



The Cancer Support Community (CSC), Lung Cancer Alliance (LCA), American Lung Association (ALA), LUNGeivity Foundation and Free to Breathe have joined together to develop this booklet for people impacted by lung cancer. It is our hope that it offers insight into understanding a diagnosis of lung cancer, making treatment decisions and coping with the emotional and practical challenges people with cancer face. As you read this booklet, you will become part of a global cancer support community and find you are not alone—there is a whole community behind you.

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You are not alone

You may have recently been given news that you didn't want to hear. You have 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 220,000 Americans will hear what you heard: They have lung cancer. Indeed, lung cancer is the most common cancer worldwide, accounting for 1.8 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 is choosing to adopt actions, behaviors and attitudes that can help you regain a sense of control over your treatment and life with cancer.

GAINING CONTROL

Once lung cancer becomes part of your life, you may be faced with a challenging but also rather straightforward decision: Can I gain control of my lung cancer or will it take control of me? Gaining control early on can lead to better outcomes and quality of life.

Gaining control is also associated with choosing 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 three to ten years ago. Today's newer therapies have not been around long enough to affect the statistics, so your prognosis may be more hopeful than the statistics 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 describe despair. 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.

There are many ways to hope. You can hope for the big things—that the cancer is successfully treated 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

How do you gain control? You can do this by:

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

“I know a lot about lung cancer, but today, you really have to be on your toes and educate yourself.”

– Ide Mills, living with lung cancer

report from your doctor. Or, you might hope that tomorrow will be a sunny day and you can get out in your garden, or you will spend time with your 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.

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 stopping or slowing the growth of the cancer. These drugs are called targeted therapies.

The immune system is also a source of great hope for people with many cancers, including lung cancer. A new kind of treatment pushes or boosts the immune system to work harder to fight the cancer and it has 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, including targeted therapies or immunotherapy. A clinical trial is a carefully controlled study of a treatment. More information on clinical trials and how to find them can be found on page 26.

COPING WITH STIGMA

There can be blame, shame and stigma associated with lung cancer, especially for those who have smoked at some point in their lives. 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. But remember, if you did smoke, you can’t change the past and 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 and even angry at those who look at you with that “I told you so” gaze. And yes, you may even be angry at government and corporations for allowing tobacco to exist in the first place. Try to move forward and not focus on blame or the past.

Stigma can be especially confusing if you are among the 15-20% who never smoked. 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 caretaking, 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 71 to ask for help and find support.

CHOOSING YOUR HEALTH CARE TEAM

The physical and emotional effects of lung cancer and its treatment can be major. It is important to know that help is available from the different people who make up your health care team. Good communication among patients, caregivers and health care team members is crucial.

WHAT YOU CAN DO TO COMBAT BLAME, SHAME AND STIGMA

- If you smoked, forgive yourself. You cannot change the past.
- 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.

IDE MILLS knew a lot about cancer. She was an experienced oncology social worker, but she was unprepared for her own diagnosis of metastatic lung cancer. It came after months of struggling with mysterious symptoms that were thought to be everything from allergies to a chronic sinus infection. In the four and half years she has lived with what she describes as a “life threatening chronic disease,” Ide has been through chemotherapy and several targeted therapies, ALK inhibitors, that have kept her cancer at bay.

“People say, ‘so when are you going to be done with your treatment?,’ ” she says. “They don’t realize that this is not like being treated for an early breast cancer. I have been blessed to have this happen to me at a time when I have benefitted from a number of new drugs, with several more in the pipeline. Knowing there are options for me is a big part of what keeps me going.”

“Lung cancer treatment today is very complicated. It’s like learning to speak a new language. It’s really important to learn as much as you can about your disease, so you can be involved in your care. And, if you are the kind of person who doesn’t want to know much, then find someone in your life, your matrix, to be your learner and your advocate.”





Actions You Can Take to Regain Control

STAY IN THE MOMENT. Try to focus on resolving only today's problems and take one step at a time, one day at a time.

ASK FOR SUPPORT. Help others understand what you need. Be as open as you can with your family and friends about how they can support you. Offer specific examples, such as driving you to appointments, helping with babysitting or going to the movies for a break. Take someone with you to medical appointments to take notes and help you remember important information.

ACKNOWLEDGE AND EXPRESS YOUR FEELINGS. Take time to listen to your body and to the things you are saying to yourself. When you are aware of your feelings, express them by talking, writing, exercise or other creative pursuits. You may want to attend a support group led by a social worker, nurse or patient advocate to share your feelings or learn from others. These groups may be held in-person or online.

DO WHAT YOU ENJOY. Continue activities you enjoy and can do comfortably. Find new activities if you feel tired or have other limitations. Ask friends to join you, or give yourself permission to be alone when you need to be.

SEEK RELAXATION. Relaxation refers to a calm, controlled physical state that will improve your well-being. Take relaxing breaks in your daily routine: Listen to music that makes you happy, read a book, do an art or craft activity or take a walk. Take time to enjoy the moment. Consider joining a yoga, tai chi or meditation class. Watching your favorite TV show may put you in a relaxed state. Relaxation is something that you may have to learn.

COMMUNICATE WITH YOUR HEALTH CARE TEAM. Prepare a list of questions for each appointment. Bring a notebook to your appointments and write things down. If you don't understand what something means, ask until you understand. Ask for a copy of your medical records, including the pathology reports that confirmed your lung cancer and ask your doctor to show you the scans that confirmed your diagnosis.

DEVELOP A TREATMENT PLAN. This plan should coordinate medical and emotional care, support you in managing your illness, link you with needed psychosocial services and identify support organizations that can help you with specific needs. Your doctors and caregivers can help. You may choose to get a second opinion on your diagnosis and treatment plan to best understand your options.

SPEND TIME WITH OTHER PEOPLE WHO HAVE HAD CANCER. People with cancer often find comfort in talking with others who share their experiences—either in person, online or by phone. Cancer support organizations such as the Cancer Support Community, Lung Cancer Alliance, American Lung Association and LUNGevery Foundation can help you connect with others living with lung cancer.

HOLD ONTO HOPE. You can find hope in many things. Hope is desirable and reasonable. Even if your own cancer recovery does not seem possible, you can set small goals and enjoy daily pleasures. Get tickets to a concert. Participate in a religious study class. Attend a birthday, anniversary or other event for someone you love. Talk about what gives you hope and what you hope for—now and in the future. Share these hopes with your family, friends and the members of your health care team.

If you are uncertain about your diagnosis, the members of your team, the treatments they are suggesting or just want to know about other options, you can ask for a second opinion or consider changing doctors or hospitals. Another hospital or doctor may offer a different treatment or more useful support services, or be a better fit for you in other ways. Do not worry about hurt feelings. Many people seek second opinions, and some doctors even encourage it. Your first concern is your own health.

Choosing the members of your health care team and your treatment center will be

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.

one of the most important decisions you will make. Remember that, in maintaining control of your lung cancer, you are ultimately the person who makes that decision. It is important to understand the role played by each member of your health care team. Members of your health care team may include:

■ **MEDICAL OR THORACIC ONCOLOGIST.** Specializes in diagnosing and treating cancer with drugs like chemotherapy, immunotherapy or targeted therapy. The oncologist may work with other specialists involved in your care. It is good to work with a medical oncologist who specializes in lung cancer or whose practice is at least 50% dedicated to the treatment of lung cancer.

■ **THORACIC SURGEON.** May be trained specifically in lung surgery. Try to talk with a thoracic surgeon who is “board-certified” in thoracic surgery and specializes in lung cancer, rather than a cardiac or general surgeon. If no one with this training is available, find the general surgeon who performs the most lung cancer surgeries in your area.

■ **RADIATION ONCOLOGIST.** Uses various forms of radiation to safely and effectively treat cancer. Like surgery, this is a highly technical specialty that requires advanced training.

