

Second Edition

Living With a Diagnosis of Lung Cancer

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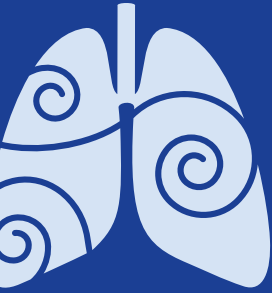


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Introduction

You have just been diagnosed with lung cancer. We hope this booklet will help prepare you for what lies ahead.

The first thing you must know, and something you should repeat to yourself over and over, is there is reason for hope! Much is being done for lung cancer patients and new treatments are being developed and tested every day.

Of course, you may experience many strong emotions; it is part of the process of dealing with your diagnosis. But a key part of living with lung cancer is to learn the facts. This resource is meant to help give you an overview of your disease and treatment options; you can mark areas where you have specific questions and bring them to your doctor for discussion.



Additional information can be found at our website:
www.NationalLungCancerPartnership.org

This booklet is not designed to be a substitute for medical advice provided by your treatment team.



What Is Lung Cancer?

Only cancers that begin in the lungs are called “lung cancer.” Sometimes cancer from other parts of the body may spread to the lungs, but when that happens, it is not called lung cancer. For example, breast cancer that spreads to the lungs is still breast cancer and will be treated as breast cancer, not lung cancer. Lung cancer that spreads to the liver is treated as lung cancer, not liver cancer.

A cancer forms when cells start to multiply out of control. All of the normal cells in your body have very specific jobs and functions. For example, intestine cells absorb vitamins, minerals and other nutrients from our food; red blood cells carry oxygen throughout the body; and white blood cells fight infections. Normal cells stop growing and dividing when they get old. Normal cells also die if they are injured.

Cancer cells are different. They do not function normally and they often divide uncontrollably. Cancer cells do not die when they grow old. They may spread to nearby organs. They also can spread through the blood stream, invade nearby **lymph nodes** (small collections of white blood cells scattered throughout the body), and **metastasize** (travel to other organs). Common lung cancer metastasis sites include the brain, bones, and liver.



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Why does cancer happen?

Every cell contains genes. Genes are the “brains” that tell the cell what to do. When the cell’s genes are **mutated** (damaged or changed), cancer may result. Some of these changes are inherited – they are passed down from parent to child; others may be due to things you are exposed to, such as cigarette smoke, radon, and asbestos. These mutations in the genes can cause cells to multiply uncontrollably, resulting in a mass of tissue called a tumor.

Types of lung cancer

There are 2 main types of lung cancer: **non-small cell lung cancer (NSCLC)** and **small cell lung cancer (SCLC)**. There are several subtypes of NSCLC. The most common are:

- Adenocarcinoma
- Squamous cell carcinoma
- Large cell carcinoma

If you have NSCLC, it is important to know the subtype because it will help your medical team develop the right treatment plan for you. The majority of lung cancers (about 8 out of 10) are NSCLC.

Small cell lung cancers tend to grow and spread more rapidly and cause symptoms sooner than NSCLC. For these reasons, surgery is usually not a good option for SCLC, and treatment is more likely to be with chemotherapy.

Bronchioloalveolar Carcinoma (BAC)

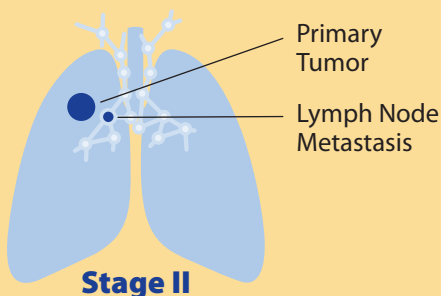
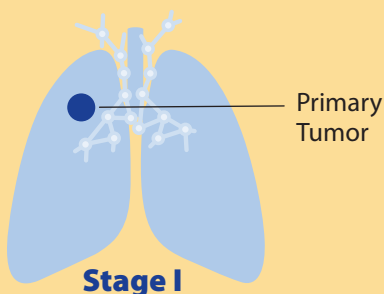
Bronchioloalveolar Carcinoma is a rare form of adenocarcinoma. The number of cases of BAC is rising worldwide. BAC spreads throughout the lung, unlike more typical cancer cells, which tend to “stick together” and form solid, individual tumors. The cause of BAC is not known. Although people who smoke can get BAC, it often occurs in people who have never smoked.

What is staging, and why is it important?

When you are diagnosed with lung cancer, your doctors will determine the type of lung cancer you have and the stage of the disease. **Staging** is based on the tumor's size and whether it has spread to any lymph nodes in the area or to other organs.

It is important to know what stage of cancer you have because the type and stage of the cancer will help your medical team determine which treatment plan is right for you. NSCLC is staged as I, II, III, or IV, while SCLC is usually classified as limited or extensive stage.

