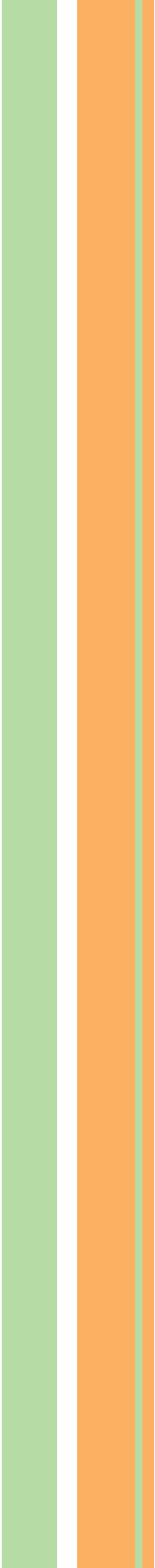




TOGETHER

FACING LUNG CANCER


A Guide
to Help Patients & Caregivers
Face the Challenges of Lung Cancer



Facing the Challenges of Lung Cancer

While hearing the word “cancer” is frightening, the words “lung cancer” are even more frightening, in part because of how the illness is viewed in our culture. One of the major problems in coping with lung cancer is the way that society has regarded it as a cancer the person caused by smoking. The question is usually asked, “Oh, did you smoke?” This blaming makes people coping with this illness feel more isolated, vulnerable, and sad. Smoking was such a popular habit that most people did smoke after World War II and stopping was not easy, even as news of the association between smoking and lung cancer became known. While smoking, either current or in the past, is clearly a risk factor for lung cancer, there are increasing numbers of people diagnosed with lung cancer who never smoked. People also have believed that less research has gone into lung cancer because of this fact, though this is changing rapidly as new treatments are found and the public is becoming more aware of the frequency of this cancer.

For these reasons it is important for you to have the best information about lung cancer, available treatments, and how to gain a sense of mutual respect with your oncologist, as well as the importance of viewing him or her as a partner in your treatment plan.



Certainly, there will be physical and emotional challenges with lung cancer, but they can be more manageable when you are able to recognize that a medical team (your oncologist will have others on the team who are essential in treating lung cancer) is there for you and committed to your care. Equally important is identifying and working with your “personal team” – your family, close friends, colleagues, and others facing lung cancer who understand in ways no one else can. The hope is that this small booklet gives you the “basics” and helps you cope with lung cancer. The better informed you are, the more active and helpful you can be in your own treatment.

UNDERSTANDING YOUR DIAGNOSIS OF LUNG CANCER


“Exactly what is lung cancer and what do I need to know about it?”

First, a few facts about cancer cells. They are cells that, for some reason, differ from normal cells in the body. Cancer cells are the result of a mutation in the cell's DNA, which is composed of chromosomes, which in turn are made up of genes. Damage to a gene results in a mutation that may occur for many different reasons, but the damaged cells start to grow and, unlike normal cells, they do not die. This uncontrolled cell growth can form cancerous tumors.

It is important to know the types of lung cancers because sometimes treatments vary according to which type you have. Depending on where it originates, its behavior, and the type of cell producing the cancer, lung cancer can be divided into two main categories:

- **Non-small cell lung cancer:** The more common type of lung cancer is non-small cell lung cancer (NSCLC). It is composed of squamous cell carcinoma, adenocarcinoma, and large cell carcinoma. They are grouped together because they behave similarly. However, there is a subtype of adenocarcinoma called bronchioloalveolar carcinoma (BAC), which is less common, but appears to be increasing, particularly among young women who are nonsmokers.
- **Small cell lung cancer:** This represents about 13 percent of lung cancer. It is more sensitive to chemotherapy and radiation and, because of its tendency for more rapid spread and growth, surgery is not usually recommended first.

Who gets lung cancer? Lung cancer usually occurs in older adults, and there has been an epidemic, first among men, related to the popular habit of cigarette smoking that began in the early 1900s. Deaths from lung cancer are now diminishing among men, but increasing among women because cigarettes became popular with women at a later time. Despite women's fears of breast cancer, it is lung cancer that is the leading cause of death among both men and women.