■ **PULMONOLOGIST.** Specializes in diagnosing and treating diseases and conditions involving the lungs. They are often the ones who diagnose lung cancer and help with breathing issues during and after treatment.

■ **PATHOLOGIST.** This “silent” member of the team, whom you may never meet, specializes in the laboratory science used

FIND A LUNG CANCER SPECIALIST

Where can I find a lung cancer specialist?

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

ADDITIONAL RESOURCES FOR REFERRAL INFORMATION

- American College of Surgeons, Commission on Cancer (CoC)
800-422-6237
www.facs.org/cancerprogram
- American Lung Association Lung HelpLine
800-586-4872
www.Lung.org
- Cancer.net
www.cancer.net
- Lung Cancer Alliance
800-298-2436
www.lungcanceralliance.org
- The National Cancer Institute
800-422-6237
www.cancer.gov

to diagnose cancer. They look at samples of tissue, fluid or blood taken from a biopsy. They use a variety of tools to try to understand as much as they can about your cancer. Their findings help the rest of the team make treatment decisions.

■ **ONCOLOGY NURSE.** Cares for people with cancer. Similar to doctors, oncology nurses may specialize in the surgical or medical management of a patient's care. They are often a valuable source of information, support and education. Some oncology nurses are certified to give chemotherapy or other treatments for your lung cancer, or may have advanced nursing training or certification, such as nurse practitioner or clinical nurse specialist.

■ **ONCOLOGY SOCIAL WORKERS AND COUNSELORS.** Can help you cope with the emotional impact of cancer and identify other resources you may need. You or your family can talk with them about day-to-day needs, money or legal questions, stress, sadness or anything else affected by your diagnosis. Do not underestimate the support these individuals provide. Many hospitals, cancer centers and oncology practices have specially trained oncology social workers who work with people diagnosed with cancer through group or individual counseling.

■ **PATIENT NAVIGATOR.** May be an oncology nurse, oncology social worker or a trained lay person. A navigator is available to assist you through the health care system, identify members of your health care team and explain things in words you can understand.

TALKING WITH YOUR HEALTH CARE TEAM

You will have important decisions to make about treatment. Never be afraid to ask your health care team questions that can guide you through the treatment process. Write down questions as you think of them between visits and take them to your next appointment.

QUESTIONS TO ASK YOUR HEALTH TEAM

- What type of lung cancer do I have?
- What stage of lung cancer do I have?
- Has my tumor been tested in a lab for abnormalities, biomarkers or genetic mutations?
- What treatment do you recommend and why?
- Are there other treatments besides the one you recommend?
- What are the benefits of these treatments?
- What are the risks of the recommended treatment?
- How long will the recommended treatment take?
- What side effects will I have?
- What can be done about the side effects?
- How and when will you determine if my treatment is working?
- What is a clinical trial? Is there one that might be right for me?
- Is there a targeted therapy that might work for me? (If yes, go through the questions above to understand the treatment, its benefits and risks and what is involved.)
- Is a new kind of treatment like immunotherapy an option for me? (If yes, go through the questions above to understand the treatment, its benefits and risks and what is involved.)

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.

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Understanding lung cancer

Cancer is a condition in which cells multiply uncontrollably to form growths called tumors. The cancer cells invade and destroy normal, healthy tissue and can spread to other parts of the body. Tumors that are cancerous are called malignant, and noncancerous tumors are called benign. Cancer cells can spread from their original site to other parts of the body in a process known as metastasis. The word metastatic is often used to describe cancer that has spread. 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.

The lungs are two organs in the chest that are responsible for breathing. 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, and even a large tumor may be present without any feelings of pain or discomfort. As a result, only 15% of lung cancers are discovered in the earliest stages.

The more you know about your type of lung cancer and its cells and tissues, 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 has many subtypes. The three most common ones are adenocarcinoma, squamous cell carcinoma and large cell carcinoma. NSCLC makes up 85% of cases, and SCLC only 15%.

The difference between NSCLC and SCLC has to do with the way the cancer cells look under the microscope, but is also associated with how quickly they spread to other parts of the body and how they respond to different treatments.

RISK FACTORS

A risk factor is something that increases your chances of developing a disease. Risk can come from your body, your family history or your lifestyle. The following risk factors are associated with lung cancer:

■ **HISTORY OF SMOKING OR EXPOSURE TO SECONDHAND SMOKE.** A history of smoking is the main 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. Secondhand smoke is exposure that comes from living with someone who smokes or working in a location where smoking is or was allowed.

■ **AGE.** The average age of diagnosis with lung cancer is between 65 and 74 years old. As with most cancers, the risk of developing lung cancer increases as a person ages.

■ **ENVIRONMENT.** An increased risk of lung cancer can be tied to exposure to high levels

of certain natural gases and chemicals 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. In a relatively small number of instances, asbestos has been linked to a rare form of lung cancer. Asbestos is more commonly associated with another type of cancer that can affect the lungs called mesothelioma.

■ **FAMILY HISTORY.** In some cases, genetics may play a part in the development of lung cancer. If members of your family have had lung cancer, it is important to talk to your doctor about your possible risk.

DIAGNOSIS AND STAGING

Your doctor may use several different tests to determine if you have lung cancer, what type (“diagnosis”) and where it has spread (“staging”).

Staging is a vital part of treatment planning. It helps determine where the cancer is in your body and match what is learned about your cancer into one of several distinct groups to help guide treatment. Tests used for diagnosis and staging of lung cancer can be complex, and no single plan is right for every patient. The results of these tests allow both NSCLC and SCLC to be grouped into stages using the “TNM” system (short for Tumor, Nodes, Metastasis), which labels tumors by their tumor size, if and where lymph nodes are affected and the presence or absence of spread to other parts of the body (“metastasis”). Once TNM labels are assigned,

tumors are placed into numeric categories called stages, which range from I to IV. (Please refer to Chapters 4 and 5 for more information on the staging of NSCLC and SCLC.)

Talk with your health care team about the tests you will need. Ask if and how far in the body the cancer has spread. The results of these tests will provide information you and your health care team can use to decide which treatments are best for you. Some or all of the tests and procedures listed here may be used.

HEALTH HISTORY

When diagnosing lung cancer, it is critical for your health care team to have a detailed medical history. They will ask questions about your smoking history, exposure to secondhand smoke or chemicals in the environment and any key symptoms such as nagging cough, shortness of breath, fatigue and back or chest pain. In addition, your family health history provides information that may indicate a greater likelihood that you will develop lung or other cancers.

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

BIOMARKERS FOR DIAGNOSIS AND TREATMENT

Biomarkers are features of the tumor or the person with cancer that help guide treatment decisions. They are sometimes called signature molecules or molecular markers. Biomarkers can be genetic or non-genetic.

HENRY When Henry’s wife of 54 years, Ruth, was diagnosed with lung cancer, he was by her side, where he remained throughout her journey, driving her to appointments 55 miles away and eventually caring for her in their home. Soon after Ruth’s diagnosis, Henry developed stomach pains.

“I went to different doctors and they couldn’t figure it out. I had a CAT scan, and was going through what Ruth went through.” As Ruth grew more ill, friends would ask after the couple. “People asked, ‘How are you doing? How is Ruth doing?’ and I was doing fine but gradually I was doing worse and worse as Ruth got worse and worse and I was so busy as a caretaker I just didn’t know exactly what to do.” A low point came when Ruth fell out of bed one night, and Henry could not lift her. A kind policeman came to the rescue that night and again two weeks later. By relying on resources like the police and a “wonderful” hospice program, Henry was able to give Ruth the care she needed.



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. According to the National Comprehensive Cancer Network, a group of cancer centers that develops recommendations about treatment, people at high risk for lung cancer include:

- 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.
- People who have had lung cancer already: If you survived one lung cancer, you have a very 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 computed tomography (CT). Remember, the ultimate goal of lung cancer screening is to find lung cancer at a time when treatments will work best.

