

ASCO<sup>®</sup>answers

# Non-Small Cell Lung Cancer



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American Society of Clinical Oncology**

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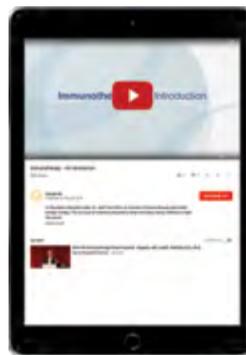
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# Introduction

It is one of many people's biggest fears—sitting in the doctor's office and hearing the word "cancer." People diagnosed with non-small cell lung cancer (NSCLC) often say they were stunned by their diagnosis and could not hear, much less remember, what the doctor said afterward. However, absorbing the news of a cancer diagnosis is a key part of the coping process.



In the weeks to come, you may find it helpful to have family members or friends come to your appointments with you. They will give you some much needed support. They can also help listen to and remember the information your health care team provides.

Using this *ASCO Answers* guide may also be helpful. This guide explains some of the medical terms doctors may use when talking about NSCLC. The guide can also help you keep track of the specifics of your diagnosis and treatment plan. In addition, you will find questions to ask your doctor, nurse, or another member of your health care team. You can use the notes sections to write down their answers or other important information. There are also checkboxes you can use to identify the tests, procedures, and treatments that will make up your cancer care plan.

It is important to keep track of this information, regardless of how you choose to do it. Getting the facts about your diagnosis will help you make the best decisions for your situation in the coming days. Being an informed, involved patient who voices questions and concerns will help you and your health care team form a partnership in your care. Tell your doctor and nurse how you prefer to receive information. Also tell them how much you want to know about your diagnosis, treatment, and prognosis, which is the chance of recovery. Don't be afraid to ask questions or to let your health care team know you don't know what questions to ask.

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# Non-Small Cell Lung Cancer Basics

The lungs are part of a group of organs and tissues, known as the respiratory system, that help a person breathe. When you inhale, your lungs absorb oxygen from the air. Then they bring the oxygen into the bloodstream for delivery to the rest of your body. As your body's cells use oxygen, they release carbon dioxide. The bloodstream carries carbon dioxide back to the lungs, and the carbon dioxide leaves the body when you exhale.

The lungs contain many different types of cells. Most cells in the lungs are epithelial cells. These cells line the airways and make mucus, which lubricates and protects the lungs. The lungs also contain nerve cells, hormone-producing cells, blood cells, and structural or supporting cells.

## Non-small cell lung cancer development

NSCLC is the most common form of lung cancer. The disease begins when healthy cells in the lung change and grow out of control, forming a mass called a tumor, lesion, or nodule. A tumor can begin anywhere in the lung and can be cancerous or benign. A cancerous tumor is malignant, meaning it can spread to other parts of the body. A benign tumor means the tumor can grow but will not spread.

NSCLC begins in the epithelial cells. Your doctor will determine which type of NSCLC you have based on the way the cancer looks under a microscope. The different types of NSCLC are:

- ▶ Adenocarcinoma
- ▶ Squamous cell carcinoma
- ▶ Large cell carcinoma
- ▶ NSCLC-NOS (not otherwise specified) or NSCLC undifferentiated

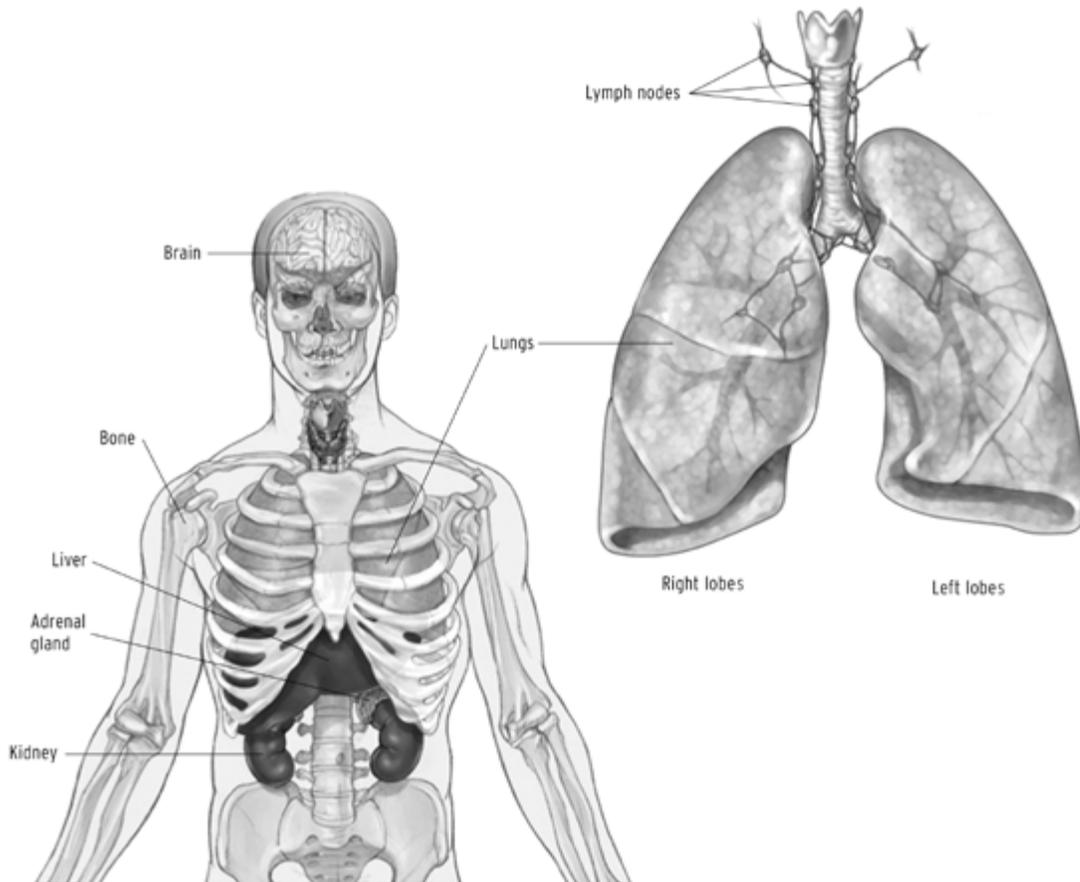
It is important for doctors to distinguish between lung cancer that begins in the squamous cells from lung cancer that begins in other cells. Your doctor will use this information to determine your treatment options.

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**It is important for doctors to distinguish between lung cancer that begins in the squamous cells from lung cancer that begins in other cells.**

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MEDICAL ILLUSTRATIONS FOR MANY TYPES OF CANCER ARE AVAILABLE AT [WWW.CANCER.NET](http://WWW.CANCER.NET).

## Non-small cell lung cancer spread

As a cancerous lung tumor grows, it may or may not shed cancer cells. These cells can be carried away in blood or float away in lymph, the fluid that surrounds lung tissue. Lymph flows through tubes called lymphatic vessels. These vessels drain into collecting stations called lymph nodes, the small, bean-shaped organs that help fight infection. Lymph nodes are located in the lungs, the center of the chest, and elsewhere in the body. The natural flow of lymph out of the lungs is toward the center of the chest. This explains why lung cancer often spreads there first. When a cancer cell moves into a lymph node or to a distant part of the body through the bloodstream, it is called metastasis.

NSCLC can metastasize anywhere in the body. The most common places it spreads are the lymph nodes, other parts of the lungs, bones, brain, liver, and structures near the kidneys called the adrenal glands. When NSCLC spreads, it can cause breathing difficulties, bone pain, abdominal or back pain, headache, weakness, seizures, and speech difficulties. Rarely, a lung tumor can release hormones that cause chemical imbalances, such as low blood sodium levels or high blood calcium levels. No matter the size and location of the tumor, whether the cancer has spread, or how far it has spread, there are treatments available.



### QUESTIONS TO ASK THE HEALTH CARE TEAM

- ▶ Who will be part of my health care team, and what will each member do?
- ▶ Did the cancer start in the lungs or has it spread from another part of the body?
- ▶ Where can I find more information about NSCLC?
- ▶ If I have questions or problems, who should I call?



# Understanding Your Diagnosis

Doctors use many tests to diagnose NSCLC and find out if it has spread from the lung. Some tests may also determine which treatments may be the most effective. A biopsy is the only way to make a definitive diagnosis of NSCLC. Doctors may use imaging tests to find out whether the cancer has spread. However, imaging tests can never be used alone to diagnose NSCLC.

Not every test is right for every person. Your doctor may consider these factors when choosing a diagnostic test:

- ▶ Type of cancer suspected
- ▶ Your signs and symptoms
- ▶ Your age and general health
- ▶ The results of earlier medical tests



## Making a cancer diagnosis

In addition to a physical exam, doctors may use the following tests to diagnose and stage NSCLC. Your doctor will talk with you about the test(s) that will provide the most useful information about your cancer.

