

# Living With Lung Cancer

Patient Education Guide



Your doctor has just told you that you have lung cancer. Even if you thought that you might have something seriously wrong, those words probably made you feel as if the floor dropped away beneath your feet. You don't want to believe this terrible news. You wonder how this could have happened to you.

Maybe you had some symptoms such as pneumonia that seemed to keep coming back. Or, it seemed as if you were always taking antibiotics. Maybe you were coughing a lot. Sometimes there was blood in your sputum. Maybe you just felt tired, or you got out of breath walking your dog. Maybe you had no symptoms at all. Maybe you were having your regular checkup and your doctor thought your lungs sounded different than usual. No matter how the diagnosis came about, it is shocking and not something anyone wants to hear.

## A Team Approach

One of the first things that happens when cancer is suspected is that you will be meeting with many different types of doctors. Each one specializes in a certain aspect of cancer diagnosis or treatment. Your primary care doctor may refer you to a pulmonologist for your diagnosis. A pulmonologist specializes in diagnosing and treating diseases of the lungs, but not necessarily the treatment of cancer. You may need tests done by a pulmonologist, a radiologist, a surgeon, and a pathologist to actually make the diagnosis. Some lung cancers can be removed by surgery. If you are one of the people with operable lung cancer, you will be referred to a thoracic (chest) surgeon. Other specialists who treat cancer are the medical and radiation oncologists. A medical oncologist treats cancer with chemotherapy. A radiation oncologist treats cancer with radiation. Often, the treatment uses several of these approaches. The different doctors will work together to treat you in the best possible way.

While all this may seem very confusing, in a short period of time, you will learn a great deal about lung cancer and the people who are there to help you during this difficult time.

Your primary care doctor may still be your main contact. As you move into treatment, one of the other specialists may take over the role as lead doctor for a period of time. However, it is important to make sure that your primary care doctor is always aware of what is going on with your cancer and your treatments.

## Making the Diagnosis

The most important test you had is the biopsy. This is when your doctor removed a piece of, or the entire, suspected tumor. The pathologist then studied it carefully with a microscope. This is how you and your doctor know, with certainty, that you have lung cancer.

Sometimes, the images of large tumors, as seen by an x-ray or computed tomography (CT) scan, look clearly like lung cancer. In this case, you may have been referred directly to a surgeon who removed the entire lobe with the tumor without doing a biopsy first. In this case, the pathologist studied the tumor after its removal from the lung to confirm the diagnosis.

When you had your biopsy, your doctors may have also checked the lymph nodes in the middle part of your chest to find out if the cancer had spread to any of these nodes. When cancer cells move from the original tumor to other places in the body, it is called metastasis. Checking for metastasis is one of the first steps that must be taken in order to find out the stage of your cancer.

The pathologist can tell by looking at the tissue taken from the tumor in your lungs whether you have small cell or non-small cell lung cancer. Four out of five people diagnosed with lung cancer will have non-small cell lung cancer. If you have non-small cell lung cancer, the pathologist will determine which kind you have. There are three different kinds: adenocarcinoma, squamous cell, and large cell. Each of these types of non-small cell lung cancer also has subtypes. The pathologist will also be able to find out other things about the tumor. They will find out about how rapidly the cells divide. For example, bronchioloalveolar cancer is a subtype of adenocarcinoma. Generally, it grows very slowly.

The goal of treatment is to select the best treatment for the specific type of lung cancer that you have. Together, you and your doctor will set a goal for your treatment. If you have early stage lung cancer, the goal will be to possibly cure the disease and certainly to prolong your life compared to what it would be without treatment. If you have late stage lung cancer, where the chance of cure is less likely, the goal of treatment is more often to extend life and to manage the symptoms.

## Staging of Cancer

Staging is very important. It will help your doctor make recommendations about what treatments will be best for you. To stage your cancer, your doctors will need to know exactly where in your body cancer cells can be found. Most people with lung cancer have both a chest x-ray and CT scans. A positron emission tomography (PET) scan can also be used as part of the staging process. Detailed images can be made of your lungs and other organs and bones. If cancer is present, and at least the size of a marble or larger, it will show up in the PET scan in a way to alert your doctors.

