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Mesothelioma basics

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Being diagnosed with cancer can be frightening and overwhelming. This guidebook will help you make sense of all the information that's out there. It will also describe your options for treatment. Taken together, you'll have the confidence to make well-informed decisions.

What is mesothelioma?

Malignant pleural mesothelioma—often simply called mesothelioma—is a rare cancer that develops in the thin layers of tissue that surround the lungs.

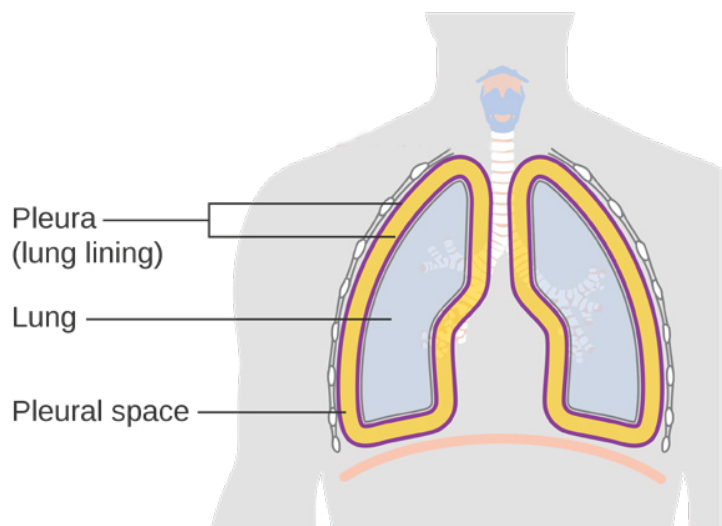
The term *malignant pleural mesothelioma* requires more explanation, though. Let's break it down, from last word to first, to figure out exactly what it means:

- **Mesothelioma** – A mesothelioma is a cancer of the cells in a layer of tissue called the mesothelium. The mesothelium is a thin but strong membrane that lines many organs inside the body. Its main job is to protect the organs but also allow the organs to move when needed. The mesothelium has different names when it covers different organs. Around the lungs, it's called the pleural mesothelium.
- **Pleural** – This word refers to the pleura. The pleura is made of mesothelium and connective tissue. The pleura consists of two thin layers that surround and protect the lungs and the inside of the chest. One pleural layer covers the lungs (visceral pleura) and the other pleural layer lines the inside of the chest cavity (parietal pleura). In between the pleural layers is a very thin space called the pleural cavity. This narrow space is filled with a slippery liquid called pleural fluid. This fluid lets the

The pleura

The pleura is made of two layers of mesothelium tissue. The inner layer (the visceral pleura) covers the lungs. The outer layer (the parietal pleura) lines the inside of the chest wall. In between the two layers is a narrow space called the pleural cavity or pleural space.

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pleural layers slide easily against one another. This sliding ability allows the lungs to move freely within the chest during breathing.

- **Malignant** – Malignant describes a medical condition that is dangerous and possibly fatal if left untreated. Cancer cells are malignant when they multiply and spread out of control.

Now, let's put it all together:

Malignant pleural mesothelioma is a dangerous and potentially deadly cancer that develops from cells in the lining of the lungs.

Malignant pleural mesothelioma is the most common type of mesothelioma. It accounts for about 85% of all cases of mesothelioma.

But there are other areas of mesothelium in the body, so there are other types of mesothelioma. Other types of mesothelioma include cancer of the lining of the abdomen (peritoneal mesothelioma) and cancer of the lining around the heart (pericardial mesothelioma). These mesotheliomas are even more rare than pleural mesothelioma.

This book discusses only malignant pleural mesothelioma. From this point on, we'll refer to malignant pleural mesothelioma simply as mesothelioma.

What is cancer?

Cancer is a disease where cells—the building blocks of the body—grow out of control. This can end up harming the body. There are many types of cells in the body, so there are many types of cancers.

Cancer cells don't behave like normal cells. Normal cells have certain rules. Cancer cells don't follow these rules.

- Cancer cells develop genetic errors (mutations) that allow them to multiply and make many more cancer cells. The cancer cells crowd out and overpower normal cells. Cancer cells take away energy and nutrients that normal cells need.
- Normal cells live for a while and then die. Cancer cells avoid normal cell death. They survive much longer than normal cells do.
- Cancer cells can spread to other areas of the body. They can replace many normal cells and cause organs to stop working well.
- Treatment may get rid of cancer at first but sometimes the cancer comes back later.
- Cancer can stop responding to treatment that worked before.

Scientists have learned a great deal about cancer. As a result, today's treatments work better than treatments in the past. Also, many people with cancer have more treatment choices now than before.

What causes mesothelioma?

Asbestos is the main cause of mesothelioma. Asbestos is a group of naturally occurring minerals. It's found in rocks and soil in many parts of the United States and around the world.

Asbestos is made up of bundles of long, thin fibers. These fibers are so small that they can only be seen under a microscope. Asbestos fibers are strong, flexible, and resistant to heat and fire. Because of these traits, asbestos

has been widely used in construction and commercial materials such as insulation, roofing, brake pads, and more.

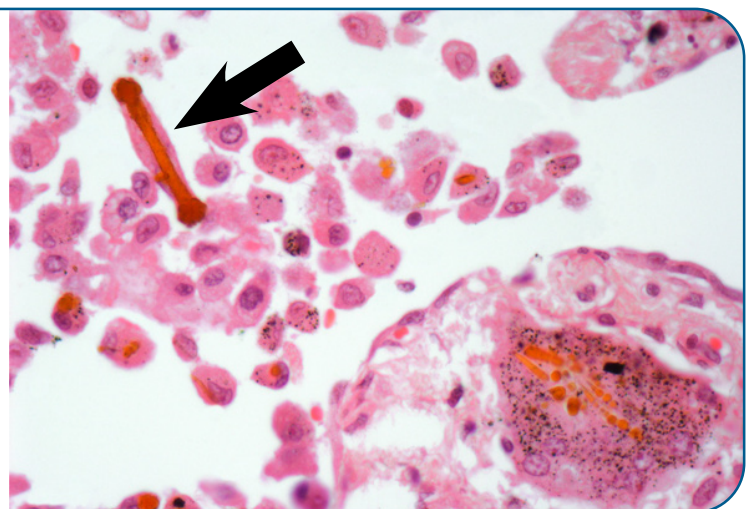
But asbestos is also harmful. Asbestos can break into tiny pieces that can become airborne. These particles can be inhaled or even swallowed. When asbestos fibers are inhaled, they can enter the lungs. In the lungs, some of the fibers can travel to the ends of the small airways, where they enter a space between the pleural layers called the pleural cavity. The long asbestos fibers sometimes get

Asbestos

Asbestos is made up of bundles of long, thin fibers. It's found in rocks and soil in many parts of the United States and around the world.



Asbestos can break into tiny pieces that can become airborne. These particles can be breathed in and enter the lungs. The arrow points to an asbestos fiber caught in lung tissue.



stuck in the pleural cavity and remain there for years, even decades. The fibers can irritate and injure the cells of the pleura, causing inflammation. Many scientists think that this process causes changes in the cells, which result in cancer.

Mesothelioma develops over many years. The average time between contact with asbestos and being diagnosed with mesothelioma ranges from 15 to 50 years. Mesothelioma is often unnoticed during this in-between period and usually remains undiagnosed until age 75 years or older. That's because many mesothelioma-related problems—like shortness of breath or having a cough that just won't go away—may appear to be related to another type of illness. And serious mesothelioma-related health effects, like chest pain, haven't become a big problem yet.

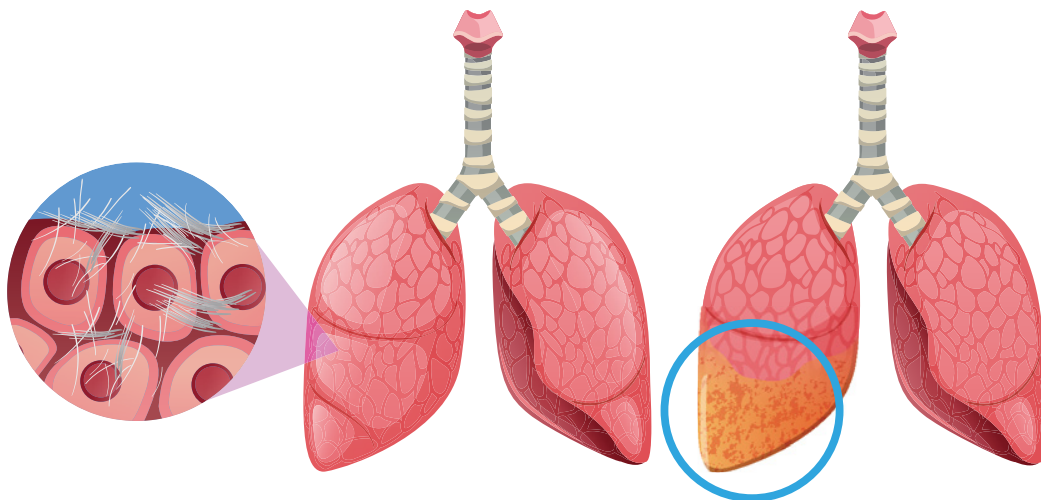
Asbestos exposure

Most people who develop mesothelioma have been in contact with asbestos. About 4 out of 5 people with mesothelioma have been around or worked with asbestos. Asbestos fibers in the body will continue to cause harm even if the person is no longer around asbestos.

Workers who use, install, or remove asbestos as part of their jobs are much more likely to get mesothelioma than other workers. The occurrence of mesothelioma among people who worked with it is 40 times greater than for people in the general workforce. Mesothelioma occurs more often in men because they're more likely to work in industries that use asbestos. Some common jobs with possible asbestos exposure include construction, shipbuilding, and vehicle brake repair. Women who worked as teachers in poorly maintained

How asbestos activates mesothelioma

If you inhale asbestos fibers, they can travel through the lungs and get caught in the pleura—the layers of tissue that surround the lungs. In the pleural cells, the asbestos fibers will irritate the tissue and cause swelling and scarring. Over years, this irritation may trigger cancer in the pleura, eventually causing symptoms like coughing or shortness of breath.



schools containing exposed asbestos have also developed mesothelioma. Even “secondary exposure,” when workers bring home asbestos fibers on work clothes, can expose family members or other people to asbestos and a higher risk of mesothelioma. In addition, some samples of talcum powder, which was used in products like baby powder and makeup, were found to be contaminated with asbestos.

However, most people who are exposed to asbestos, even a lot of it, don’t develop mesothelioma. What’s more, about 1 in 5 people with mesothelioma have had no known contact with asbestos. This fact suggests that there may be other causes of mesothelioma besides asbestos.

Mesothelioma develops outside the lungs. So it’s not lung cancer. Lung cancer begins inside



Let us know what you think!

Please take a moment to complete an online survey about the NCCN Guidelines for Patients.