It is important to remember these figures represent averages, and they are based on numbers from the past when treatment options were few and are not reflective of the rapid changes and improvements in lung cancer treatment we recognize today. Remember, “You are a statistic of one,” and while you need to have this overview of lung cancer, there is every reason to embark on treatment with confidence.

What are the stages of lung cancer? Stage is a term that healthcare professionals use to describe the aggressiveness and the degree of growth, or spread, of the cancer. Below are the stages your oncologist may use to measure how far the disease has spread:

- **Stage I** – Cancer is only in one lung and has not spread. Stage I is divided into IA or IB, depending on the tumor size.
- **Stage II** – Cancer has spread to nearby lymph nodes, chest wall, lining of the lungs, or the outer lining that surrounds the heart. Stage II is divided into IIA or IIB, depending on tumor size.
- **Stage III** – Cancer has spread to surrounding structures and to the lymph nodes in the area of the chest between the heart and lungs. Blood vessels in this area or the lower neck may also be affected. Stage III is divided into IIIA and IIIB, depending on tumor size.
- **Stage IV** – Cancer has spread to the other lung or to other areas in the body.

Treatment choices for lung cancer largely depend on the stage of your cancer. Your treatment options may include surgery, radiation, chemotherapy, newer targeted treatments, or even watchful waiting, a term that means watching carefully to see the effects of the cancer, rather than choosing a specific form of treatment or treatment only to alleviate pain. Which treatment approach works best for you depends on several factors. For this reason, your treatment will probably include one or more of the following:

- **Surgery** – Removes the tumor. This can be done if the tumor is small and has not spread. Surgery can be the first step in your treatment plan.
- **Radiation** – Uses high-energy X-ray beams to shrink the tumor, or, in advanced cases of NCSLC (Stage IV), may be used to ease pain.
- **Chemotherapy** – Drugs given to you through a needle inserted into your vein (intravenously) to destroy cancer cells. This treatment may be used with radiation to help shrink the tumor before surgery or may be used after surgery or radiation to destroy any cancer cells that may have been left behind.
- **Targeted therapy** – Affects only certain cancer cell activities. May help slow the tumor growth and destroy cancer cells. Some new targeted treatments are oral tablets you take by mouth.

GOALS OF YOUR CANCER TREATMENT

“Are we all on the same page?”

While the diagnosis of lung cancer is very frightening, there are many treatment options to explore. Knowing your treatment options and establishing treatment goals that are mutually understood and agreed upon is an important step. By speaking with your physician, family, nurses, social workers, and other people involved in your cancer care – your treatment “team” – you can reach an informed decision on what options are best for you.

Identifying your support network or “team” is a first step toward learning more about your diagnosis, understanding the treatment options available, and making decisions that are informed and appropriate for you as an individual. Your team should comprise individuals who bring various skills, knowledge, and types of support to you as you manage and cope with lung cancer.

They can help you with all phases of your therapy, as well as with the more personal and emotional aspects of your situation. One person on your team might simply be someone you can count on to drive you to and from your medical appointments, while others, such as your oncologist, have a very direct impact on your treatment. No matter what their roles, your team consists of people you can count on and trust to help you in all aspects of your life as you manage your diagnosis.

Your team can help you:

- Understand essential information about your specific type and stage of lung cancer, including facts about how fast it usually grows and what effects it can have on bodily functions.
- Discuss specific options for treating the cancer, as well as expectations for the response to each treatment.
- Evaluate the anticipated short- and long-term effects treatment options may have on you and your loved ones.
- Discuss strategies to help you manage or cope with having cancer and undergoing the specific cancer treatments you choose. These include strategies for managing pain, sleep, breathing, coughing, and fatigue, as well as strategies for maintaining or improving nutrition, staying physically active, coping with difficult emotions, and maintaining function and independence.
- Make decisions about involving specially trained nurses, social workers, dietitians or nutritionists, therapists or counselors, home care staff, as well as patient care representatives to discuss costs, insurance, and other financial considerations.