Genetic biomarkers can be:

- **INHERITED.** Present in all cells of the body and passed on to children.
- **ACQUIRED.** Genetic changes or mutations present only in the tumor and not passed on to children.

Most of the biomarkers that are helpful to making treatment decisions in lung cancer are acquired. They are found by studying tumor tissue in a laboratory.

Non-genetic biomarkers are also important and can help determine the type of lung cancer (squamous versus non-squamous) and the best treatment. In particular, your doctor may want to look at a protein called PD-L1, which can be helpful in choosing immunotherapies.

The best time to get your tumor tested for biomarkers is during the first biopsy. That way, when it comes time to discuss treatment options, you will know if you are eligible for certain targeted therapies or immunotherapies without waiting for results from another biopsy to come back.

Cancer researchers continue to try to find new biomarkers that can be detected in the blood. In the future, such markers may make it possible to detect lung cancer earlier. A list of biomarkers for lung cancer appears on page 34.

Questions to Ask About Biomarker Testing

- Was my tissue sent for molecular testing?
- Which tests were requested?
- Are you looking for any specific biomarkers?
- How will you use the information to recommend a treatment plan?
- Will my insurance pay for the biomarker testing?

TOOLS FOR DIAGNOSIS

Imaging scans provide a picture of the lungs and surrounding area. Major types include:

- **CHEST X-RAY.** A special radiographic picture is taken 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.
- **CT AND MRI SCANS.** CT (computed tomography) and MRI (magnetic resonance imaging) use computers to produce detailed, three-dimensional images that help diagnose lung cancer and can determine the size, shape and location of a tumor. 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) uses a radioactive substance and a special camera to see how organs and tissues are working. PET scans 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. PET scans do not provide as detailed an image so they are often used as a follow-up to other tests or to diagnose recurrent disease.

A sample of tissue or fluid will be needed to confirm the presence of cancer cells or cancer and identify its type and stage. There are many ways to obtain a sample. Common ones include:

- **NEEDLE BIOPSY.** A small piece of lung tissue is removed and looked at under a microscope.
- **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 and also provides a sample to 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 three-dimensional virtual "roadmap" that enables a doctor to biopsy hard-to-reach parts of the lungs.

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Making treatment decisions

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, you will probably talk with family, friends and members of your health care team.

It is important to understand as much as you can about your treatment options. Individual treatment plans depend on the type and stage of the cancer—where the cancer is located, if or where it has spread and whether it is affecting other parts of the body. Many people find that it helps to get a second or even third opinion from another oncologist, and many doctors encourage it. Different doctors have different experiences with various treatments, and seeking multiple opinions can help you make a decision or confirm your current treatment plan. Newer treatments that are showing success are sometimes only available through clinical trials. Every hospital does not offer clinical trials or the same clinical trials. You may want to check with your insurance company first to find out if a specific doctor or health care system will be covered by your policy.

Common Terms

These terms are used to describe the different types or approaches to treatment. Refer to Treatment Options on page 22 for more information on specific treatments.

FIRST-LINE THERAPY: The initial cancer treatment. Second-line therapy may follow if the first line is not successful or stops working, and so on.

MAINTENANCE THERAPY: Lower intensity therapy given after first-line therapy to delay the recurrence of the cancer.

NEOADJUVANT THERAPY: Treatment given to shrink the tumor before the primary treatment, often surgery.

ADJUVANT THERAPY: Treatment given after the first or primary treatment, often surgery.

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.

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: Cancer signs are decreasing or have disappeared.

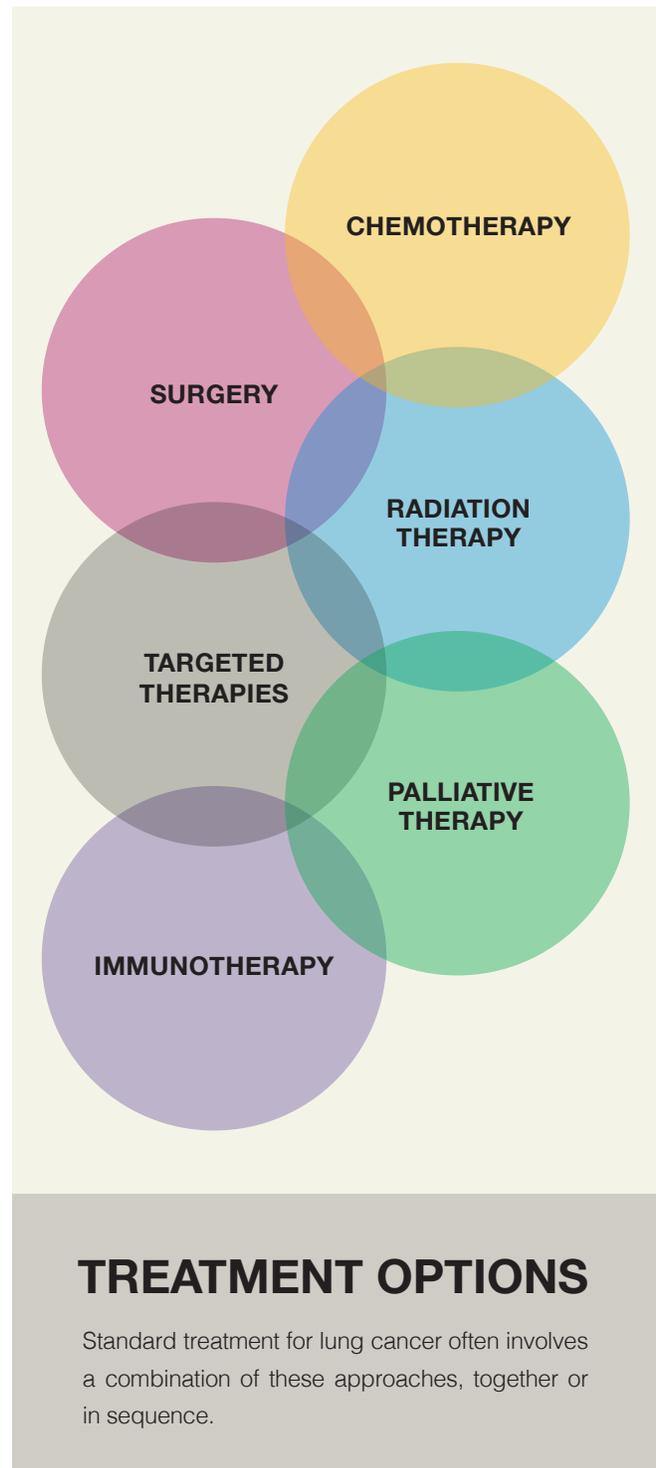
RECURRENT DISEASE: Cancer that has returned.

Learning about all of the treatments commonly used for your type of cancer will help you and your health care team make shared treatment decisions.

TREATMENT OPTIONS

Standard treatment for lung cancer often involves a combination of these approaches, together or in sequence:

- **SURGERY:** an operation to remove the tumor when the cancer has not spread to other tissues in the chest or beyond.
- **CHEMOTHERAPY:** the use of drugs to destroy or damage cancer cells so they cannot divide and multiply.
- **RADIATION THERAPY:** high-energy x-rays 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 eliminate a tumor.
- **TARGETED THERAPIES:** the use of drugs or other substances that work by targeting specific biological changes or differences that enable cancer cells to grow.
- **PALLIATIVE THERAPY:** treatment to help with symptoms and side effects of the cancer but not treat cancer itself. It focuses on pain management, improving quality of life and perhaps extending life when cure is not likely. Attention to quality of life early on and during treatment has been shown to help people with advanced lung cancer live longer.



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.

MEDICAL BACKGROUND QUESTIONS

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

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

3. How does my current health status affect my treatment options?
(i.e., age, other medical conditions)

4. What is the goal of my treatment?

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

TREATMENT OPTIONS

6. 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.)