[NCCN.org/patients/response](https://www.nccn.org/patients/response)

Facts about mesothelioma

- Mesothelioma is a rare cancer. It’s diagnosed in about 3,000 people in the United States each year.
- Mesothelioma that affects the chest (malignant pleural mesothelioma) is the most common type of mesothelioma, accounting for 85% of all cases.
- Asbestos is the number 1 cause of mesothelioma. About 4 out of 5 people who develop mesothelioma have been exposed to asbestos in their lifetime.
- The average time between contact with asbestos and being diagnosed with mesothelioma ranges from 15 to 50 years.
- Asbestos has been completely banned from use in more than 60 countries. Though the use of asbestos has greatly decreased in the United States, it hasn’t been officially banned.

the lungs. However, mesothelioma sometimes spreads from the pleura to other areas in the chest and to other areas of the body, including the lungs.

How is mesothelioma found?

Mesothelioma is usually found after a person develops certain symptoms. A symptom is a feeling or problem you have that can indicate a disease or condition. Symptoms of pleural mesothelioma may not appear until decades after contact with asbestos. Some common symptoms are shortness of breath, chest pain, fever, extreme tiredness (fatigue), and unexplained weight loss.

Let your doctor know if you have these or other symptoms. Your symptoms may be the first step toward a diagnosis. A diagnosis means identifying an illness based on tests.

Diagnosing mesothelioma can be a lengthy and worrisome experience. Because mesothelioma is so rare, it can be mistaken for other conditions that are more common. Some respiratory conditions, like pneumonia or chronic obstructive pulmonary disease (COPD), have many of the same symptoms as mesothelioma.

Mesothelioma is also difficult to distinguish from other cancers. That's why your doctor will request several different tests to determine the location, the extent, and the cell type of the cancer you have. Knowing these facts will help to determine your treatment.

It can take time to diagnose mesothelioma, but it's important to find the correct diagnosis so you can get the right treatment.

Symptoms of mesothelioma

Shortness of breath



Chest pain



Persistent cough



High temperature (fever)
and sweating



Fatigue (extreme tiredness)



Loss of appetite and
unexplained weight loss



Trouble swallowing/
hoarseness



What's the best treatment for mesothelioma?

There's no single "best" treatment for mesothelioma. Treatment is focused on you—your age, your current health, how advanced your cancer is, and other factors.

Treatment helps to destroy cancer cells and keep cancer cells from spreading. Treatments for mesothelioma include surgery, chemotherapy, immunotherapy, and radiation therapy. Mesothelioma can be difficult to treat, so two or more of these therapies may be required. Treatment may continue, off and on, for the rest of your life.

Researchers are constantly investigating more effective treatments for mesothelioma. Treatments currently in development may work better than those that have been available up to now. A clinical trial of a potential new therapy is another treatment option that people with mesothelioma can consider.

Can mesothelioma be cured?

Mesothelioma can be cured sometimes, though this is rare. Treatment is improving as doctors and researchers learn more about the disease.

When mesothelioma is caught early, treatment options and outcomes improve. However, the time between contact with asbestos and the emergence of the disease can take decades. So, mesothelioma is often at an advanced stage when it's diagnosed.

However, even for advanced-stage mesothelioma, treatment can relieve

Mesothelioma is rare and can be difficult to diagnose and treat. Seek out a medical center that specializes in the diagnosis and treatment of mesothelioma.

symptoms and extend life. In some cases, people with mesothelioma have survived for many years.

In the past, the outlook for people with mesothelioma wasn't good. Even today, the outlook can be discouraging. Most people diagnosed with mesothelioma will have a difficult road ahead.

Still, there's hope. Things are changing. Better testing is identifying mesothelioma earlier. Newly introduced medicines are showing greater effectiveness in treating mesothelioma. Other promising therapies that are specifically designed to treat mesothelioma are currently being studied in clinical trials. The number of these trials has increased in recent years, offering more hope to patients.

Key points

- The mesothelium is a layer that surrounds and protects organs inside the body.
- The pleural mesothelium protects the lungs and the inside of the chest.
- Mesothelioma is a rare cancer that starts in the cells of the pleural mesothelium. Over time, it can spread within the chest and to other areas of the body.
- Asbestos is the most common cause of mesothelioma. About 4 out of 5 people with mesothelioma have been around or worked with asbestos.
- Asbestos is a group of minerals made of tiny fibers that are strong and flexible.
- Asbestos can break into tiny pieces that may be breathed in or swallowed.
- Diagnosing mesothelioma can take time because it's frequently mistaken at first for more common conditions.
- Mesothelioma is often at an advanced stage when it's diagnosed.
- Mesothelioma treatments include surgery, chemotherapy, immunotherapy, and radiation therapy.
- Mesothelioma is rarely cured, but care is improving all the time.



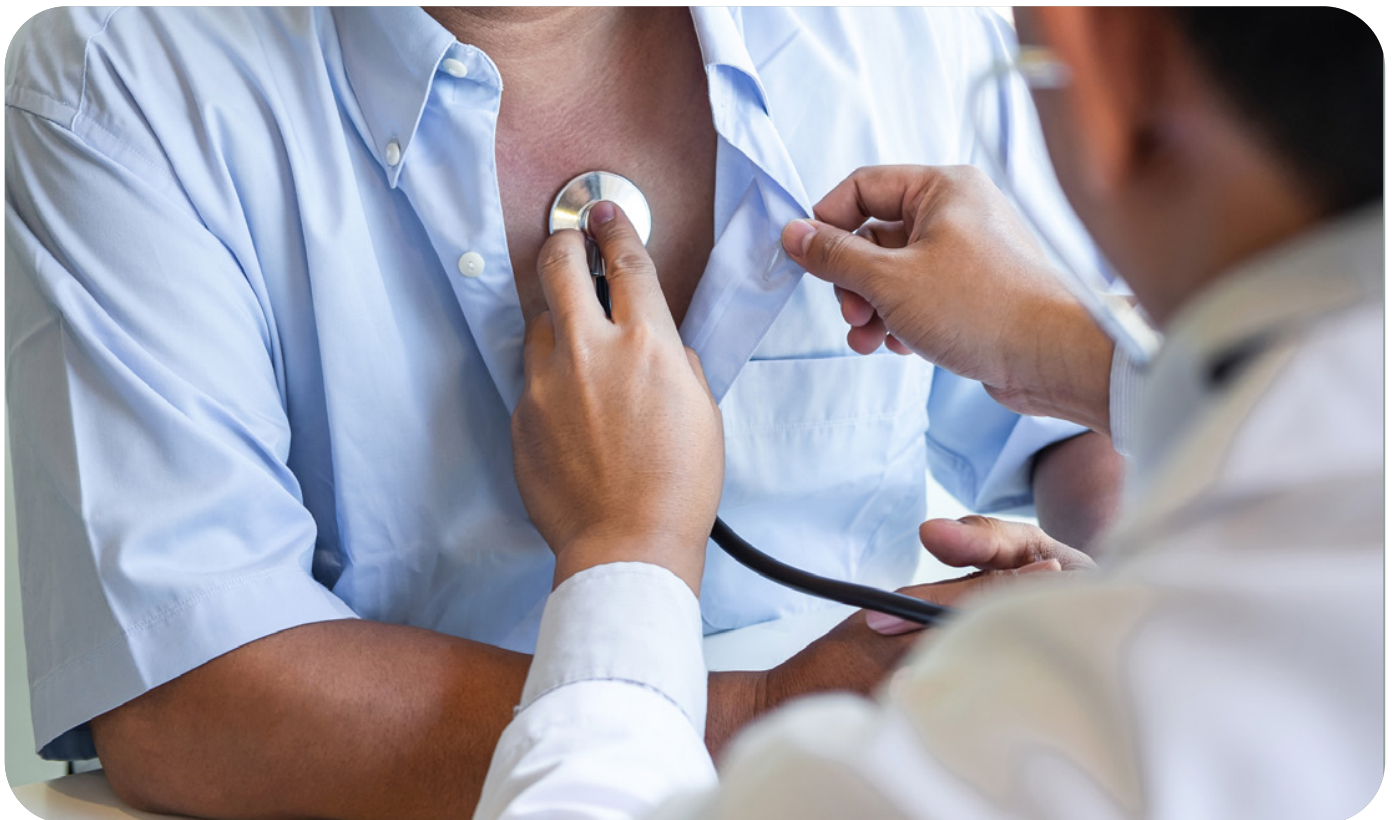
I think the absolute best thing you can do as a mesothelioma patient is seek out the oncologists who specialize in this field. Pick their brains, ask questions, ask more questions, and get comfortable with their expertise leading the plan. Stay involved and on top of the treatments and breaking news. ”

– Laura, mesothelioma patient

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Tests for mesothelioma

16	Health history
18	Physical exam
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25	Your diagnosis
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Doctors use a variety of tests to diagnose mesothelioma. Testing is necessary to find out whether you have cancer. If you do have cancer, testing can show whether you have mesothelioma or a different cancer. Testing can also give your doctors clues about what treatments may be most appropriate for you.

The thought of cancer is scary. Even having tests for cancer can be scary. This chapter will help you know what to expect during testing. Testing will show how much cancer there is and provide a diagnosis, which will help to plan treatment. These steps can help put thoughts into action, which may reduce some of the anxiety.

There's no single test that will show whether you have mesothelioma. Rather, several tests are required to reach a final diagnosis. Testing begins with an examination of your general health and an evaluation of your symptoms. Bring someone with you to listen, ask questions, and write down the answers.

Not every person with mesothelioma will receive every test listed here.

Health history

Your doctors need to have all of your health information. They'll ask you about any health problems and treatments you've had. Be prepared to talk about any illness or injury you've had and when it happened. Bring a list of old and new medicines and any over-the-

Tips for testing

Results from blood tests, imaging studies, and biopsies will be used to determine your treatment plan. It's important you understand what these tests mean. Ask questions and keep copies of your test results. Online patient portals are a great way to access your test results.

Remember these tips for testing:

- Bring someone with you to doctor visits, if possible.
- Write down questions and take notes during appointments. Don't be afraid to ask your care team questions. Get to know your care team and let them get to know you.
- Get copies of blood tests, imaging results, and reports about the specific type of cancer you have.
- Organize your papers. Create files for insurance forms, medical records, and test results. You can do the same on your computer.
- Keep a list of contact information for everyone on your care team. Add it to your phone. Hang the list on your refrigerator or keep it in a place where someone can access it in an emergency. Keep your primary care physician informed of changes.

Don't put too much stock in survival statistics

You should think twice when reading about survival rates. The numbers used to compile those statistics probably aren't current. It takes years to gather that information. So the statistics you read today likely reflect survival rates from a few years ago. In the meanwhile, new and improved treatments have become available, giving today's patients better results.

And don't forget: You're not a statistic. Your cancer isn't the same as anyone else's. Statistics based on general averages don't necessarily apply to individuals—including you.



counter medicines, herbals, or supplements you take.

You'll be asked whether you've been exposed to or worked with asbestos, or whether you lived with someone who worked with asbestos. If no one asks you, be sure to share this information. Sometimes a person can get mesothelioma by being close to another person who works with or around asbestos. The asbestos fibers can be carried home in the worker's hair or clothes. This is called second-hand or secondary asbestos exposure.

