)

Geographic location. Think about travel that might be needed for treatment. How will you get there? How often will you need to go? Are you able to travel farther if it means getting better care? In some cities, nonprofit organizations provide housing or host families for people being treated at a local hospital. If you need help with housing or transportation, call our Cancer Support Helpline toll-free at 888-793-9355, Mon-Fri 9am-9pm ET.

Insurance. Your choice of doctors may be limited by your insurance. Check with your insurance provider and your doctor to make sure your care will be covered. Ask about appointments, tests, and treatments. If you do not have health insurance, see chapter 7 for a list of government and nonprofit organizations that can help or refer to CSC's *Coping with the Cost of Care* book:

www.CancerSupportCommunity.org/cost.

Urgent care needs. Is the medical oncologist available for urgent care needs? Does this doctor work with a team? Who is available to answer questions after hours?

KEY MEMBERS OF YOUR HEALTH CARE TEAM

Each member of your health care team will take care of you in a different way. Your team may include some or all of these:

Medical or thoracic oncologist — A doctor who diagnoses and treats cancer with drugs such as chemotherapy, immunotherapy, or targeted therapy. They will oversee your treatment and work with others involved in your care. Try to find someone who specializes in lung cancer (at least 50% dedicated to lung cancer treatment).

Oncology nurse practitioner (NP) or Oncology physician assistant (PA) — Can diagnose and treat medical problems and prescribe medicine. They may see you with a doctor or alone. This may be the person you contact with urgent questions or concerns.

Radiation oncologist — A doctor who uses energy beams, such as very strong x-rays or protons, to treat cancer.

Thoracic surgeon — A surgeon who is trained in lung surgery. Look for a thoracic surgeon who is “board-certified” in thoracic surgery and specializes in lung cancer. If no one with this training is available, find the general surgeon who performs the most lung cancer surgeries in your area. Ask how many times they have done that operation.

Radiologist — A doctor who oversees the scans used to diagnose and monitor you, including ultrasound, x-ray, MRI, CT scan, bone scan, and PET scan. Note that this is different from a Radiation Oncologist.

Pathologist — You may never meet this doctor. But they are one of the most important members of your team. This doctor focuses on diagnosing cancer. They look at samples of your tissue, fluid, or blood and run tests on these samples in a lab. They try to understand as much as they can about your cancer to help the rest of the team make treatment decisions. Ask to have your samples seen by a pathologist who focuses on lung cancer.

Pulmonologist — A doctor who diagnoses conditions involving the lungs, and assists the rest of the team in draining fluid around the lungs or helping to keep your airways open if blocked by a tumor. They often diagnose lung cancer. They can help with breathing issues during and after treatment.

Primary care physician — A doctor who performs regular check-ups and can help you with non-cancer-related issues like diabetes, hypertension, or asthma.

Oncology nurse — A registered nurse (RN) who specializes in cancer. They may focus on surgery or general oncology. They may provide treatments and other medicines. This person can help you understand cancer and its treatment. They can be a good source of information and support.

Oncology pharmacist — A pharmacist with special training in cancer medicines. They can teach you about drugs and how they interact. They can help you manage side effects. They also may help you find co-pay assistance or discounts.

Palliative care specialist — A doctor, nurse, social worker, or other health care professional who helps manage symptoms, pain, and side effects.

Patient navigator — May be a nurse, social worker, or trained layperson. They can help you find what you need in the health system, talk with your health care team, set up appointments, and explain things in words you can understand.

Oncology social worker and counselors — Can provide counseling and help you find resources. You or your family can talk with them about day-to-day needs, money, transportation, home care, legal questions, stress, sadness, or anything else related to life with cancer.

Psychologist/psychiatrist — Both can provide mental health care to support you before, during, or after treatment. A psychiatrist can prescribe medicine.

Nutritionist/registered dietitian — Can help find foods to eat or ways to eat them to get the nutrients you need. Look for a registered dietitian (RDN) who has experience working with people with cancer.

Physical therapist or rehabilitation medical therapist — Can help treat discomfort that interferes with daily life. Some are certified in cancer or are pulmonary rehabilitation specialists.

Chaplain — Can offer emotional and spiritual support. You also may find support from clergy outside of a hospital.

Interventional radiologist — A doctor who uses imaging to biopsy a tumor or radiation to kill cancer cells.

STEP 2: LEARN HOW TO WORK WITH YOUR TEAM – COMMUNICATION IS KEY

You've chosen your health care team. The next step is to make sure that you work with them in a way that is most helpful to you. In order to get the best possible care, it is important to maintain open communication. You want to be able to report on how you feel. You also want to understand enough about your cancer to help make treatment decisions that match your goals. Here are some tips for communicating with your health care team:

- Keep a running list of questions to bring to office visits. Write down questions as they come to you, so you don't forget later.
- Bring a friend or family member to appointments. It can be hard to take in all the information by yourself. Take notes or ask the person with you to take notes. You can also ask your doctor if you can record the discussions during your visit, especially if no one is available to come with you to your appointment.
- Ask about the best way to get your questions answered. Should you bring a list to every office visit? Do they prefer email? Is there an online patient portal? Do you need to schedule an extra appointment if your list is very long? Find out who to contact with questions and concerns between visits. Write down phone numbers and email addresses in the same place where you take notes and keep track of symptoms and side effects.
- Ask questions until you are sure you understand. You deserve to get your questions answered in a way that makes

sense to you. It's okay to ask the same question again. Tell your doctor if you need something described in a different language or format. For example, you can ask your doctor to draw a picture or compare what they are talking about to something you already know.

- ALWAYS tell your team about:
 - Any side effects or symptoms. This is especially important for those that make you uncomfortable or interfere with your daily life. Your team can help only if they know what's bothering you.
 - Any natural treatments you are taking. This includes herbs, vitamins, supplements, or any kind of other treatments. They may interfere with some cancer drugs. Your doctor can tell you what is safe to take, what isn't, and what is known or unknown about the various treatments.
 - Medicines prescribed by any other doctor for other health conditions. Your doctors need to be aware of what you are taking. They should communicate with each other about your care.
- ALWAYS make sure your goals for treatment are known and honored.

A patient navigator can also help you communicate with your health care team. Ask if your treatment center has patient navigators. Take a look at the worksheet Questions for My Health Care Team on pages 30-31 for questions to ask.

STEP 3: UNDERSTAND THE GOALS OF TREATMENT

The goal of treatment for lung cancer depends on many factors, including the stage at

diagnosis. Lung cancer is often found after it has spread. In that case, the goal is to cure if possible, and, if not possible, to increase the quality and quantity of your life. If the lung cancer is found early, the likelihood of cure is higher. But even with cancer that has spread, modern therapies give hope of cure in some circumstances.

It is important to have a realistic understanding of the situation so you can make better decisions. There are many treatments for lung cancer. The number is growing every year. Researchers discover new treatments, test them in clinical trials, and offer them to patients. Each person's cancer is different. Responses to treatment vary from patient to patient. No one treatment or series of treatments is best for everyone. People often try different treatments, staying with one for as long as it is working.

STEP 4: CHOOSE THE RIGHT TREATMENT FOR YOU

As you start to learn about possible treatments, you will be asked to make decisions. Some of the information may be hard to hear, and these conversations might feel overwhelming at times. Work with your health care team to understand your options and think about what is important to you. Before recommending a specific treatment, your doctor should consider, among other factors:

- The type and subtype of lung cancer you have, including biomarker testing results for advanced stages of NSCLC
- Treatment you may have had for lung or other cancers in the past
- The drug's potential side effects
- Your lifestyle and quality of life

As you consider treatments, be sure to:

- Ask questions. Learn about the different treatments. Find out why one might work better for you than another.
- Ask about the goal of each recommended treatment.
- Ask about possible side effects. Work with your health care team to find the best ways to manage your side effects.
- Ask how much time away from home or work a treatment will require.
- Ask about getting treatment through a clinical trial.
- Talk with family, friends, and your health care team as you consider your next steps.
- Seek support from a support group or mental health professional.
- Consider getting a second or even third opinion. Talking with another doctor can help you better understand your disease and how to treat it.
- Use our Questions for My Health Care Team worksheet (pages 30-31). Review it before each visit to decide the most important questions to ask your health care team.
www.CancerSupportCommunity.org/lung
- Tell your health care team about your goals and what you hope to get out of treatment.
- Tell your health care team about special events in the coming weeks or months that are important to you. They may be able to arrange a “drug holiday” so that you can feel as well as possible at the time of the event.

Treatment Options

Learning about the treatments used for your type of lung cancer will help you and your health care team make shared decisions. Standard treatment for lung cancer often involves a combination of these approaches, together or in sequence. Refer to Chapter 4 for more information on these forms of treatment.



SURGERY: an operation to remove the tumor when the cancer has not spread to other tissues in the chest or beyond. It may also be used when the cancer has spread and is causing further medical risks and/or discomfort.



CHEMOTHERAPY: the use of drugs to destroy or damage cancer cells so they cannot divide and multiply.



RADIATION THERAPY: strong energy beams used to shrink tumors, relieve pain and pressure, decrease symptoms, and improve quality of life.



IMMUNOTHERAPY: treatment that boosts the body's natural defenses to shrink or destroy a tumor.



TARGETED THERAPIES: the use of drugs that work by targeting specific biological changes or differences that enable cancer cells to grow.