Non-Small Cell Lung Cancer (NSCLC)



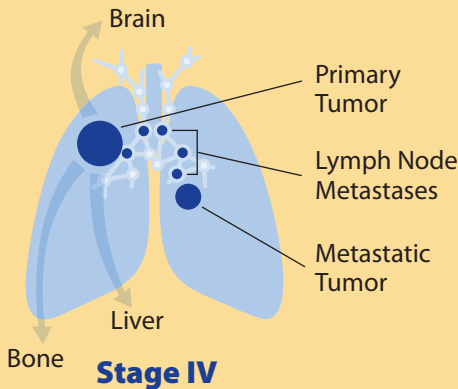
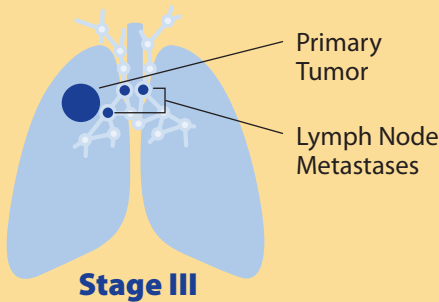
Stage I

A tumor that has not spread to any lymph nodes or other organs and is up to 5 cm wide is classified as stage I. This tumor is typically **resectable** (can be removed surgically). **Stage IA** cancers are 3 cm or smaller, and **stage IB** cancers are between 3 and 5 cm.

Stage II

A tumor that is up to 5 cm wide and has spread to lymph nodes on the same side of the chest, or a tumor that is 5-7 cm but has not spread to any lymph nodes is **stage IIA**. Tumors that have not spread to any lymph nodes but are larger than 7 cm, have begun to invade structures within the chest, or have another tumor in the same lobe of the lung are **stage IIB**. Tumors that are 5-7 cm and have spread to lymph nodes on the same side of the chest are also **stage IIB**. Generally, these tumors can be removed surgically.





Stage III

A tumor that does not appear to have spread to other organs beyond lymph nodes in the chest is classified as stage III. Often, stage III tumors are **unresectable** (cannot be removed surgically).

Stage IIIA tumors have spread to lymph nodes in the center of the chest. **Stage IIIB** tumors have spread to lymph nodes on the opposite side of the chest or involve major structures, such as the heart or arteries.

Stage IV

Cancer that is accompanied by **pleural effusion** (a fluid build-up between the lungs and the chest wall) or that has **metastasized** (spread) to other parts of the body is called stage IV. Although stage IV cancers are quite difficult to cure, there are treatments available that may help you live longer.

Small Cell Lung Cancer (SCLC)

Limited-stage SCLC is a cancer that is limited to the chest such that radiation can be used to treat it, in addition to chemotherapy.

Extensive-stage SCLC is cancer that has spread to other areas of the chest or other parts of the body. Although it is rarely cured, this type of cancer often responds well to chemotherapy and patients experience a great improvement in symptoms.

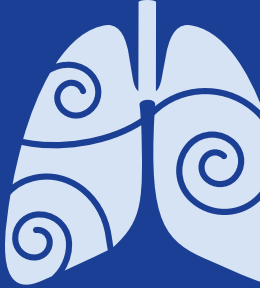
How will doctors know the stage of my cancer?

Doctors will determine stage by using any combination of the following procedures:

- **Computed tomography (CT)** scans are sophisticated X-rays that show the location and size of the tumor.
- **Positron emission tomography (PET)** is based upon the fact that cancer cells are growing faster than normal cells, and thus consume more sugar. A small amount of special imaging medicine containing sugar is injected into a vein, and a machine is used to see where the sugar builds up. PET scans can help determine where tumors are in the body.
- **Bronchoscopy** is a procedure in which a doctor puts a camera down the airway to see any tumors and possibly performs a **biopsy** (removal of a sample of the tumor or lymph nodes) using a needle.
- **Endobronchial ultrasound (EBUS)** is a newer, more specialized type of bronchoscopy that uses sound waves to create an image of the tumor and nearby tissues to help the doctor decide what to biopsy.
- **Bone scans** create pictures of the bones. A special imaging medicine is injected into a vein, and a specialized camera is used to see how healthy the bones are and whether there are any tumors in them.
- **Magnetic resonance imaging (MRI)** uses magnetic fields to produce detailed images of the body. MRI is particularly useful for finding abnormal growths in the brain.



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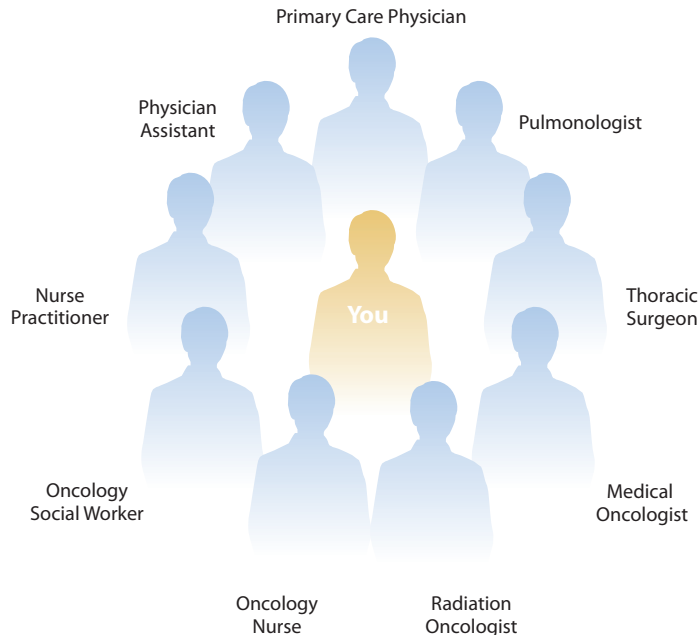


Who Should Treat My Lung Cancer?