Some people with mesothelioma haven't had any contact with asbestos that they're aware of. This suggests that some people may have unknown asbestos exposure or other risk factors. A risk factor is something that increases the chance of getting a disease. Risk factors can be things in the environment,

activities that people do, or traits passed down from parents to children through genes.

Asbestos is the only known risk factor for mesothelioma, but there might be more. Scientists are studying other possible risk factors, including:

- **Genetic abnormality** – A genetic abnormality (mutation) is an unusual change in the specific instructions for making and controlling cells. Scientific studies have shown that having a mutation in the *BAP1* gene may increase the risk of developing mesothelioma. Mutations in other genes—like *NF2* and *CDKN2A* genes—have also been linked to mesothelioma.
- **Radiation therapy** – Previous treatment with radiation therapy might be a cause of mesothelioma, but this is very rare.

- **Simian virus 40** – Some researchers believe that being infected with this virus may increase the risk of mesothelioma in people who've been exposed to asbestos.

Smoking is not a risk factor for mesothelioma. (People who smoke and have been in contact with asbestos do have an increased risk for lung cancer, though.) People with mesothelioma who smoke should try to quit, because smoking may interfere with cancer treatment. For example, smoking delays wound healing after surgery.

Symptoms

A symptom is a feeling or problem that can indicate a disease or condition. Possible symptoms of mesothelioma can be found in [Guide 1](#).

Guide 1

Symptoms of mesothelioma

Shortness of breath

Chest or lower back pain

Cough

Fever

Fatigue

Heavy night sweats

Unexpected weight loss

Trouble swallowing

Hoarseness

Swelling of the face and arms

Symptoms are often related to the location of the mesothelioma as well as its size. Mesothelioma in its early stages may cause only mild symptoms or no symptoms at all. However, mesothelioma can produce fluid around the lung that constricts or presses on the lung, causing shortness of breath.

Other respiratory problems—like pneumonia or the flu—can have the same symptoms as mesothelioma. This can cause confusion that delays finding the real cause of the problem. For the most accurate diagnosis, be sure to tell your doctor about any symptoms you're having, even if they seem unrelated.

If you have one or more of these symptoms, your doctor will request that you have a physical exam to take a closer look.

Physical exam

A physical exam allows your doctor to look for any signs of mesothelioma. During a physical exam, your doctor may examine your chest using one or more of these devices:

- Stethoscope
- X-ray
- Ultrasound

These tests can show if you have any indications of mesothelioma, such as fluid in your chest or scarring of pleural tissue. These problems may be signs of asbestos-related disease.

Signs of asbestos-related disease

Pleural effusion and pleural thickening can develop due to asbestos exposure.

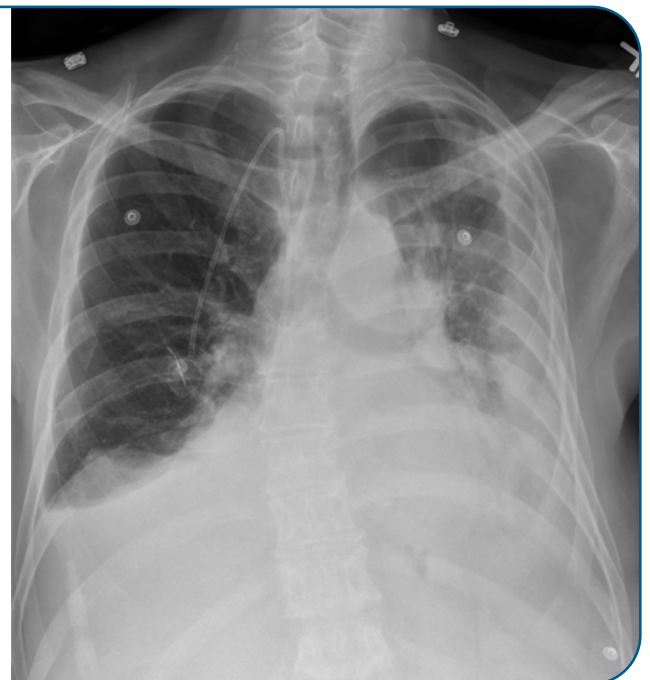
- **Pleural effusion** – Fluid around the lung is called pleural effusion. Pleural effusion is often the earliest sign of asbestos-related disease. However, not everyone who has pleural effusion will have mesothelioma. Pleural effusion is an unusual buildup of extra fluid in the pleural cavity. Normally, the pleural space holds only a small amount of fluid—about 1 teaspoon. But the amount of fluid in the pleural space can swell to more than 1 gallon in some cases of pleural effusion. This excess fluid puts pressure on the lungs, making it more difficult to breathe. Other symptoms are cough and chest pain.

- **Pleural thickening** – Pleural thickening is what happens when there's widespread scarring of the pleural tissue. Asbestos is one cause of pleural thickening. The asbestos fibers scratch and scrape the pleural lining. This irritation causes inflammation (swelling) of the pleural tissue. Over time, the irritation and inflammation create scar tissue. This scar tissue can cause plaques that harden (calcify) over time. Increased scar tissue leads to thickening of the pleural layers, which can restrict the movement of the lungs. A person whose lungs can't fully expand can have a feeling of breathlessness. Other symptoms are chest pain and cough.

If you have pleural thickening or have had pleural effusion more than once, or have both, then you should get checked for mesothelioma. Certain tests are used to find

X-ray of pleural effusion

This chest x-ray shows pleural disease affecting both lungs, with worse disease in the patient's left lung (seen on the right side in this x-ray). The left lung has extensive pleural disease and a large pleural effusion. The right lung has a moderate sized pleural effusion.



mesothelioma, see how far it has spread, and plan treatment:

- Imaging of the chest
- Fluid biopsy
- Tissue biopsy

Let's discuss each of these tests in turn.

Imaging of the chest

If your symptoms suggest mesothelioma, your doctor will want you to get an imaging test. An imaging test takes pictures (images) of the insides of your body. The images show areas in the body that might have cancer. The images can reveal the cancer's location, size, and other features.

A chest x-ray is usually the first imaging test done when someone has symptoms in the chest. A chest x-ray may show pleural thickening, pleural fluid (effusion), or a mass or masses within the chest. Sometimes it's difficult to tell the difference between thickening, fluid, or a mass by looking only at an x-ray, so other imaging must be done.

A computed tomography (CT or CAT) scan is another type of imaging test. A CT machine uses x-rays to take many images of your body from different angles. A computer then combines the pictures to make a 3-D image.

A CT of the chest is recommended when a chest x-ray shows something that looks abnormal. A CT scan can show any unusual thickening of the pleura, which can be an indication of mesothelioma. Your doctors will be able to see where tumors have formed and the size of the tumors. They can also see if the

CT scan

A CT scanner is a large machine with a tunnel in the middle. During the test, you'll lie on a table that moves slowly through the tunnel. The machine will scan your chest with x-rays and produce images that can show evidence of cancer.



cancer has created fluid inside the chest or has spread to areas in the chest away from the pleura.

Your treatment team will tell you how to prepare for an imaging scan. You may need to stop taking some medicines and stop eating and drinking for a few hours before the scan. You also should remove any metal objects on your body. You'll likely be asked to wear a hospital gown during the test.

Some imaging tests use a contrast agent (also called contrast dye). Contrast is used to make blood vessels, organs, and other tissues stand out more clearly in the imaging. Contrast is injected into the bloodstream and flushed out in urine.

A CT scanner is a large machine that has a tunnel in the middle. During the test, you'll need to lie on a table that moves slowly through the tunnel. Pillows or straps may be used to keep you still during the test. Tell your team if you get nervous in small spaces. You may be given a sedative (medicine) to help you relax.

You'll be alone, but a technician will operate the machine in a nearby room. The technician will be able to see, hear, and speak with you at all times.

As the machine takes pictures, you may hear buzzing, clicking, or whirring sounds. A CT scan is done in about 30 seconds, but the entire process takes 20 to 30 minutes.

After the CT scan, your images will be studied by a radiologist. A radiologist is a doctor who's an expert in reading imaging tests like CT scans. The radiologist will send the imaging

Diagnosis vs. prognosis

What's the difference between your diagnosis and your prognosis? These two words sound alike but they're very different.

Diagnosis means identifying an illness based on tests. Your diagnosis names what illness you have.

Prognosis is the likely course and outcome of a disease based on tests and your response to treatment. Your prognosis predicts how your illness will turn out.

results to your doctor. This information helps your doctor plan the next steps of your care.

Biopsy

A biopsy is a surgical procedure that removes a small amount of fluid or tissue for testing.

If your CT scan shows fluid or a mass (something that looks like it might be a tumor), your doctor will want to take a sample of the fluid or the tissue.

Fluid biopsy

Taking fluid out of the chest is called a thoracentesis. Fluid from a thoracentesis is usually sent for many different tests. Some of the fluid is sent for chemistry testing, some to check for infection, and some to look for cancer cells. Thoracentesis is also a procedure for removing excess fluid in a person with a pleural effusion.

For thoracentesis, your skin will be cleaned and numbed with a local anesthetic. Next, a needle will be inserted between your ribs into your chest to get the fluid. You may be given an x-ray before and after the biopsy. This is done to help the doctor guide the needle into your chest and afterward to check if the biopsy went well.

The fluid sample will then be sent to a lab to be tested for the presence of cancer cells and other tests.

Tissue biopsy

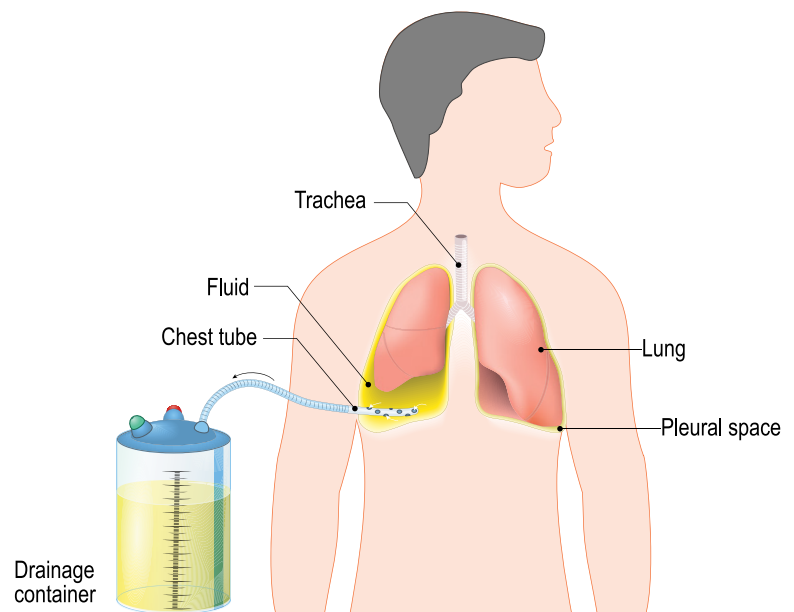
A pleural biopsy is when one or more samples of pleural tissue are removed. The tissue samples are then sent to a lab to be tested for cancer cells.