PALLIATIVE (SUPPORTIVE)

CARE: medical care focused on relieving the symptoms and stress of a serious illness. It does not treat the cancer itself. It can be used at any age and at any stage. Palliative care is different from end-of-life treatment or hospice care. You can get palliative care while you are getting treatment for your cancer. The goal is to improve quality of life for both the patient and the family. Palliative care is provided by a specially-trained team of doctors, nurses, and other specialists. They work with your other doctors to provide an extra layer of support.

Take Care of Your Body

As you plan to start treatment, try to take good care of your body. Focus on quitting smoking if you smoke, eating well, exercising, getting enough rest, and managing other health conditions. It can be hard to focus on all of these areas at once. Set reasonable goals, and seek support from family, friends, and your health care team, in meeting them.

SMOKING CESSATION

If you smoke, consider stopping. Your treatment is more likely to be successful if you stop smoking. Continuing to smoke increases the chance that the cancer will grow or not respond to treatment. It is also important to avoid secondhand smoke.

Ask those who smoke not to do so in your home or car. If you smoke, or feel as though you might start again, ask your doctor or nurse

what they can do to help you or members of your family stop smoking. Helpful resources can be found here:

www.lung.org/stop-smoking/.

NUTRITION

What you eat can make a difference in how you feel during and after treatment. Consider meeting with a nutritionist or dietitian before you start any treatment to help make sure you are getting the nutrition you need before, during, and after treatment. Be sure to discuss any vitamin or mineral supplements you are taking with your health care team, as some may interfere with your treatment. Be sure to ask your doctor if there are any foods you should be avoiding or increasing while you are being treated. Visit www.CancerSupportCommunity.org/TreatmentNutrition for hints, tips, and recipes to help you eat healthy food during treatment.

PHYSICAL ACTIVITY

Physical activity is important in helping you get the most benefit from 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. Discuss your exercise program with your health care team. If you have not been physically active, speak with your health care team about the best ways to begin activity. A good rule of thumb is to start slowly and work your way up to more challenging activities. For many people, walking is a good starting point. If you are feeling fatigued, mild to moderate exercise can often help you feel less so. For help developing an exercise plan, visit www.CancerSupportCommunity.org/exercise-wellness.

REST

Try to get enough rest. Take naps if needed. Talk with your health care team if pain or discomfort interferes with sleep. Visit www.CancerSupportCommunity.org/sleep-changes for hints coping with sleep problems.

OTHER CONDITIONS

People with cancer may also have other conditions, such as high blood pressure, infections, and diabetes. These conditions can cause symptoms unrelated to cancer or its treatment, such as shortness of breath and fatigue. Let your health care team know about these conditions. Tell them about any symptoms you are experiencing. Fatigue and pain can be treated. It is critical to let your health care team know as soon as possible how these symptoms are affecting you.

QUESTIONS FOR MY HEALTH CARE TEAM

This tool is designed to help you discuss treatment options with your doctor. You are encouraged to tear this page out, take it with you to appointments, and use it as a guide to help you with discussions. Or download and print at www.CancerSupportCommunity.org/Lung.

1. What type of lung cancer do I have? Non-small cell (NSCLC)—adenocarcinoma, squamous cell, large cell? Small cell (SCLC)? (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. If my cancer has metastasized, where are the metastases located?
4. If it is advanced non-small cell lung cancer, has a sample of my tumor been sent for comprehensive biomarker testing? If my tumor is an adenocarcinoma, what are the results for EGFR, ALK, BRAF, HER2, ROS1, NTRK, KRAS, RET, and MET? Does my cancer express PD-L1? What do the results mean for me?
5. How does my current health affect my treatment options? (i.e., age, other medical conditions)
6. What is the goal of my treatment? A cure? To stop or slow the cancer's growth?

TREATMENT OPTIONS

7. Which treatments do you recommend and why?
8. What are the benefits of these treatments?
9. What are the risks of the recommended treatments?
10. What side effects might I expect? 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.)
11. Are there other treatments besides the ones you recommended?

QUESTIONS FOR MY HEALTH CARE TEAM (Continued)

12. How will treatment affect my quality of life? What will it involve in terms of time and travel? (e.g., required clinic visits to receive treatments, monitoring blood counts, restricted activity, hospitalization, etc.)
13. How likely is it that this treatment will work for me?
14. Is surgery an option? (i.e., can the tumor be removed?)
15. Will I have chemotherapy before or after surgery?
16. Will I have radiation before or after surgery?
17. What kind of radiation?
18. What is the name of the chemotherapy I might receive?
19. Will I have immunotherapy? What kind?
20. Am I a candidate for targeted therapy? What kind?
21. Am I eligible for any clinical trials? Where can I learn more about clinical trials?
22. Will I be given any combination treatments (from above)?
23. How and when will you determine if the treatment is working?
24. Are there other resources that can help me during this time?
25. How much will this treatment cost me? Is there a financial counselor I could talk to? Is there a treatment that is just as effective but that costs less?

Open to Options[®] If you are facing a cancer treatment decision, Open to Options[®] is a research-proven program that can help you prepare a list of questions to share with your doctor. In less than an hour, our Open to Options specialists can help you create a written list of specific questions about your concerns for your doctor. Call 888-793-9355 to schedule an appointment.



Ginni

Helping Others and Helping Yourself

Ginni knows the emotional burden that comes with an illness. She was diagnosed with lung cancer three years ago. In addition, she is also a caregiver to her husband, who was diagnosed with leukemia, and has experienced grief with the passing of close family members due to other health conditions.

“Through my experience, I’ve learned to be faithful and journal daily. It’s between me and God. I also love to knit and crochet. I made a hat and wore it during a chemo session; a woman complimented me on it and I gave it to her. I thought to myself, there must be others who would like to receive hats as well. So I knit and crochet hats and give them all away. It helps me to know that I am helping other people.”





IN THIS CHAPTER:

- Treatment by Type & Stage
- Common Terms
- Types of Treatment
 - Surgery
 - Chemotherapy
 - Radiation Therapy
 - Chemoradiation
 - Targeted Therapy
 - Immunotherapy
 - Ablation Therapy
- Taking Cancer Pills at Home
- Palliative (Supportive) Care
- How Will I Know My Treatment Is Working?
- Clinical Trials
- Complementary and Integrative Medicine

4

Treating Lung Cancer

We have learned a lot about treating lung cancer in recent years. Doctors now know more about how lung cancer starts and how to slow its growth and spread. This progress has been a joint effort of scientists, doctors, and patients who participate in clinical trials.

Learning about treatment for lung cancer is an important step in gaining control over your life with cancer. The more you know, the better you will be able to work with your health care team to find a treatment plan that is right for you.

This chapter provides an overview of the different approaches to treating lung cancer.

Your treatment options will depend on the type and stage of your lung cancer. More information, including the latest drugs approved for lung cancer, can be found in Cancer Support Community’s *Treatment for Lung Cancer* booklet in the back pocket of this book or available at www.CancerSupportCommunity.org/lung.

Treatment Overview By Type and Stage

Your treatment options will be determined by your type and stage of lung cancer and the results of your biomarker tests. Refer to pages 15-17 for more information on lung cancer staging.

NON-SMALL CELL LUNG CANCER (NSCLC) TREATMENT	
STAGE 0 (Carcinoma In Situ)	<ul style="list-style-type: none"> • Most often treated with surgery
STAGES IA & IB (1A & 1B)	<ul style="list-style-type: none"> • Most often treated with surgery • Radiation or chemotherapy after surgery may be used, if: <ul style="list-style-type: none"> – Cancer cells are found near the edges of the tissue removed during surgery – Tests show that the tumor appears to be fast growing • If surgery is not an option, radiation (sometimes with chemotherapy) is often used
STAGES IIA & IIB (2A & 2B)	<ul style="list-style-type: none"> • Most often treated with surgery and chemotherapy <i>Chemo may be given before, after, or before and after surgery</i> • Radiation may also be used • If surgery is not an option, chemotherapy and radiation are used
STAGE IIIA (3A)	<ul style="list-style-type: none"> • Treatment depends on where the tumor is, its size, and if the cancer has spread to the lymph nodes <i>Chemo may be given before, after, or before and after surgery</i> • Radiation may also be used • If surgery is not an option, chemotherapy and radiation are used • Immunotherapy may also be used
STAGES IIIB, IIIC, IVA & IVB (3B, 3C, 4A, & 4B)	<ul style="list-style-type: none"> • Surgery is rarely an option • Goals of treatment are to help you live longer and feel better • Most often, immunotherapy or chemotherapy with or without radiation are used • Targeted therapy is used if certain biomarkers are present

SMALL CELL LUNG CANCER (SCLC) TREATMENT

LIMITED STAGE

- Most often treated with chemotherapy and radiation at the same time (chemoradiation)
- Surgery is seldom possible, but may be an option
- Lower dose radiation therapy to the head may be used to prevent spread to the brain. (About half of people with SCLC who don't have preventative treatment will have cancer spread to their brain)

EXTENSIVE STAGE

- Most often treated with immunotherapy and chemotherapy given at the same time
- Radiation may also be used

COMMON TERMS

These terms are used to describe the different types or approaches to treatment. Refer to Treatment Options on page 28 for more information on specific treatments.

First-line therapy: The initial cancer treatment. Second-line therapy may follow if the first treatment is not successful or stops working.

Maintenance therapy: Lower intensity therapy given after first-line therapy to delay the recurrence of the cancer or to try to prevent further progression.

Neoadjuvant therapy: Treatment given to shrink the tumor before surgery; often chemotherapy or radiation.