### □ Biopsy

A biopsy is the removal of a small amount of tissue for examination under a microscope. A pathologist then analyzes the tissue samples. A pathologist is a doctor who specializes in interpreting laboratory tests and evaluating cells, tissues, and organs to diagnose disease. Doctors have learned that it is helpful to have a larger tumor sample to determine the type of NSCLC and to do additional molecular testing, which is described below. If the first biopsy does not remove enough of the tumor to do these tests, you may need another biopsy.

### ❑ **Molecular testing of the tumor**

Depending on your tumor, your doctor may recommend running laboratory tests on a tumor sample to identify specific genes, proteins, and other factors unique to the tumor. This is called molecular testing. There are several genes that may be changed, called mutations, in a lung tumor that can help the cancer grow and spread. These mutations are found in the tumor. They are not in healthy cells in the body. This means they are not inherited or passed down to your children. Mutations known to contribute to lung cancer growth often occur on 1 or more of several genes. They include *EGFR*, *ALK*, *KRAS*, *BRAF*, *HER2*, *ROS1*, *RET*, *MET*, and *NTRK*.

Testing the tumor for some of these genes is now common for later-stage non-squamous NSCLC. Sometimes, earlier-stage cancer is also tested for these genes.

Results from molecular testing help doctors decide whether your treatment options should include a type of treatment called targeted therapy, which is described on page 17. Doctors can direct this therapy at specific mutations. Mutations that can be targeted with specific medications are much more likely to occur in patients with the adenocarcinoma type of NSCLC and in patients who never smoked.

If you have later-stage NSCLC, your doctor may also recommend PD-L1 testing. PD-L1 is found on the surface of cancer cells. This protein stops the body's immune cells from destroying the cancer. Knowing if the tumor has PD-L1 helps your doctor decide whether your treatment options include certain types of immunotherapy (see page 20). These types of immunotherapy block PD-L1 and allow the body's immune system to target the cancer.

### ❑ **Bronchoscopy**

The doctor passes a thin, flexible tube with a light on the end into the mouth or nose. The tube goes down through the main windpipe and into the breathing passages of the lungs. A surgeon or pulmonologist may perform this procedure. A pulmonologist is a medical doctor who specializes in the diagnosis and treatment of lung disease. The tube lets the doctor see inside the lungs. Tiny tools inside the tube can take samples of fluid or tissue so the pathologist can examine them. Patients get mild anesthesia during a bronchoscopy. Anesthesia is medication that blocks the awareness of pain.

### ❑ **Needle aspiration/core biopsy**

First, a special type of radiologist, called an interventional radiologist, numbs the skin. Then the radiologist uses a needle to remove a sample of the lung tumor for testing. This can be done with a smaller needle or a larger needle, depending on how much tissue the pathologist needs. Often, the radiologist uses special imaging equipment to guide the needle. In general, core biopsies, which use the larger needle and provide greater amounts of tissue, are more common.

**❑ Thoracentesis**

First the doctor numbs the skin on the patient's chest. Then the doctor inserts a needle through the chest wall. The needle goes into the space between the lung and the wall of the chest where fluid can collect. The doctor removes the fluid, which is checked for cancer cells by a pathologist.

**❑ Thoracoscopy**

A surgeon makes a small cut in the skin of the patient's chest wall. Then the surgeon inserts a special instrument and a small video camera to assist in the examination of the inside of the chest. Patients need general anesthesia for this procedure. However, recovery time may be shorter with a thoracoscopy than other tests because the incisions are smaller. Doctors may call this procedure video-assisted thoracoscopic surgery or VATS.

**❑ Mediastinoscopy**

A surgeon makes a small incision at the top of the breastbone. Then the surgeon examines and takes a sample of the lymph nodes in the center of the chest underneath the breastbone. This procedure requires general anesthesia and is done in an operating room.

**❑ Thoracotomy**

A surgeon makes an incision in the patient's chest. The surgeon then examines the lung and takes tissue samples for testing. A thoracotomy is the procedure surgeons most often use to completely remove a lung tumor. This procedure also requires general anesthesia and an operating room.

**Imaging tests**

In addition to biopsies and surgical procedures, imaging tests are very important in the care of people with NSCLC. But no scan can diagnose the disease. Your doctor will combine chest x-ray and scan results with your medical history, a physical examination, blood tests, and information from a biopsy. All of this information helps the doctor figure out where the cancer began and whether or where it has spread.

**❑ Computed tomography (CT or CAT) scan**

This test produces images that allow doctors to see the size and location of a lung tumor and/or lung cancer metastases. A CT scan takes pictures of the inside of the body using x-rays taken from different angles. A computer combines these pictures into a detailed, 3-dimensional image that shows any abnormalities or tumors. A CT scan can also be used to measure the tumor's size. Sometimes, a special dye called a contrast medium is given before the scan to provide better detail on the image. This dye can be injected into a patient's vein or given as a pill to swallow.

### ❑ **Positron emission tomography (PET) scan or PET-CT scan**

A PET scan is usually combined with a CT scan, called a PET-CT scan. However, you may hear your doctor refer to this procedure just as a PET scan. A PET scan is a way to create pictures of organs and tissues inside the body. A small amount of a radioactive sugar substance is injected into the patient's body. This sugar substance is taken up by cells that use the most energy. Because cancer tends to use energy actively, it absorbs more of the radioactive substance. A scanner then detects this substance to produce images of the inside of the body.

### ❑ **Magnetic resonance imaging (MRI) scan**

This test also produces images that allow doctors to see the location of a lung tumor and/or lung cancer metastases and measure the tumor's size. However, an MRI uses magnetic fields, not x-rays, to produce detailed images of the body. A special dye called a contrast medium is given before the scan to create a clearer picture. This dye can be injected into a patient's vein or given as a pill to swallow. MRI scanning doesn't work well to take pictures of parts of the body that are moving. That includes your lungs, which move with each breath you take. For that reason, doctors rarely use the MRI scan to look at the lungs. Instead, the scan may help find NSCLC that has spread to the brain or bones.



### ❑ **Bone scan**

A bone scan uses a radioactive tracer to look at the inside of the bones. The tracer is injected into a patient's vein. It collects in areas of the bone and is detected by a special camera. Healthy bone appears lighter to the camera, and areas of injury, such as those caused by cancer, stand out on the image. PET scans (see above) have been replacing bone scans to find NSCLC that has spread to the bones.

## **Finding out where the cancer started**

NSCLC starts in the lungs. However, many other types of cancer start elsewhere in the body and then spread to the lungs when they metastasize. For example, breast cancer that has spread to the lungs is still called breast cancer. Therefore, it is important for doctors to know if the cancer started in the lungs or elsewhere.

To find where the cancer started, your doctor will take into account your symptoms and medical history, physical examination, how the tumor looks on x-rays and scans, and your risk factors for cancer. A pathologist can perform tests on the biopsy sample to help find out where the cancer began. Your doctor may recommend other tests to rule out specific types of cancer.

If the doctor is still not sure where the cancer started, you may receive a diagnosis of metastatic cancer “of unknown primary.” Most treatments for metastatic cancer of unknown primary that is first found in the chest are the same as those for metastatic lung cancer.



## Stages

Doctors can often classify NSCLC with a “stage” when giving a person their diagnosis. Staging is a way of describing where the cancer is located, if or where it has spread, and whether it is affecting other parts of the body. Doctors use diagnostic tests to find out the cancer’s stage, so staging may not be complete until they finish all the tests. Knowing the stage helps your doctor decide what kind of treatment is best. The stage can also help predict your prognosis.

In general, a lower number stage of NSCLC is linked with a better outcome. However, no doctor can predict how long a patient will live with lung cancer based only on the stage of the disease. This is because lung cancer is different in each person, and treatment works differently for each tumor.

The stage of NSCLC is described by a number, from 0 through 4 (Roman numerals I through IV). One way to determine the staging of NSCLC is to find out whether a surgeon can completely remove the cancer.

**Stage 0.** This is called in situ disease, meaning the cancer is “in place.” It has not grown into nearby tissues or spread outside the lung.

**Stage I.** A stage one (I) lung cancer is a small tumor that has not spread to any lymph nodes. That means it is possible for a surgeon to completely remove it. Stage I is divided into 2 substages, stage IA or stage IB, based on tumor size. Tumors 3 centimeters (cm) or less in size are classified as stage IA. Tumors greater than 3 cm but 4 cm or less in size are stage IB.

**Stage II.** Stage two (II) lung cancer is divided into 2 substages. Stage IIA cancer describes a tumor larger than 4 cm but 5 cm or less in size that has not spread to the nearby lymph nodes. Stage IIB lung cancer describes a tumor that is 5 cm or less in size that has spread to the lymph nodes. It also describes a tumor more than 5 cm but 7 cm or less in size that has not spread to the lymph nodes. Sometimes, surgeons can completely remove a stage II tumor. Other times, patients need more treatments.