A pleural biopsy can be done in several ways. Options include a thoracoscopic biopsy, a CT- or ultrasound-guided core biopsy, or an open biopsy. A thoracoscopic biopsy is the preferred method because it can obtain enough tissue for an accurate diagnosis. However, it may not be the right option for every patient.

- **Thoracoscopic biopsy** – For a thoracoscopic biopsy—also called video-assisted thoracoscopic surgery (VATS)—a small hole is cut into the chest. Next, an instrument called a thoracoscope is inserted through the hole. A thoracoscope has a tiny light, a video camera, and a tool to remove a tissue sample. The surgeon watches the video monitor to

Fluid biopsy

Thoracentesis is a procedure for removing excess fluid in the pleural cavity (pleural effusion). A sample of the fluid removed from the pleural cavity can be used for a fluid biopsy.



guide the instrument inside the chest. Before the surgery, general anesthesia is used to put you to sleep.

- **CT-guided or ultrasound-guided core biopsy** – A CT-guided or ultrasound-guided core biopsy uses images from a CT scan or ultrasound device to guide a needle into your body. First, your skin will be cleaned and numbed with a local anesthetic. Next, the needle will be inserted through a small cut and guided into your chest between your ribs. Then, the sample will be removed by the sharp end of the needle and held in a hollow space within the needle.
- **Open biopsy** – An open biopsy requires a surgical opening into the chest. It's performed while you're under general anesthesia. The larger cut of the opening allows the surgeon to see directly into your chest. Tissue samples are collected with a surgical knife. For this biopsy, you'll have to stay in the hospital overnight.

What happens when a biopsy sample is sent to a lab? At the lab, a specialist called a pathologist will examine the sample under a microscope. Pathologists are doctors who are experts at examining cells and tissue to find disease.

For mesothelioma, the main types of tests include histology, immunohistochemistry, and genetic testing.

Histology

The pathologist will use a microscope to look at cells in your biopsy sample. This is called histology—the study of cell and tissue structures viewed under a microscope. The size, shape, and structure of the cells can

tell the pathologist whether your sample is malignant (cancerous) or benign (not cancerous).

If it's malignant, the pathologist can also get an idea of how aggressive your cancer is by looking at the cells. Cancer cells that look almost like normal cells indicate that the cancer cells are growing and spreading slowly. Cancer cells that look very different from normal cells suggest that the cells are growing and spreading quickly.

Histology can be used to predict the outlook (prognosis) of the cancer and plan treatment.

Immunohistochemistry

The pathologist can identify the type of cancer cell with another laboratory method called immunohistochemistry. Immunohistochemistry is used to find specific proteins linked with only a certain type of cell. Pathologists use immunohistochemistry to tell the difference between mesothelioma cells and cells of similar-looking cancers.

To identify mesothelioma, the cells should have certain proteins and also be without other particular proteins. Proteins that help confirm mesothelioma have names such as BAP1, MTAP, WT1, D2-40, and calretinin. Proteins that help rule out (exclude) other cancers are claudin-4, TTF-1, napsin A, and polyclonal CEA.

Immunohistochemistry is also used to identify different mesothelioma cell subtypes. Your mesothelioma subtype may be used to guide your treatment. The three major subtypes of mesothelioma cells are described in [Guide 2](#).

Genetic testing

Genetic testing looks for abnormal changes in the genes of cells. Genes carry DNA—the “instructions” for making new cells and for controlling how cells behave. An abnormal change in a gene can disrupt how some cells behave, which can cause diseases like cancer.

Then again, an abnormal genetic change may not necessarily cause mesothelioma but may make a person more vulnerable to asbestos-related disease.

How does a genetic abnormality lead to mesothelioma? Let’s look at the *BAP1* gene, for example. *BAP1* is known as a tumor-suppressing gene. Its job is to prevent mesothelioma tumors from growing. But if *BAP1* has or develops an abnormal genetic

Your pathology report

Lab results used for diagnosis are put into a pathology report. This report will be sent to your doctor. It’s used to plan your treatment. A meeting among all your doctors may be helpful for treatment planning once the pathology report is finished.

Guide 2 Mesothelioma cell subtypes

Cell subtypes	Cell subtype details	Prognosis
Epithelioid	Epithelioid cells are uniform and arranged in organized patterns. This is the most common mesothelioma cell subtype.	Treatment for the epithelioid subtype tends to be more effective. People with this subtype may have a better prognosis.
Sarcomatoid	Sarcomatoid cells are rod-shaped and found in disorganized patterns. Sarcomatoid is the least common cell subtype.	Treatment tends to be less effective for the sarcomatoid subtype. People with this subtype may have a poorer prognosis.
Biphasic (mixed)	The biphasic subtype has a mix of both epithelioid and sarcomatoid cells. It’s the second most common mesothelioma cell type.	Prognosis for people with the biphasic subtype depends on the proportion of epithelial cells compared to sarcomatoid cells.

change that affects its job, the gene will no longer be able to stop mesothelioma.

In addition to *BAP1*, several other genes are known to develop abnormal changes that may lead to mesothelioma. These include *NF2*, *CDKN2A*, *TP53*, and other genes.

What causes an abnormal genetic change? Sometimes an abnormal change is hereditary, which means it's passed from a parent to a child. Other times, the genetic abnormality occurs all by itself. Both kinds of genetic alterations occur in mesothelioma, though the hereditary kind occurs much less often.

Genetic testing is becoming increasingly important in cancers like mesothelioma. One reason is that it can lead to a more precise prognosis. Another reason is that researchers are learning to match genetic abnormalities with specific treatments, which are resulting in better outcomes.

Reviewing your test results

It may take several days after any test to receive the results. Your cancer doctor or your lung specialist will review the test results with you.

Lab tests don't always provide a clear-cut diagnosis, especially with a hard-to-identify cancer like mesothelioma. When this happens, you may need to have more tests or another biopsy before a reliable diagnosis can be made.

Your doctors will need to confirm your diagnosis before making a treatment plan.

Your diagnosis

When someone is given a diagnosis of cancer, they can feel overwhelmed and frightened. Many people want to have treatment right away. Others may blame themselves for getting mesothelioma. The important thing to do is to make sure you're getting the best care.

Ask for a second opinion

A second opinion means asking another doctor to look at your test results and come up with a treatment plan. With a rare cancer like mesothelioma, it's very common to get a second opinion. Doctors understand this. Your doctor may even suggest the idea of a second opinion. Ask for a second opinion at a center that sees many patients with mesothelioma. (For more about second opinions, see [Chapter 7](#).)

If your biopsy and other test results show that you do have mesothelioma, you may need even more tests before you can start treatment. First, your doctor will want to know how much cancer you have and how far it has spread within your body. (This is called staging, explained further in [Chapter 3](#).) Knowing the extent of the cancer will help your team determine the best treatment for you.

Key points

- Asbestos is the main risk factor for mesothelioma.
- Second-hand asbestos exposure is when someone carries asbestos fibers home, where they're inhaled or ingested by another person.
- People who smoke and have been exposed to asbestos have a higher risk for lung cancer.
- Pleural effusion is an unusual buildup of extra fluid in the pleural cavity.
- Pleural thickening is widespread scarring of the tissue around the lungs.
- Imaging tests, like a CT scan, can show where tumors are located.
- To confirm whether you have mesothelioma, a sample of pleural fluid or tissue must be removed from your body and tested. This is called a biopsy.
- Immunohistochemistry can show the difference between mesothelioma cells and cells of similar-looking cancers.
- An abnormal genetic change can turn a regular pleural cell into a harmful cancer cell.
- Getting a second opinion is very common with a rare cancer like mesothelioma.



When I got the gloomy outlook, my sister, who is a critical care nurse and a cancer patient herself, took my hand and said, “Now you’re on a journey. This is your journey and it will not be like anybody else’s journey. You define and decide how you’re going to travel on this journey. You can fight and have a positive outlook despite the medical evidence, or you can give in and let the disease take you. I am praying you have an enlightening journey and that you will beat this cancer.”

– Stephen, mesothelioma patient

3

Planning treatment

28 How widespread is the cancer?

29 Multidisciplinary care

31 Key points



After diagnosis, the next phase of care is determining the extent of the cancer. Before treatment starts, you'll need to have more tests to see if the cancer is limited or more advanced. This will help find the right therapies for you.

How widespread is the cancer?

Before your team can prepare a treatment plan, they'll need to know how far the mesothelioma has grown and spread in your body. This is called cancer staging.

A cancer stage is a number that stands for the extent of cancer in the body. The stages of mesothelioma range from numbers 1 to 4. The four cancer stages signify the extent of the cancer and whether it has affected other body parts. Generally, a lower number means the cancer has grown less and a higher number means it has grown more. The stage of cancer is based on the results of your biopsy and imaging.

CT of the chest and abdomen

CT imaging is essential for staging. It can show your doctors where the cancer is, how big it is, and if it has spread. If you haven't already had a CT scan of your chest, you'll have one now, sometimes with a CT of your belly area (abdomen). Contrast should be used if possible. For more about CT scans, see [Chapter 2](#).

Generally speaking, if the CT scan shows that the cancer is confined to the pleura or areas close to the pleura, the cancer is less advanced—it's at an earlier stage. When

mesothelioma involves the pleura and nearby areas as well as organs and tissues farther away, it's considered to be advanced—it's at a higher stage.

How does cancer spread?

Mesothelioma can spread to nearby organs and tissues as well as those that are farther away through metastasis. Metastasis means the spread of cancer to a different body part from where the cancer started. Mesothelioma most commonly spreads by growing and invading other nearby organs or structures in the chest. It can also spread to nearby lymph nodes in the chest.

Occasionally, cancer cells use the bloodstream or the lymphatic system like a highway to travel to distant areas in the body. Once there, they can invade organs and tissues and cause other (secondary) tumors to develop. However, metastasis to distant sites is less common with mesothelioma than with many other cancers.

What is the lymphatic system?

The lymphatic system is a network of organs and vessels that fights infections and transports a fluid called lymph throughout the body. A key part of the lymphatic system are lymph nodes. Lymph nodes are small, disease-fighting clusters that filter the lymph fluid to remove germs. Mesothelioma that has metastasized to the lymph nodes may indicate more advanced disease.

What stage is the cancer?

Staging is used to plan which treatments are best for you. Treatment options are based on your overall health, the type of mesothelioma, how fast the cancer is growing, and where the cancer is located in your body.

For simplicity's sake, we can condense the four stages into two:

- **Early-stage mesothelioma** – For people with early-stage mesothelioma (stages 1 to 3), surgery may be an option to use with other treatments. To learn about treatment options for early-stage mesothelioma, turn to [Chapter 4](#).
- **Advanced-stage mesothelioma** – Most people with mesothelioma are at an advanced stage (stage 3 or 4) when they're diagnosed. Due to several factors, surgery usually isn't possible for people with advanced mesothelioma. To learn about treatment options for advanced-stage mesothelioma, turn to [Chapter 5](#).