As a partner in your own healthcare, it is important that you feel comfortable with the team of cancer specialists and others who will work with you to manage your disease. Choosing the right healthcare team, beginning with your **oncologist** (a doctor who is a cancer specialist) is the first step in being an active patient.

It is very important that you feel comfortable talking to members of your cancer care team. You should feel free to ask questions, discuss your treatment options and openly express your concerns, emotions, and wishes.

Your Lung Cancer Treatment Team



Who Should Treat My Lung Cancer?

Your healthcare team

Lung cancer treatment options depend upon the type and stage of your disease. Your healthcare team will develop a detailed treatment plan for you, taking into consideration your cancer as well as your other health needs.

Specialists who may be part of your cancer treatment team:

A **medical oncologist** will prescribe the drugs, such as chemotherapy, targeted therapy agents, and supportive care treatments needed to help manage your disease. A **thoracic oncologist** specializes in treating lung cancer patients.

A **radiation oncologist** uses x-rays to kill cancer cells. Radiation and medical oncologists often work together to decide on and carry out treatment plans.

A **thoracic surgeon** has special training to operate to remove or locally treat lung cancer tumors. If there is not a thoracic surgeon available in your area, ask which nearby surgeon performs the most lung cancer surgeries.

Nurse practitioners and **physician assistants** are specially trained to provide you with medical care ranging from preventive care and physical exams to ordering tests and prescribing certain medications. They work with your doctors to check on your overall health and how you are responding to your treatment(s), and can help you manage the side effects of your treatments.

Oncology nurses are specially trained in the care of cancer patients. They will journey with you on your treatment road and, along with your doctors, carefully check your progress. Oncology nurses may give you any drugs you may receive. If you are part of a study testing a new treatment, **research nurses** will help check on you and bring any concerns or questions to your doctor. They also help collect information needed for the study.

Oncology social workers provide counseling and support. They can connect you with resources you may need in addition to medical treatment. For example, a social worker may help you and your family find a place to stay during treatment if your cancer center is far

from home. A social worker might also help you with payment or other financial issues you may face as a result of your cancer.

Depending on your needs, other specialists could be part of your cancer team. A **nutritionist** will discuss foods and supplements that can help keep you healthy while you are in treatment; a **psychologist** can help you and your family deal with the emotions surrounding your cancer diagnosis and treatment; a **case manager** will coordinate your care; and/or a **respiratory therapist** or **pulmonologist** can help if you have trouble breathing.

Even though you will be seeing specialists for your cancer treatment, you will still need regular medical care and someone to oversee your general health. Your **primary care physician (PCP)** should be kept informed about your condition and updated about your cancer treatment. It is best when your oncologist and PCP work together as a team. This is usually done with written reports sent to your PCP after your visits with your cancer care team.

If You Smoke

If you smoke, it is important to work with your treatment team to quit smoking. Quitting smoking will help you breathe easier, put less stress on your heart and lungs and help your treatments work better. Studies have shown that quitting smoking helps you live longer, even once you have lung cancer. Talk with your oncology social worker, case manager or psychologist to find out about programs to help you develop a plan and quit smoking. This plan may include counseling and medications designed to make quitting easier. It is not too late to quit!

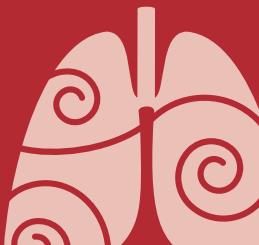
What Should Lung Cancer Patients Know?

What is my prognosis?

This is often the first question asked by patients after being diagnosed with lung cancer. You may see estimates that say how long a person may live after being diagnosed with a particular type or stage of lung cancer and assume that this is what will happen to you. *Don't* think this way. Don't do it for these reasons:

1. (Most important) *You are not a statistic.* Statistics cannot predict what will happen to *you*. You are a unique individual with your own health issues. The statistics estimate the average survival for all people with that type or stage of lung cancer. Although the type and stage of lung cancer will influence how well you do, *you* are not “everyone else”; you are *not* among the cases that make up the statistics.
2. (Also important) The statistics are based on old information, many from studies that were done years ago. Today's newer therapies have not been around long enough to affect the statistics, so the outcome for your disease may be far more hopeful than the statistics suggest.

The chances of being cured of lung cancer depend mostly upon what stage of lung cancer you have. Early-stage cancer is the easiest to treat and has the best chance of being cured. If the cancer has spread to other places in the body, the goals of treatment are to keep the cancer under control for as long as possible. Doctors are often able to do this with chemotherapy and/or radiation therapy.



If you read or are told your cancer cannot be cured, remember that *incurable cancer does not always mean that the cancer can't be treated.*

Newer treatments are helping some lung cancer patients live good lives for years.

What steps should I take before considering my treatment options?

More and more, the choice of treatments and/or clinical trial options depends on the specific genetic characteristics of your tumor. You should ask your doctor about whether genetic testing of your tumor is appropriate for you. In some instances, this testing may require an additional sample of your tumor. Information from the genetic testing may help guide specific treatment choices for you now and/or in the future.