COPING WITH HAVING CANCER

“How can I stay positive as my whole world changes?”

You can best understand what is going on if you know what is coming. Fear is common when the outcome is unknown, especially in the face of an illness that may be life-threatening and full of uncertainties. Seeking and obtaining information from your support team is an excellent way to help cope. Checking out your assumptions, or asking a lot of questions, will help you understand information, clear up misunderstandings, and make decisions.

Another way to cope with having cancer is to become an active partner in your own care. Research studies demonstrate that patients who are actively involved in medical decision making are more satisfied, have a better quality of life, and have better health outcomes.¹


Asking questions, researching on the Internet, and sharing decision making responsibility can help you become more involved in your own care. However, some people do not take on these tasks naturally. We often do not feel comfortable taking an active role in medical decision making during an office visit; for example, patients ask an average of only two questions during an entire medical visit that lasts about 15 minutes.^{2,3}

Studies also show patients are relatively uninformed about their condition or the most appropriate treatment, despite the fact that most patients state they want more information. A useful tool developed and tested with three large Veterans Affairs Medical Centers can help patients “PREPARE” for office visits with physicians and staff. These six steps encourage you to be a more active partner in your healthcare, and are especially valuable as you cope with your cancer diagnosis and treatment:⁴

Step One: Plan: Think about what you want to tell or learn from your doctor or clinician. Write it down and take it with you to the visit.

Step Two: Report: Tell your physician or nurse what you want to talk about during your visit. You may wish to prioritize your concerns in case your scheduled time is limited.

Step Three: Exchange information: Be sure to describe your concerns and ask questions so you are clear about what your doctor or clinician has explained to you.



Step Four: Participate: Discuss with your doctor or clinician the treatment and management options which are available to you now and in future stages of your cancer and the possible effects of each on your outcomes and quality of life. Ask members of your healthcare team if they can provide written material that would help you further understand your options and enhance your ability to share information about options with your loved ones and other team members for their input and consideration.

Step Five: Agree: Be sure you agree on next steps, such as a treatment plan that is fully understood by you and fits with your beliefs, goals, and lifestyle. Do not be afraid to question your doctor when you do not understand or do not agree with something he or she has said.

Step Six: Repeat: Tell your doctor or nurses what you think you will need to do to take action on the next steps. Repeating it helps ensure you are both in agreement and you fully understand the plan.

The diagnosis of cancer can bring forth a range of emotions, including shock, disbelief, anger, guilt, and depression. These emotions are very common responses to coping with an illness that may feel overwhelming at times. Knowing this range of feelings is expected and normal, and sharing them with a supportive and understanding team member, can ultimately lead to acceptance, which can allow you to cope and maintain a positive attitude.

The bottom line is there is no generic “one-size-fits-all” coping style for dealing with cancer. You are unique, and your tried-and-true ways of coping that have worked in past crises are likely your best bet for dealing with the crisis of cancer. However, there is overwhelming proof that how you cope with your illness can improve your overall quality of life. Having a caring medical and personal team, which includes your physicians, nursing staff, family, and friends, is extremely valuable to help you through both the expected and the unexpected. In addition, your willingness to seek and accept support from your family and friends as integral members of your team will go a long way to help you cope and appreciate those around you.

Building Your Support Team

THE TREATMENT TEAM

Medical Oncologist – This is the doctor who often takes over after your surgeon and will manage your treatment with chemotherapy. The oncologist is trained in internal medicine and often serves as your primary doctor.

Pulmonologist – This is a lung doctor who specializes in all diseases of the lung and may be the first person you see, who then sends you to a surgeon for a biopsy.

Oncology Nurse – This is the nurse who works with the medical oncologist, usually as a close-knit unit. The oncology nurse administers the chemotherapy and is available for phone calls and questions – and usually constitutes a strong and central member of the medical team – providing medical information and emotional support for you and your family.