Keep in mind that these are general recommendations. Your treatment may be very different from another person with the same stage of mesothelioma.

Once your doctors know how far the mesothelioma has grown and spread in your body, a number of experts from different medical fields will work as a team to create a treatment plan for you. This is called multidisciplinary care.

Multidisciplinary care

Receiving a diagnosis of mesothelioma can turn your life upside down. This illness may affect you in many ways—physically, emotionally, socially, and financially.

But you're not alone.

The next step of care involves a multidisciplinary team who will work together with you to decide on a treatment plan. It's essential to build strong relationships with the members of your team who can assist, support, and guide you through the management of this disease.

A multidisciplinary team is made up of specialists from different “disciplines” (areas of expertise). By working and communicating together, a multidisciplinary team brings the best knowledge from all sides to solve a problem.

Your team may include a medical oncologist, radiation oncologist, chest (thoracic) surgeon, pulmonologist, primary care doctor, psychologist, nurses, social workers, palliative care specialists, and allied health providers. Each member of your multidisciplinary team should have experience with mesothelioma, if possible.

After determining the extent of the cancer, your team's main goal is to develop a treatment plan. A treatment plan is a written course of action that covers every stage of the treatment process. The plan will be based on the extent of cancer in your body and your other health needs, as well as your personal choices. A treatment plan for mesothelioma often involves two or more different types of therapy.

Who's on your treatment team?

Treating mesothelioma is a team effort. Your team of doctors, specialists, and nurses will work together to provide you with the best available care. You may not need every person listed below, but it's helpful to understand the role that each team member plays.



Diagnostic imaging specialist – A health care professional who performs imaging exams such as x-rays, CT scans, and MRIs.

Chest (thoracic) surgeon – A doctor who operates on organs and structures inside the chest.

Medical oncologist – A doctor who treats cancer using chemotherapy and other drugs.

Radiation oncologist – A doctor who treats cancer using radiation therapy.

Pulmonologist – A doctor who specializes in diseases of the respiratory system.

Oncology nurse – A specialized nurse who works only with cancer patients. Oncology nurses help coordinate care and administer treatment.

Palliative care specialist – A physician or other health provider focused on improving the patient's quality of life.

Ask who will coordinate your care and what efforts can be made to schedule appointments together.

Tip: Keep a list of names and contact information for each member of your care team. Make copies of your list and take them with you to appointments. When someone at a doctor's office asks you which other doctors and specialists you're seeing, simply hand them a copy. (While you're at it, make a similar list of all your medicines.)

Key points

- The cancer stage is a number that represents the extent of cancer within a patient.
- Cancer staging is used to plan treatment.
- CT imaging is essential for staging. It shows where the cancer is, how big it is, and if it has spread.
- Cancer spreads to near and distant organs and tissues through a process called metastasis.
- Mesothelioma that has metastasized to the lymph nodes may indicate advanced disease.
- Treatment options for mesothelioma are based on the overall health of the patient, the type of cancer, as well as the spread and the location of cancer in the body.
- Most people with mesothelioma are at an advanced stage when they're diagnosed.
- A multidisciplinary team will work together with you to decide on a treatment plan.
- A treatment plan for mesothelioma often involves two or more different types of therapy.



My oncologist always says to me 'Never waste a worry.' It has been a source of comfort for me before every CAT scan. ”

– Hope, mesothelioma patient

A treatment plan is a written course of action that covers every stage of the treatment process. A treatment plan for mesothelioma often involves two or more different types of therapy.

4

Treatment for early-stage mesothelioma

33 Multiple therapies

33 Surgery

36 Systemic therapy

39 Radiation therapy

41 Clinical trial

43 Key points



Treatment options for mesothelioma vary depending on your overall health, the type of cancer, the stage of the cancer, and other factors. Your care team will work with you to figure out the best treatments for you.

Multiple therapies

There are many ways to try to treat mesothelioma, but there's no one-size-fits-all therapy. Mesothelioma treatment often involves multiple therapies. Options include surgery, chemotherapy, immunotherapy, radiation therapy, or a combination of these.

Treatment isn't focused only on reducing or destroying the cancer. There are also therapies for reducing mesothelioma symptoms and for the side effects of treatment itself.

Different treatments are recommended for different stages and subtypes of mesothelioma.

For people with early-stage mesothelioma, treatment may begin with surgery to remove most or all of the tumor, followed by chemotherapy combined with other therapies to catch any cancer cells that surgery left behind. Or, your doctors may recommend chemotherapy first, before surgery. Both options are reasonable.

For people with advanced-stage mesothelioma, treatment often begins with chemotherapy or immunotherapy.

This chapter explains early-stage treatment. To read about advanced-stage treatment, turn to [Chapter 5](#).

If you have an earlier stage of mesothelioma (stages 1 to 3) as well as the epithelioid subtype, surgery may be a good option to remove the tumor. Having good health and being relatively younger (below age 65) also improves the likelihood of surgery as an option.

If surgery can't remove most of the tumor, or you choose not to have surgery, then you may receive treatment with chemotherapy, immunotherapy, radiation, or a combination of these.

If your doctors think the cancer can be removed by surgery, then you'll have more tests. To learn about these tests, see [Guide 3](#).

These tests are done for a few reasons:

- To see how far the cancer has spread
- To make sure your body can handle the procedure
- To plan surgery

Surgery

The goal of mesothelioma surgery is to remove every part of the tumor that can be found. Surgery alone is not considered a cure because some microscopic cancer cells will always be left behind. However, when surgery is combined with systemic therapy or radiation therapy, cure can be achieved in some patients.

Guide 3

Recommended tests before surgery

Pulmonary function tests	Pulmonary function tests show how well your lungs are working. These include tests to measure how fast you can exhale air from your lungs, how much air your lungs can hold, how well oxygen gets into your blood, and more.
Perfusion scanning, if needed	Perfusion scanning shows the blood flow in and out of your lungs. You may have this test if your pulmonary function tests suggest your lungs aren't working well.
PET/CT scan	A PET/CT scan uses two imaging tests together: computed tomography (CT) and PET (positron emission tomography). PET/CT scanning helps find mesothelioma that has spread to lymph nodes or other organs.
Mediastinoscopy	A mediastinoscopy is a surgical biopsy of the lymph nodes in the area in between the lungs. This space is called the mediastinum. A viewscope is inserted through a small surgical cut just above your breastbone and guided down to the mediastinum. Looking through the viewscope, the surgeon uses a long tool to remove lymph node samples for biopsy.
Endobronchial fine-needle aspiration	An endobronchial fine-needle aspiration is another way to perform a biopsy of the mediastinal lymph nodes. But it doesn't require any surgery. A viewscope attached to an ultrasound device is guided down your throat into your lungs. The device has a very thin needle that extends into the mediastinum to take the biopsy sample.
Cardiac stress test	This test measures how well your heart works during exercise. Some heart problems are easier to find when your heart is working hard.
Performance status	Performance status is an evaluation of your overall health and your ability to do day-to-day activities. Doctors measure performance status to get a sense of the degree of treatment you may be able to handle.
Chest MRI, if needed	MRI is an imaging test that uses radio waves and powerful magnets. An MRI scan of your chest is another way to see if the cancer has spread to your chest wall, spine, diaphragm, or blood vessels. This information can help guide surgery to remove mesothelioma tumors.
VATS or laparoscopy, if needed	These two types of surgeries are used to get a better look inside your chest. One or both of these tests are used if imaging scans show that mesothelioma has affected the pleuras of both lungs or the lining of the belly area (abdomen).

Surgery should be performed by a thoracic surgeon who has experience with mesothelioma. A thoracic surgeon is an expert at operating on organs inside the chest.

There are two types of surgery for mesothelioma:

- **Pleurectomy/decortication (P/D)** removes the tumor and the pleura without removing the lung. Sometimes the pericardium (the lining around the heart) and part of the diaphragm are also removed.
- **Extrapleural pneumonectomy (EPP)** removes both pleural layers and the lung. This procedure may also remove part of the diaphragm and often the pericardium.

Your doctors will consider a number of factors before recommending which operation is best for you. These factors include your overall health, performance status, symptoms, cancer stage, and the cell subtype of the mesothelioma.

Sometimes, the surgeon will have to begin operating first to see what's going on inside your chest before deciding which surgery is the most appropriate one for you.

If the surgeon looks inside your chest and decides that no surgery is the right option, you may still have treatment with chemotherapy, immunotherapy, or radiation therapy (or a combination) after you recover from the operation.

Surgery has risks and benefits. EPP is more aggressive than P/D at removing tumor tissues. However, P/D is less invasive and has fewer risks of complications. Your doctors will

Before you start any treatment, let your doctors know what medicines you're taking, including vitamins, over-the-counter supplements, or complementary therapies. These might have an effect on your treatment.

talk to you about how the risks compare to the benefits in your particular case.

In either surgery, you'll have to stay in the hospital for the operation. You'll be given general anesthesia, which means you'll be asleep and feel no pain during the surgery. You'll be positioned on your side on the operating table. The surgeon will make a cut into the side of your chest. Your ribs will be spread or one rib will be partly removed to make an opening wide enough to take out the pleura, pieces of tumor, lung, or other necessary tissues.

The surgeon will also take samples of the lymph nodes in between your lungs (mediastinum). This is done to find out if the cancer has spread to the lymphatic system.

You'll be given time to recover after the surgery. However, you'll likely have other therapies after surgery. Chemotherapy may be given either before or after surgery.

Surgical complications

A surgical complication is an unwanted or unexpected result of an operation. Every surgery has risks of complications. Let your treatment team know if you have any symptoms after the surgery, such as:

- Racing or irregular heartbeat
- Shortness of breath
- Persistent cough
- Fever
- Bleeding

These could be signs of a complication. Surgical complications can be successfully treated, especially if caught early.

Systemic therapy

A treatment that affects the whole body is called systemic therapy. Systemic drugs for cancer travel throughout the body to find tumor cells. The main systemic therapy for cancer is chemotherapy (“chemo”).

Chemotherapy is the use of drugs to kill cancer cells. Chemotherapy damages rapidly dividing cells throughout the body. Because cancer cells divide and multiply rapidly, they’re a good target for chemotherapy. Chemotherapy can harm healthy cells, too. That’s why chemotherapy can cause side effects.

You may receive chemotherapy either before or after surgery, or by itself. Chemotherapy is done before surgery to shrink the tumor, which makes it easier to remove the tumor during surgery. Chemotherapy given after surgery is meant to “clean up” any cancer cells that were

left behind after the procedure. Chemotherapy is also given by itself without surgery.

How is it given?

Chemotherapy treatment for mesothelioma usually involves a mix of liquid drugs, which are given intravenously. This means they’re injected slowly into a vein in your arm or another part of your body (IV infusion). The drugs travel in the bloodstream to reach cancer cells throughout the body.