Adjuvant therapy: Treatment given after surgery, often chemotherapy or radiation.

Multimodality or combined modality therapy: Treatment using a combination of chemotherapy, surgery, radiation therapy, immunotherapy, and/or targeted therapy.

The following words are used to describe different types of responses to treatment, or how the treatment is working:

Complete response or no evidence of disease (NED): On the imaging scan, the cancer appears to be completely gone as a result of treatment. This only means that it cannot be detected on scans, not that it is necessarily completely gone.

Partial response: The tumor has shrunk in size by at least 30%.

Stable disease: The cancer did not shrink but it did not grow either.

Progressive disease: The tumor is growing in spite of the treatment received. When this happens, the current therapy is not working and is usually stopped or changed in some way.

Remission: The cancer has decreased in size ("partial remission") or has disappeared ("complete remission").

Recurrent disease: Cancer that has returned.

Types of Treatment

Lung cancer is treated using one or more of the following therapies. As you talk with your doctor about your options, fill out the *Questions for My Health Care Team* form on pages 30-31. This form can help you learn what you need to know about each treatment that is considered. You can also print a copy from www.CancerSupportCommunity.org/lung.

SURGERY

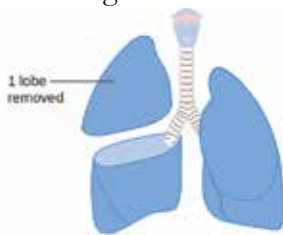


Surgical removal of the tumor is the first choice when the cancer has not spread to other tissues in the chest or beyond, and is still the treatment modality most likely to result in cure. It is mostly used to treat early stage NSCLC and occasionally SCLC. Types of surgical procedures include:

WEDGE OR SEGMENTAL RESECTION: removal of a small part of the lung.

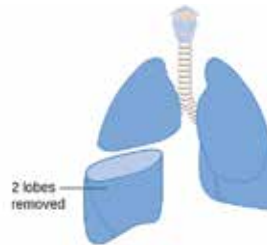
SEGMENTECTOMY: removal of one or more segments (regions supplied by distinct blood and air supply routes) of the lung that are affected by the lung cancer.

LOBECTOMY: removal of an entire section (lobe) of the lung.

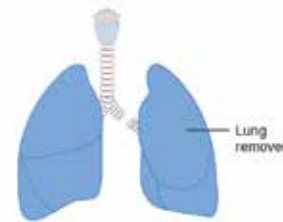


Credit: Cancer Research UK
[CC BY-SA 4.0 (<https://creativecommons.org/licenses/by-sa/4.0>)]

BILOBECTOMY: removal of two lobes of the same lung.



PNEUMONECTOMY: removal of an entire lung.



THORACOTOMY: a cut is made across the side of the chest and the ribs are spread apart so that the surgeon can reach the lung.

VIDEO-ASSISTED THORACIC SURGERY (VATS): uses a tiny video camera to guide the surgeon; may reduce complications and shorten hospital stays and recovery time by avoiding large incisions.

ROBOTIC SURGERY: uses a machine with remote-controlled robotic arms and miniature instruments, making a smaller cut to reduce recovery time. A surgeon moves the machine by hand and foot controls. Sometimes called robotic-assisted thoracoscopic surgery (RATS).

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

- Spread through the tissue covering the lung, involving the fluid between the lung and chest wall.

- Spread to lymph nodes in the neck, opposite the mediastinum (an area located in the center of the chest, but outside the lungs) from where the primary tumor is located, or to other organs (e.g., the liver, adrenal glands, or brain).
- Developed in part of the lung that cannot be removed.
- Developed in a person who has other medical conditions that make surgery not possible, such as heart or lung disease.

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

CHEMOTHERAPY



Chemotherapy (also called chemo) uses drugs to attack and kill cancer cells. These very strong drugs attack fast-growing cells like cancer. Chemotherapy can be used to shrink tumors, slow cancer's growth, relieve symptoms, or help people live longer. It is used to treat both NSCLC and SCLC.

While it is destroying cancer cells, chemotherapy also harms some normal fast-growing cells. This is what leads to some of the more common side effects. (See Chapter 5 for more information on managing symptoms and side effects.)

Chemotherapy is given as a single drug or as a combination of drugs. Most chemotherapy drugs are given by IV infusion (through a needle inserted in a vein). Some chemotherapy drugs can be taken 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 or cycle.

People with late-stage (stage IV) cancer who respond well to their first chemotherapy treatment may be offered maintenance therapy. In some cases, maintenance therapy may use more of the same drug or drugs. In other cases, “switch maintenance” is used, meaning different drugs are used to maintain the response. Talk with your health care team if you have questions about maintenance therapy.

Refer to CSC's booklet *Treatment for Lung Cancer* in the back pocket of this book (with updates available at www.CancerSupportCommunity.org/lung) for more details on specific drugs and how they work.

RADIATION (OR RADIOTHERAPY)



Radiation uses strong energy beams to kill cancer cells and shrink tumors. Radiation beams are pointed directly at areas with cancer cells or tumors to avoid normal tissues as much as possible. These beams are like those used for x-rays, but a million times stronger and designed to kill the cancer. Radiation is used to treat NSCLC and limited-stage SCLC.

The most common type of radiation used for lung cancer is external-beam radiation therapy (EBRT). The procedure is painless. Each treatment lasts only a few minutes. The setup—getting you into place for treatment—usually takes longer.

Stereotactic radiation (for example, SRS, CyberKnife®, Gamma Knife®, radiosurgery,

TAKING ORAL CANCER THERAPIES (PILLS) AT HOME

It's very important to take your pills as prescribed. The exception is if your doctor tells you to hold or reduce your pills due to side effects. Missing a number of doses could make the cancer more likely to spread or return. Here are some tricks that may help you take drugs as prescribed:

- Set reminders on your phone or watch.
- Use a pill calendar or a pillbox to organize your pills by day and time. This will help you see if you have missed a dose.
- Sometimes drugs will come in a blister pack that helps you see whether you took your dose at the right time.
- Store pills at the correct temperature and in a place you will see them every day.
- Follow your doctor or pharmacist's instructions on what to do if a dose is missed.
- Tell your doctor about any missed doses at your regular appointments.
- Check with your doctor to see if you should take your medication with food or if there are certain foods you should be avoiding.
- Ask your doctor if the medication can be taken at the same time as other medication you take.

Based on the drug ordered, your insurance company will tell you where you can get these drugs (such as through a specialty pharmacy, mail order, or a local pharmacy). If using a specialty or mail order pharmacy, you will need to allow extra time for delivery and set reminders to reorder your drugs in time.

SBRT, or SABR) is another type of external-beam radiation. It uses precisely focused, high-dose beams of radiation to kill cancer cells and shrink tumors.

CHEMORADIATION

This is a combination of chemotherapy and radiation therapy. It can be more effective than either alone in treating locally advanced NSCLC or limited-stage SCLC.



TARGETED THERAPY

Targeted therapy is a newer form of cancer treatment. It may be used to treat advanced NSCLC. In recent years, scientists have learned more about what makes cancer cells grow out of control. They have found ways that cancer cells are unlike normal cells and have figured out how to develop drugs that “target” some of these differences. Targeted therapies block the action of certain genes, proteins, or molecules that cause cancer to grow and spread.

Your doctor will need to test your tumor for biomarkers to find out if targeted therapy is right for you. This is called biomarker testing. There are a number of lung cancer biomarkers that have matching FDA-approved treatments. If you have one of these biomarkers, your tumor can be more successfully treated first-line with targeted therapy than with chemotherapy or immunotherapy. Drugs for other biomarkers may be available through clinical trials. Ask your doctor if this is an option for you.

Most often, targeted therapy is given in the form of a pill that you take at home once or twice a day. The pill may need to be taken at a certain time of day, with or without food or liquid. You need to remember to take the pill.

A few targeted drugs are given by IV (into a vein), sometimes in combination with chemotherapy. If this is the case, you may have to go into the clinic every 3 to 4 weeks for treatment. Be sure to ask how your treatment works. Let your health care team know of anything that could get in the way of you following your treatment plan.

Refer to CSC’s booklet *Treatment for Lung Cancer* in the back pocket of this book or our *Targeted Therapy and Biomarkers for Lung Cancer* booklet (www.CancerSupportCommunity.org/TargetedLung) for more on targeted therapies and biomarkers.

ANGIOGENESIS INHIBITORS

Other targeted drugs stop angiogenesis. Angiogenesis is the process by which the tumor makes new blood vessels. By blocking blood vessel growth, the drugs can prevent a tumor from getting the oxygen and nutrients it needs to grow. These drugs may be used to treat advanced NSCLC.

These drugs are also known as VEGF inhibitors. No biomarker test is needed for treatment. They are most often given along with another treatment.



IMMUNOTHERAPY

This form of treatment uses the body’s natural defenses (its own immune system) to identify, attack, and kill cancer cells. By the time a person is diagnosed with cancer, the body’s immune system has tried and failed to fight the cancer. Scientists now know several ways that cancer cells “turn off” the body’s immune response in order to survive. As a result, drugs have been developed to turn the immune system back on or boost the

immune system to kill the cancer. These drugs are called checkpoint inhibitors. They most often target proteins called PD-1 or PD-L1. They are used to treat locally advanced or advanced NSCLC or extensive-stage SCLC. Other checkpoint inhibitors are being studied in lung cancer on their own and in combination with other treatments.

New research is looking at other kinds of immunotherapy to treat lung cancer. These include vaccines or T-cell therapy. Ask your doctor about clinical trials.