7. What is the likelihood that this treatment will work for me?

8. Is surgery an option? (i.e., can the tumor be removed?)

9. Will I have pre- or post-surgery chemotherapy?

10. Will I have pre- or post-surgery radiation?

11. What kind of radiation?

12. What is the name of the chemotherapy I might receive?

13. Am I a candidate for immunotherapy? What kind?

14. Am I a candidate for targeted therapy? What kind?

15. Am I eligible for any clinical trials? Where can I learn more about clinical trials?

16. Will I be given any combination treatments (from above)?

17. Are there other resources that can help me during this time?

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.”





CLINICAL TRIALS

Cancer clinical trials are research studies that test whether new drugs or other treatments are safe and effective for the prevention, diagnosis or treatment of cancer. Before the U.S. Food and Drug Administration (FDA) approves a new treatment for use, it must move successfully through a multi-level clinical trial process. Thus, the current standard drugs were once in clinical trials and tomorrow's drugs are in them today. Trials are generally available for each stage and type of lung cancer, although every individual may not be eligible for a given trial.

IS A CLINICAL TRIAL RIGHT FOR YOU?

Doctors are always working to improve the ways we treat cancer. They do research to develop new drugs, or figure out how to use the drugs we have better. They look for treatments that have fewer side effects, or are easier for people to tolerate.

The goal is to make sure that every person facing cancer has the best available treatment. That means that treatments are always changing as doctors make discoveries and use that knowledge for new and better cancer treatments.

IF YOU WANT TO SEARCH MORE WIDELY FOR CLINICAL TRIALS, THE FOLLOWING RESOURCES CAN HELP

- Lung Cancer Alliance & LUNGeVity Foundation

Clinical Trial Matching Service

800-698-0931

www.emergingmed.com/networks/LungCancerAlliance/ or

www.emergingmed.com/networks/LUNGeVity

- Cancer Support Community's Clinical Trials Resources

800-814-8927

www.cancersupportcommunity.org/clinicaltrials

- National Cancer Institute

800-422-6237

www.cancer.gov/clinicaltrials

Every cancer treatment we have today was developed in a clinical trial. Cancer clinical trials are research studies to determine whether new treatments and interventions are safe and effective for the prevention, diagnosis or treatment of cancer. They provide patients with access to new therapies, the next generation of cancer treatment. Before the FDA approves a new treatment for use, the treatment must move successfully through the clinical trial process. There are now thousands of trials going on all over the world to study new drugs and treatments that will become the therapies of the future. Each study has specific conditions a person must meet in order to participate. Participation in a clinical trial is always voluntary and participants may choose to leave the study at any time.

If you have cancer, it's important to know about clinical trials and how they work. Not every cancer patient will be on a trial—or needs to be. But, everyone should be aware that a clinical trial can be the best treatment option at some point during your care, and everyone should have the chance to talk about clinical trials with your doctor. Your health care team can provide you with information about the clinical trials available at your hospital or treatment center.

PREPARING FOR TREATMENT

■ **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. You can and should 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.

■ **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.

■ **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.

■ **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.

4

Non-small cell lung cancer and its treatment

Non-Small Cell Lung Cancer (NSCLC) is the most common kind of lung cancer, accounting for approximately 85% of all lung cancers. There are three main types of NSCLC: adenocarcinoma, squamous cell carcinoma and large cell carcinoma. They are distinguished by the size, shape and location of the cancer cells. The diagnosis of NSCLC can require many tests to determine the stage or extent of the disease. Staging is the process of finding out how much cancer is in a person's body and where it is located. Your health care team will need this information in order to provide the best treatment.

STAGING OF NSCLC CANCER

Staging for treatment planning may happen at diagnosis or before or after surgery. Sometimes, your health care team may restage a cancer based on how well a treatment is working or to get more information about a cancer that has come back after treatment. Usually some of the same tests that were done when the cancer was first diagnosed will be repeated. After this, your health care team may assign the cancer a new stage.

The TNM Staging System is one of the most commonly used cancer staging systems, standardizing cancer staging internationally. 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?

Each letter is graded with a number:

- The letter “T” plus a number from 0 to 4 describes the size and location of the tumor, including how much the tumor has grown into nearby tissues. A larger tumor or one that has grown more deeply into the surrounding tissue receives a higher number.
- The letter “N” plus a number from 0 to 3 describes whether cancer has been found in the lymph nodes, and which nodes are involved. Generally, the farther the involved nodes are from the tumor, the larger the number assigned.
- The letter “M” indicates whether the cancer has metastasized, or spread, to other parts of the body. If the cancer has not spread,

it is labeled M0. If the cancer has spread, it is considered M1.

This process results in a group of three pairs (for example, T2, N1, M1). Now a numerical stage can be assigned. There are five numerical stages associated with NSCLC lung cancer. Roman numerals 0 to IV are used, with a lower number usually associated with a better outcome.

In general, cure rates are better for cancers diagnosed at lower stages than higher ones but keep in mind that there are other factors tied to outcome besides staging. They include your overall health and the type of lung cancer.

TREATMENT OF NSCLC

Treatment of NSCLC may involve just one type of therapy, but more frequently a combination of therapies is used.

SURGERY

Surgical removal of the tumor is the first choice when the cancer has not spread to other tissues in the chest or beyond. 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 is affected by the lung cancer.
- **LOBECTOMY:** removal of an entire section (lobe) of the lung.
- **BILOBECTOMY:** removal of two lobes of the same lung.
- **PNEUMONECTOMY:** removal of the entire lung.

■ **THORACOTOMY:** an incision is made across the side of the chest and the ribs are spread apart so that the surgeon can gain access to the lung.

■ **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 remotely controlled robotic arms to perform the minimally invasive surgery with miniature instruments; a surgeon moves the machine by hand and foot controls.

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

■ Spread into the tissue covering the lung, causing 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, especially for people who do not have a regular exercise program. Sometimes inhalers, like those used to treat asthma, can also help improve breathing function to prepare people for surgery.

CHEMOTHERAPY

Chemotherapy uses drugs to destroy or damage cancer cells. The idea is to kill the cancer cells before they can spread. Chemotherapy can be used to shrink tumors, slow cancer's growth, relieve symptoms or help people live longer. While it is destroying cancer cells, chemotherapy also harms some

Examples of chemotherapy drugs for NSCLC include:

- Carboplatin (Paraplat® or Paraplatin®)
- Cisplatin (Platinol®-AQ or Platinol®)
- Docetaxel (Taxotere®)
- Etoposide (Toposar® or VePesid®)
- Gemcitabine Hydrochloride (Gemzar®) with cisplatin (Platinol®-AQ or Platinol®)
- Methotrexate (Abitrexate®, Folex PFS®, Folex®, Methotrexate LPF®, Mexate®-AQ, or Mexate®)
- Paclitaxel (Taxol®), in combination with cisplatin (Platinol®-AQ or Platinol®)
- Paclitaxel Albumin-stabilized Nanoparticle Formulation (Abraxane®) - also referred to as albumin-bound paclitaxel or nab-paclitaxel
- Pemetrexed disodium (Alimta®)
- Topotecan hydrochloride (Hycamtin®)
- Vinorelbine tartrate (Navelbine®)

normal cells. This is what leads to some of the more common side effects. (See Chapter 6 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 intravenously (through a vein). Some chemotherapy drugs can be given orally, as a pill. Because the drugs continue to work for days or weeks after they are taken, a period of rest and recovery follows each dose or cycle.

People with late-stage (stage IV) cancer who respond well to their initial chemotherapy treatment may be offered maintenance therapy. Maintenance therapy involves using more of the same or a different chemotherapy treatment. It is helpful to talk with your health care team if you have questions about maintenance therapy.

RADIATION

Radiation therapy uses high-energy rays (such as x-rays) or particles to kill cancer cells. These rays are like the radiation used for chest x-rays and CT scans, but a million times stronger and designed to kill the cancer. The most common type of radiation therapy used for lung cancer is external-beam radiation therapy. The procedure itself is painless. Each treatment lasts only a few minutes, although the setup—getting you into place for treatment—usually takes longer.