You’ll sit in a chair or bed at the hospital or clinic while receiving the medicine or medicines. A treatment session can last from a few minutes to a few hours. A chemotherapy treatment session for mesothelioma usually involves an infusion of one medicine followed by an infusion of another medicine.

How often will I have it?

Chemotherapy is given in cycles of treatment days. One cycle may include treatment given once a week or once every few weeks, followed by days or weeks of rest. This rest period allows the body to recover before the next treatment cycle. Cycles vary in length depending on which drugs are used.

What drug is it?

For mesothelioma, the preferred systemic therapy is a combination of pemetrexed and cisplatin.

Pemetrexed is a chemotherapy drug that helps prevent cancer cells from growing. It’s also used to treat people with lung cancer. Cisplatin is a chemotherapy drug that contains platinum. Platinum-based chemotherapy drugs help stop cancer cells from multiplying. (If cisplatin might

Guide 4 First-line systemic therapy options

Treatment before or after surgery	<ul style="list-style-type: none"> • Pemetrexed + cisplatin*
Treatment without surgery	<ul style="list-style-type: none"> • Pemetrexed + cisplatin* + bevacizumab
	<ul style="list-style-type: none"> • Nivolumab + ipilimumab
Other treatment regimens used in certain cases	<ul style="list-style-type: none"> • Gemcitabine + cisplatin • Pemetrexed • Vinorelbine

* or carboplatin

Guide 5 Second-line systemic therapy options

<ul style="list-style-type: none"> • Pemetrexed
<ul style="list-style-type: none"> • Nivolumab with or without ipilimumab
<ul style="list-style-type: none"> • Vinorelbine
<ul style="list-style-type: none"> • Gemcitabine

cause excessive side effects, carboplatin will be used instead.)

The first treatment given is referred to as first-line therapy. In this case, it's pemetrexed and cisplatin. First-line therapy options can be found in [Guide 4](#).

If first-line therapy doesn't work or stops working, then another regimen can be given. This is called second-line therapy because it's the second treatment to be tried. The goal of second-line therapy is to stop the cancer from getting worse. Second-line options can be found in [Guide 5](#).

What if I don't have surgery?

As noted previously, people with early-stage mesothelioma may be given chemotherapy either before or after surgery. However, if surgery can't remove the tumor or if you choose not to have surgery, then you'd receive first-line treatment with chemotherapy, immunotherapy, radiation therapy, or a combination of therapies.

If you're not having surgery, the systemic regimen may include chemotherapy drugs (pemetrexed and cisplatin or carboplatin) plus a targeted therapy drug. A targeted therapy drug identifies and attacks a specific feature of cancer cells with less harm to normal cells. The targeted therapy drug used for mesothelioma is bevacizumab (Avastin).

Another systemic regimen is a combination of immunotherapy drugs. Immunotherapy drugs help a patient's own immune system fight the cancer. Immunotherapy drugs used

for mesothelioma are nivolumab (Opdivo) and ipilimumab (Yervoy).

Your medical oncologist will discuss your treatment options with you.

What are the side effects?

A side effect is an unpleasant or harmful physical or emotional response to treatment. The side effects of chemotherapy depend on many factors. These include the drug, the dose, the length of treatment, and the person. Some people have many side effects. Others have few.

Some side effects can be very serious. Many side effects aren't serious but are still unpleasant. Side effects often appear shortly after treatment starts and stop in the days or weeks after treatment is over. Other side effects are long-term or may even appear years later.

What is chemotherapy?

Chemotherapy ("chemo") is the use of drugs to kill cancer cells. The drug is often a liquid medicine that's infused (slowly injected) into your arm while you sit in a chair. Some people, like this man, receive chemo through a port implanted in their chest.



Common side effects of chemotherapy include:

- Nausea and vomiting
- Diarrhea
- Constipation
- Fever
- Mouth sores
- Not feeling hungry
- Hair loss
- Blood clots
- Low blood cell counts
- Feeling very tired or weak (fatigue)
- Hearing loss
- Numbness or tingling in fingers or toes (neuropathy)

Not all side effects of chemotherapy are listed here. And not everyone will experience all of these side effects. Ask your treatment team for a complete list of common and rare side effects. Tell your treatment team about any side effect you have. There are often ways to help you feel better. There are also ways to prevent side effects.

Radiation therapy

Radiation therapy uses high-energy rays to treat cancer. The rays damage a cell's DNA (its instructions for making and controlling cells). This damage either kills the cancer cells or stops new cancer cells from being made. Unlike a systemic therapy that affects the whole body, radiation therapy is considered a

What is a regimen?

A regimen is a plan that defines the dosage, schedule, and duration of a treatment.

local or regional therapy because it affects only the part of the body that's irradiated.

For people with early-stage mesothelioma (stages 1 to 3), radiation therapy can be used on its own or used with chemotherapy. When radiation therapy is used with chemotherapy, the treatments may be given one after another or sometimes at the same time.

Radiation therapy is sometimes given on its own simply to reduce pain or other symptoms.

Your treatment team will decide the best time for you to have radiation therapy. To plan your radiation treatment, you'll first have a CT scan in the treatment position. This is called a simulation. Your radiation plan will be tailored to your individual needs.

How is it given?

For radiation treatment, you'll lie on a table in the same position as you were during the simulation. Immobilization devices may be used to keep you from moving so that the radiation targets the exact tumor location.

You'll be alone while the radiology technician operates the machine from a nearby room. The technician will be able to see, hear, and speak with you through an intercom and video system.

A large machine will move around you as it delivers the radiation. The radiation beams will be aimed at the location of the tumor. The radiation oncologist will use your imaging to help guide the process.

As treatment is given, you may hear noises from the machine. You won't see, hear, or feel the radiation. It passes through your skin and other tissues to reach the cancer cells.

How often will I have it?

The total dose of radiation is spread out over a number of treatments (fractions). The number of treatments varies among people with mesothelioma. Treatments are usually given once a day, up to 5 days a week, for about 4

to 6 weeks. One treatment session can take about 15 to 30 minutes. Most of this time is spent getting you into position, with only a few minutes of actual radiation time.

Radiation can harm normal cells as well as cancer cells. Your radiation oncologist will use technology to reduce the radiation applied to the normal tissues surrounding the tumor.

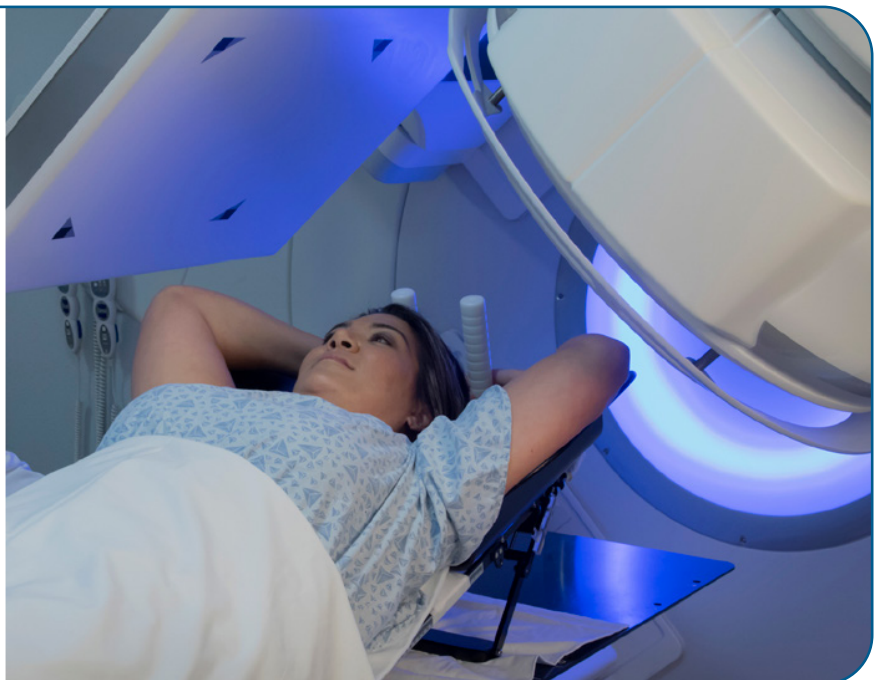
What are the side effects?

Radiation can cause side effects if it harms normal cells. Side effects may include:

- Feeling very tired or weak (fatigue)
- Not feeling hungry
- Reddened skin (like a sunburn)
- Difficulty swallowing
- Nausea
- Lung irritation

What is radiation therapy?

Radiation therapy is the use of high-energy radiation to kill cancer cells.



Ask your treatment team for a list of all the side effects of radiation therapy. Be sure to tell them if you have any side effects.

Clinical trial

Another avenue of treatment is a clinical trial. A clinical trial is a type of medical research study. After being tested in a laboratory, potential new ways of fighting cancer need to be studied in people. If found to be safe and effective in a clinical trial, a drug, device, or treatment approach may be approved by the U.S. Food and Drug Administration (FDA).

Participating in a clinical trial isn't a "last-ditch" effort. A clinical trial can be a first-line treatment option for many people with mesothelioma. Clinical trials give people access to options that they couldn't usually receive otherwise. Everyone with cancer should carefully consider all of the treatment options available for their cancer type, including standard treatments and clinical trials.

NCCN recommends that people with mesothelioma consider a clinical trial as their first-line therapy, if available. Talk to your doctors about whether a clinical trial is recommended for you.

Phases

Most cancer clinical trials focus on treatment. Treatment trials are done in phases.

- **Phase I trials** study the dose, safety, and side effects of a drug or treatment approach. They also look for early signs that the drug or approach is helpful.

- **Phase II trials** study how well the drug or approach works against a specific type of cancer.
- **Phase III trials** test the drug or approach against a standard treatment. If the results are good, it may be approved by the FDA.
- **Phase IV trials** study the long-term safety and benefit of an FDA-approved treatment.

Who can enroll?

Every clinical trial has rules for joining, called eligibility criteria. The rules may be about age, cancer type and stage, treatment history, or general health. These requirements ensure that participants are alike in certain ways in order to compare how they respond to a specific treatment.

Informed consent

Clinical trials are managed by a group of experts called a research team. The research team will review the study with you in detail, including its purpose and the risks and benefits of joining. All of this information is also provided in an informed consent form. Read the form carefully and ask questions before signing it.

Take time to discuss this with family, friends, or other people you trust. Keep in mind that you can leave and seek treatment outside of the clinical trial at any time without penalties.

Start the conversation

Don't wait for your doctor to bring up clinical trials. Start the conversation and learn about all of your treatment options. If you find a study that you may be eligible for, ask your treatment



Finding a clinical trial

In the United States NCCN Cancer Centers

[NCCN.org/cancercenters](https://www.nccn.org/cancercenters)

The National Cancer Institute (NCI)

[cancer.gov/about-cancer/treatment/clinical-trials/search](https://www.cancer.gov/about-cancer/treatment/clinical-trials/search)

Worldwide

The U.S. National Library of Medicine (NLM)

clinicaltrials.gov

Need help finding a clinical trial?