**Stage III.** Stage three (III) lung cancers are classified as stage IIIA, IIIB, or IIIC. The stage is based on the size of the tumor and which lymph nodes the cancer has spread to. Stage III cancers have not spread to other distant parts of the body. For many stage IIIA cancers, and nearly all stage IIIB cancers, the tumor is difficult, and sometimes impossible, to remove with surgery. For example, the lung cancer may have spread to the lymph nodes located in the center of the chest, which is outside the lung. Or, the tumor may have grown into nearby structures in the lung. In either situation, it is less likely that the surgeon can completely remove the cancer. The cancer must be removed bit by bit.

**Stage IV.** Stage four (IV) means the lung cancer has spread to more than 1 area in the other lung, the fluid surrounding the lung or the heart, or distant parts of the body through the bloodstream. Once released in the blood, cancer can spread anywhere in the body. But NSCLC is more likely to spread to the brain, bones, liver, and adrenal glands. Stage IV is divided into 2 substages. Stage IVA cancer has spread within the chest and/or has spread to one area outside the chest. Stage IVB has spread outside of the chest to more than one place in one organ or to more than one organ.

In general, surgery is not successful for most stage III or stage IV lung cancers. Lung cancer can also be impossible to remove if it has spread to the lymph nodes above the collarbone. It can also be impossible to remove if it has grown into vital structures within the chest. These vital structures include the heart, large blood vessels, or the main breathing tubes leading to the lungs. In these situations, the doctor will recommend other treatment options.

**Recurrent.** Recurrent cancer is cancer that has come back after treatment. It is often treated as stage IV NSCLC.

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**Learn more about what to expect when having common tests, procedures, and scans at [www.cancer.net/tests](http://www.cancer.net/tests).**



### QUESTIONS TO ASK THE HEALTH CARE TEAM ABOUT YOUR DIAGNOSIS

- ▶ What type and stage of NSCLC do I have? What does this mean?
- ▶ What other diagnostic tests or procedures may be necessary?
- ▶ How can I prepare myself for each test or procedure?
- ▶ Where do I need to go to have these tests?
- ▶ When will I get the results? How will I get the results (over the phone, at the next appointment, etc.)?
- ▶ Who will explain the results to me?
- ▶ Should I see another doctor for a second opinion? Can you give me names of doctors I could see?
- ▶ If I get a second opinion, will I have to repeat any tests or procedures?
- ▶ What is my prognosis?

# Non-Small Cell Lung Cancer Treatment

In cancer care, different types of doctors often work together to create your overall treatment plan that combines different types of treatment. This is called a multidisciplinary team. Cancer care teams include a variety of other professionals, such as physician assistants, nurse practitioners, oncology nurses, social workers, pharmacists, and dietitians.

The type and stage of NSCLC and your overall health influence your prognosis. Although NSCLC is treatable at any stage, only some people with certain stages can be cured. Doctors measure a patient's general strength and health using an index known as performance status. Patients who are strong enough to go about their daily activities without assistance and work outside their home can safely receive chemotherapy, radiation therapy, and/or surgery. Your care plan should also include treatment for symptoms and side effects. This is called palliative care or supportive care (see page 23).

It is important to note that a patient's age has never been useful in predicting whether a patient will benefit from treatment. The average age of patients with lung cancer in the United States is 71. A patient's age should never be used as the only reason for deciding what treatment is best. This is especially true for older patients who are otherwise physically fit and have no other medical problems besides lung cancer.

When making treatment decisions, you are also encouraged to consider clinical trials as an option. A clinical trial is a research study that tests a new approach to treatment to evaluate whether it is safe, effective, and possibly better than the treatment that doctors use now. Clinical trials may test such approaches as a new drug, a new combination of treatments, or new doses of current therapies.

Before treatment begins, it is important to discuss the goals and possible side effects of treatment with your doctor. Ask about the likelihood that the treatment will work and its potential effect on your quality of life.

To start a conversation with your doctor about all your treatment options, you may want to ask:

- ▶ What are the treatment options for my type and stage of NSCLC?
- ▶ Will I need more than 1 type of treatment?
- ▶ Based on the results of diagnostic testing, do you recommend targeted therapy or immunotherapy? Why or why not?
- ▶ What treatment plan do you recommend for me? Why?
- ▶ What is the goal of the treatment(s) you recommend? Is it to eliminate the cancer? To relieve my symptoms? Or both?
- ▶ What is the expected timeline for my treatment plan?
- ▶ When do I need to make a decision about starting treatment?
- ▶ If I am worried about managing the cost of treatment, who can help me?

## Surgery

A thoracic surgeon is specially trained to perform lung cancer surgery. The goal of surgery is the complete removal of the lung tumor and the nearby lymph nodes in the chest. The tumor must be removed with a surrounding border or margin of healthy lung tissue.

The time it takes to recover from surgery depends on how much of the lung is removed and your health before surgery. Talk with your health care team before your surgery about what to expect.

### ❑ Lobectomy

The lungs have 5 lobes, 3 in the right lung and 2 in the left lung. During a lobectomy, the surgeon removes an entire lobe of the affected lung. A lobectomy is often the most effective type of surgery for NSCLC, even when the lung tumor is very small.

### ❑ Wedge resection

If the surgeon cannot remove an entire lobe of the lung, the surgeon can remove the tumor, surrounded by a margin of healthy lung.

### ❑ Segmentectomy

This is another way to remove the cancer when an entire lobe of the lung cannot be removed. The surgeon removes the portion of the lung where the cancer developed.

### ❑ Pneumonectomy

If the tumor is close to the center of the chest, the surgeon may have to remove the entire lung.



### QUESTIONS TO ASK THE HEALTH CARE TEAM ABOUT SURGERY

- ▶ Which type of surgery do you recommend? Why?
- ▶ What is the goal of this surgery?
- ▶ Will lymph nodes or any other tissue need to be removed?
- ▶ Will I need to be admitted to a hospital for this operation? If so, how long will I need to stay in the hospital?
- ▶ Will my tumor tissue be saved? Where will it be stored? For how long? How can it be accessed in the future?
- ▶ What will my recovery from surgery be like?
- ▶ What are the potential short-term and long-term side effects of this type of surgery?
- ▶ Will I need any additional treatment after surgery?
- ▶ Who should I contact about any side effects I experience? And how soon?

## Adjuvant therapy

Adjuvant therapy is treatment given after surgery to lower the risk of NSCLC returning. Adjuvant therapy may include radiation therapy, chemotherapy, targeted therapy, or immunotherapy. The goal is to get rid of any lung cancer cells that may still be in the body after surgery. The therapy can help decrease the risk of recurrence. However, there is always some risk that the cancer will come back.

### Radiation therapy

Radiation therapy is the use of high-energy x-rays or other particles to destroy cancer cells. Radiation works by damaging the DNA of cancer cells. Radiation therapy using photons is the most common because it is able to reach internal organs. If you need radiation therapy, you will see a radiation oncologist. This is a doctor who specializes in giving radiation therapy to treat cancer. The most common type of radiation treatment is called external-beam radiation therapy. This is radiation given from a machine outside the body.

Sometimes doctors use CT scans to plan exactly where to direct the radiation to lower the risk of damaging healthy parts of the body. This is called intensity modulated radiation therapy (IMRT) or stereotactic body radiation therapy (SBRT). It is not an option for all patients. However, doctors may use it for patients with early-stage NSCLC or small tumors when surgery is not an option.

Like surgery, radiation therapy cannot be used to treat widespread cancer. Radiation therapy only destroys cancer cells directly in the path of the radiation beam. It also damages any healthy cells in its path. If enough of these cells are damaged, side effects occur.

Patients with NSCLC who receive radiation therapy often experience fatigue and loss of appetite. If radiation therapy is given to the neck or center of the chest, patients may also develop a sore throat and have difficulty swallowing. Skin irritation, similar to a sunburn, may also occur at the treatment site. Most side effects go away soon after treatment.

If radiation therapy irritates or inflames the lung, patients may develop a cough, fever, or shortness of breath. About 15% of patients develop this condition, called radiation pneumonitis. It can occur months or sometimes years after radiation therapy ends. If it is mild, radiation pneumonitis does not need treatment and goes away on its own. If it is severe, a patient may need treatment with steroid medications, such as prednisone



(multiple brand names). Radiation therapy may also cause permanent scarring of the lung tissue near the original tumor location. Typically, the scarring does not cause symptoms. However, severe scarring can cause a permanent cough and shortness of breath.



### QUESTIONS TO ASK THE HEALTH CARE TEAM ABOUT RADIATION THERAPY

- ▶ What type of radiation therapy do you recommend? Why?
- ▶ How often will my radiation treatments occur, and how long will I need to receive treatment?
- ▶ How much time will each treatment take?
- ▶ Will you describe what I'll experience when I receive radiation therapy? Will it hurt or cause me discomfort?
- ▶ How much healthy lung tissue will be included in the radiation field?
- ▶ What are the possible short-term and long-term side effects of this treatment?
- ▶ What can be done to reduce these risks?
- ▶ Who should I contact about any side effects I experience? And how soon?