Stereotactic radiation (for example, SRS, CyberKnife®, radiosurgery, SBRT or SABR) is a type of external-beam radiation that uses precisely-focused, high-dose beams of radiation to eliminate a small localized tumor.

CHEMORADIATION

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

TARGETED THERAPY

Over the past 20 years, scientists have made many discoveries about what makes cancer cells multiply out of control. They have found a number of ways that cancer cells are unlike normal cells, and have learned how to develop drugs that “target” some of these differences. There are various types of targeted therapies. They are alike in that they work by fixing or stopping a specific abnormality that is causing cancer cells to grow or spread. For example, normal cells make chemicals called growth factors that attach to proteins called receptors—like a baseball fitting into a catcher’s glove. This causes a chemical reaction inside the cell that leads to normal cell growth. In tumor cells, these receptors can be damaged and stuck in the “on” position. Targeted therapies have been designed to turn these “drivers” to the “off” position, resulting in tumor shrinkage. In people whose tumors have these changes, blocking the receptors with drugs such as afatinib dimaleate (Gilotrif®), crizotinib (Xalkori®) and erlotinib hydrochloride (Tarceva®) can cause the cancer to shrink and prevent it from growing or spreading.

ANGIOGENESIS INHIBITORS

Some other types of targeted therapy drugs, such as bevacizumab (Avastin®), can stop

BIOMARKERS & TARGETED THERAPIES

Biomarker testing of lung cancer tissue can provide helpful information to your health care team about treatment options. Testing is currently done in NSCLC for these biomarkers:

BIOMARKER	WHAT IT DOES
EGFR— Epidermal Growth Factor Receptor mutation	Proteins on the surface of cells that appear to aid in the growth of cancer cells and cause lung tumors to grow
ALK — Anaplastic Lymphoma Kinase gene rearrangement	A gene that makes a protein involved in cell growth, and if mutated (changed), may aid in the growth of cancer cells
KRAS — Kirsten rat sarcoma virus gene	A protein that is involved primarily in regulating cell division, and, when mutated, has the potential to cause normal cells to become cancerous
ROS-1 rearrangement mutation	A protein that, when abnormally fused with another protein, activates cellular activity that leads to tumor growth

Current Food and Drug Administration (FDA) approved targeted therapies for NSCLC are presented in the chart below.

DRUG	TARGET	APPROVED FOR
Erlotinib (Tarceva®)	EGFR	Initial treatment of advanced NSCLC with certain types of EGFR mutations. Maintenance treatment for advanced NSCLC after initial treatment. Second- or third-line treatment of advanced NSCLC regardless of EGFR status
Afatinib (Gilotrif®)	EGFR	Advanced NSCLC that has certain types of EGFR genes, which are identified using a biomarker test that is FDA approved. People who have not had previous treatment for cancer that has spread to other parts of the body. First-line therapy for people with tumors that have EGFR mutations harboring an exon 19 or exon 21 (L858R) deletion
Crizotinib (Xalkori®)	ALK	Treatment for advanced NSCLC if tumor has ALK gene rearrangement; can be used in any line of therapy
Ceritinib (Zykadia™)	ALK	Treatment for people with ALK-positive metastatic NSCLC whose disease has progressed or who are not able to take crizotinib
Bevacizumab (Avastin®)	VEGF	Treatment of metastatic NSCLC used in combination with the drugs carboplatin and paclitaxel

angiogenesis (a process where the tumor makes new blood vessels). Blocking the ability of a tumor to make blood vessels can prevent it from getting the oxygen and nutrients it needs to grow.

TAKING ORAL THERAPIES

The addition of oral therapies has dramatically changed the landscape of cancer therapy. Yet many people do not take pills as prescribed. There may be reasons but it can lead to serious outcomes. Missing doses may mean a greater likelihood that the cancer will spread or return.

When you start a medication, ask questions about its use, side effects and dosing schedules. It is a good idea to understand what might happen if doses are missed.

Here are some things that help people take their medicine as prescribed:

- Pill boxes can help you organize your pills by day and provide visual cues as to whether you took the day's medicine.
- Blister packs allow access to one dose of medication at a specific time labeled on the package. This allows you to easily see whether or not you have taken a dose at the right time. Medicine packed in this way may cost more.
- Medication electronic monitoring system (MEMS) bottle caps contain a computerized microchip that keeps track of each time that the bottle has been opened, forming a record of medication use.

Understanding the importance of taking medications as prescribed is very important. The Multinational Association for Supportive

Care in Cancer (MASCC) has developed tools for people who take oral cancer treatments. The MASCC Oral Agent Teaching Tool is available free of charge at www.mascc.org.

IMMUNOTHERAPY

This approach uses the body's own immune system to destroy 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 have been very interested in why the body's "immune response" does not work, and now know several ways that cancer cells "turn off" the 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.

In 2015, the FDA approved two immunotherapies for the treatment of advanced lung cancer in patients who have not responded to chemotherapy:

- Nivolumab (Opdivo®): works by targeting the cellular pathway known as PD-1/PD-L1.
- Pembrolizumab (Keytruda®): approved for people with metastatic NSCLC whose tumors express a protein called PD-L1.

These drugs work completely differently than chemotherapy and targeted therapies. They also have very different side effects that result from boosting or revving up of the body's immune system, which then attacks itself. Some people may experience hormonal imbalances or inflammation of the bowel or lungs. If you are considering these drugs, ask your doctor about these unique side effects. Overall, immunotherapies are showing success as second-line treatments

“Lung cancer is a disease that ten years ago you wouldn’t think of as an immunologically responsive cancer. Today, patients have dramatic responses and durable benefit to these new therapies.”

– David Carbone, MD

for non-small cell lung cancer and are being investigated in first-line NSCLC and SCLC.

ABLATION THERAPY

Radiofrequency ablation (RFA) uses heat made by radio waves to kill cancer cells. It may be used in people with early-stage NSCLC who can’t have surgery. RFA involves a small probe (like a needle) that goes through the chest and directly into the tumor.

PALLIATIVE CARE

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. This type of treatment is often provided by a palliative care specialist. A palliative care specialist is a health care professional who specializes in treating symptoms, side effects and emotional problems experienced by 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.

EVALUATING THE EFFECTS OF TREATMENT

After you have been in treatment for a while, imaging tests like CT and PET 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 your performance status as well.

RECURRENT NSCLC

Recurrent NSCLC is when the cancer returns after treatment. The cancer may come back in the brain, lungs or other parts of the body. In these cases, treatment may be recommended. Many people experience great improvement with additional treatment, even after their cancer has recurred.

TREATMENT OVERVIEW BY STAGE

STAGES IA AND IB

In most cases, the standard treatment for stage IA and IB non-small cell lung cancer is surgery. If there are cancerous cells close to the edges of the tissue removed during surgery, or if certain tumor characteristics indicate that the cancer may be more aggressive, radiation or chemotherapy may be recommended after surgery. If the tumor cannot be operated on or the person cannot have surgery, radiation (sometimes with chemotherapy) is generally recommended.

STAGES IIA AND IIB

Surgery is the preferred approach in treating stage II non-small cell lung cancer and is usually followed by chemotherapy. However, depending on the location of the tumor, chemotherapy with or without radiation may be recommended before surgery.

There are situations where chemotherapy is recommended both before and after surgery. If the tumor cannot be operated on or the person cannot have surgery, chemotherapy and radiation are generally recommended.