NCI's Cancer Information Service (CIS)

1.800.4.CANCER (1.800.422.6237)

[cancer.gov/contact](https://www.cancer.gov/contact)

team if you meet the requirements. If you've already started standard treatment, you may not be eligible for certain clinical trials. Try not to be discouraged if you can't join. New clinical trials are always becoming available.

Frequently asked questions

There are many myths and misconceptions surrounding clinical trials. The possible benefits and risks are not well understood by many people with cancer.

Will I get a placebo?

Placebos (inactive versions of real medicines) are hardly ever used alone in cancer clinical trials. It's common to receive either a placebo with a standard treatment or a new drug with a standard treatment. You'll be informed, verbally and in writing, if a placebo is part of a clinical trial before you enroll.

Are clinical trials free?

There's no fee to enroll in a clinical trial. The study sponsor pays for research-related costs, including the study drug. You may, however, have costs indirectly related to the trial, such as the cost of transportation or child care due to extra appointments. Depending on the trial, you may continue to receive standard therapy in addition to any experimental therapy. The standard therapy is billed to—and often covered by—insurance. You're responsible for copays and any costs for this care that aren't covered by your insurance.

Key points

- Mesothelioma treatment often involves multiple types of therapies.
- The goal of mesothelioma surgery is to remove every part of the tumor that can be seen or felt by the surgeon.
- Pleurectomy/decortication (P/D) removes the lining of the lung and chest wall without removing the lung.
- Extrapleural pneumonectomy (EPP) removes the lung and all of the pleural lining.
- Systemic therapy is a treatment that affects the whole body. Chemotherapy and immunotherapy are examples of systemic therapy.
- Local or regional therapy affects only a part of the body. Surgery and radiation are examples of local therapy.
- First-line therapy is the first treatment regimen given. If first-line therapy doesn't work or stops working, then a second line of therapy can be given.
- Chemotherapy is a type of systemic therapy that uses drugs to kill cancer cells. For mesothelioma, the preferred chemotherapy treatment to use with surgery is a combination of pemetrexed and cisplatin.
- Immunotherapy is a type of systemic therapy used to encourage a patient's immune system to kill cancer cells.
- Radiation therapy uses high-energy rays to kill cancer cells and stop new cancer cells from being made.
- Side effects are unpleasant or harmful physical or emotional responses to treatment.
- A clinical trial is a type of medical research study. It can be a first-line treatment option for people with mesothelioma.
- Clinical trials give people access to new treatment options that they usually couldn't receive otherwise.



If you smoke or vape

If you smoke tobacco or use e-cigarettes, it is very important to quit. Smoking can limit how well cancer treatment works. Smoking greatly increases your chances of having side effects during and after surgery. It also increases your chances of developing other cancers.

Nicotine is the chemical in tobacco that makes you want to keep smoking. Nicotine withdrawal is challenging for most smokers. The stress of having cancer may make it even harder to quit. If you smoke, ask your doctor about counseling and medicines to help you quit.

For online support, try these websites:

- [SmokeFree.gov](https://www.smokefree.gov)
- [BeTobaccoFree.gov](https://www.betobaccofree.gov)
- [CDC.gov/tobacco](https://www.cdc.gov/tobacco)



If something doesn't feel right—like you can't stop throwing up, you have pain that won't go away, or you're really short of breath—call your medical provider. Trust your gut. ”

– Heather, mesothelioma survivor

5

Treatment for advanced-stage mesothelioma

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Most people with mesothelioma are at an advanced stage (stage 3 or 4) when they're diagnosed. People with advanced-stage mesothelioma have fewer treatment options than people with early-stage mesothelioma.

Though there are fewer treatment options for advanced-stage mesothelioma, treatment may still prolong and improve life. Treatment for advanced-stage mesothelioma depends a lot on performance status.

Performance status

Performance status is a measure of overall health and the ability to do ordinary activities. It represents how well a person can endure a demanding therapy. For people with advanced-stage mesothelioma, performance status is a main factor that determines their next steps:

- **Good performance status.** People with good or very good performance status will either take a watch-and-wait strategy (called observation) or be treated with systemic therapy.
- **Poor performance status.** People with poor or very poor performance status may not benefit from surgery or other treatment and may do better with supportive care. Supportive care is given to ease pain or discomfort. For more about supportive care, see [Chapter 6](#).

Consider quality of life

Quality of life is a term used often in cancer care. It refers to a person's overall enjoyment of life, including their sense of well-being and ability to participate in regular activities. In certain cases, aggressive cancer treatment may extend a person's life but reduce their quality of life. That's one example why quality of life should be an important consideration when making decisions about cancer treatment.

Observation

Observation is a watch-and-wait strategy. Because mesothelioma takes decades to develop, it may continue to grow very slowly after it has been found and won't need treatment right away in some people. This means you'll see your doctor often during this time but you won't receive any treatment unless you begin to have symptoms or until imaging, like a CT scan, shows that your mesothelioma is growing.

Observation works best for people with epithelioid mesothelioma who don't have symptoms and who have very little evidence of cancer on their CT scans. Discuss the risks and potential benefits of this approach with your oncologist.

Systemic therapy

Systemic therapy is treatment that affects the whole body. As mentioned previously, systemic therapy may be an option for people with advanced-stage mesothelioma. In these cases, the preferred systemic therapy is chemotherapy or a combination of immunotherapy drugs: nivolumab (Opdivo) and ipilimumab (Yervoy). This is called first-line therapy because it's the first treatment given.

Immunotherapy

What do immunotherapy drugs do?

Immunotherapy destroys cancer cells by using your own immune system. The immune system is your body's natural defense against infection and disease. Immunotherapy drugs improve your body's ability to find and attack cancer cells.

How is immunotherapy given?

Nivolumab and ipilimumab are given intravenously. This means they're injected slowly into a vein in your arm or another part of your body (IV infusion).

How often will I have immunotherapy?

You'll receive nivolumab once every 3 weeks and ipilimumab once every 6 weeks.

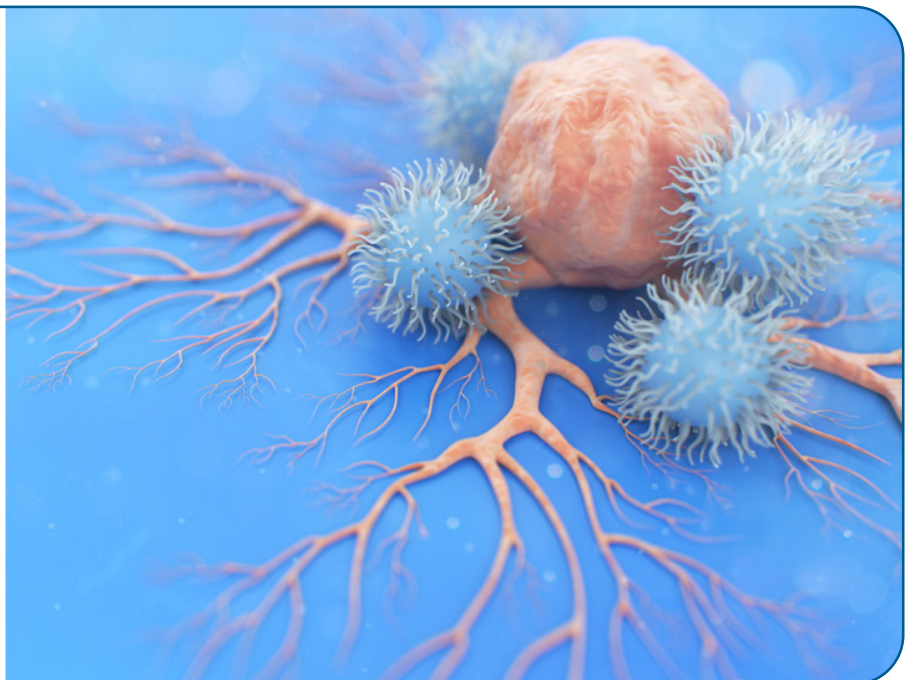
What are the side effects?

A side effect is an unpleasant or harmful physical or emotional response to treatment. The side effects of immunotherapy depend on factors like the drug, the dose, the length of treatment, and the person. Some people have many side effects. Others have few.

Some side effects can be very serious. Most aren't serious but are still unpleasant. Side effects often appear shortly after treatment

Immunotherapy

Immunotherapy takes advantage of the body's own immune defenses to attack cancer cells. Here, a cancer cell (large pink cell) is being destroyed by natural immune cells (spiky blue cells) that have been aided by immunotherapy drugs.



starts and stop in the days or weeks after treatment is over.

Common side effects of ipilimumab and nivolumab include:

- Feeling very tired or weak (fatigue)
- Pain in muscles, bones, or joints
- Skin rash or itching
- Diarrhea
- Nausea
- Shortness of breath
- Not feeling hungry
- Cough

Not all side effects of immunotherapy are listed here. And not everyone will experience all of these side effects. Ask your treatment team for a complete list of common and rare side effects. It's important that you tell your treatment team about any side effect you have. There are often ways to help you feel better. There are also ways to prevent side effects.

Chemotherapy

If the combination of immunotherapy drugs doesn't work or stops working, then a different systemic therapy may be given. This is called second-line therapy because it's the second therapy to be tried. The second-line therapy for people with advanced mesothelioma is often a combination of chemotherapy drugs: pemetrexed and cisplatin. (If cisplatin might cause excessive side effects, carboplatin will be used instead.)

Chemotherapy is the use of drugs to kill cancer cells. Chemotherapy damages rapidly dividing



Create a medical binder

A medical binder or notebook is a great way to organize all of your records in one place.

- Make copies of blood tests, imaging results, and reports about your specific type of cancer. It will be helpful when getting a second opinion.
- Choose a binder that meets your needs. Consider a zipper pocket to include a pen, small calendar, and insurance cards.
- Create folders for insurance forms, medical records, and tests results. You can do the same on your computer.
- Use online patient portals to view your test results and other records. Download or print the records to add to your binder.
- Take notes during your visits and keep a list of questions so you don't forget to ask them.
- Bring your medical binder to appointments. You never know when you might need it!

cells throughout the body. Because cancer cells divide and multiply rapidly, they're a good target for chemotherapy.

Chemotherapy treatment for mesothelioma usually involves a mix of liquid drugs. You'll sit in a chair or bed at the hospital or clinic while receiving the medicine. A treatment session can last from a few minutes to a few hours. Read more about chemotherapy (systemic therapy) on [page 36](#).

Response to treatment

During and after treatment, your doctors will want to know whether the treatment is working. Has it reduced the cancer? If it has, they'll want to know how much, if any, cancer is left. Doctors refer to this as "response to treatment."

To determine your response to treatment, you'll have more tests, like blood tests and CT scans. The point of these tests is to compare their results against the results of tests before you started treatment. The difference between the two rounds of testing indicates how well you've responded to the treatment.

There are four basic levels of response to treatment:

- **Complete response** means there are no signs or symptoms of cancer in the body.
- **Partial response** means signs and symptoms of cancer have decreased.
- **Stable disease** means the cancer hasn't shrunk but it also hasn't grown.