There are four stages of non-small cell lung cancer.

Stage I is early lung cancer, where the tumor is small and located only in one part of a lobe of the lungs. Cancer is not found in any lymph nodes. Stage IA tumors are less than 3 centimeters (cm) in size, like a large walnut or smaller (2.5 cm equals about 1 inch). Stage IB tumors are those that are larger than 3 cm. Many people who have a very small tumor (a small stage IA tumor) can be cured.

Stage IIA and IIB tumors are divided into the same sizes as stage I, but the pathologist has also found cancer cells in the lymph nodes within your chest.

Stage III tumors are also divided into A and B categories. Stage III tumors have spread to the lymph nodes in the center of the chest and to some of the tissue that surrounds the lungs, such as the pleura, the outer lining of the lungs. Cancer cells may also be in the diaphragm, the muscle below your lungs that works to help you breathe. The cancer may have also spread to the outer lining around your heart, the pericardium. The important thing about stage III cancer is that the cancer is still found only in your chest.

Stage IV tumors have spread outside the chest. The most common places where tumor cells might be found are the liver, the brain, the bones, or the adrenal glands.

Small cell lung cancer is usually found after it has spread. It is most often found as multiple tumors in the lungs. This is one of the ways your doctors may begin to suspect that you have lung cancer, specifically small cell lung cancer. The four stages for non-small cell lung cancer also apply to small cell lung cancer. However, many doctors may talk only about two stages for this type of lung cancer. Limited, or early stage, is only in the chest. Extensive, or advanced stage, has spread to other areas of the body.

Once your doctor knows the type of lung cancer you have and the stage, you will be referred to the specialists who can provide the best treatments.

## Treatment

As your doctors consider the best treatments for your particular type and stage of lung cancer, they usually talk to each other. Your primary care doctor has important information about other medical conditions you have or medications you are taking. It is also important for your cancer specialists to know how active you are or were before your diagnosis. They will use this information as a baseline. They understand that quality of life is important for people. Once you and your doctors have all the facts about your cancer, they will be able to make recommendations about your treatment.

Small cell lung cancer has a tendency to spread to other areas of the body. It is also very sensitive to chemotherapy, so this is how it is usually treated. Surgery and/or radiation may be used in some cases.

Treatment for non-small cell lung cancer is based on the stage of cancer, as well as on the type. Stage I and II can usually be treated with surgery since there is only one tumor. Stage I cancer can almost always be removed surgically, and the chance of cure is high. A cure in cancer is measured by living cancer-free for 5 years after the treatment. One or more lobes of a lung will be removed, depending on where the tumor is located and how large it is. A few months after surgery, you should feel pretty much as you did before the surgery. If the surgery is extensive or if you also have lung disease, such as emphysema, you may find that you tire more easily. You may also get out of breath more easily. A regular exercise plan can help to build your muscles and reduce the symptoms of tiredness and shortness of breath.

Stage IIA and IIB tumors and the affected lymph nodes are generally removed with surgery.

Often, people with stage I and II lung cancer are treated with both surgery and chemotherapy. People with stage II lung cancer may also be treated with radiation. Talk to your doctor about whether a referral to a medical or radiation oncologist would be of benefit to you.

If you have stage III or IV lung cancer, you will probably be advised to consider treatment with chemotherapy and/or radiation therapy. Stage III cancer is treated with chemotherapy and/or radiation therapy and sometimes with surgery. A combination therapy regimen works best in this situation. This means that you will be given more than one drug at the same time or in sequence. A multimodality therapy regimen means that you are getting chemotherapy and radiation, and sometimes surgery, as well. The approach that is used will depend on your specific situation. The order in which the treatments are given depends on the size and location of the cancer. Surgery may be delayed until the tumor is reduced in size by the other therapies.