What are my treatment choices? Which are recommended for me? Why?

Your treatment options will be based on the particular stage and type of lung cancer you have and where the cancer is located. Your treatment plan may include chemotherapy, radiation, surgery, and/or targeted therapy.

(For more information on treatments, see page 13.) You may want to consider a clinical trial as part of your treatment choices. Pages are included at the back of this booklet to allow you to keep track of your treatment plan.

How long will my treatment last?

The length of your treatment will depend on the type and stage of lung cancer you have, and how well you respond to treatment. Your treatment plan will be explained to you before therapy begins. If you have questions, be sure to ask them. You will be checked at regular intervals, or if you have any unexpected problems. If your cancer does not respond to the first treatment you receive, other treatments may be discussed with you.

Should I consider joining a clinical trial?

Clinical trials are a special kind of research used to see how well new drugs, treatments or tests work, or to find out more about cancer or other diseases. Many patients feel they get more attention, care and more frequent check-ups if they participate in a clinical trial.

Trials are generally available for every stage and type of lung cancer, although every individual may not be eligible for a given trial. (See page 22 for more information on clinical trials.)

How much will treatment cost? How do I find out what my insurance covers?

The costs depend on the kind of insurance you have, the treatments you need and whether you get them at home, in a clinic, or in a hospital.

For instance, most health insurance policies, Medicare, and Medicaid cover most of the cost of many different types of chemotherapy. Cancer centers and most hospitals have patient assistance departments that should be able to help you find out what your insurance will cover and whether you qualify for assistance. (See page 29 for more information about organizations that can help with money matters.)

What about alternative therapies?

When you have been diagnosed with lung cancer, you may hear about “alternative therapies,” such as herbal remedies, dietary supplements, massage therapy, acupuncture or chiropractic treatments. While some of these therapies may be helpful in managing pain or side effects of treatment, they are *never* a substitute or replacement for proven medical treatments prescribed by the specialists on your cancer care team. Also, some of these alternatives may be harmful to you. They may cause problems with the treatment you are receiving or keep it from working. Always talk with your cancer specialists before taking part in any alternative therapy plan.



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Standard Treatments for Lung Cancer

The most common treatments for lung cancer are surgery, radiation therapy, and chemotherapy. Some patients also may be prescribed targeted therapy, which includes drugs that “target” cancer cells. There also are some new treatment options being tested in clinical trials. Be sure to talk with your doctor if you are interested in participating in a clinical trial.

Surgery

Surgery, or having an operation, is the physical removal of the cancer tumor and any lymph nodes that may contain cancerous cells. Ideally, a thoracic surgeon, who is an expert in lung cancer surgery, should perform the operation. Seek out a surgical center that does a lot of lung cancer surgeries. Don't be afraid to ask whether your recommended surgeon is a thoracic surgeon and how many lung cancer surgeries he or she does each year.

Whether you can be treated with surgery depends on:

- The type and stage of your cancer (see pages 3-5). Surgery is generally not recommended if the cancer has spread to other organs (stage IV NSCLC) or for SCLC.
- The location and size of your tumor. If the surgeon cannot get to or safely remove your tumor, the disease is called inoperable, or unresectable, and surgery may not be an option (stage IIIB and some stage IIIA NSCLC patients).
- Whether you are otherwise healthy enough to have surgery. If you have heart or lung disease in addition to lung cancer, you may not be able to have surgery.



If you have traditional lung surgery, it usually takes 6 to 8 weeks to fully recover. Depending on the size and location of your tumor, you may be able to have a newer type of lung surgery with a shorter recovery time: **video-assisted thoracic surgery (VATS)**. This type of surgery is less invasive because it uses a video camera to guide the surgeon. Recovery time will vary depending on your particular surgery, your general health and how well you heal.