Immunotherapy drugs work differently than chemotherapy and targeted therapies. They also have very different side effects. When the body's immune system is boosted or revved up, it may attack normal tissues. Some people may experience hormonal imbalances or inflammation of the bowel or lungs. If you are considering these drugs, ask your doctor about side effects you should watch for. More information on side effects can also be found in Chapter 5.

Refer to CSC's booklet *Treatment for Lung Cancer* in the back pocket of this book or www.CancerSupportCommunity.org/IO Lung for updates and more on immunotherapy and lung cancer.

ABLATION THERAPY

Radiofrequency ablation (RFA) uses heat made by radio waves to kill cancer cells. Cryotherapy uses freezing to do the same thing. Either approach may be used in people with early-stage NSCLC who can't have surgery. These treatments involve a small probe (like a needle) that goes through the chest and directly into the tumor.

Palliative (Supportive) Care

Maintaining your best possible quality of life is an important goal too. Some care you receive may not be designed to treat your cancer. Instead, it will address possible symptoms caused by your cancer or side effects from treatments, such as pain. Some can also help you with psychological, social, or spiritual concerns you may have. This kind of care is called palliative care or supportive care.

Many hospitals offer palliative care to people while they are receiving other treatments for cancer. It is often provided by a palliative care specialist. A palliative care specialist is a health care professional who focuses on treating the symptoms, side effects, and emotional needs of patients. If you have lung cancer and you are not referred to a palliative care specialist soon after your diagnosis, ask to see one.

If a specialist is not available, be sure to let members of your health care team know how you are feeling and tell them about symptoms and side effects, even if they seem minor. This is important to do before, during, and after diagnosis and treatment.

How Will I Know If My Treatment Is Working?

After you have been in treatment for a while, imaging tests like CT and MRI scans will be done to see how the treatment is working—that is, if the cancer has disappeared, shrunk in size, is unchanged, or has grown. Your health care team may request other tests and consider how you are functioning as well.

Clinical Trials

Be sure to ask about clinical trials. Clinical trials are research studies to test new treatments or learn how to use existing treatments better. Today's standard treatments were developed in yesterday's clinical trials. Today's clinical trials may become tomorrow's standard of care. Trials are generally available for each stage and type of lung cancer, although every individual may not be eligible for a given trial.

KEY THINGS TO KNOW:

- No one receives a placebo or “sugar pill” in place of appropriate treatments.
- Clinical trials for lung cancer test new treatments, new combinations of treatments, or better ways of using existing treatments.
- A doctor experienced in treating lung cancer should be able to recommend specific trials.
- The U.S. Food and Drug Administration (FDA) and local review boards oversee all U.S. clinical trials to keep patients safe.
- If you join a clinical trial, you can leave at any time.
- Every doctor does not have the same trials.
- Often, the trial pays the costs of the drug being studied. Then, your health insurance and your copay cover “standard” treatment costs. Be sure to ask about the costs to you.
- There are phase I, II, and III clinical trials; make sure you understand the goals of a clinical trial you join.

- Some clinical trials may make you ineligible for a future trial or treatment, so make sure to ask questions about this.

See the resources below for help finding clinical trials that might be right for you.

RESOURCES TO HELP SEARCH FOR CLINICAL TRIALS:

Cancer Support Community's Clinical Trials Resources

888-793-9355

[www.CancerSupportCommunity.org/
Finding-Clinical-Trial-1](http://www.CancerSupportCommunity.org/Finding-Clinical-Trial-1)

GO₂ Foundation for Lung Cancer

LungMATCH clinical trial matching and navigation service

1-800-298-2436

www.lungmatch.org

LUNGeVity Foundation

Clinical Trial Finder

clinicaltrials.lungevity.org

National Cancer Institute

800-422-6237

www.cancer.gov/clinicaltrials

Complementary and Integrative Medicine

People who have cancer often consider approaches that are outside of traditional western medicine. They may be presented as cancer treatments or as ways to manage side effects. You may hear about complementary and integrative medicine (CIM) therapies from a friend or family member, on the internet, in a magazine, or on the radio or television.

CIM is a broad area. The words to describe it are often used interchangeably. Yet, they have different meanings. Some CIM therapies may be harmless or even helpful. Others can have severe consequences or even counteract known effective therapies. It is important to let your health care team know about anything you are doing or considering doing to prevent, treat, or help with the symptoms of lung cancer or the side effects of treatment. The following definitions may be helpful:

COMPLEMENTARY MEDICINE is used together with conventional medicine.

It may include meditation for stress reduction, peppermint tea for nausea, acupuncture for back pain, or massage. These approaches complement, or add to, conventional treatments.

ALTERNATIVE MEDICINE is a term referring to treatments that are promoted for use in place of conventional medicine. Alternative therapies are not scientifically proven and may be dangerous.

INTEGRATIVE MEDICINE is treatment that combines conventional medicine with complementary therapies that have been proven safe and effective after being studied in people.

Most CIM therapies have not been approved by the U.S. Food and Drug Administration (FDA). This is because they have not been shown to be safe and effective in clinical trials. For this reason, be sure to speak with your health care team about taking or using any complementary, alternative, or integrative therapies while being treated for lung cancer.

QUESTIONS TO ASK ABOUT CIM

- Will this interfere with or work against my current treatment?
- Is this used to cure the cancer or help standard treatment to work better?
- Does it relieve symptoms or side effects?
- Are recognized experts in cancer treatment offering this therapy?
- Has research about this been published in scientific journals?
- Is this promoted only through mass media, or also in scientific journals?
- Is this expensive? Will insurance cover the cost?

CIM RESOURCES

Organizations that provide good information about CIM practices and the role they may play in cancer treatment include the National Center for Complementary and Integrative Health and the National Cancer Institute's Office of Cancer Complementary and Alternative Medicine. Please refer to the Cancer Support Resources section on page 75 for additional information.

Lorna and Her Family

Facing Cancer Together

Lorna was being treated for bronchitis for the fifth time in a year. Her husband, Joe, spoke up. He pointed out that Lorna's breathing difficulties and chest pain came back after each round of antibiotics. Her doctor ordered a CT scan. When Joe and Lorna didn't get the test results back quickly, they picked them up themselves and took them to a different medical facility. Though it was much further from their home, they wanted the best treatment available. There they learned that Lorna had adenocarcinoma, a form of lung cancer.

The new medical team presented treatment options. A positive biomarker test for BRAF revealed that Lorna might benefit from a therapy that would target the BRAF 9 gene without the complications caused by chemotherapy. Joe says, "It's been a rough ride financially and emotionally, but this year's been better because of this medicine." Before, Lorna often woke multiple times in the night gasping for air.

Joe knew that the family needed more than just medical care. His call to a radio talk show brought them to Gilda's Club South Jersey. The organization has been a steadfast source of support for Lorna, Joe, and their kids ages 10 and 16. The family truly appreciates the information, community, and support that Gilda's provides. Lorna's faith helps her face her challenges, and their church is also an important source of support for her and the whole family.

Although they struggle, the family is grateful for access to good health care. "We're doing okay," Joe says. Lorna now receives top care from a high-quality cancer center and support and education from their local Gilda's Club.



IN THIS CHAPTER:

- Symptoms of Lung Cancer & Side Effects of Treatment and How to Manage Them:
 - Difficulty breathing
 - Inflammation of the lungs
 - Low blood cell counts
 - Fatigue
 - Eating and digestive problems
 - Hair loss
 - Pain and discomfort
 - Skin problems
 - Chemobrain
 - Immunotherapy side effects
 - Peripheral neuropathy and hearing loss
 - Intimacy Concerns

5

Managing Treatment Side Effects

Treatment side effects can be one of the hardest parts of a cancer experience. Discuss possible side effects with your doctor and nurse before you begin treatment so that you understand what may happen and what to do if they occur. It is your job to report side effects to your health care team. Often, side effects can be managed, but your team needs to know you're having them.

It is possible that some of the symptoms of lung cancer will remain with you during treatment and require management as well.

Pay attention to your body's physical signs. Keep track of any changes you notice. Talk with your health care team and your family about how you are feeling. Ask if there is a palliative care doctor who can help you feel better. Open communication with the people involved in your care can help you feel as good as possible throughout and beyond treatment.

Symptoms and side effects may include:

DIFFICULTY BREATHING

It is common for people with lung cancer to have breathing problems. Trouble breathing can decrease energy and cause fatigue. Breathing can become uncomfortable. You may feel like you can't get enough air into your lungs. It can be a scary sensation. Breathlessness or breathing problems can be caused by tumors or blood clots in the lung or airways, an infection, certain chemotherapy drugs, fluid around the lungs or heart, a condition called radiation fibrosis, or feelings of stress or anxiety.

Sometimes, lifestyle changes can help with breathing problems. In other cases, medical treatment may be needed.

Tips for 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, corticosteroid therapy, and pulmonary rehabilitation 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.

For more tips, go to:

www.CancerSupportCommunity.org/breathing-problems.

INFLAMMATION OF THE LUNGS

Immunotherapy and some targeted therapies can cause inflammation of your lungs. This is a rare side effect but it can be fatal. Call your health care team if you experience a worsening cough, chest pain, or shortness of breath while taking a targeted therapy or immunotherapy. The problem can reverse itself by stopping treatment—temporarily or permanently—or using steroids.