Oncology Social Worker – Most lung cancer treatment centers have social workers who are available to help with practical problems, such as transportation, but also with emotional problems or those that arise related to work or family. They are the “first line” of defense to help you and your loved ones cope with the problems that can occur during treatment.

Psychologists/psychiatrists – Sometimes the normal distress of coping with illness can become great, and you can experience anxiety with restlessness, insomnia, and fears that interfere with treatment, or a sense of demoralization that interferes with your ability to be a full partner. These are signs that suggest counseling might be helpful.

PHYSICIAN-PATIENT RELATIONSHIP

Your oncologist is one of the most important members of your team. As the most knowledgeable and involved individual in the medical aspects of your treatment, you need to feel comfortable with your choice of an oncologist.

The importance of the physician-patient relationship is highly dependent on both players working together. Physicians who provide effective communication will listen to you in an empathetic and caring way. The “4 R” approach to promoting effective communication with cancer care professionals, described below, provides standards for assessing the quality of communication between you and your oncologist, and other members of your healthcare team.⁵

RELATE: The physician or other healthcare team member takes the time to discuss your concerns and preferences for information and treatment and involves you appropriately and respectfully in decision making.

REVIEW: Information regarding your condition, progress, and response to treatment is appropriately shared with you, including lab results, pathology reports, and results of radiation, chemotherapy, and surgery.

REVISE: Over the course of your treatment your goals may change, which may require your team to work with you to redefine goals and methods of care.

REFLECT: You and your physician are working together as partners in your lung cancer care. The physician should be able to reflect upon his/her role in your care, assess whether your needs are being met, and, if not, provide you with appropriate resources and referrals for transitions in your care.

You can help with the information exchange by sharing any change you have noted in your condition as clearly as possible. It may help to keep notes to enhance accurate reporting to your healthcare team. Sometimes we refer to this as “journaling,” which includes keeping track of all changes in bodily functions, from sleep to bowel habits to headaches.


Not every physician is a great communicator. You may wish to seek a nurse or social worker to aid in communication. Be prepared to offer your own ideas to help resolve the issue. Satisfaction of both the patient and the physician is enhanced when there is a good working relationship.

Getting a second opinion about your diagnosis and treatment is highly recommended, and your oncologist should encourage you to do this, especially if there are doubts or concerns about your diagnosis or which treatment option is best for you.

GETTING THE REST OF THE TEAM ON-BOARD: FAMILY AND FRIENDS

Patients are no longer passive recipients of care – they work in partnership with the oncologist and the rest of their healthcare team, which includes various specialists, family, friends, and community resources. YOU are the most important resource on this team. Communicating with members of your team helps give you a sounding board and helps them to understand what you are experiencing and feeling. This allows your team to respond to your needs, expectations, and concerns.

Your team also may be able to help you better understand and accept your cancer treatment plans and feelings. A family member or friend can be invaluable in helping you cope, seek information about treatments, and even accompany you to doctor visits.



These “caregivers” also serve as a second set of ears to receive information about what is happening. One person, or a small number of delegated persons, is most appropriate to achieve mutual understanding and increased trust with the physician and other members of the oncology team.

SUPPORT GROUPS

Support groups can play an important role for some patients, but may not be for everyone. They bring together others who will help you live a more productive and fulfilling life while dealing with your cancer care. Support groups are made up of individuals with cancer who are in different stages of their treatment. Talking to other lung cancer patients can be invaluable. There is no one who understands like another person who is experiencing similar concerns and treatments. They can help you cope with problems, daily stress, pain, and personal development issues related to having cancer.

In support groups, you can learn coping and problem-solving strategies, share responsibility for others, and, in turn, help yourself. Today, millions of Americans turn to support groups to help them cope with some of life’s most difficult problems.

The following guidelines may help you consider the benefits a support group can offer:

- Approach your first meeting with an open mind and try to find out all you can.
- Attend several meetings before you make a final judgment.
- If you do not find the right group the first time, try another group.
- Look for warmth and friendliness between members and a welcoming attitude toward new members.
- Seek structure and focus in meetings with an ongoing agenda.
- Expect speakers and participants who can share educational concepts with you.
- Online cancer support groups also are available if face-to-face meetings are not available or accessible in your area.
- Consider that a support group may not be right for you; however, a caregiver group might be good for a family member or friend.