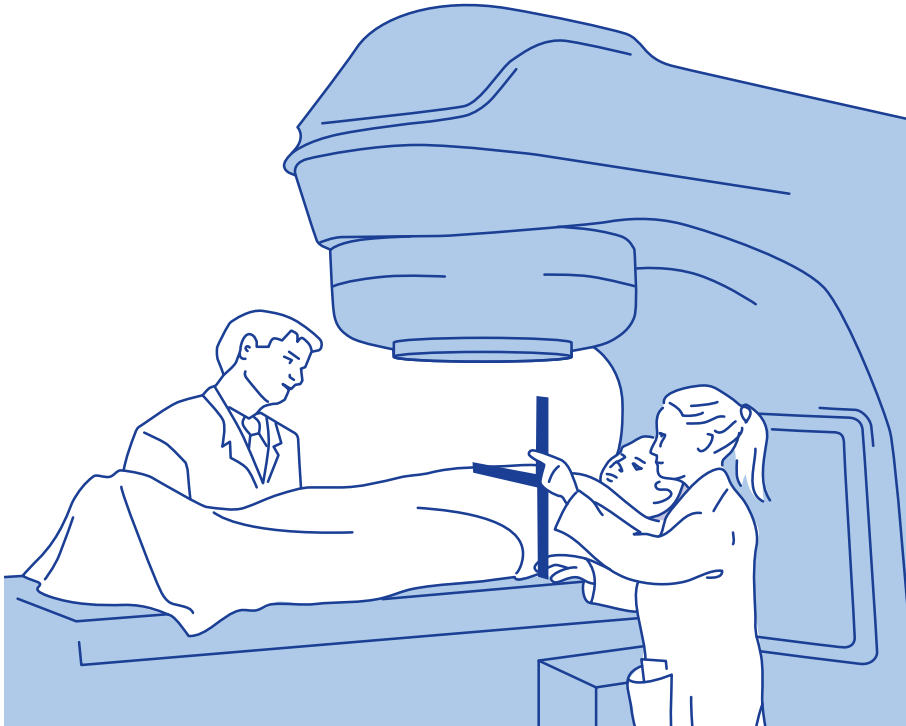
Managing Your Pain

You may experience pain from your cancer, surgery or radiation therapy. There are many effective pain medicines available. Pain medicines are much better at keeping pain away than they are at reducing pain after it occurs, so talk with your doctor or nurse about ways to treat your pain early in your treatment process. Although many people may fear getting addicted to or “hooked” on pain medications, research has shown that is unlikely to occur when the medications are used correctly for pain.



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Radiation therapy



Radiation therapy (also sometimes referred to as radiotherapy, x-ray therapy, or irradiation) is the use of x-rays to damage cancer cells and stop them from growing or multiplying. Because radiation also affects normal cells, this therapy is aimed only at the cancer tumor. Like surgery, radiation is a local form

of therapy and not a **systemic** (whole-body) treatment, such as chemotherapy. High **doses** (amounts) of radiation are given when the tumor is confined to the chest, with the hope that it will kill all of the tumor cells in that area. This might involve daily doses of radiation for up to 6 weeks or longer.

When the cancer has spread from the lungs to other parts of the body, radiation may be given in smaller doses to relieve symptoms in affected areas, such as the brain or bones. Radiation, given for periods ranging from 1 day to 4 weeks, can kill enough cancer cells to bring relief from symptoms such as pain, breathing difficulties, and headaches.

Side effects from radiation therapy depend upon where the radiation is focused and how much radiation is given. Radiation treatment can make you tired, for example, or give you a painful sore throat. For more details about the side effects you can expect from your treatment, talk with your oncology nurse or radiation oncologist.

Specialized Radiation Therapy

Your radiation oncologist may recommend a specialized type of treatment for you called **stereotactic body radiation therapy (SBRT)**. SBRT uses radiation from multiple angles, allowing higher doses of radiation to be focused on the tumor, avoiding normal tissues. You may hear about Gamma-knife or CyberKnife treatments, which are methods of delivering SBRT.

Other advances in radiation therapy are being developed and may be available after the printing of this booklet.



For more information, visit our website:
www.NationalLungCancerPartnership.org

Chemotherapy



Chemotherapy drugs are used to kill cancer cells. Unlike surgery and radiation, which are used to treat local disease, chemotherapy is usually systemic, that is, it goes through the whole body and should affect cancer cells anywhere they may be. There are a number of different chemotherapy drugs that are used

for lung cancer, often in combination. They are administered intravenously (IV) or taken as pills by mouth. Usually, chemotherapy drugs are given for 4 to 6 “cycles.” Each cycle is a treatment followed by about a 3-week rest period. Therefore, if you are prescribed 4 cycles, it usually means you will receive the

chemotherapy drugs four times, each given about 3 weeks apart, for a total of 12 weeks of therapy. However, depending on your particular cancer and overall health, your doctors may recommend a different schedule for your treatment.

Many people are concerned about the side effects of chemotherapy. It is important to know that different types of cancers are treated with different types of chemotherapy, and that chemotherapy has changed a lot over the years. If someone tells you what they or a friend went through, remember that your experience may be very different, particularly if the other person did not have lung cancer or received different chemotherapy drugs than you are prescribed. Typical side effects of chemotherapy include (but are not limited to):

- Hair loss. Not all types of chemotherapy cause hair loss. If this is important to you, be sure to ask your oncologist about your treatment options.
- Severe nausea/vomiting. This is largely a thing of the past due to the newer anti-nausea medicines that are available.

- Lowering the blood cell count. Chemotherapy affects all of the blood cells in your body, and your **blood count** (the number of these cells) generally goes down. Your blood count is likely to go down about 1 to 2 weeks after your treatment and should return to normal about a week later.

- Red blood cells: Low red blood cell counts can cause you to feel more tired than usual or short of breath.
- White blood cells: Having a low white blood cell count means you may not be able to fight off infections, such as colds or the flu, as easily, so you will want to do your best to protect yourself from these illnesses during your treatment. Avoid being around people who are sick. Wash your hands often.
- Platelets: Having a low platelet count puts you at risk for bleeding, although complications from this are rare.

Each individual chemotherapy drug has its own side effects. For more details about the possible side effects of your chemotherapy, ask your oncologist or nurse.

Targeted therapy: New lung cancer treatments

Over the past decade, scientists have made many discoveries about what makes cancer cells multiply out of control. They are developing drugs that “target” cancer cells. There are different types of targeted therapy.