## Chemotherapy

Chemotherapy is the use of drugs to destroy cancer cells, by keeping the cancer cells from growing, dividing, and making more cells. Chemotherapy is given by a medical oncologist, a doctor who specializes in treating cancer with medication.

Systemic chemotherapy gets into the bloodstream to reach cancer cells throughout the body. Common ways to give chemotherapy include an intravenous (IV) tube placed into a vein using a needle or in a pill or capsule that's swallowed. Most chemotherapy used for NSCLC is given by IV injection. A person may receive 1 drug at a time or a combination of different drugs at the same time. The type of NSCLC you have affects which ones are used for chemotherapy. Some common drugs include:

- ▶ Carboplatin or cisplatin (both are available as generic drugs)
- ▶ Docetaxel (Taxotere)
- ▶ Gemcitabine (Gemzar)
- ▶ Nab-paclitaxel (Abraxane)
- ▶ Paclitaxel (Taxol)
- ▶ Pemetrexed (Alimta)
- ▶ Vinorelbine (Navelbine)

Chemotherapy has been shown to improve both the length and quality of life for people with all stages of NSCLC. However, it is important to talk with your doctor about whether

chemotherapy should be part of your treatment plan.

The side effects of chemotherapy depend on the individual and the dose used. The side effects can include fatigue, risk of infection, nausea and vomiting, loss of appetite, diarrhea, hair loss, low blood counts, mouth sores, and numbness or tingling in the hands and feet. These side effects usually go away once treatment ends. Your doctor can also prescribe drugs to help relieve many of them. Talk with a member of your health care team about ways to prevent or manage potential side effects.



### QUESTIONS TO ASK THE HEALTH CARE TEAM ABOUT CHEMOTHERAPY

- ▶ What type of chemotherapy do you recommend? Why?
- ▶ How long will I need to have chemotherapy?
- ▶ How will the treatment be given?
- ▶ How will chemotherapy affect my daily life? Will I be able to work, exercise, and perform my usual activities?
- ▶ What are the potential side effects of this treatment? What can be done to prevent or manage these side effects?
- ▶ Where can I get more information about the medications I will be taking?
- ▶ Who should I contact about any side effects I experience? And how soon?

### Targeted therapy

Targeted therapy is a treatment that targets the cancer's specific genes, proteins, or the tissue environment that contributes to cancer growth and survival. This type of treatment blocks the growth and spread of cancer cells and limits damage to healthy cells.

Studies show that not all lung tumors have the same targets. To find the most effective treatment, your doctor may run tests to identify the genes, proteins, and other factors in your tumor. For some lung cancers, abnormal proteins are found in unusually large amounts in the cancer cells. This helps doctors better match each patient with the most effective treatment whenever possible.

In addition, many research studies are taking place to find out more about specific molecular targets and new treatments directed at them. Talk with your doctor about the best possible treatment option for your type of NSCLC.

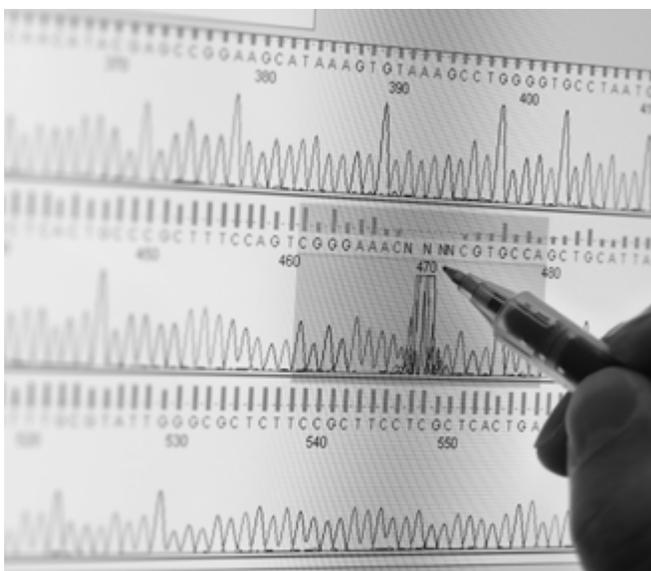
For NSCLC, doctors may use the following types of targeted therapy, particularly in clinical trials. Talk with your doctor about possible side effects of a specific medication and how they can be managed.

**Epidermal growth factor receptor (EGFR) inhibitors.** Researchers have found that drugs that block EGFR may be effective for stopping or slowing the growth of NSCLC.

- ❑ Osimertinib (Tagrisso) is a first treatment option for some people with NSCLC whose tumors have *EGFR* mutations. Osimertinib is also approved for the treatment of metastatic NSCLC with an *EGFR* mutation when other drugs listed earlier no longer work.
- ❑ Erlotinib (Tarceva) has been shown to work better than chemotherapy if the lung cancer has a mutation in the *EGFR* gene. It is an option for patients with locally advanced and metastatic NSCLC. It may also be used as a maintenance therapy for patients with NSCLC that has not grown or spread after at least 4 cycles of chemotherapy.
- ❑ Afatinib (Gilotrif) is an initial treatment option for NSCLC. It may also be an option for patients who have already received other treatments for squamous NSCLC. It is a type of drug called a tyrosine kinase inhibitor (TKI).
- ❑ Dacomitinib (Vizimpro) is approved as an initial treatment for NSCLC that has an *EGFR* mutation. However, it is not frequently used.
- ❑ Gefitinib (Iressa) is a first-generation *EGFR* inhibitor that is not widely used in the United States. It is more commonly used in Asia and some other parts of the world.

**Anaplastic lymphoma kinase (ALK) inhibitors.** ALK is a protein that is a part of the cell growth process. When present, this mutation helps cancer cells grow. ALK inhibitors help stop this process. Mutations in the *ALK* gene are found in about 5% of people with NSCLC. The following drugs are currently available to target this genetic change:

- ❑ Alectinib (Alecensa)
- ❑ Brigatinib (Alunbrig)
- ❑ Ceritinib (Zykadia)
- ❑ Crizotinib (Xalkori)
- ❑ Lorlatinib (Lorbrena)



**Drugs targeting *ROS1* genetic changes.** Rare mutations to the *ROS1* gene can cause problems with cell growth and cell differentiation, the process by which cells change from one type of cell into another. Drugs targeting changes to the *ROS1* gene include:

- ❑ Ceritinib (Zykadia)
- ❑ Crizotinib (Xalkori)
- ❑ Entrectinib (Rozlytrek)

**Drugs targeting *NTRK* fusion.** This type of genetic change is found in a range of cancers, including lung cancer, and causes cancer cell growth. Larotrectinib (Vitrakvi) is used to treat *NTRK* fusion for people with NSCLC.

**Drugs targeting *BRAF* V600E mutations.** The *BRAF* gene makes a protein that is involved in cell growth and can cause cancer cells to grow and spread. A *BRAF* V600E mutation can be targeted with a combination of dabrafenib (Tafinlar) and trametinib (Mekinist).

**Drugs targeting *MET* Exon 14 Skipping.** *MET* Exon 14 Skipping is a genetic mutation found in 3% of NSCLC. Capmatinib (Tabrecta) and tepotinib (Tepmetko) have been approved to target this genetic change.

**Drugs targeting *RET* fusion.** Up to 2% of all NSCLC cases are *RET* fusion positive. Selpercatinib (LOXO-292) is approved to treat these genetic changes involving *RET*, which lead to uncontrolled cell growth.

**Anti-angiogenesis therapy.** Anti-angiogenesis therapy is focused on stopping angiogenesis, which is the process of making new blood vessels. Because a tumor needs the nutrients delivered by blood vessels to grow and spread, the goal of anti-angiogenesis therapies is to “starve” the tumor. The following anti-angiogenic drugs may be options for lung cancer:

- ❑ Bevacizumab (Avastin, Mvasi) is an anti-angiogenic drug given along with chemotherapy for lung cancer. It may also be used along with chemotherapy and the immunotherapy drug atezolizumab (Tecentriq; see below) for metastatic NSCLC.

The risk of serious bleeding for patients taking bevacizumab is about 2%. However, it is more common for patients with squamous cell carcinoma, so bevacizumab is not recommended for patients with this type of NSCLC.

- ❑ Ramucirumab (Cyramza) is approved for NSCLC along with the chemotherapy drug docetaxel.

Treatment with targeted therapy for NSCLC is changing rapidly due to the pace of scientific research. New targeted therapies are being studied in clinical trials now. Talk with your doctor about additional options that may be available to you.

Side effects of targeted therapy depend on the drug(s) you have been prescribed. Talk with your doctor about possible side effects for a specific medication and how they can be managed.

## Immunotherapy

Also called biologic therapy, immunotherapy is designed to boost the body's natural defenses to fight the cancer.