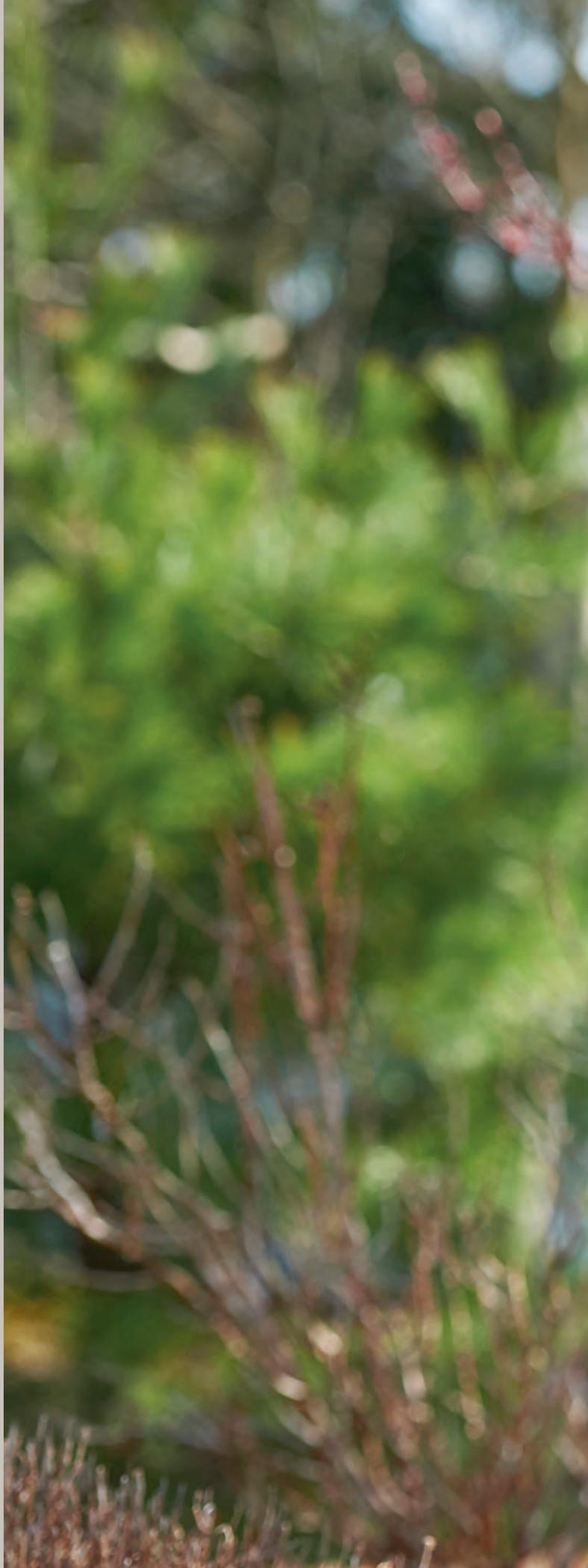
STAGE IIIA

Depending on where the tumor is, its size and if the cancer has spread to the lymph nodes, chemotherapy with or without radiation may be recommended before surgery or after surgery for stage IIIA non-small cell lung cancer. There are situations where chemotherapy is recommended both before and after surgery. If the tumor cannot be operated on or the person cannot have surgery, chemotherapy and radiation are generally recommended.

STAGE IIIB AND STAGE IV

Although there are a limited number of situations where surgery is possible, it is rarely an option in stage IIIB or stage IV. The goal of treatment in these stages is typically to prolong survival and improve quality of life. The treatments usually include chemotherapy with or without radiation, depending on the location of the tumor(s); targeted therapy if certain biomarkers are present; or immunotherapy.

DARLEEN. As caregiver for her mother with non-small cell lung cancer, Darlene 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, Darlene and her sister shared responsibility for her care, dividing time and tasks to ensure that their mother's needs were met. Darlene 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."





5

Small cell lung cancer and its treatment

Small Cell Lung Cancer (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. This kind of cancer is sometimes called oat cell cancer. Like NSCLC, SCLC may require many tests to determine the stage and extent of the disease. Staging is the process of finding out how much cancer is in a person's body and where it is located. Your health care team will need this information to provide the best treatment. The most common way doctors stage small cell lung cancer is by classifying the disease as limited stage or extensive stage.

STAGING OF SCLC

■ **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. Chemotherapy plus radiation therapy has a greater chance of cure than either alone or both sequentially.

■ **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. 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. Chemotherapy is the primary treatment for this stage.

In addition, the TNM staging system (stages 1 through 4), described on page 31, is also used for small cell lung cancer.

Keep in mind there are other factors tied to outcome besides staging. They include your overall health.

TREATMENT OF SCLC

Chemotherapy and radiation therapy are the standard treatments for people with SCLC. Most people with SCLC do not undergo surgery because this cancer tends to spread to other sites early in its course. In about half of people with SCLC, the cancer will eventually spread to the brain if no preventive measures are taken. For this reason, you may be given radiation therapy to the head to try to prevent this. The dose of radiation is lower than would be used to treat cancer that has spread to the brain.

Most people treated with chemotherapy (with or without radiation) for their limited-stage SCLC will have their tumors shrink significantly. In many, the cancer will shrink to the point where it can no longer be seen on imaging tests. Unfortunately, for most people, the cancer will return.

EXAMPLES OF CHEMOTHERAPY DRUGS USED IN TREATING SCLC INCLUDE:

- Carboplatin (Paraplat® or Paraplatin®)
- Cisplatin (Platinol®)
- Etoposide (Toposar® or VePesid®)
- Paclitaxel (Taxol®)
- Paclitaxel Albumin-stabilized Nanoparticle Formulation (Abraxane®) - also referred to as Albumin-bound Paclitaxel or Nab-paclitaxel
- Vinorelbine Tartrate (Navelbine®)

Treatment for SCLC may also include palliative care to help with symptoms and side effects and address any psychosocial concerns. Refer to page 36 for more information on palliative care.

MARIA BURRELL believes in being positive. Since her cancer diagnosis, she has made a point of surrounding herself with positive people and finding ways of generating positive energy. She has her share of bad days, times when she is “feeling low,” and sometimes is overwhelmed by the fatigue that comes with both her disease and its treatment, but she still finds ways to feel joy in life.

“I’m an outside person,” she says. “so sitting on the beach, watching the leaves change or walking my dog can be special moments. I also read a lot of books on spiritual topics, but my real security comes from my involvement with the Cancer Support Community. I can go to my group and sometimes, I don’t have to say anything. I can just sit there, be there and I always receive something from the other people. They get what I am going through in ways even my family doesn’t always understand.”

“It took me a couple of years after my diagnosis to realize that I just can’t do all the things I used to do. I read the earlier entries in my journal and sometimes, I feel sad, but I also find memories and moments that were so good or so much fun. Now I have reached a kind of acceptance. I’m happy to be here and I’m still finding ways to be positive.





6

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 responsibility to report side effects to your health care team. Often, side effects can be successfully managed, but your team needs to know you're having them.

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

It is important to pay attention to your body's physical signs and keep track of your symptoms and side effects. Talk with your health care team and your family about any changes you have noticed. Ask if there is a palliative care doctor who can help you manage side effects. Open communication with the people involved in your care can help you feel as good as possible throughout and beyond treatment.

“It’s important to learn about potential side effects before beginning treatment. Every person is different and can experience side effects differently.” - Jennifer Maloney, MS, ACNP-BC

Symptoms and side effects may include:

■ **BREATHLESSNESS AND COUGHING.** It is common for people with lung cancer to have breathing problems, which can also decrease energy and cause fatigue. Breathing can become uncomfortable, and you may feel like you can’t get enough air into your lungs. It can be a scary sensation. Breathlessness or breathing problems can have many different causes including: 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.

■ **ERLOTINIB HYDROCHLORIDE (TARCEVA®).** Can cause interstitial lung disease, an inflammation of the 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 erlotinib. The problem can reverse itself by stopping treatment 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.

■ **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. Feeling fatigued is not an indication 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.

■ **EATING AND DIGESTIVE PROBLEMS.** Cancer treatments may lead to loss of appetite, diarrhea, constipation, changes in the way food tastes and smells and sores in the mouth and throat. Radiation treatment can cause a condition called esophagitis, which makes swallowing painful and difficult. 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.