For example, some drugs stop substances called growth factors from working. These growth factors are made by tumor cells and “tell” other tumor cells to multiply. Blocking these growth factors from working can stop the cancer from growing and/or spreading. Some other types of targeted therapy drugs can stop the tumor from making new blood vessels, a process known as angiogenesis. Choking off the blood supply to a tumor can prevent it from getting needed oxygen and nutrients. There are different types of targeted therapies, but all are designed to target cancer cells and stop or limit the growth and spread of cancer.

At the time of this booklet’s publication, there are targeted therapies available to treat NSCLC in certain cases. Some of these treatments work best in people whose tumors have specific genetic mutations, so testing the tumor tissue for these mutations can be important. Many more drugs are being tested in clinical trials to see if they will help people with NSCLC and SCLC. Even more drugs are in development.



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Non-Small Cell Lung Cancer (NSCLC) Treatments by Stage

Stage I

The ideal treatment for stage I NSCLC is surgery. New research is helping doctors predict which stage I NSCLC patients will need chemotherapy after their surgery and which will not.

Stage II

The optimal treatment for stage II NSCLC is surgery followed by chemotherapy.

Stage III

For **stage IIIA** cancer, chemotherapy is the standard treatment, either in conjunction with radiation therapy or surgery. Research is under way to help doctors decide the best timing for these different treatments. Your treatment team will develop a plan based on your needs and their best experience in fighting this disease. **Stage IIIB** cancer is usually treated with chemotherapy and radiation therapy; surgery is generally not recommended.

Stage IV

Because stage IV cancer has spread to other parts of the body, surgery is not usually recommended. Chemotherapy is used because it fights the cancer throughout the body. Targeted therapy also may be prescribed, depending on the type, size and location of the tumors, and whether you are on other medications. Radiation may be used to shrink tumors that are causing symptoms.

Continuing a drug or using a different drug after the initial course of chemotherapy, often called **maintenance therapy**, can continue to treat the cancer and help keep it from spreading. However, not every person will be able to manage the side effects of these drugs so soon after their initial chemotherapy. The decision to go on maintenance therapy will be individual to you and your experience.

Recurrent NSCLC

If your cancer has progressed after one type of chemotherapy, other chemotherapy and targeted therapy drugs may be recommended. Many people experience great improvement with additional treatment, even after their cancer has recurred.

Small Cell Lung Cancer (SCLC)

Treatments by Stage

Limited Stage

Limited-stage SCLC is typically treated with radiation and chemotherapy. **Prophylactic cranial irradiation (PCI)** is radiation to the whole brain. PCI is sometimes given to SCLC patients who have done well with chemotherapy. The brain is a common site for cancer to come back in patients with SCLC because chemotherapy does not get to the brain as well as other tissues. PCI is recommended for SCLC patients who have gone into **remission** (the cancer has gone away) as a result of their initial chemotherapy.

Extensive Stage

Individuals with extensive-stage SCLC are treated with chemotherapy. Should remission occur, PCI also will be used.

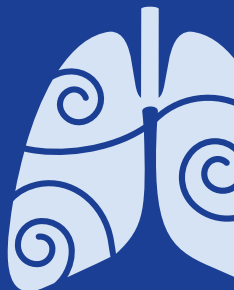
Supportive care

Your treatment team may recommend drugs that do not treat your cancer, but can help you maintain your overall health during treatment. These drugs are referred to as supportive care agents. You may receive suggestions to take any or all of the following:

- A drug to strengthen your bones, if your cancer has spread to the bones
- Drugs to prevent you from becoming nauseous when you receive chemotherapy treatments
- A drug to prevent you from becoming constipated
- A drug to treat **anemia** (a low red blood cell count)
- A drug to treat low counts of **white blood cells** (the cells that fight off disease)

Ask your oncology nurse, nurse practitioner, physician assistant or doctor to talk with you about how these or other supportive care methods may help you manage your cancer and side effects of your treatments.

What Should I Know About Lung Cancer Research and Clinical Trials?



When you are diagnosed with lung cancer, participating in a clinical trial is something you should discuss with your doctor early in your treatment process. It is important that more people with lung cancer take part in clinical trials. Treatment advances—and, someday, cures—cannot happen unless patients get involved in clinical research. If you are interested in taking part in a clinical trial and your doctor does not discuss this option with you, ask if there may be opportunities for you to participate.

Treatment-based clinical trials might involve the use of drugs, radiation therapy, surgery, or other ways to treat cancer. Such trials are only performed in people after a great deal of laboratory research shows promising results.

Treatment-based clinical trials are often **randomized** (each individual is assigned by computer to the new treatment plan or the existing treatment). In clinical trials for other diseases, some patients may be given **placebos** (inactive pills, injections, or treatments) while others are given the medicine being tested, and then what happens to patients is compared. Typically, when placebos are used in cancer clinical trials, some patients are given the placebo *in addition* to the best treatments currently available, while others are given the medicine being tested plus the best treatment currently available.

Participating in a clinical trial may make newer treatments available to you. The results also can help others who will be diagnosed with lung cancer in the future.



For more information, visit our website:
www.NationalLungCancerPartnership.org

Clinical trial phases

Before a new drug, treatment, or procedure is approved by the federal government's Food and Drug Administration (FDA) for use in people, it must undergo 3 phases of clinical trials. Each phase is watched carefully by both the FDA and the hospitals or treatment centers where the clinical trials are carried out. It is only after all 3 phases are successfully completed that a new treatment can be approved for use in all patients.