It uses materials made either by the body or in a laboratory to improve, target, or restore immune system function. For example, the PD-1 pathway may be critical in the immune system's ability to control cancer growth. Blocking this pathway with PD-1 and PD-L1 antibodies has stopped or slowed the growth of NSCLC for some patients. The following drugs block this pathway:

- Atezolizumab (Tecentriq)
- Cemiplimab (Libtayo)
- Durvalumab (Imfinzi)
- Ipilimumab (Yervoy)
- Nivolumab (Opdivo)
- Pembrolizumab (Keytruda)



### QUESTIONS TO ASK THE HEALTH CARE TEAM ABOUT TARGETED THERAPY AND IMMUNOTHERAPY

- ▶ Based on my test results, will I benefit from targeted therapy or immunotherapy? Why or why not?
- ▶ How long will I need to have this treatment?
- ▶ How will the treatment be given?
- ▶ What are the possible side effects of this treatment?
- ▶ How will these side effects be managed?
- ▶ How will my treatment be monitored?
- ▶ Who should I contact about any side effects I experience? And how soon?
- ▶ If I'm worried about managing the cost of treatment, who can help me?

## Clinical trials

Doctors and scientists are always looking for better ways to care for patients with NSCLC. To make scientific advances, doctors create research studies involving volunteers. These studies are called clinical trials. Every drug that is now approved by the U.S. Food and Drug Administration (FDA) was tested in clinical trials.

Many clinical trials focus on new treatments. Researchers want to learn if a new treatment is safe, effective, and possibly better than the treatment doctors use now. These studies evaluate new drugs and methods of treatment, new approaches to treatments, and new prevention methods. There are also clinical trials that study new ways to ease symptoms and side effects during treatment and to manage the late effects that may occur after treatment.

Patients who participate in clinical trials can be some of the first to get a treatment before it is available to the public. However, there are some risks with a clinical trial, including possible side effects and the chance that the new treatment may not work. People are encouraged to talk with their health care team about the pros and cons of joining a specific study.

Patients decide to participate in clinical trials for many reasons. For some patients with NSCLC, a clinical trial is the best treatment option available. Because standard treatments are not perfect, patients are often willing to face the added uncertainty of a clinical trial in the hope of a better result. Other patients volunteer for clinical trials because they know these studies are a way to contribute to the progress in treating NSCLC. Even if they do not benefit directly from the clinical trial, their participation may benefit future patients with NSCLC.



Insurance coverage and costs of clinical trials differ by location and by study. In some programs, some of the patient's expenses from participating in the clinical trial are reimbursed. In others, they are not. It is important to talk with the research team and your insurance company first to learn if and how your treatment in a clinical trial will be covered.

Sometimes people have concerns that, in a clinical trial, they may receive no treatment by being given a placebo or a "sugar pill." However, researchers usually combine placebos with standard treatment in most cancer clinical trials. Study participants will always be told when a placebo is used in a study.

To join a clinical trial, patients must participate in a process known as informed consent.

During informed consent, the doctor should:

- ▶ Describe all of the patient’s options so that the person understands how the new treatment differs from the standard treatment.
- ▶ List all of the risks of the new treatment, which may or may not be different from the risks of standard treatment.
- ▶ Explain what will be required of each patient in order to participate in the clinical trial, including the number of doctor visits, tests, and the schedule of treatment.

Clinical trials also have certain rules called “eligibility criteria” that help structure the research and keep patients safe. You and the research team will carefully review these criteria together.

People who participate in a clinical trial may stop participating at any time for personal or medical reasons. This may include that the new treatment is not working or there are serious side effects. Clinical trials are also closely monitored by experts who watch for any problems with each study. It is important that people participating in a clinical trial talk with their doctor and researchers about who will be providing their treatment and care during the clinical trial, after the clinical trial ends, and/or if they choose to leave the clinical trial before it ends.



**To learn more about clinical trials, visit [www.cancer.net/clinicaltrials](http://www.cancer.net/clinicaltrials).**



**QUESTIONS TO ASK THE HEALTH CARE TEAM ABOUT CLINICAL TRIALS**

- ▶ How do clinical trials help people with NSCLC?
- ▶ What clinical trials are available for me? Where are they located, and how do I find out more about them?
- ▶ What happens during a clinical trial?
- ▶ How do the costs of participating in a clinical trial compare with the costs of standard treatment?
- ▶ Where can I learn more about clinical trials?

## Managing symptoms and side effects

In addition to treatment to slow, stop, or eliminate NSCLC, an important part of cancer care is relieving a person's symptoms and side effects. This approach is called palliative care or supportive care. It includes supporting the patient's physical, emotional, and social needs.



Palliative care is any treatment that focuses on reducing symptoms, improving quality of life, and supporting patients and their families. Any person, regardless of age or type and stage of cancer, may receive

palliative care. This treatment works best when it is started as early as needed in the cancer treatment process. People often receive treatment for the cancer and treatment to ease side effects at the same time. In fact, patients who receive both at the same time often have less severe symptoms, a better quality of life, and are more satisfied with treatment.

Palliative treatments vary widely and often include medication, nutritional changes, relaxation techniques, emotional support, and other therapies. You may also receive palliative treatments similar to those meant to eliminate the cancer, such as chemotherapy, surgery, or radiation therapy. Talk with your doctor about the goals of each treatment in your treatment plan.

For people with NSCLC, palliative care may include:

- ❑ **Radiation therapy**—Radiation therapy can shrink a tumor in the chest that is bleeding or blocking the lung passages.
- ❑ **Bronchoscopy**—During this procedure, doctors can open lung passages blocked by cancer to improve breathing.
- ❑ **Surgery**—A surgeon can use a laser to burn away a tumor or place a stent to prop open an airway.
- ❑ **Drainage catheter**—Fluid around the lungs, also called malignant pleural effusion, can be uncomfortable. A drainage catheter allows patients to drain excess fluid from around the lungs at home.
- ❑ **Pain medications**—Many hospitals and cancer centers have pain control specialists who provide pain relief, even for very severe cancer pain. Many drugs used to treat cancer pain, such as morphine, can also relieve shortness of breath caused by cancer.

- ❑ **Corticosteroids**—Prednisone or methylprednisolone (multiple brand names) can reduce inflammation caused by lung cancer or radiation therapy and improve breathing.
- ❑ **Other medications**—Medications can be used to suppress cough, open closed airways, or reduce bronchial secretions.
- ❑ **Supplemental oxygen**—Extra oxygen from small, portable tanks can help make up for the lungs’ reduced ability to draw oxygen from the air.
- ❑ **Bisphosphonates**—These medications strengthen bones, lessen bone pain, and help prevent future bone metastases.
- ❑ **Appetite stimulants and nutritional supplements**—These can improve appetite and reduce weight loss.
- ❑ **Practical, emotional, and spiritual support**—Your health care team can also give you advice and resources for addressing financial and legal concerns, transportation issues, employment concerns, depression, anxiety, sexual health concerns, and family and other relationship issues. If needed, your team can also connect you with a chaplain or other spiritual or religious resources in your community.

Before treatment begins, talk with your health care team about the possible side effects of your specific treatment plan and palliative care options. During and after treatment, be sure to tell your health care team if you are experiencing a problem so it can be addressed as quickly as possible.



**For more information about palliative care, visit [www.cancer.net/palliativecare](http://www.cancer.net/palliativecare).**



**QUESTIONS TO ASK THE HEALTH CARE TEAM ABOUT PALLIATIVE CARE**

- ▶ What can be done to manage any symptoms and side effects I may experience?
- ▶ Can you recommend someone who specializes in palliative care?
- ▶ Where can I receive palliative care services?
- ▶ What other support services are available to me? To my family?

## **Developing a treatment plan**

For people with NSCLC, the stage of the cancer helps determine the treatment or combinations of treatments needed. Clinical trials are also an option for people with all stages of lung cancer.

### **Stages I and II**

In general, doctors treat stage I and stage II NSCLC with surgery. Many patients are cured with an operation. Before or after surgery, a patient may be referred to a medical oncologist. Some patients with a large tumor or signs that the tumor has spread to the lymph nodes may benefit from chemotherapy before the surgery. This is called neoadjuvant chemotherapy or induction chemotherapy. Some patients may benefit from adjuvant chemotherapy given after surgery to reduce the chance the cancer will return. Radiation therapy may be used to treat, and can sometimes cure, a lung tumor when surgery is not recommended.

### **Stage III**

There is no single best treatment for stage III NSCLC. Treatment options depend on the size and location of the tumor and the lymph nodes involved. The options generally include radiation therapy, chemotherapy, and surgery. In general, patients with stage III NSCLC receive at least 2 different types of treatment, sometimes 3. Doctors usually recommend a combination of chemotherapy and radiation therapy.

Surgery may be an option after initial chemotherapy or chemotherapy with radiation therapy. Sometimes, surgery may be the first treatment, particularly when cancer is unexpectedly found in the lymph nodes after a person has originally been diagnosed with stage I or stage II cancer. If this occurs, surgery is generally followed by chemotherapy and often radiation therapy.

### **Metastatic or stage IV**

Most patients with stage IV NSCLC do not receive surgery or radiation therapy. Occasionally, doctors may recommend surgery for a metastasis in the brain or adrenal gland if that is the only place the cancer has spread. Patients with stage IV disease have a very high risk of the cancer spreading or growing in another location. Many patients at this stage of NSCLC receive chemotherapy, targeted therapy, or immunotherapy. These types of treatments are often called systemic therapy.