LOW BLOOD CELL COUNTS

Chemotherapy and radiation can destroy healthy cells as well as cancer cells. Low blood counts are among the most common side effects of chemotherapy or radiation. Your health care

team will watch your blood cell counts carefully. Low blood cell counts can lead to anemia, infection, or bleeding. Transfusions or drugs called growth factors can help boost your blood cell counts when they get low. For more information and tips on coping, go to: www.CancerSupportCommunity.org/anemia-infection-bleeding

FATIGUE

Of all the side effects associated with treatment, fatigue is the most common and distressing complaint of many people with lung 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. Fatigue does not mean that your cancer is worse. Tell your health care team if you feel fatigued. Generally, for most people, fatigue will begin to decrease within a few weeks or months after treatment, and your energy will return. For tips on coping with fatigue, go to: www.CancerSupportCommunity.org/fatigue.

EATING AND DIGESTIVE PROBLEMS

Cancer treatments may lead to loss of appetite, diarrhea, constipation, nausea, vomiting, changes in the way food tastes and smells, weight loss, and sores in the mouth and throat. Radiation treatment can cause a condition called esophagitis, which makes swallowing painful and difficult. It is often described as a feeling of food getting stuck in your throat. There are many medicines to treat eating and digestive problems, some of which are sold over-the-counter. Ask your doctor or nurse which one would be the best for you. Go to www.CancerSupportCommunity.org/TreatmentNutrition for tips on coping and recipes to help with eating and digestive problems.

HAIR LOSS

Hair loss is one of the most well-known side effects of cancer treatment. It does not happen to everyone. It varies by person and treatment. Some chemotherapy drugs and radiation to the head can cause some people to lose some or all of their hair. Hair loss is also called alopecia. When it occurs, hair loss usually happens 10 to 21 days after the first treatment. You may lose the hair on your head, body, or around your eyes. Do not make any assumptions about how the cancer is responding to treatment based on your hair loss. Ask your health care team if you are likely to lose your hair and, if so, when. Knowing the timing will help you prepare. By planning ahead, you may feel more control over hair loss and your cancer. Visit www.CancerSupportCommunity.org/hair-loss for tips on coping with hair loss.

PAIN AND DISCOMFORT

Cancer and some cancer treatments may 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 bra line. Headache is a common side effect of some treatments too. If you have pain, know that it can often be relieved. Remember that you have the right to relief from pain. So be sure to ask for it. For more on coping with pain, visit www.CancerSupportCommunity.org/pain-neuropathy.

SKIN PROBLEMS

A variety of skin problems, including pain, redness, scaling, dryness, sun sensitivity, hives, itching, and sometimes hyperpigmentation (darkening) of the skin, may be side effects of radiation, immunotherapy, and chemotherapy.

Targeted therapies can cause skin rash, some forms of acne, and sometimes darkening of the skin and nails. Ask about this side effect before you start treatment so that you can have medicine on hand and know how to use it in case a problem occurs. If a rash from a targeted therapy becomes severe enough that painful pustules (small pus-filled bumps) develop, or if you are concerned about your appearance, call your health care team right away. Some rashes can become severe if infected and must be managed carefully by your team. For more on coping with skin and nail changes, visit www.CancerSupportCommunity.org/cancer-treatment-side-effects/skin-nail-changes.

CHEMOBRAIN

It is estimated that one in five people who undergo chemotherapy will experience what many refer to as chemobrain. Symptoms such as forgetfulness, lack of concentration, confusion, difficulty finding the right words, and trouble multitasking have all been described by people who have had cancer. Although 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. If you feel that you may have chemobrain, talk with your health care team about the problems you are experiencing. It is also a good idea to tell the people around you what is going on so that they can support you. Coping strategies like writing things down and making lists, focusing on one thing at a time, eating well, and getting even a small amount of exercise can help you feel more on top of things. For more on coping with cognitive changes, visit www.CancerSupportCommunity.org/cognitive-changes.

IMMUNOTHERAPY SIDE EFFECTS

We tend to think of immunotherapy as “natural”—as a stronger version of our body’s own defense system. However, immunotherapy can still have side effects. In many cases, they are minor and may be short-lived or easy to manage. Less often, they are severe and may even be life-threatening. Little is known about whether there are long-term side effects. The side effects listed here are seen with checkpoint inhibitor immunotherapy drugs.

Common side effects:

- Flu-like symptoms (fever, chills, headache, nausea, cough, loss of appetite)
- Fatigue (some people get extreme fatigue)
- Rashes, redness, or itching
- Pain or soreness
- Muscle or joint pain
- Drops in blood pressure

Less common side effects:

- Colitis or other gastrointestinal problems (stomach pain, diarrhea)
- Thyroid problems
- Lung problems (cough, shortness of breath)
- Other serious autoimmune conditions (such as pituitary disorders or diabetes)

Most side effects can be treated early and managed well. Sometimes a side effect will occur several months later. Having one or more side effect does not always mean that you must stop taking drugs that are working for you.

If you are on immunotherapy, it is important to let your health care team know right away if you notice any change in how you feel.

PERIPHERAL NEUROPATHY AND HEARING LOSS

Some chemotherapy can cause numbness and tingling, particularly in the fingers and toes, and sometimes extending to the hands and feet. This is also called peripheral neuropathy. It can also cause hearing loss. If you experience any of these side effects, make sure you tell your doctor, as dosing adjustments may need to be made. For more on coping with peripheral neuropathy, visit www.CancerSupportCommunity.org/pain-neuropathy.

INTIMACY CONCERNS

Many people have said that, after being diagnosed with cancer, they experience a change in their interest and desire for sexual activity. They may 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 health care team before you start treatment for lung cancer. For concerns about intimacy, talk with your partner and members of your health care team who may be able to point you to resources or support that may be helpful during this time. For more on coping with intimacy issues and/or fertility, visit www.CancerSupportCommunity.org/intimacy-sex-and-fertility-issues.

Elaine

Managing Side Effects

Managing the side effects of treatment was one of the hardest parts of Elaine's lung cancer experience. "I had many challenges from my treatment at the very beginning. The original chemo was very tough to handle." Once Elaine began to trust her health care team, she learned to rely on them for advice. "My relationship with my health care team grew over time. At the beginning, I didn't know what to expect. Through time, I came to realize that they're phenomenal." In particular, Elaine recognized the importance of communicating with her health care team. "I learned that it's okay to ask. It's better than okay. It's necessary." Elaine offers this advice to the newly diagnosed, "You find a hospital you trust and you do what they say. And then as you're going through the process and you're coming across difficulties, you speak up."



IN THIS CHAPTER:

- Dealing with the Emotional Impact
 - Depression & anxiety
 - Anger
 - Stress
- Children
- Intimacy
- The Impact on Caregivers
- Respite Care
- Support at End of Life, including Hospice

6

Coping and Support

Living with cancer can affect your emotional and mental health. You may feel depressed, shocked, worried, or even panicked. There may be changes in family roles and issues related to self-esteem. You may struggle with money or health insurance.

The emotional impact of a lung cancer diagnosis on a person or family can vary greatly. It may depend on the extent of the disease, its treatment, and each person's situation and personality. At 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 to have. Try 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, counselor, or clergy person or joining a cancer support group.

The diagnosis and treatment of cancer can cause a great deal of stress. Three of the most common social and emotional stressors for people with cancer are:

Loneliness. Some cancer support organizations may be able to connect you to people in similar situations throughout the cancer experience. These connections can help reduce the feeling that you are alone and increase your 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, and what is hoped for may change. For example, when physical cure does not seem possible, the focus can shift to hope for physical comfort and emotional and spiritual healing.

Depression and Anxiety

Sometimes the emotional, social, or spiritual effects of lung cancer can feel unmanageable. You may find that you have lost interest in things that used to make you happy. Discuss these feelings with your health care team; they may be able to help. Your team may prescribe a change in your medicines or recommend that you speak to an oncology social worker or therapist.

Signs of depression include:

- Persistent sad or empty feelings most of the day
- Loss of interest or pleasure in ordinary activities
- Difficulty sleeping or excessive sleeping
- Change in appetite
- Change in body weight (loss or gain)
- Difficulty concentrating or making decisions
- Fatigue or restlessness
- Thoughts of suicide or death. If you or a loved one has thoughts of suicide, help is just a phone call away. Call the National Suicide Prevention Lifeline at 800-273-8255 to talk to a skilled, trained counselor near you. This service is available 24 hours a day, seven days a week.

Anger

Anger is a normal response to being diagnosed with lung cancer. It is an emotion you may feel at any point as you go through treatment. You may think, “Why me?” or “I’m too young.” You may think, “I want to see my kids or grandkids grow up.” Or “I led a healthy life.” You may feel angry at the tobacco industry, your doctor, or the sight of others smoking. If you are a smoker

and still smoke, you may feel angry or guilty when others mention quitting when you feel as though smoking is your only “comfort” left.

Some people feel angry when they are not communicating well with their health care team or family. You may feel this way once in a while. Or, if anger is an ongoing concern, you may want to speak with someone. Ask your health care team or refer to the list in this book to find resources to help you deal with anger.

STRESS MANAGEMENT

Stress management techniques can become valuable tools you can use. 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.
- It is very helpful to maintain some level of physical activity when living with a cancer diagnosis. Walking, yoga, qi gong, and many other types of physical activity can help you to manage your emotions and mood.

Stress

You also can learn how to control how you respond to stress.

Family members may 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. Know that the resources available to support you may be able to help your loved ones as well.