A **phase I** clinical trial helps determine the best amount of a drug or radiation therapy, for example, that should be used and the best way to administer a new treatment or procedure. Phase I trials also are designed to make sure the treatment is safe. About 12 to 60 people usually participate in a phase I study. Depending on the treatment being studied, these patients may have different types of cancer, different stages of the disease and different amounts and types of prior treatment.

A **phase II** trial is designed to see whether a new drug or treatment actually has a positive impact on the disease in question. These studies are designed to learn what percentage of patients respond to the treatment, how long it takes until patients experience the response, and how long the response lasts. Most phase II studies involve between 20 to 100 people.

A **phase III** study compares a new treatment to the best existing therapies. These studies typically involve hundreds or thousands of patients in many clinics across the country or elsewhere in the world to see if the new treatment works better than 1 or more current treatments. A phase III study is the only way to scientifically determine whether the new therapy works better than the treatments doctors are already using.

Locating clinical trials

You can find listings of clinical trials specific to your condition and area of the country. Ask your doctor for referrals and check out the following resources:

[www.emergingmed.com/networks/
NationalLungCancerPartnership/](http://www.emergingmed.com/networks/NationalLungCancerPartnership/)

www.clinicaltrials.gov

www.cancertrialshelp.org

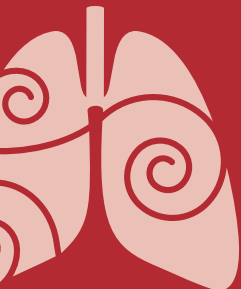
Stories of Strength

To learn about lung cancer patients' experiences with clinical trials, please visit our website at www.NationalLungCancerPartnership.org to view or order our video, *Stories of Strength: Making the Decision to Enter a Lung Cancer Clinical Trial*.

Living with Lung Cancer

There isn't one best or easiest way to live with a diagnosis of lung cancer. Here are some suggestions for ways you can live with your diagnosis and treatment:

- **Get a second opinion.** Arm yourself with knowledge of *all* of your options. If you do not get a recommendation from your doctor for where to get a second opinion, consider going to a National Cancer Institute–designated Comprehensive Cancer Center (http://cancercenters.cancer.gov/cancer_centers/index.html). These centers are ideally suited to provide you with the treatment you need. The experts you consult may all tell you the same thing or they may suggest new options or clinical trials you may want to consider. You should start treatment with the confidence that you have made the best decision you can.
- **Become your own best advocate.** Talk with your doctors and nurses. Ask questions. Ask them to repeat what you don't understand. Repeat back to them what you think you heard and ask them to confirm that you understood. Be active in your care and choices. Use the pages at the end of this booklet to keep track of questions you have, and information about your health and disease, such as your latest test results, medical reports and notes. Bring a family member or friend with you to all appointments so that you can make sure they heard the same information you did.



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- **Don't let anyone steal your hope.** There is much that even the experts don't understand about lung cancer, especially how each person will respond to treatment. Forget or ignore the statistics. They tell you nothing about what is going to happen to you. Find doctors who share your hope for survival and are willing to fight right along with you.

Your family and friends

Although you are the one with a diagnosis of lung cancer, your family and other loved ones are experiencing it with you. They are dealing with their own sadness, fears and worries. One way for them to handle their feelings is to try to take care of you. If possible, allow them to help you. It is part of their healing process as well as yours. When it comes to family and friends, be sure to

- surround yourself with positive and encouraging people;
- take someone to doctor visits with you to help listen or take notes;
- accept offers for help. When people ask, "What can I do?" it is because they truly want to "do" something. Allow them the pleasure and privilege of helping you. You will be helping them through this hard time, too.

For the Young Person with Lung Cancer

Most lung cancer patients are over age 60. However, a large number of young people, even those under 40, are diagnosed with this disease. If you haven't started or completed your family and it's important to you, be sure to talk with your doctor before you start treatment about options for preserving your ability to have children in the future.

Support groups

Support groups offer a chance to talk with others going through situations similar to yours. Yet, many lung cancer patients are not comfortable seeking out these groups. Some people actually feel guilty about a diagnosis of lung cancer: if you have smoked, you may feel that it is your own "fault" that you got lung cancer. These negative feelings make support groups especially important for you. You must recognize that *no one deserves lung cancer*. Support groups also can help your family and loved ones who are affected by your illness.

You may find that in the beginning you come to a group to seek encouragement and hope but that later you are the one to offer that same encouragement and hope to someone else. Many kinds of support are available. (See pages 27-30 for more information about support services.)

Ongoing care

Even if there is no sign of lung cancer after your treatment is completed, the fear of the cancer returning is often on the mind of survivors. You may find yourself dealing with treatment side effects, or you may feel the loss of the attention of your medical team and support groups. This is a time that can be difficult; feelings of depression are not unusual. Many people continue to find comfort from support groups even after their treatment has ended. Also, these groups allow you to share your experiences with those who are facing what you have already gone through, which can be rewarding.