The goals of systemic therapy are to shrink the cancer, relieve discomfort caused by the cancer, prevent the cancer from spreading further, and lengthen a patient's life. These treatments can occasionally make metastatic lung cancer disappear. Doctors also know from experience that the cancer will usually return even if it does disappear.

Systemic therapy and palliative care have been proven to improve both length and quality of life for patients with stage IV NSCLC. If the cancer worsens or causes too many severe side effects, the treatment may be stopped. Patients would continue to receive palliative care and may be offered treatment in a clinical trial.

The first drug or combination of drugs a patient takes is called “first-line” treatment, which may be followed by “second-line” and “third-line” treatment. No specific treatment or combination of treatments works for every patient. If the first-line treatment causes too many or dangerous side effects, does not appear to be working, or stops working, the doctor may recommend a change in treatment.

**Radiation therapy for brain metastases.** Chemotherapy is often not as effective as radiation therapy or surgery to treat NSCLC that has spread to the brain. For this reason, NSCLC that has spread to the brain is usually treated with radiation therapy, surgery, or both. This can cause side effects such as hair loss, fatigue, and redness of the scalp. With a small tumor, a type of radiation therapy called stereotactic radiosurgery can focus the radiation only on the tumor in the brain and lessen the side effects.

Targeted therapies, such as osimertinib and alectinib, have shown that they can work well to treat brain metastases. In addition, immunotherapy may also be an option. This may allow many patients to avoid the side effects that come from chemotherapy and radiation therapy to the brain.

**Palliative care.** Palliative care will also be important to help relieve symptoms and side effects. Radiation therapy or surgery may also be used to treat metastases that are causing pain or other symptoms. Bone metastases that weaken major bones can be treated with surgery, and the bones can be reinforced using metal implants.

For most people, a diagnosis of metastatic cancer is very stressful and difficult. You and your family are encouraged to talk about how you feel with doctors, nurses, social workers, or other members of the health care team. It may also be helpful to talk with other patients, including through a support group.

## Recurrent lung cancer

If NSCLC returns after the original treatment, it is called recurrent cancer. It may come back in the same place (local recurrence), nearby (regional recurrence), or in another place (distant recurrence). When there is a recurrence it is most often stage IV disease.

When there is a recurrence, a new cycle of testing will begin to learn as much as possible about the recurrence. After this testing is done, you and your doctor will talk about your treatment options. The treatment plan will be based on the cancer’s stage and may include surgery, chemotherapy, and radiation therapy. However, they may be used in a different

combination or given at a different pace. Your doctor may also suggest clinical trials that are studying new ways to treat recurrent NSCLC.

People with recurrent cancer often experience emotions such as disbelief or fear. Patients are encouraged to talk with their health care team about these feelings and ask about support services to help them cope.



**For more information about NSCLC treatment, visit [www.cancer.net/lung](http://www.cancer.net/lung).**



### **QUESTIONS TO ASK THE HEALTH CARE TEAM ABOUT YOUR TREATMENT PLAN**

- ▶ Who will be leading my overall treatment and follow-up care?
- ▶ What is the goal of my treatment plan?
- ▶ How will each treatment option benefit me? What are the risks?
- ▶ What is the expected timeline for each treatment option?
- ▶ What clinical trials are available for me?
- ▶ What is my prognosis?

## **Increasing treatment effectiveness**

NSCLC treatment may not be as effective for patients with bone or liver metastases from lung cancer, excessive weight loss, ongoing tobacco use, or preexisting medical conditions, such as heart disease or emphysema.

Although you cannot change some of these factors, if you are a smoker, quitting tobacco following a diagnosis of NSCLC is a change that can make a big difference. People who stop smoking have an easier time with treatments, feel better, live longer, and have a lower risk of developing a second lung cancer or other health problems.



Continuing to smoke can lead to:

- ▶ Shorter life
- ▶ Less chance of successful, effective treatment
- ▶ More complications from surgery and a slower recovery
- ▶ More treatment-related side effects from chemotherapy, including infection, fatigue, and weight loss
- ▶ Additional side effects from radiation therapy, such as dry mouth, mouth sores, loss of taste, and problems with your bones and soft tissues
- ▶ Increased chance of recurrence
- ▶ Increased risk of developing other serious illnesses

Stopping smoking is never easy, and it can be even harder when facing the diagnosis of NSCLC. People who smoke are strongly encouraged to seek help from family, friends, programs for quitting smoking, and health care professionals. None of the products available to quit smoking interfere with cancer treatment.



**You can learn more about stopping tobacco use after a diagnosis of cancer at [www.cancer.net/quittingtobacco](http://www.cancer.net/quittingtobacco).**



### **QUESTIONS TO ASK THE HEALTH CARE TEAM ABOUT IMPROVING TREATMENT EFFECTIVENESS**

- ▶ Are there any factors or behaviors that might make my treatment plan less effective?
- ▶ Is there anything I can do to increase the effectiveness of my treatment(s)?
- ▶ If I am a smoker, will smoking affect how well my cancer treatment works? Will I experience more or different side effects from treatment if I continue to use tobacco?
- ▶ What medications and other quitting smoking resources are available to me?
- ▶ How can you and your team help me manage the stress of quitting smoking along with the stress of my diagnosis?

# Coping With Side Effects

Fear of treatment side effects is common after a diagnosis of NSCLC. It may help to know that preventing and controlling side effects is a major focus of your health care team. Before treatment begins, talk with your doctor about the possible side effects of each type of treatment you will receive. Ask which side effects are most likely to happen, when they are likely to occur, and what can be done to prevent or relieve them. During and after treatment, let your health care team know what side effects you experience so they can help manage them.

Everyone's experience with NSCLC treatment is different. The specific side effects you may experience during and after treatment depend on a number of factors, including the cancer's location, your individual treatment plan, and your overall health. Some of the potential physical, emotional, and social effects experienced by people being treated for NSCLC are described in this section.

## Physical effects

**Pain.** Pain can be caused by the tumor, be a side effect of cancer treatment, or result from causes not related to the cancer. Untreated pain can make other parts of cancer seem worse, such as fatigue, weakness, shortness of breath, nausea, constipation, sleep disturbances, depression, anxiety, and mental confusion. However, it is important to know that up to 95% of cancer pain can be treated successfully using medication or other strategies. Your doctor or a pain specialist can help you find an effective pain-relief strategy.



KAREN ELSHOUT PHOTOGRAPHY

**Nausea and vomiting.** Nausea and vomiting are common side effects of many cancer treatments. Nausea is feeling the urge to vomit or throw up. Vomiting may happen before treatment, within 24 hours after treatment, or 2 or more days after treatment. Mild nausea and vomiting can be uncomfortable, but they usually do not cause serious problems. Severe vomiting, however, can cause dehydration; the loss of minerals, such as potassium and sodium, from the body; weight loss; and depression. In addition to medications that help prevent nausea and vomiting, many people find that behavioral treatments help control these side effects. Talk with your health care team about ways to change the expectation and fear of nausea and vomiting.

**Fatigue.** Cancer and its treatment often cause a persistent feeling of physical, emotional, or mental tiredness or exhaustion. Most people receiving cancer treatment experience some type of fatigue, which can make even a small effort, such as walking across a room, seem like too much. Fatigue can seriously affect all aspects of a person's life, from relationships with friends and family to the ability to perform at work. It is important to tell your doctor if you are experiencing fatigue because there are things your health care team can do to help.

**Shortness of breath.** Also called dyspnea, shortness of breath is a feeling of breathlessness that many people with advanced cancer experience. It also occurs in those with earlier-stage lung cancer. A person may experience dyspnea even though the actual levels of oxygen are within a normal range. Dyspnea may be caused by a tumor or by other conditions related to cancer, and many of these causes are treatable. Your doctor can help you address the cause and relieve the symptoms of this side effect.



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**For more information about managing side effects, visit [www.cancer.net/sideeffects](http://www.cancer.net/sideeffects).  
For more information about managing cancer-related pain, visit [www.cancer.net/pain](http://www.cancer.net/pain).**

## Emotional and social effects

You may also experience emotional and social effects. For many people, a diagnosis of NSCLC is stressful and can trigger difficult emotions. Unfortunately, many people with NSCLC feel that others believe that personal choices, such as smoking, caused the disease and will not provide as much support or help.

The fact is not all patients with NSCLC smoke. NSCLC is a disease that can affect anyone. Most people who get lung cancer today have either stopped smoking years earlier or never smoked at all.