If you have stage IV lung cancer, your doctor may suggest therapy to extend your life and improve your quality of life. Chemotherapy has a good chance of being able to do both. There are also many supportive or palliative care treatments available. These are designed to manage the symptoms of lung cancer.

For more in-depth information about treatments, check the resources listed in the Resources section at the end of this brochure.

## Clinical Studies

When you think about treatment, consider clinical studies. There are clinical studies in every area of cancer treatment. A surgical study might include a new type of surgery coupled with a special follow-up. Treatment studies are common ways of testing new drugs or other types of therapies, new methods of giving radiation, or giving both of those treatments together. In lung cancer studies such as these, you either get the treatment that is considered to be the standard of care or you receive treatment with the new test procedure or product. Many people find hope and gratification when they take part in a clinical study. They know that they are helping themselves, as well as others. Clinical studies offer the advantage of generally providing the study treatment at no cost to you. You will still be responsible for other treatment costs. Many clinical studies also require more detailed follow-up of the people who enroll in them. This means you will be more closely watched during and after your treatment than you might be outside the study. If you are interested in clinical studies, check the Resources section listed in this brochure.

## Living With Lung Cancer

You are probably wondering what your life will be like now that you have lung cancer.

Many people with lung cancer can be cured. Many others who are treated go on to lead normal lives, often for years. This is especially true if you have early stage lung cancer. It will be very important that you follow your doctor's advice about frequent checkups. You will need to have either CT scans or chest x-rays, as advised, especially during the first several years after your treatment ends.



If your cancer is more advanced, for example, you have cancer that has spread to the lymph nodes in your chest and maybe to other areas as well, you may also have years to live. This will depend on the type of cancer you have and how well the treatments work for you. New treatments become available almost every year. Your doctors may try some and then switch you to others. Remember there are options available to you. Your doctors will be able to tell you how well they think you are doing and how effective they think the treatments are for you.

One of the questions most people with lung cancer want to ask is, "How long do I have to live?" Your doctors know a lot, but no one can answer that question. Some may give a range of time that they would expect you to live. But, those numbers are based on groups of people. It is difficult to apply such numbers to one person. It may be more helpful to ask your doctor to describe how you are likely to feel in the upcoming months. Ask your doctor to tell you what sorts of things you may or may not be able to do. This information can help you plan for the future. Studies show that people who have good support from family and friends usually do better as cancer survivors. People who try to stay active and make plans for the future often also do better. It is helpful if you think of yourself as one of the people who will do well during treatment and that you can and will continue to have a productive, good life.

## Resources

### **Alliance for Lung Cancer Advocacy, Support, and Education (ALCASE)**

Toll-free phone number: (800) 298-2436

Internet site: [www.alcase.org](http://www.alcase.org)

### **American College of Chest Physicians (ACCP)**

Toll-free phone number: (800) 343-ACCP

Internet site: [www.chestnet.org](http://www.chestnet.org)

### **American Cancer Society (ACS)**

Toll-free phone number: (800) ACS-2345

Internet site: [www.cancer.org](http://www.cancer.org)

### **Cancer Care**

Toll-free phone number: (800) 813-4673

Internet site: [www.cancercare.org](http://www.cancercare.org)

### **Lungcancer.org**

Toll-free phone number: (877) 646-LUNG

Internet site: [www.lungcancer.org](http://www.lungcancer.org)

### **National Cancer Institute (NCI)**

Toll-free number: (800) 4-CANCER

Internet site: [www.cancer.gov](http://www.cancer.gov)

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**Additional Lung Cancer  
Patient Education  
Guides Available**

**Lung Cancer... Am I At Risk?**

**What If I Have a Spot on My Lung? Do I Have Cancer?**

**Advanced Lung Cancer: Issues To Consider**

The American College of Chest Physicians is the leading resource for the improvement of cardiopulmonary health and critical care worldwide. Its mission is to promote the prevention and treatment of diseases of the chest through leadership, education, research, and communication.

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