Once your treatment is over, it is also important that you receive regular follow-up care. Visit your doctor as prescribed to monitor for any return of cancer. The American Society of Clinical Oncology recommends that you have follow-up appointments with your specialist every 3 months during the first 2 years after treatment, every 6 months during years 3 through 5 and yearly after that. You should feel free to schedule more frequent appointments if you are experiencing symptoms that worry you or have other healthcare concerns. Ask your physician what symptoms you should be on the lookout for. Report them promptly should they occur.



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Resources

Lung cancer information

National Lung Cancer Partnership

(www.NationalLungCancerPartnership.org; 608-233-7905)

The National Lung Cancer Partnership is the only lung cancer advocacy organization founded by doctors and researchers. Dedicated to improving treatments for lung cancer patients, the Partnership works together with lung cancer survivors and patient advocates to provide resources for patients and their families, raise and distribute funds for lung cancer research, and generate awareness of the disease.

Global Resource for Advancing Cancer Education (GRACE)

(www.CancerGrace.org/lung)

Medical specialists provide online information on current and emerging cancer management options in order to empower patients, caregivers, and health professionals to become direct partners in cancer care.

Cancer.net

(www.cancer.net/patient/Cancer+Types/Lung+Cancer; 571-483-1780 or 888-651-3038)

This website, sponsored by the American Society of Clinical Oncology, provides information that has been reviewed by experts to help patients and families make informed healthcare decisions.



National Cancer Institute: Lung Cancer

(www.cancer.gov/cancertopics/types/lung;
800-422-6237)

On this website, sponsored by the federal government, you will find a section describing lung cancer, its causes and treatments. There is information on clinical trials and research relating to lung cancer as well as a glossary of cancer terms.

Wikipedia: lung cancer

http://en.wikipedia.org/wiki/lung_cancer

This online, publicly developed encyclopedia entry contains a great deal of information about lung cancer, its causes and treatments.

Lung Cancer Alliance

(www.LungCancerAlliance.org; 202-463-2080 or
800-298-2436)

This organization is dedicated to advocating for people living with lung cancer or those at risk for the disease. Lung Cancer Alliance also offers patient education and support programs focused on helping people directly affected by lung cancer.

Support services

CancerCare

(www.LungCancer.org; www.CancerCare.org;
800-813-4673)

This national not-for-profit organization provides free, professional support services for anyone affected by cancer. Counseling, education, financial assistance, and practical help are provided by trained oncology social workers. Support is available in person, online and by telephone.

The Cancer Support Community

(www.CancerSupportCommunity.org;
202-659-9709 or 1-888-793-9355)

The Cancer Support Community was created from a merger between Gilda's Club and The Wellness Community. This national not-for-profit organization provides professional programs of emotional support, education, and hope for people affected by cancer at no charge so that no one faces cancer alone.



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CarePages

(www.CarePages.com; 888-852-5521)

CarePages is an online community of people coming together to share the challenges, hopes and triumphs of anyone facing a life-changing health event. This service allows people to create personalized websites to help families and friends connect during and after major medical situations, and provides a place for patients and their families to journal their experience or connect with others facing similar circumstances.

Lotsa Helping Hands

(www.LotsaHelpingHands.com)

This website helps friends, family, colleagues, and neighbors assist loved ones in need. It provides an easy-to-use private group calendar, specifically designed for organizing helpers, so everyone can pitch in with meal delivery, rides and other tasks that can be helpful during a crisis.

Financial assistance

CancerCare Co-Payment Assistance Foundation

(www.CancerCareCopay.org; 212-601-9750 or 866-552-6729)

This foundation is a not-for-profit organization that addresses the needs of individuals who cannot afford their insurance co-payments to cover the cost of medications for treating cancer.

Patient Advocate Foundation

(www.PatientAdvocate.org; 1-800-532-5274)

This national nonprofit organization seeks to safeguard patients through effective mediation to assure access to care, maintenance of employment, and preservation of financial stability.

Lance Armstrong Foundation

(www.LiveStrong.org; 1-866-673-7205)

The LIVESTRONG SurvivorCare program provides free, confidential, one-on-one support to anyone affected by cancer. Through this program, you can receive assistance with counseling referrals, financial, employment and insurance concerns, and information and financial assistance related to fertility preservation.

Partnership for Prescription Assistance

(www.pparx.org; 888-477-2669)

This organization helps qualifying patients without prescription drug coverage get the medicines they need for free or nearly free. They offer a single point of access to more than 475 public and private programs.

United Way

(<http://National.UnitedWay.org>; 703-836-7112)

Your local United Way can help with basic living expenses, including rent/mortgage, utility payments, and food.

If your doctor recommends a particular drug that you have trouble paying for, contact the drug company that makes it. Most drug companies have programs to help patients get the drugs they need when insurance, co-pay, or other money matters get in the way. If you don't know which company makes the drug(s) you are prescribed, talk with your nurse, social worker or case manager.



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The **National Lung Cancer Partnership** is the only lung cancer advocacy organization founded by doctors and researchers working together with survivors and advocates to increase lung cancer awareness and research funding.

Our mission is to decrease deaths due to lung cancer and help patients live longer and better through research, awareness, and advocacy.

For additional patient resources, including our video profiling lung cancer patients' experiences with clinical trials, *Stories of Strength: Making the Decision to Enter a Lung Cancer Clinical Trial*, please visit our website at:

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**National Lung
Cancer Partnership**

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