■ **HAIR LOSS.** Radiation to the head and some chemotherapy drugs can cause some people to lose some or all of their hair (a condition called alopecia), including scalp hair, body hair, eyebrows and eyelashes. When alopecia occurs, it usually happens 10 to 21 days after the first chemotherapy treatment. Talk to your health care team about whether your treatment may cause hair loss. Not everyone who undergoes cancer treatment will lose their hair; it varies

depending on the person and the treatment. Do not make any assumptions about how the cancer is responding to treatment based on your hair loss. If you are uncomfortable with hair loss or possible hair loss, ask a member of your health care team for advice or resources to help you feel more comfortable.

■ **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. 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.

■ **SKIN PROBLEMS.** A variety of skin problems, including pain, redness, scaling, dryness, sun sensitivity, hives and sometimes hyperpigmentation (darkening) of the skin, may be side effects of radiation and certain chemotherapies. Targeted therapies such as erlotinib hydrochloride (Tarceva®) tend to 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.

■ **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.

■ **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.

■ **HORMONAL IMBALANCE.** Immunotherapy can cause hormone imbalances resulting in various symptoms including rapid heartbeat, weight gain or loss, hunger or thirst, frequent urination, dizziness, fainting, hair loss, sweating, feeling cold, constipation, deepening voice, muscle aches or a headache that does not go away. Be sure to contact your health care team right away if you experience these side effects.

■ **INTIMACY.** 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.

COMPLEMENTARY AND ALTERNATIVE MEDICINE (CAM) OR INTEGRATIVE MEDICINE

People who have cancer often consider treatments or ways to manage side effects that are outside of traditional western medicine. After diagnosis, you may hear about complementary and alternative medicine (CAM) therapies from a friend or family member, on the Internet, in a magazine or on the radio or television. CAM is a broad area and the words to describe it are often used

QUESTIONS TO ASK ABOUT CAM

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

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

interchangeably even though they have different meanings. While some CAM therapies may be harmless or even helpful, others can have severe consequences. 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. Complementary therapies may include, for example, supportive methods such as 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.

Since the majority of CAM therapies have not been approved by the United States Food and Drug Administration (FDA) or have not demonstrated safety and effectiveness in clinical trials, be sure to speak with your health care team about taking or using any complementary or integrative therapies while treated for lung cancer.

ELAINE 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 healthcare 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.”



7

Coping and support

Living with cancer can often affect your emotional and mental health. Depression, shock, anxiety and even panic are some possible reactions to a cancer diagnosis. There may also be changes in family roles and issues related to self-esteem and financial resources.

The emotional impact of a lung cancer diagnosis on an individual or family can vary greatly depending on the extent of the disease, its treatment and each person's situation and personality. At cancer support 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. It is a good idea to find people with whom you can share and express your feelings. Some people are able to do this with close friends and family; others benefit from talking one-on-one with a therapist or counselor, 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 are available 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
- 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?” You may feel angry at the tobacco industry, your doctor or the sight of others smoking. If you still smoke, you may feel angry or guilty when others mention quitting 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. Feelings of lack of communication may be a temporary reaction, or it may indicate a deeper concern that needs to be addressed. Ask your health care team or refer to the list in this book to find resources to help you deal with anger.

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

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, qijong, and many other types of physical activity can help you to manage your emotions and mood.

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.

RELATIONSHIPS

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.

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.

CAREGIVERS

Caregivers are people who provide help to or arrange help for relatives or friends who are ill or disabled. Help can be physical, emotional, spiritual, financial or logistical. Some caregivers may live with the person but others may not. Caring for someone who has a serious disease is not easy. People with cancer and the people who care about them face many problems and challenges. Coping with these issues can be easier with information and support.

Caregiving can be a full-time job itself. 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.

RESPITE CARE

Respite care is short-term, temporary relief to caregivers who are providing full-time support to an ill loved one. Respite care offers intensive care for people in their homes so a caregiver can take a break. 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.archrespice.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 cause death within a limited period of time. The amount of time is difficult to predict, but it could be weeks to several months.

If you are at this stage and active treatment is stopped, it is normal to experience a wide range of emotions such as anger, denial, fear,

sadness and even acceptance. Open and honest 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, these people can still be important resources.

HOSPICE

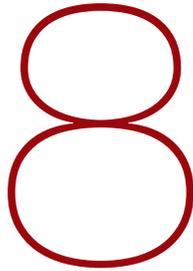
When a person is unlikely to live longer than six months, hospice care is often recommended. It involves the care of all aspects of an individual's and family's needs. People receive help with pain management, as well as the psychological, social and spiritual aspects of suffering. It does not typically 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.

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.

KEVIN In just two years, Kevin has been on eleven treatment trials for lung cancer. Coping with cancer hasn't been easy but the connections and empathy he has found through a men's cancer support group have helped him maintain perspective. "In the beginning, I was very angry. Going to the men's support group the first time, obviously, you're very emotional and you hear about other people and then you start telling your story to the world, and you're scared to death. You're scared to death because you don't know what to anticipate. Just being around those fifteen or twenty people in there, they're total strangers to me, and knowing that they're thinking for me as much as I'm thinking for them, I think that gets me through." As Kevin navigates the next stages of his cancer journey, he advises, "If you sit there and have a pity party, it's not going to work. So you've just got to keep fighting and keep moving forward."



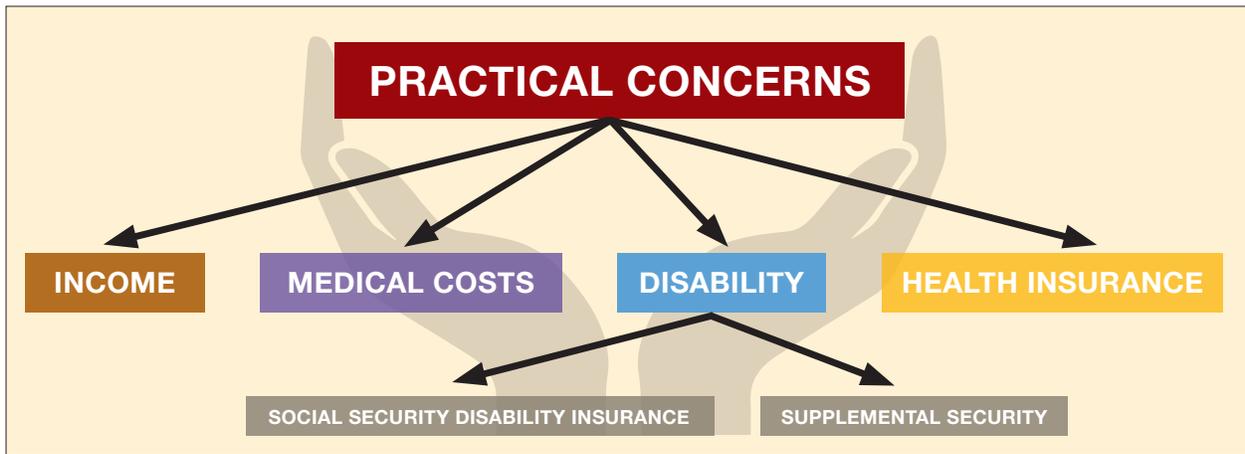


Practical concerns

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.

Although many people with lung cancer feel unable to work during treatment, some find it valuable to maintain as much of their "normal" lifestyle as possible. There is no reason why a person with lung cancer who feels able to work, even part time, should not be able to do so.



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 and 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 the specifics of your policy, call your insurance provider and ask about your coverage. You can also talk with your human resources department or manager at work. If you don't have 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

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

Social Security pays disability benefits under two programs:

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

If you and your health care team anticipate that you will be out of work for at least one year due to lung cancer treatment, you should apply for SSDI as soon as possible. The sooner you apply, the sooner you will 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.socialsecurity.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 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.”