Still, for many patients, these fears add extra stress to an already difficult situation and may lead to anxiety and, less commonly, depression. Therefore, it is important to express how you are feeling. Research has shown that sharing fears and anxieties with family, friends, counselors, clergy, or support groups helps strengthen patients emotionally and perhaps even physically. Because not all people find it easy to open up to others, you may want to express your feelings in other ways, such as:

- ▶ Writing in a journal or starting a blog
- ▶ Doing artistic projects, such as painting
- ▶ Praying or meditating
- ▶ Reading
- ▶ Slowing down and reflecting

However, even with outlets to express their feelings, sometimes people with NSCLC and those closest to them continue to experience emotional and social effects. If you feel anxious, depressed, or stressed about your diagnosis and treatment, think about telling a member of your health care team, such as an oncology nurse. Oncology nurses have a wealth of experience and knowledge about cancer, cancer treatment, and side effects. They can also provide you with emotional and social support, as well as help you develop effective coping strategies.



Another good resource is an oncology social worker. An oncology social worker can:

- ▶ Help you navigate the health care system
- ▶ Help you find support to manage the day-to-day challenges of living with cancer
- ▶ Provide counseling, education, information services, and discharge and home care planning services
- ▶ Provide referrals to community resources for you and your family and friends

Oncology social workers practice in many settings, including cancer centers, hospitals, doctors' offices, cancer-related agencies, hospices, and private practices. If there is not an oncology social worker where you receive treatment, call the nearest cancer center or hospital and ask if there is one on staff.



**Learn more about coping with the physical, social, and emotional effects of lung cancer at [www.cancer.net/coping](http://www.cancer.net/coping). For a list of support organizations and other resources, visit [www.cancer.net/support](http://www.cancer.net/support).**



### **QUESTIONS TO ASK THE HEALTH CARE TEAM ABOUT SIDE EFFECTS**

- ▶ What are the potential short-term and long-term side effects of each treatment in my treatment plan?
- ▶ Are there ways to help me prepare for treatment and decrease the chance of experiencing side effects?
- ▶ What can be done to manage these side effects?
- ▶ What support services are available to me? To my family?
- ▶ If I'm worried about managing the costs of my cancer care, who can help me?

## Follow-Up Care

Cancer care does not end when active treatment finishes. Your doctor will outline a program of tests and visits to monitor your recovery and check that the cancer has not returned. This plan may include regular physical examinations and/or medical tests for the coming months and years.

People treated for NSCLC may continue to have side effects, even after treatment ends. Common post-treatment issues include pain, fatigue, and shortness of breath. Feelings of depression and anxiety may also continue after treatment. Worrying that the cancer may come back is also very common. Often people feel that they have less support once treatment has ended and that there is less assistance available. Your doctor, nurse, or social worker can help you develop a plan to manage any problems that continue after treatment.



Cancer rehabilitation may be recommended. This could mean any of a wide range of services, such as physical therapy, career counseling, pain management, nutritional planning, and emotional counseling. The goal of rehabilitation is to help people regain control over many aspects of their lives and remain as independent as possible.

People who develop NSCLC are also at higher risk for developing a second lung cancer. That is why it is very important for you to keep an eye out for signs that the cancer has come back, even if this thought is scary. The symptoms of a lung cancer recurrence include:

- ▶ Fatigue
- ▶ Cough
- ▶ Shortness of breath
- ▶ Chest pain
- ▶ Appetite loss
- ▶ Coughing up phlegm or mucus
- ▶ Coughing up blood
- ▶ Hoarseness
- ▶ Malaise, which is a general feeling of discomfort or illness

If you are concerned about any changes you experience, please talk with your doctor. Your doctor may recommend scans to check for a recurrence so any new cancers can be found as early as possible.

Survivors of NSCLC who have smoked cigarettes in the past also have a high risk of heart disease, stroke, emphysema, and chronic bronchitis. Certain cancer treatments can further increase these risks. Therefore, nothing helps recovery more than stopping smoking. There are many tools and approaches available. Enlist the support of your family, friends, nurses, and doctors because it can be very difficult to stop on your own.

Even if you do not smoke, making healthy lifestyle choices after cancer, such as maintaining a healthy weight, eating well, limiting alcohol, and managing stress, are important for your overall well-being. Additionally, moderate physical activity can help rebuild your strength and energy level. Recovering patients, even those using oxygen, are encouraged to walk for 15 to 30 minutes each day to improve their heart and lung function. Your doctor can help you create an appropriate exercise plan based on your needs, physical abilities, and fitness level.



For cancer treatment summaries and survivorship care plans, visit [www.cancer.net/survivorship](http://www.cancer.net/survivorship).



### QUESTIONS TO ASK THE HEALTH CARE TEAM ABOUT FOLLOW-UP CARE

- ▶ What are the chances that my cancer will return?
- ▶ Is there anything I can do to reduce the risk of recurrence?
- ▶ What follow-up tests will I need, and how often will I need them?
- ▶ How often will I need to see a doctor?
- ▶ What symptoms should I tell you about right away?

# Non-Small Cell Lung Cancer Dictionary

**Adjuvant therapy:** Treatment given after the main treatment to reduce the chance of cancer coming back by eliminating any remaining cancer cells. It usually refers to chemotherapy, radiation therapy, and/or targeted therapy given after surgery.

**Anesthesia:** This is medication to block the awareness of pain.

**Benign:** A tumor that is not cancerous. The tumor can grow but does not usually invade nearby tissue or spread to other parts of the body.

**Biopsy:** The removal of a small amount of tissue for examination under a microscope. Other tests can suggest lung cancer is present, but only a biopsy can make a definite diagnosis.

**Bisphosphonate:** Drugs that prevent and treat bone problems by blocking osteoclasts, the cells that cause bone destruction.

**Bronchoscopy:** A procedure that allows a doctor to look inside the breathing passages of the lungs.

**Chemotherapy:** The use of drugs to destroy cancer cells, usually by keeping the cancer cells from growing, dividing, and making more cells.

**Clinical trial:** A research study that involves volunteers. Many clinical trials test new treatments and/or prevention methods to find out whether they are safe, effective, and possibly better than the current standard of care, which is the best known treatment.

**Computed tomography (CT or CAT) scan:** An imaging technique that creates a 3D picture of the inside of the body.

**Cure:** To fully restore health. This term is sometimes used when a person's cancer has not returned for at least 5 years after treatment. However, the concept of "cure" is difficult to apply to cancer because undetected cancer cells can sometimes remain in the body after treatment, causing the cancer to return later. Recurrence after 5 years is still possible.

**External-beam radiation therapy:** Radiation therapy given from a machine located outside the body.

**Imaging test:** A procedure that creates pictures of internal body parts, tissues, or organs to make a diagnosis, plan treatment, check whether treatment is working, or observe a disease over time.

**Immunotherapy:** Also called biologic therapy; designed to boost the body's natural defenses to fight the cancer. It uses materials made either by the body or in a laboratory to improve, target, or restore immune system function.

**Invasive cancer:** Cancer that has spread outside the layer of tissue in which it started and has the potential to grow into other tissues or parts of the body. Also called infiltrating cancer.

**Laboratory test:** A procedure that evaluates a sample of blood, urine, or other substance from the body to make a diagnosis, plan treatment, check whether treatment is working, or observe a disease over time.

**Late effects:** Side effects of cancer treatment that occur months or years after treatment has finished.

**Lobectomy:** Surgery to remove an entire lobe of the lung.

**Localized cancer:** Cancer that is confined to the area where it started and has not spread to other parts of the body. Also called in situ.

**Lymphatic system:** A network of small vessels, ducts, and organs that carry fluid to and from the bloodstream and body tissues. Cancer can spread to other parts of the body through the lymphatic system.

**Maintenance therapy:** The use of ongoing chemotherapy or another treatment to help lower the risk of recurrence.

**Malignant:** A tumor that is cancerous. It may invade nearby healthy tissue or spread to other parts of the body.

**Metastasis:** The spread of cancer from the place where it began to another part of the body. This occurs when cancer cells break away from the primary tumor and travel through the blood or the lymphatic system to the lymph nodes, brain, bones, adrenal glands, or other organs.

**Neoadjuvant therapy:** Treatment given before the main treatment. It may include chemotherapy or radiation therapy given before surgery to shrink a tumor so it is easier to remove.

**Non-small cell lung cancer (NSCLC):** Lung cancer that begins in the epithelial cells, which line the airways and produce mucus. The most common type of lung cancer.

**Oncologist:** A doctor who specializes in treating cancer.

**Palliative care:** Any form of treatment that concentrates on reducing a patient's symptoms or treatment-related side effects, improving quality of life, and supporting patients and their families. Also called supportive care. Any person, regardless of age or type and stage of cancer, may receive palliative care.

**Pathologist:** A doctor who specializes in interpreting laboratory tests and evaluating cells, tissues, and organs to diagnose disease.

**PD-L1:** A protein found on the surface of cancer cells. This stops the body's immune cells from destroying the cancer. If a tumor has PD-L1, it may be treatable with immunotherapy.

**Pneumonectomy:** The surgical removal of an entire lung.

**Positron emission tomography (PET) scan or PET-CT scan:** A diagnostic test used to detect cancer and find out the cancer's stage. This scan is sometimes used to evaluate the effectiveness of cancer treatments, such as chemotherapy or radiation therapy.