Children

Children sense and know more than adults often give them credit for. Children will overhear telephone conversations, pick up on their parents’ anxiety, blame themselves, and fear the worst if they are given no information. It is important to talk to children. Young children up to the age of eight will not need a great deal of detailed information. Older children and adolescents will need to know more.

Parents and grandparents may want to set aside a quiet time for this conversation. Keep these tips in mind:

- Try to understand that unusual behavior may be your child’s way of showing how upset they are.
- Give them small pieces of news, gradually building up a picture of your illness.
- Do not keep secrets, because even small children can guess when something is wrong.
- Remember that their fears of what might happen are likely to be far worse than the real situation.

- Remember that uncertainty or not knowing may be more difficult for them to cope with than the truth.

Many children need regular reassurance that your illness is not their fault. Whether they show it or not, children often feel in some way to blame and may feel guilty for a long time. Young children especially may have trouble understanding. Teenagers also may feel guilt because they have reached an age when they want to get away and become independent but now feel that they ought to be at home to help or provide support. Support groups or other forms of peer support can be very helpful for teenagers. Offering a teen counseling options can also be helpful.

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 ones may allow them the opportunity to provide emotional or physical closeness.

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. For more, go to:

www.CancerSupportCommunity.org/intimacy-sex-and-fertility-issues.

Caregivers

Lung cancer affects not just the person with the disease, but also the people who care for them. A caregiver is anyone who provides physical, emotional, financial, spiritual, or logistical support to a loved one with cancer. Some caregivers may live with the person but others may not. Caring for someone with cancer 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.

The role of a caregiver can change over time. At some points it may just require a few hours a week. At others, it may be a full-time job. Caring for someone with cancer can lead to work-related issues such as missed days, low productivity, and work interruptions. Some caregivers need to take unpaid leave, turn down promotions, or lose work benefits. The stress of caring for someone on top of worrying about keeping your job can be overwhelming. Dealing with these issues is important to both employers and employees.

Caregivers are often so focused on taking care of their loved ones that they neglect their own mental, emotional, and physical health. That is why caregiver support groups are a vital resource to assist caregivers. Caregivers may face numerous issues, including struggling to maintain a normal life. In addition, caregivers may feel depressed at times. In-person and online support groups are a great place for members to share concerns and obtain help, and may help caregivers feel less alone. For more information and resources for caregivers, go to: **www.CancerSupportCommunity.org/caregivers**.

Respite Care

Respite care is short-term, temporary relief to primary caregivers who support an ill loved one. Respite care offers a way for caregivers to take a break. You may use respite care for a few hours, a full day, or several days or weeks. It may be provided in your home, in a nursing home, or in an adult day care center. It is often a positive experience for everyone involved.

You can contact a respite care organization when you need time away. To find such a program or learn more, visit www.archrespite.org.

End of Life

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 may have a difficult time with these conversations and think this means the person who has cancer is giving up. This is not always the case. If possible, try to have these discussions when you are healthy and strong as part of the coping process.

When cancer is described as terminal, it means that it cannot be cured and is likely to eventually lead to death. The amount of time is difficult to predict, but it could be weeks, months, or years.

If you are at the stage where active treatment has been stopped, it is normal to experience a wide range of emotions such as anger, denial, fear, sadness, and even acceptance. Open and honest communication with both your health care team and your family can help you maintain control over this time and provide an opportunity for you to accomplish certain goals or achieve closure that might give you a sense of peace.

During this time, it is important to take care of yourself and find enjoyment and comfort where you can. Ask for pain medication and other treatments to help manage symptoms and side effects. The goal is to feel as comfortable as possible. Eat when you feel like it, and let your loved ones know if eating is making you feel uncomfortable. If you have questions or need additional support, talk to members of your health care team. Even if you are not in active treatment, they can still be important resources.

Hospice

When a person is unlikely to live longer than six months, hospice care is often recommended. It involves the care of all aspects of an individual's and family's needs. People receive help with pain management, as well as the psychological, social, and spiritual aspects of suffering. It does not typically involve treatments that cure your cancer (for example, it's rare to be offered chemotherapy or radiation unless these therapies are given to relieve pain or other symptoms).

Yet, some research has found that people receiving hospice care may live longer than those in treatment. Some people even become stronger in hospice care, leave hospice, and resume treatment.

Hospice care can be provided in the comfort of your home, in a nursing home, or at a hospice facility. Usually multiple care professionals are involved to meet your physical and emotional needs, as well as the emotional needs of your family.

Ask your health care team about hospice early in your treatment. Many people are referred to hospice later than they could be. That means that they and their families miss the opportunity to benefit from everything hospice has to offer.



Darleen

Caregiving and Support

As caregiver for her mother with non-small cell lung cancer, Darleen acted as a go-between, letting her mother's doctors know about side effects and concerns. "I quickly learned that I needed to let the doctors know any kind of subtle change I saw... somebody needed to help speak for her when she wasn't feeling up to it, or cared to convey her feelings."

After relocating their mother from Virginia to New Jersey, Darleen and her sister shared responsibility for her care, dividing time and tasks to ensure that their mother's needs were met. Darleen made sacrifices, including a missed family vacation, yet she recalls the experience in a positive way. "It was an incredible journey. As much as it was hard emotionally, it was a privilege to be with her through all of that. I'm glad I was there, and that I could be there the whole time. I wouldn't have given it up for anything in the world."

IN THIS CHAPTER:

- Dealing with Practical Issues
 - Medical costs
 - Health insurance
 - Disability
- Helpful Legal Documents

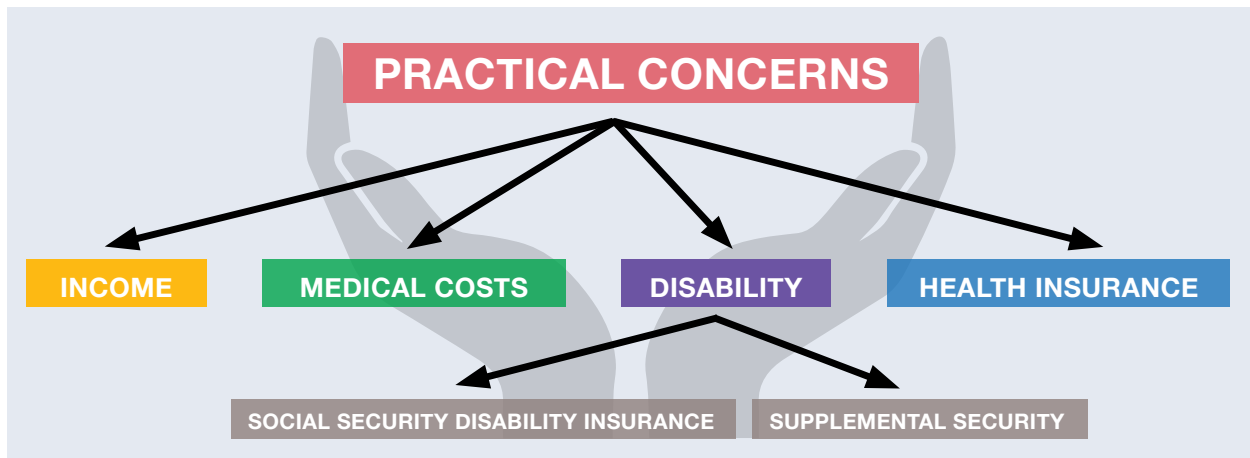
7

Practical Concerns

When you're told you have cancer, how to pay for your care is not usually the first thing that comes to mind. But having health insurance coverage for your cancer treatment and all of the needed follow-up care is critical for most people.

Some people must resolve money issues before they can even start treatment. For others, affording care can become a problem after treatment begins. Either way, it takes time and energy to manage your medical bills, insurance, and finances. This can be especially difficult when you have cancer.

Many people with lung cancer feel unable to work during treatment. Others find it helpful 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.



Medical Costs

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

In most cases, help is available. There may be government programs and nonprofit organizations that offer advice and resources for support. (See the Resources section for more information.) Additionally, there may be a member of your health care team who can answer questions about insurance choices. One of the most important things you can do is discuss the cost of cancer treatment with your health care team.

Health Insurance

If you have health insurance and have questions about your policy, call your insurance provider. Ask about your coverage. You can also talk with your human resources department or manager at work. If you don't have insurance or need financial assistance, there are organizations and programs that offer help. Talk to social workers or business officers in your clinic or hospital about the financial concerns you may have.

Disability

Short- and long-term disability insurance may provide financial help while you're being treated for lung cancer. This may be an option even if you do not have health insurance. Some employers carry disability insurance for their employees. Policies can also be bought 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 receive SSI are also eligible for Medicaid.

If you and your health care team expect 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 receive assistance if you are eligible. You can apply for benefits by calling the toll-free Social Security number, 800-772-1213, or go online at www.ssa.gov.

LEGAL CONCERNS

It is a good idea for all adults, regardless of their current health status, to prepare for the future by having their legal 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) if you die. In many states, an agent of the state will make these decisions if there is no will. Decisions take much longer without a will.

LIVING WILL OR ADVANCE DIRECTIVE

A legal document that details your wishes regarding future medical care if you are no longer able to speak for yourself.

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. It is also known as a health care agent or health care proxy. 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. 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 in the event that you are unable to make your own medical decisions. Be sure your medical POA and health care team have copies of the signed directives.

DO-NOT-RESUSCITATE (DNR) ORDER

An order that your doctor writes on your chart if you decide 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 that 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 health care team before you become seriously ill. Your decisions about resuscitation should be documented in your living will and should be discussed with your POA.