9

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 find that they want to share what they learned or provide support to others who are going through the same experience. Others may be interested in working to change laws or policies to help more people. 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 provide support to others 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, making sure that the recruiting process is appropriate and ensuring that the patient's point of view is considered. People who have had cancer are also sometimes needed to sit on government committees or review grant proposals from a patient perspective.

TAKING CARE OF YOURSELF

Once 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, 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? 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 productive ways to express your feelings is helpful.

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

ADVANCED DIRECTIVE—A legal document containing written instructions about your future medical care if you become unable to speak for yourself.

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

ALTERNATIVE THERAPY—Nontraditional methods of diagnosing, preventing or treating cancer that are used instead of proven methods.

ANAPLASTIC LYMPHOMA KINASE (ALK)—A gene that makes a protein involved in cell growth and if mutated, may aid in the growth of cancer cells.

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

ANGIOGENESIS—The process of making new blood cells.

ANGIOGENESIS INHIBITOR THERAPY—Therapy to prevent 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 biological marker found in cells or tissues that is a sign of a normal or abnormal process, or of a condition or disease.

BIOMARKER TESTING—Uses samples of a person's cancer. The samples are taken by the 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—Surgical removal of a small piece of tissue for evaluation under a microscope.

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

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, 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.

DYSPHAGIA—Difficulty swallowing.

DYSPNEA—Difficult, painful breathing or shortness of breath.

EPIDERMAL GROWTH FACTOR RECEPTOR (EGFR)—Naturally occurring proteins on the surface of cells that appear to aid in the growth of cancer cells and cause lung tumors to grow.

EGFR INHIBITOR—A substance that blocks the activity of a protein called epidermal growth factor receptor (EGFR). Blocking EGFR may keep cancer cells from growing.

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

FATIGUE—Decreased capacity for activity that is often accompanied by feelings of weariness, sleepiness or irritability.

FIRST-LINE THERAPY—Medical therapy recommended for the initial treatment.

GENETIC MARKERS—A gene or piece of DNA associated with a certain disease.

HISTOLOGY—Study of tissues to determine their specific characteristics, which may lead to identifying a specific type of lung cancer.

IMMUNOTHERAPY—Using the body’s own immune system to destroy cancer cells.

INTERSTITIAL LUNG DISEASE—Group of disorders, most of which cause progressive scarring of lung tissue, that create difficulty breathing and getting enough oxygen into the bloodstream.

LIVING WILL—A legal document that details 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.

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 and tailored to 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.

NEOADJUVANT THERAPY—Chemotherapy or radiotherapy used before surgery to shrink a tumor.

NON-SMALL CELL LUNG CANCER (NSCLC)—One of the two main types of lung cancer. NSCLC makes up the majority of lung cancers.

OXYGEN THERAPY—Used to relieve breathing problems by providing supplemental oxygen.

PALLIATIVE THERAPY—Used to relieve pain and other symptoms without the intent to cure the disease.

PARTIAL REMISSION—When a cancer tumor has shrunk in size but has not totally disappeared. The cancer can still be detected and other treatments may be recommended.

PERIPHERAL NEUROPATHY—Damage to the nervous system. Some chemotherapy drugs can cause this condition. Symptoms include weakness or tingling in the hands or feet.

PET SCAN (POSITRON EMISSION TOMOGRAPHY)—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 collection 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 modified in some way.

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

PULMONARY REHABILITATION—Education about behavior and lifestyle changes to help patients with chronic lung disease decrease breathing problems, return to daily activities and improve quality of life.

RADIATION FIBROSIS—When radiation treatment triggers the immune system to form scar tissue inside the lung.

RADIATION THERAPY—High doses of high-energy radiation beams (x-rays), carefully focused on a tumor, will kill cancer cells.

REFRACTORY DISEASE—Cancer that is resistant 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 therapy.

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

STANDARD THERAPY—Current primary therapy that has 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 cellular pathways that enable cancer cells to grow.

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

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

THORACIC PATHOLOGIST—A specialist in pathology of chest illnesses.

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

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

TRACHEA—The windpipe.

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

VASCULAR ENDOTHELIAL GROWTH FACTOR (VEGF)—Protein that stimulates new blood vessel formation. 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 and 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 long-time 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 Mon-Fri 9 am- 9 pm ET.

OPEN TO OPTIONS ®

If you are facing a cancer treatment decision, this research-proven program can help you. In less than an hour, our trained specialists can help you create a written list of specific questions about your concerns for your doctor. Appointments can be made by calling 888-793-9355, visiting www.cancersupportcommunity.org or by contacting an Affiliate providing this service.

FRANKLY SPEAKING ABOUT CANCER ®

CSC's landmark cancer education series provides trusted information for cancer patients and their loved ones. Information is available through publications, online, and in-person programs.

AFFILIATE NETWORK SERVICES

Over 50 locations plus more than 100 satellite locations around the country offer on-site support groups, educational workshops, and healthy lifestyle programs specifically designed for people affected by cancer at no cost to the member.

CANCER EXPERIENCE REGISTRY®

The Registry is a community of people touched by cancer. The primary focus of the Registry is on collecting, analyzing and sharing information about the experience and needs of patients and their families. To join, go to www.CancerExperienceRegistry.org.

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, a free Lung HelpLine and an online support community for those facing lung disease.

BONNIE J. ADDARIO LUNG CANCER FOUNDATION

650-598-2857

www.lungcancerfoundation.org

One of the largest patient-driven philanthropies devoted to eradicating lung cancer through research, awareness, education, early detection and treatment.

CANCER SUPPORT COMMUNITY

888-793-9355

www.cancersupportcommunity.org

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.

FREE TO BREATHE

608-833-7905

www.freetobreathe.org

A partnership of lung cancer survivors, advocates, researchers, healthcare professionals and industry leaders united in the belief that every person with lung cancer deserves a cure.

GIANNI FERRAROTTI LUNG CANCER FOUNDATION

313-532-0983

www.gianniscause.org

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

LUNG CANCER ACTION NETWORK

www.lungcan.org

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

LUNG CANCER ALLIANCE

800-298-2436

www.lungcanceralliance.org

Provides support and advocacy to people affected by lung cancer.

LUNGCANCER.ORG

800-813-4673

www.lungcancer.org

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

LUNG CANCER FOUNDATION OF AMERICA

507-354-1361

www.lcfamerica.org

Committed to saving lives by improving the survival rate of lung cancer by raising money from the private sector and channeling those funds to lung cancer researchers, so that researchers find effective ways to predict, detect, and treat lung cancer.

LUNGEVITY FOUNDATION

312-407-6100

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

www.cancer.gov/cam

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

NATIONAL CENTER FOR COMPLEMENTARY AND ALTERNATIVE MEDICINE

888-644-6226

www.nccam.nih.gov

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

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

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.disabilityrightslegalcenter.org/cancer-legal-resource-center

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.

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PROGRAM PARTNERS**



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CANCER SUPPORT COMMUNITY MISSION

As the largest professionally led nonprofit network of cancer support worldwide, the Cancer Support Community (CSC) is dedicated to ensuring that all people impacted by cancer are empowered by knowledge, strengthened by action and sustained by community. CSC achieves its mission through three areas: direct service delivery, research and advocacy. The organization includes an international network of Affiliates that offer the highest quality social and emotional support for people impacted by cancer, as well as a community of support available online and over the phone. The Research and Training Institute conducts cutting-edge psychosocial, behavioral and survivorship research. CSC furthers its focus on patient advocacy through its Cancer Policy Institute, informing public policy in Washington, D.C. and across the nation. For more information, please call the toll-free Cancer Support Helpline® at 888-793-9355, or visit www.CancerSupportCommunity.org. So that no one faces cancer alone.®www.cancersupportcommunity.org | 888.793.9355



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WWW.CANCERSUPPORTCOMMUNITY.ORG

888-793-9355

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