**Primary cancer:** The area in the body where a cancer started.

**Prognosis:** Chance of recovery; a prediction of the outcome of a disease.

**Psychosocial effects:** Emotional and social concerns related to cancer and cancer treatment that can greatly affect patients' well-being. These may include lack of information and support; emotional difficulties, including depression and anxiety; lack of transportation; disruptions to work, school, and family life; and difficulty with the cost of cancer care.

**Pulmonary fibrosis:** Permanent scarring of the lungs caused by radiation therapy.

**Pulmonologist:** A doctor who specializes in diagnosing and treating lung diseases.

**Radiation pneumonitis:** Inflammation of lung tissue caused by radiation therapy.

**Radiation therapy:** The use of high-energy x-rays or other particles to destroy cancer cells. Also called radiotherapy.

**Recurrence:** Cancer that has returned after a period during which the cancer could not be detected. Local recurrence means that the cancer has come back in the same general area where the original cancer was located. Regional recurrence refers to cancer that has come back in the lymph nodes or other tissues near the original cancer site, usually by direct spread. Distant recurrence refers to cancer that has come back and has spread to other parts of the body, usually by traveling through the lymphatic system or bloodstream.

**Regimen:** A treatment plan that includes which treatments and procedures will be done, medications and their doses, the schedule of treatments, and how long each treatment will last.

**Response:** How the cancer reacts to the treatment; how effective the treatment is.

**Risk:** The likelihood of an event.

**Secondary cancer:** Describes either a new primary cancer, which is a different type of cancer that develops after treatment for the first type of cancer, or cancer that has spread to other parts of the body from the place where it started (see Metastasis).

**Side effect:** An undesirable result of treatment, such as fatigue, nausea, vomiting, pain, anxiety, infertility, sexual problems, or hair loss.

**Small cell lung cancer:** Lung cancer that begins in the nerve cells or hormone-producing cells of the lung. The term "small cell" refers to the size and shape of the cancer cells when viewed under a microscope.

**Stage:** A way of describing where the cancer is located, if or where it has spread, and whether it is affecting other parts of the body.

**Standard of care:** Care that experts agree or guidelines show is the most appropriate and/or effective for a specific type or stage of cancer.

**Surgery:** The removal of cancerous tissue from the body during an operation.

**Survivorship:** This term means different things to different people. Common definitions include having no disease after the completion of treatment and the process of living with, through, and beyond cancer.

**Survivorship care plan:** A personalized schedule of follow-up examinations and tests that the doctor recommends after a patient's active treatment period ends. This may include regular physical examinations and/or medical tests to monitor a person's recovery for the coming months and years. It's often used with a treatment summary. Also called a follow-up care plan.

**Systemic therapy:** Treatment with chemotherapy, targeted therapy, or immunotherapy to shrink the cancer, relieve discomfort caused by the cancer, prevent the cancer from spreading further, and lengthen a patient's life.

**Targeted therapy:** A treatment that targets the cancer's specific genes, proteins, or the tissue environment that contributes to cancer growth and survival.

**Thoracic surgeon:** A doctor who performs operations on the heart, lungs, esophagus, and other organs in the chest.

**Treatment summary:** A written summary of the therapies that a person had during their active treatment period. This is often used with a survivorship care plan to help monitor a survivor's long-term health.

**Tumor:** A mass, lesion, or nodule formed when healthy cells change and grow out of control. A tumor can be benign, meaning it is noncancerous, or malignant, meaning it is cancerous and can spread to other parts of the body.

**Unresectable:** A tumor that cannot be removed with surgery.



**For more definitions of common terms you may hear before, during, and after treatment, visit [www.cancer.net/cancerterms](http://www.cancer.net/cancerterms).**

# My Health Care Team

Medical Oncologist: \_\_\_\_\_

Contact Information: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Pulmonologist: \_\_\_\_\_

Contact Information: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Radiation Oncologist: \_\_\_\_\_

Contact Information: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Thoracic Surgeon: \_\_\_\_\_

Contact Information: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Primary Care Doctor: \_\_\_\_\_

Contact Information: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Oncology Nurse: \_\_\_\_\_

Contact Information: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Oncology Social Worker: \_\_\_\_\_

Contact Information: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Counselor/Therapist: \_\_\_\_\_

Contact Information: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Nutritionist/Dietitian: \_\_\_\_\_

Contact Information: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Pharmacist: \_\_\_\_\_

Pharmacy: \_\_\_\_\_

Contact Information: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Palliative Care Specialist: \_\_\_\_\_

\_\_\_\_\_

Contact Information: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

## Other Team Members:

Name: \_\_\_\_\_

Contact Information: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

# Diagnosis Summary

**TYPE:**

- NSCLC**
  - Adenocarcinoma
  - Squamous cell carcinoma
  - Large cell carcinoma
  - NSCLC-NOS (not otherwise specified) or NSCLC undifferentiated
  - Other: \_\_\_\_\_
- Metastatic Cancer of Unknown Primary**

**STAGE:**

- Stage 0
- Stage IA
- Stage IB
- Stage IIA
- Stage IIB
- Stage IIIA
- Stage IIIB
- Stage IIIC
- Stage IVA
- Stage IVB
- Recurrent

**OTHER RESULTS OF DIAGNOSTIC OR IMAGING TESTS:**

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**MY TREATMENT PLAN**

- Surgery
- Radiation therapy
- Chemotherapy
- Targeted therapy
- Immunotherapy
- Clinical trial
- Palliative care

**TREATMENT GOALS**

- Eliminate the cancer
- Slow cancer growth/spread
- Shrink the tumor
- Relieve symptoms
- Manage side effects
- Other:

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# My Follow-Up Care Plan

Use this page to help discuss your follow-up care with your doctor and keep track of their recommendations. Talk with a member of your health care team if you have any questions.

Need for ongoing (adjuvant) treatment for cancer:  Yes  No

Additional treatment name	Purpose	For how long

## SCHEDULE OF FOLLOW-UP VISITS

Doctor's name	When/How often

## CANCER SURVEILLANCE/OTHER RECOMMENDED TESTS

Test/Procedure	When/How often

It is important to continue to see your primary care doctor for all general health care recommended for a person of your age, including screening tests for other cancers, when appropriate. You should also tell your doctor about:

1. Anything that could be a brand new symptom
2. Anything that continues to be a persistent symptom
3. Anything you are worried about that might be related to the cancer coming back

Signs or symptoms to tell the doctor about right away: \_\_\_\_\_

\_\_\_\_\_

Possible late and long-term effects: \_\_\_\_\_

\_\_\_\_\_

What concerns do you have as you transition into survivorship?

- |   |   |   |
|---|---|---|
| <input type="checkbox"/> Emotional and mental health    | <input type="checkbox"/> Insurance                    | <input type="checkbox"/> Sexual health    |
| <input type="checkbox"/> Fatigue                        | <input type="checkbox"/> Memory or concentration loss | <input type="checkbox"/> Stopping smoking |
| <input type="checkbox"/> Fertility                      | <input type="checkbox"/> Parenting                    | <input type="checkbox"/> Weight changes   |
| <input type="checkbox"/> Financial advice or assistance | <input type="checkbox"/> Physical functioning         | <input type="checkbox"/> Other: _____     |
|   | <input type="checkbox"/> Work/School                  | _____                                     |

## Looking for More Patient Information Resources?

Visit [www.cancer.net/ascoanswers](http://www.cancer.net/ascoanswers) to see all of the available titles in the *ASCO Answers* series.

***ASCO Answers Guides*** are comprehensive manuals, covering specific cancer types, survivorship, and caregiving. Worksheets and checklists for managing care are included.

***ASCO Answers Fact Sheets*** are brief introductions to different cancer types and topics in diagnosis, treatment, and side effects. More than 70 fact sheets are available, including translations in Spanish, Portuguese, and more.

***ASCO Answers Booklets*** are in-depth guides to specific topics in cancer care, including advanced cancer care planning, pain, cost of care, managing weight, palliative care, and stopping tobacco use.

***Patients and Caregivers:*** For more educational materials, visit [www.cancer.net/ascoanswers](http://www.cancer.net/ascoanswers) to find and download all of our available materials.

***Oncology Professionals:*** Bulk quantities of high-quality print materials can be purchased at [www.cancer.net/estore](http://www.cancer.net/estore) or by calling 1-888-273-3508. For free promotional materials for your practice, email [contactus@cancer.net](mailto:contactus@cancer.net).



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[www.asco.org](http://www.asco.org) | [www.cancer.net](http://www.cancer.net)

For more information about ASCO's patient information resources,  
call toll-free 888-651-3038 or e-mail [contactus@cancer.net](mailto:contactus@cancer.net).

To order more copies of this booklet,  
call 888-273-3508 or visit [www.cancer.net/estore](http://www.cancer.net/estore).

**WE WANT TO HEAR FROM YOU**

If you found this material helpful or if you have comments or suggestions  
about how it could be better, please let us know at [contactus@cancer.net](mailto:contactus@cancer.net).