Carmen

Receiving Kindness and Support

As a teacher and a therapist, Carmen was used to helping others. After her diagnosis with lung cancer, Carmen learned to accept support. “The hardest part for me was to realize how humble one needs to be to accept help from strangers. I cried many times when people did kind things for me, and had to believe that what was given to me was what I gave out all my life. So that helped, but it’s still challenging.”

By paying attention to her own needs, Carmen stayed strong. “One of the biggest things I learned is self-compassion. I’ve always taken care of myself, so that reinforced it, to keep taking care of myself, and to not be afraid and to admit when I was afraid.” The financial impact of cancer hit hard but Carmen managed, “I was very careful. I didn’t spend any money. I ate at home always... I used credit cards. I just made sure I had my mortgage money and I worked enough to do that.”





IN THIS CHAPTER:

- Participating in Support and Advocacy
- Taking Care of Yourself
- Finding Hope

8

Moving Forward

A diagnosis of lung cancer can make you wonder how long you or your loved one has to live. It's frightening to imagine a different future than you originally planned for yourself. It can also be difficult to talk about such painful topics.

Some people who have had cancer want to work directly with patients and caregivers to share what they have learned or provide support. Others may want to work on changing national or state laws. Some are interested in learning about lung cancer research and providing the patient perspective for clinical trial design. Still others may want to focus on taking care of themselves and spending time and energy on work, loved ones, or other interests.

Participating in Support and Advocacy

Some people who have had cancer find that they want to share what they learned or support those who are going through the same experience. Others may be interested in working

to change laws or policies to help more people. There are many ways you can become involved in the lung cancer support and advocacy community. A good starting point is to talk with the people or organizations that helped you. People just like you can be important sources of support for others or voices for change. If we all work together, we can reduce the stigma

associated with this disease. Possible ways you may become involved include:

Help others through peer support. People with lung cancer often learn and get comfort from others who have had the disease. Ask about answering support telephone lines, helping with in-person support groups, or providing support online. Reach out to support organizations or hospital staff to learn more.

Become an advocate. Advocacy is about standing up, being visible, and being heard. It is about promoting change and not accepting the status quo. Take a public stand for those causes and issues that matter to you. You can advocate for changes to disability or insurance laws or increases in government funding for lung cancer research. Advocacy can involve making phone calls, sending emails, signing petitions, writing letters or articles, or visiting government offices.

Become a patient advocate. There are many ways to be a patient advocate. Some are similar to providing peer support but focus on helping groups of people, not individuals. For example, you could work with local hospitals to make sure people are getting the care, treatment, and support they need. Being a patient advocate can also mean working with researchers to help set up clinical trials. You can make sure that the patient's point of view is considered and that the recruiting process is appropriate. People who have had cancer are also sometimes needed to sit on government committees or review grant proposals from a patient perspective. Patient-driven groups have formed around many subtypes of lung cancer in order to accelerate research to improve patient outcomes. Consider getting actively involved in one of these groups as well.

Taking Care of Yourself

If your treatment is over, it is important that you receive regular follow-up care. Visit your doctor as prescribed to check for any return of cancer. The American Society of Clinical Oncology recommends that you have follow-up appointments with your oncologist every three months during the first two years after treatment, every six months during years three through five, and yearly after that. You can schedule more frequent appointments if you are experiencing symptoms that worry you, or if you have other health care concerns. Even after treatment ends, you may experience lingering symptoms or side effects from lung cancer or its treatment. Ask your oncologist what symptoms to be on the lookout for. If symptoms occur, report them promptly.

As you finish treatment, or if your cancer is stable on treatment, you may have a lot of questions about how to move forward. Write questions down as you think of them and have them ready when you have appointments, email conversations, or phone calls with members of your health care team. Possible questions may include:

- How long will it take me to recover from my treatment?
- Are my treatment-related side effects permanent?
- Will I be able to go back to work?
- Can I take up my usual sports, hobbies, and activities again?
- Where can I get help dealing with my feelings?

- Does the cancer center or hospital provide counseling services and/or survivorship programs? Are they free or is there a fee?
- How do I get practical help at home?
- Who can advise me on money matters or help with insurance benefit claims?

Finding Hope

Your sense of “hope” can change over time. Perhaps you hope for recovery of your physical and emotional health; for peace in your relationships; for good communication with your health care team; for a way to come to terms with lung cancer and its place in your life. By doing important things such as 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 to beat their cancer. Do not expect to be positive all of the time; however, trying to view things from a positive perspective as much as possible can improve your general well-being. Finding healthy ways to express your feelings is helpful.

Lloyd

Tending to His Emotional Health

Lloyd understands the importance of participating in a support group. After being diagnosed with lung cancer he sought support from his local Cancer Support Community. Lloyd recalls, “Emotional support is not at the top of the list for us guys, but it is so important. There are a lot of men out there who need emotional support. I now meet with a group of men with different kinds of diagnoses; we eat and discuss how we are doing with our illness.”

In addition to attending support groups, Lloyd also practices mindful meditation, which has helped him live more in the present moment. “One thing I’ve learned from my cancer journey is to simply slow down. Reduce the amount of anxiety and deal with any mental issues I am experiencing. The biggest thing that has helped me is mindfulness programs. I was simply shown another way that I can effectively reduce my stress and anxiety to a point where it is nicely manageable.”



Glossary

Ablation — The removal or destruction of a body part or tissue or its function.

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

Adenosquamous Carcinoma — A subtype of non-small cell lung cancer.

Adjuvant Therapy — Treatment given soon after the first or primary treatment.

Advanced Directive — A legal document containing written instructions about your future medical care. It is used 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 Medicine — Nontraditional methods of diagnosing, preventing, or treating cancer that are used instead of proven methods. They can be harmful.

Anaplastic Lymphoma Kinase (ALK) — A gene that makes a protein involved in cell growth that, if mutated, may help cancer cells grow.

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

Angiogenesis — The process of making new blood vessels.

Angiogenesis Inhibitor — A drug that prevents the development of new blood vessels that supply blood to the tumor, thereby stopping or limiting tumor growth.

Bilobectomy — Removal of two lobes of the same lung.

Biomarker — A substance in blood, bodily fluid, or cells that doctors measure to learn more about a person's cancer.

Biomarker Testing — Also called tumor testing, genomic testing, mutation testing, or molecular testing. Looks for changes in your lung cancer's genes. Uses samples of a person's cancer. The samples are taken by biopsy or surgery. A biomarker test looks at the cancer's unique biological makeup. This information can be used to help choose treatments for a person's specific lung cancer.

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

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

Chemobrain — Common term used to describe thinking and memory problems experienced during and after cancer treatments.

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

Chemotherapy Cycle — 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 order according to a strict schedule.

Clinical Trial — A research study to test how well new medical treatments work in people. Cancer clinical trials test new ways of screening, preventing, diagnosing, or treating cancer or improving the quality of life for people with cancer.

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

Cryoablation — Uses liquid nitrogen or argon gas to freeze tumors.

Disease Progression — Term used to describe the growth or spread of cancer.

Driver Mutations — Changes in cancer cell's genes that cause or “drive” the cancer to grow, divide, and spread. Some causes of these changes are known (e.g., tobacco use, harmful chemicals, aging), but others are not.

Dysphagia — Difficulty swallowing.

Dyspnea — Difficult, painful breathing or shortness of breath.

Epidermal Growth Factor Receptor (EGFR) — Proteins on the surface of cells that appear to cause cancer cells to grow.

EGFR Inhibitor — A drug that blocks EGFR (see above) to keep cancer cells from growing.

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

Fatigue — Feeling of extreme tiredness that interferes with normal activities. Can feel like weariness, sleepiness, or irritability.

First-Line Therapy — Medical treatment recommended for the initial treatment.

Gene — Pieces of DNA present in every cell in the body.

Genetic Marker — A gene or piece of DNA associated with a certain disease.

Immunotherapy — Treatment that boosts the body's own immune system to destroy cancer cells.

Interstitial Lung Disease — Group of disorders that cause difficulty breathing and getting enough oxygen into the bloodstream. They may cause scarring of lung tissue.

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

Lobe — A major section of one lung. The right lung has three lobes, but the left has just two.

Lobectomy — Removal of one lobe of either lung.

Locally Advanced — Cancer that has spread to nearby tissue or lymph nodes.

Lymph Nodes — Small bean-shaped glands that help filter fluids and destroy harmful bacteria and viruses. There are thousands of lymph nodes throughout the body. They are part of the immune system.

Malignant — A malignant tumor is a cancerous tumor.

Medical Power of Attorney — Document that allows you to appoint a trusted person to make decisions about your medical care if you cannot make decisions yourself.

Metastasis — The spread of cancer to other tissues.

Molecular Marker — Another term for biomarker.

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

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

Mutation — A change in a cell's genes (DNA).

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

Non-Small Cell Lung Cancer (NSCLC) — The more common of the two main types of lung cancer.

Oxygen Therapy — Used to relieve breathing problems by providing supplemental oxygen.

Palliative Care — Supportive care to relieve pain, symptoms, and side effects in order to improve quality of life. Does not treat the disease itself.

Partial Remission — When a cancer tumor has shrunk in size but has not totally disappeared. Further treatment may be recommended.

Peripheral Neuropathy — Damage to the nervous system that affect messages from the brain or spinal cord to and from the rest of the body. Some chemotherapy drugs can cause this condition. Symptoms include weakness or tingling in the hands or feet.

PET (Positron Emission Tomography) 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.