What Should Others Expect?

PROVIDING SUPPORT FOR EACH OTHER

Your medical team has chosen cancer care as a profession, and each specialist is there specifically to help patients. Your team of family and friends also is there to love and support you in this time of need. Consider the acronym of LOOK as a model for supporting one another and yourself during your treatment.

Listen: Listen to others and yourself.

Observe: Be aware of each other and those around you. Keep in mind the resources of the entire team.

Overcome barriers to good communication: Appreciate the team as a source of help and support.

Keep working together: Continue to expand your awareness, resources, and mutual support.

MAKING THE MOST OF OPPORTUNITIES

The power of a team is the combined ability of experience and knowledge brought together by different talents, ideas, and experiences. Having a support system early in the

cancer care process allows someone else to take responsibility when you might not feel like being in charge. It is important for you and your family (caregivers) to share this responsibility.

The challenges faced on a daily basis for team members can include:

- Knowing their limits and sticking to them.
- Communicating openly and honestly about their experiences and emotions or feelings.
- Listening carefully to be able to reflect later on what was said to help patients make important decisions.
- Asking for help from others to prevent being overwhelmed.
- Balancing the psychological and logistical tasks of everything from giving emotional support to scheduling appointments and keeping track of medications.
- Being able to cope in order to support your loved one.

Your team members, whether professional, family, or friends, have the responsibility to be there for you. The challenge is to keep your team informed and involved in decision making. This is an opportunity for you to be in charge and participate in your care, but at the same time know that you are not alone. You have people you can count on to help you through your diagnosis.

Lung Cancer Resources

Organizations that have lung cancer resources available to patients and caregivers are listed below.

American Cancer Society (ACS) (www.cancer.org)

The American Cancer Society is a nationwide, community-based voluntary health organization with more than 3,400 local offices. As a health organization, they are dedicated to eliminating cancer as a major health problem, thereby saving lives and diminishing suffering from cancer through research, education, advocacy, and service.

American Psychosocial Oncology Society (APOS) (www.apos-society.org)

The mission of the American Psychosocial Oncology Society is to advance the science and practice of psychosocial care for people with cancer. APOS provides educational programs and explores innovative methods to enhance recognition of the psychological, social, behavioral, and spiritual aspects of cancer.

Lung Cancer Alliance (LCA) (www.lungcanceralliance.org)

The Lung Cancer Alliance is the only national organization advocating exclusively for lung cancer patients and those at risk. The LCA believes tremendous positive change can occur when facts are presented and awareness is elevated.

Lung Cancer Online Foundation (LCOF)
(www.lungcanceronline.org)

The Lung Cancer Online Foundation's goal is to improve the quality of care and quality of life for people with lung cancer. As one of the leading Web sites for lung cancer in medical journals, cancer support publications, and the media, LCOF provides information to patients and families by using a comprehensive directory of Internet information and resources. The LCOF was founded by Karen Parles, a lung cancer survivor and librarian.

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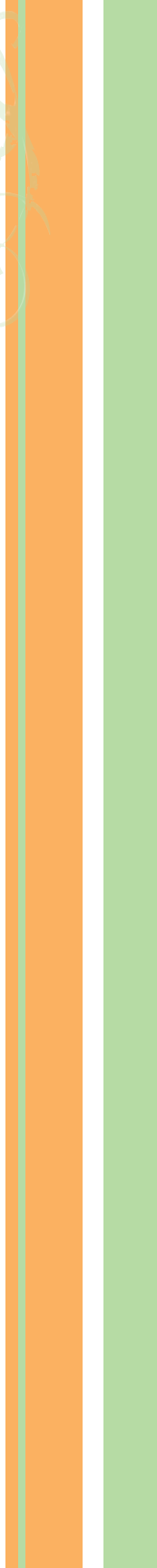
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