Pleural Effusion — Abnormal amount of fluid between the thin layers of tissue (pleura) lining the lung and the wall of the chest cavity.

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.

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 changed 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.

Radiation Fibrosis — When radiation treatment triggers the immune system to form scar tissue inside the lung.

Radiation Therapy — Uses strong energy beams, such as very strong x-rays, or protons, to kill cancer cells and shrink tumors.

Refractory Disease — Cancer that does not respond to treatment.

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

Remission — Absence of disease. A person 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.

Signature Molecule — Another term for biomarker.

Squamous Cell — Cells that are flat in shape.

Stable Disease — Disease does not get better or worse following treatment.

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

Standard of Care — See “Standard Therapy.”

Standard Therapy — Current primary therapy that has been shown to be safe and effective over time. Also known as “standard of care.”

Stereotactic Radio-Surgery — Uses high-energy x-rays to destroy cancer.

Targeted Therapies — Drugs that target specific changes in cells that enable cancer to grow.

Thoracentesis — A procedure in which a needle is inserted into the pleural space between the lungs and the chest wall. Done to remove excess fluid, known as a pleural effusion, from the pleural space to help patient breathe easier.

Thoracic — Related to the part of the body between the neck and abdomen.

Thoracic Pathologist — A specialist in analyzing diseases of the chest area, including lungs, trachea, and chest wall.

Thoracoscopy — A surgical procedure, performed under general anesthesia. An instrument called a thoracoscope is inserted through a small cut in the chest wall to allow a doctor to look at the lining of the chest wall and the surface of the lungs.

TNM Staging System — A way of describing the extent and spread of lung cancer. Doctors measure tumor spread and size, lymph nodes affected, and distant sites involved. This is used to stage lung and many other cancers at Levels I through IV.

Trachea — The windpipe.

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

Vascular Endothelial Growth Factor (VEGF) — Protein that helps new blood vessel growth. VEGF inhibitors block the activity of this protein, which may keep cancer cells from growing.

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

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 Resources

Cancer Support Helpline®

Whether you are newly diagnosed with cancer, a longtime cancer survivor, caring for someone with cancer, or a health care professional looking for resources, CSC's toll-free Cancer Support Helpline (888-793-9355) is staffed by licensed CSC Helpline Counselors available to assist you in 200 languages Monday through Friday from 9:00 a.m. - 9:00 p.m. ET.

Open To Options®

Preparing for your next appointment? Our trained specialists can help you create a list of questions to share with your doctor. Make an appointment by calling 888-793-9355 or by contacting your local CSC or Gilda's Club. www.CancerSupportCommunity.org/OpentoOptions.

MyLifeLine®

CSC's private, online community allows patients and caregivers to easily connect with friends and family to receive social, emotional, and practical support throughout the cancer journey and beyond. Sign up at www.MyLifeLine.org.

Frankly Speaking About Cancer®

Trusted information for cancer patients and their loved ones is available through publications, online, and in-person programs. www.CancerSupportCommunity.org/FSAC

Services at Local CSCs and Gilda's Clubs

With the help of 170 locations, CSC and Gilda's Club affiliates provide services free of charge to people touched by cancer. Attend support groups, educational sessions, wellness programs, and more at a location near you. www.CancerSupportCommunity.org/FindLocation

Cancer Experience Registry®

Help others by sharing your cancer patient or cancer caregiver experience via survey at www.CancerExperienceRegistry.org.

Grassroots Network®

Make sure your voice is heard by federal and state policy makers on issues affecting cancer patients and survivors by joining our Network at www.CancerSupportCommunity.org/become-advocate.

More Information on Lung Cancer

American Cancer Society

800-227-2345

www.cancer.org

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

American Lung Association

800-586-4872

www.lung.org

Provides comprehensive lung cancer education and support information, including downloadable tools and videos, advice and support on how to quit smoking, a free Lung HelpLine, and an online support community for those facing lung disease.

Cancer Support Community

888-793-9355

www.CancerSupportCommunity.org/Lung-Cancer

Offers free support groups at affiliates across the country or online, and also offers free healthy lifestyles groups, educational programs, literature, and resources.

Cancer Survivors Against Radon

www.cansar.org

Dedicated to preventing radon-induced lung cancer and saving lives through education and awareness.

Cancer.net

888-651-3038

www.cancer.net

Provides timely, oncologist-approved information to help patients and families make informed health care decisions, from the American Society of Clinical Oncology.

CancerCare

800-813-4673

www.cancercare.org

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

Food and Drug Administration

888-463-6332

www.fda.gov

Provides a list of FDA-approved drugs for lung cancer, and information on drugs approved by the FDA for diseases other than lung cancer that may be in clinical trials for lung cancer.

Gianni Ferrarotti Lung Cancer Foundation

www.gianniscause.org

Raises awareness and funds for the fight against lung cancer and offers support to those who are affected by lung cancer.

GO₂ Foundation for Lung Cancer

800-298-2436

www.go2foundation.org

Dedicated to saving, extending, and improving the lives of those vulnerable, at risk, and diagnosed with lung cancer by providing education, support, clinical trial navigation, and advocacy through the care continuum.

Lung Cancer Action Network

www.lungcan.org

A group of lung cancer advocacy organizations that have come together to raise public awareness about the realities of lung cancer.

Lungcancer.org

800-813-4673

www.lungcancer.org

A service of CancerCare that provides support, education, and financial assistance to people with lung cancer. Call the lung cancer toll-free information line to learn more.

Lung Cancer Foundation of America

www.lcfamerica.org

Committed to helping more people survive lung cancer and ultimately finding a cure for lung cancer by raising money for and calling attention to the need for innovative lung cancer research.

Lung Cancer Research Foundation

212-588-1580

www.lungcancerresearchfoundation.org

Funds innovative, high-reward lung cancer research with the potential to extend survival and improve quality of life for people with lung cancer. Also promotes lung cancer awareness and education across the nation through events and free educational materials.

LUNGevity Foundation

888-360-5864

www.LUNGevity.org

Through research, education and support, focuses on improving lung cancer survival rates, ensuring a higher quality of life for lung cancer patients, and providing a community for those impacted by lung cancer.

National Comprehensive Cancer Network

215-690-0300

www.nccn.org/patients/

An alliance of leading cancer centers devoted to patient care, research, and education and dedicated to improving the quality, effectiveness, and efficiency of cancer care.

National Cancer Institute

800-422-6237

www.cancer.gov

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

National Institutes of Health

www.clinicaltrials.gov

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

National Cancer Institute's Office of Cancer Complementary and Alternative Medicine

800-422-6237

cam.cancer.gov

Increases the amount of high-quality information and cancer research conducted about the use of CAM therapies.

National Center for Complementary and Integrative Health | NCCIH

888-644-6226

nccih.nih.gov

Conducts and supports research and provides information about complementary health products and practices.

National Coalition for Cancer Survivorship

877-622-7937

www.canceradvocacy.org

Provides information, programs, and resources on cancer survivorship.

Financial and Legal Assistance

Cancer and Careers

646-929-8032

www.cancerandcareers.org

Empowers and educates people with cancer to thrive in their workplace.
Look online for free publications, career coaching, and support groups for employees with cancer.

Cancer Legal Resource Center

866-843-2572

www.thedrlc.org/cancer/

Provides free and confidential information and resources on cancer-related legal issues to cancer patients, survivors, and their families.

Centers for Medicare and Medicaid Services

800-633-4227

www.cms.gov

Call to find out if you are eligible for government health insurance programs.

Healthcare.gov

www.healthcare.gov

The federal website offering customized information about the various health insurance options for which you may be eligible.

Patient Advocate Foundation

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.

Patient Access Network Foundation

866-316-7263

www.panfoundation.org

Provides assistance to underinsured patients. Patients or a member of their medical team can apply online or over the phone.

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The Cancer Support Community provides this information as a service. This publication does not take the place of medical care or the advice of your doctor. Talk to your doctor or other health care professional to answer your questions and learn more.

CANCER SUPPORT COMMUNITY MISSION

The Cancer Support Community (CSC) is a global non-profit network of 175 locations, including CSC and Gilda's Club centers, health-care partnerships, and satellite locations that deliver more than \$50 million in free support services to patients and families. In addition, CSC administers a toll-free helpline and produces award-winning educational resources that reach more than one million people each year. Formed in 2009 by the merger of The Wellness Community and Gilda's Club, CSC also conducts cutting-edge research on the emotional, psychological, and financial journey of cancer patients. In addition, CSC advocates at all levels of government for policies to help individuals whose lives have been disrupted by cancer. In January 2018, CSC welcomed Denver-based nonprofit MyLifeLine, a digital community that includes more than 40,000 patients, caregivers, and their supporters that will enable CSC to scale its digital services in an innovative, groundbreaking way.

For more information, visit www.CancerSupportCommunity.org
So that no one faces cancer®

FRANKLY SPEAKING ABOUT CANCER: LUNG CANCER PROGRAM PARTNERS:



FRANKLY SPEAKING ABOUT CANCER: LUNG CANCER WAS MADE POSSIBLE WITH GENEROUS SUPPORT FROM:



Photographs by Ed Cunicelli

New treatments for Lung Cancer are being developed. For the most recent and up-to-date version of our *Treatment for Lung Cancer* booklet, visit www.CancerSupportCommunity.org/Lung to download and print yourself. To order a print copy, visit Orders.CancerSupportCommunity.org or call 888-793-0355.



www.CancerSupportCommunity.org
888-793-9355