- **Progressive disease** means that the cancer is still growing. Progression can happen during therapy or after therapy. Progression indicates that it's time to try another strategy, including clinical trials. If you've tried all available treatments, then supportive care may be the right strategy for you.

Supportive care is treatment given to relieve symptoms of cancer, side effects of cancer treatment, and other related health issues. It's important to know that supportive care is available at any point during cancer care, not just at the end of life. For more about supportive care, turn to [Chapter 6](#).

Key points

- There are fewer treatment options for advanced-stage mesothelioma, but treatment may still prolong life and improve quality of life.
- Quality of life refers to a person's overall enjoyment of life, including their sense of well-being and ability to participate in regular activities.
- Performance status is a major factor in choosing treatment for advanced-stage mesothelioma.
- Immunotherapy uses your body's own immune system to destroy cancer cells.
- The preferred systemic therapy for people with advanced-stage mesothelioma is a combination of two immunotherapy drugs: nivolumab and ipilimumab.
- Response to treatment indicates how well the body reacts to therapy.
- Complete response means there are no signs or symptoms of cancer in the body.
- Progression means that the cancer is still growing even after treatment.



Take all your meds *as directed*, even if you think you don't need them—especially anti-nausea medicine. If you aren't nauseous, it means it's working. ”

– Heather, mesothelioma survivor

6

Supportive care and end-of-life concerns

52 What is supportive care?

54 What is advance care planning?

55 What is hospice care?

56 Key points



Supportive care is for the symptoms and side effects of mesothelioma, and also for psychological, social, and spiritual issues. During this time, some people with mesothelioma may start to think about end-of-life concerns. End-of-life care is about improving comfort and quality of life, not about focusing on death.

What is supportive care?

The main concern for most patients with cancer is to find treatment that works. Having cancer is not only about cancer treatment, though. Cancer care is a rollercoaster that includes many additional physical and emotional challenges. It's important to recognize and understand that you can get support for these challenges.

Supportive care is treatment to relieve the symptoms of mesothelioma, side effects of mesothelioma therapies, and other health issues related to the cancer. Supportive care also helps with psychological, social, and spiritual issues. Supportive care involves the whole person, not just their cancer.

Supportive care is given at any stage of disease, not just at end-of-life.

Supportive care addresses many needs. It can help with making treatment decisions. It can also assist with coordinating care between health providers. Notably, supportive care can help prevent or treat physical and emotional symptoms.

Supportive care can also help with spiritual support, advance care planning (which means deciding what you would want if you become too sick to make medical decisions for yourself), and end-of-life concerns.

It's important to talk openly with your treatment team about supportive care. You know your body better than anyone. Let your team members know:

- How you feel
- What you need
- What's working and what's not working

Ask questions and reach out if you need more information about your next steps.

Here are some of the common challenges you may face with mesothelioma, as well as some of the ways supportive care can help manage them:

Pleural effusion

Pleural effusion is the buildup of extra fluid in the pleural cavity. This can result in shortness of breath. One treatment for pleural effusion is a pleural catheter. A pleural catheter is a thin, flexible tube that's placed in your chest to drain the buildup of fluid in the pleural cavity.

Another treatment for pleural effusion is talc pleurodesis. Talc pleurodesis involves putting talc powder into the pleural cavity. The powder irritates the tissue and causes the two layers of pleura to fuse together while healing. This seals the pleural cavity and helps to stop fluid buildup.

Chest pain

Chest pain may be caused by cancer growing into the chest wall. Radiation therapy may be used to ease chest pain. Other ways to manage chest pain are with pain medications or chemotherapy.

Bronchial or esophageal obstruction

Mesothelioma can grow and cause an obstruction (blockage). An obstruction can block your airway or esophagus (the tube that connects your mouth to your stomach). If you feel you might have an obstruction, talk to your treatment team immediately. If this happens, radiation therapy may be used to try and shrink the tumor.

Nausea and vomiting

Nausea and vomiting are common cancer side effects. Nausea and vomiting can happen from the cancer itself, health problems caused by cancer, and from cancer treatment.

Some chemotherapy drugs and radiation therapy (to the upper abdomen) can cause these unwanted side effects. Your doctors can prescribe drugs to relieve nausea and vomiting. Other ways that might help include eating smaller meals, drinking plenty of water, or trying breathing exercises. Talk to your treatment team to ask about all the ways to help with nausea and vomiting.

Smoking cessation

Smoking can worsen your overall health and how well your lungs work. If you're a smoker, now is the time to quit. Quitting can help make treatment safer for you. Talk with your treatment team about ways to quit. You can also join a support group or talk to others who have quit.

Supportive care

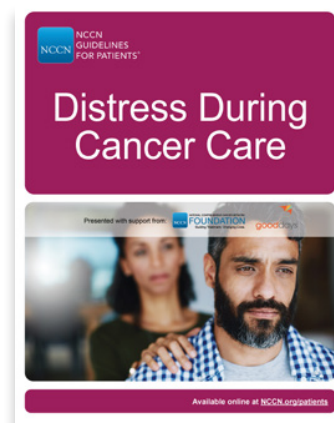
Supportive care—sometimes called palliative care—is given at any stage of disease, not just at the end of life. It involves the whole person, not just their cancer.



It's normal to feel worried

Depression, anxiety, fear, and distress are very common feelings in people with cancer. These feelings can make it harder to deal with cancer and cancer treatment. They can hold you back even when you want to move forward. Getting help when you're feeling worried or hopeless is an important part of cancer care. If you're feeling anxious or overwhelmed, ask your treatment team for help.

Read more about cancer and distress in *NCCN Guidelines for Patients: Distress During Cancer Care*, available at [NCCN.org/patientguidelines](https://www.nccn.org/patientguidelines).



Distress

Many patients with cancer experience symptoms of distress, such as anxiety and depression. You may feel anxious during testing, or you may experience depression during a hard part of treatment. Feeling distressed may be a minor problem but it can also be more serious. Serious or not, tell your treatment team so that you can get help. Help can include support groups, talk therapy, or medication. At your cancer center, cancer navigators, social workers, and other experts can help. Some people also feel better by exercising, talking with loved ones, or relaxing.

What is advance care planning?

When cancer is diagnosed very late or keeps progressing despite all treatment efforts, it may be time to set some new goals. If it becomes clear that cure is not possible, treatment becomes about making the most of your time and assuring that you can meet death on your own terms.

Advance care planning is all about making sure that your wishes are understood and respected. The focus is on you receiving the best possible care at the end of your life. Patients with incurable cancer can set up an advance care plan early on to feel less stressed and better able to cope with their condition.

The advance care planning process starts with an open and honest discussion with your doctor about your prognosis—what you may experience in the coming months—and the medications or therapies that may give you the best quality of life. Quality of life refers to a person's overall enjoyment of life, including their sense of well-being and ability to participate in regular activities.

This discussion should include your spouse or partner and other family members who love you and are likely to be with you at the end. It's important that everyone understands the goals of your care and your personal wishes about what should—and should not—be done.

Once you've made these decisions, you'll fill out a legal document that explains what you want to be done if you aren't able to tell the doctors yourself. This document is called an advance directive. Doctors are required to follow the care instructions in an advance directive when you are too ill to give instructions about your care.

Your advance directive should also identify a person who is authorized to make decisions on your behalf (health care proxy) if you can't communicate. This person may one day have to make some very tough decisions, so you should think carefully when selecting your proxy.

What is hospice care?

Hospice is a type of care designed to provide medical, psychological, and spiritual support for people who are close to the end-of-life as well as the people who love them. The goal is comfort, not a cure. Many insurance plans will only cover hospice services if your doctor has said that your life expectancy is 6 months or less and that you will not be receiving treatment designed to cure cancer.

Hospice care is all about your quality of life. Services can be provided in your home, a hospice facility, or even in the hospital. A major goal is to keep you pain-free and make sure that you can leave this world comfortably and with dignity. Hospice doctors, nurses, social workers, and chaplains are experts in helping patients work through the spiritual and emotional challenges of coping with the end of life.

Because hospice care is focused on making you as comfortable as possible, the hospice team may stop medications that aren't adding anything to your overall quality of life. The goal is to ensure that you don't have to take any more pills or injections than are absolutely necessary.

Providing support for family members is a major part of the hospice approach to end-of-life care. Most programs offer counseling and support groups for family members, including support after the patient has died. This is referred to as bereavement. It can be enormously comforting to know that your loved ones will have that kind of support after you're gone.

Key points

- Supportive care is treatment that involves the whole person, not just their cancer.
- Supportive care is given at any stage of disease, not just at the end of life.
- Nausea and vomiting are common cancer side effects. They can come from the cancer itself or from health problems caused by cancer or cancer treatment.
- If you smoke, ask for help with quitting.
- If you're feeling distressed, ask about ways to reduce anxiety or depression.
- Advance care planning is done to ensure that your end-of-life wishes are understood and respected.
- An advance directive is a legal document that explains your care if you're too ill to give instructions about it yourself.
- Hospice is care for people who are close to the end of life. It's focused on comfort and quality of life.



There's more hope now than there ever was. So don't give up. Don't take a diagnosis as a death sentence. There is hope. When hope is in the equation, the odds don't matter. ”

– Heather, mesothelioma survivor



We want your feedback!

Our goal is to provide helpful and easy-to-understand information on cancer.

Take our survey to let us know what we got right and what we could do better:

[NCCN.org/patients/feedback](https://www.nccn.org/patients/feedback)

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Making treatment decisions

58 It's your choice

59 Questions to ask your doctors

64 Online resources



It's important to be comfortable with the treatment you choose. This choice starts with having an open and honest conversation with your doctors.

It's your choice

In shared decision-making, you and your doctors share information, discuss the options, and agree on a treatment plan. It starts with an open and honest conversation between you and your doctor.

Treatment decisions are very personal. What's important to you may not be important to someone else. Some things that may play a role in your decision-making:

- What you want and how that might differ from what others want
- Your religious and spiritual beliefs
- Your feelings about certain treatments like surgery or chemotherapy
- Your feelings about pain or side effects such as nausea and vomiting
- Cost of treatment, travel to treatment centers, and time away from work
- Quality of life and length of life
- How active you are and the activities that are important to you

Think about what you want from treatment. Discuss openly the risks and benefits of specific treatments and procedures. Weigh options and share concerns with your doctor. If you make the effort to build a relationship with your doctor, it will help you feel supported when considering options and making treatment decisions.

Deciding on your treatment options

Choosing your treatment is a very important decision. It can affect your length and quality of life. But deciding which treatment option is best can be hard. Doctors from different fields of medicine may have different opinions on which option is best for you. This can be very confusing. Also, your spouse, partner, or family members may disagree with which option you want. That can be stressful. In some cases, one option hasn't been shown to work better than another.

Second opinion

People with cancer often want to get treated as soon as possible. They want to make their cancer go away before it spreads farther. While cancer can't be ignored, there's usually enough time to think about and choose which option is best for you.

You may completely trust your doctor, but a second opinion about which option is best can help. A second opinion is when another doctor reviews your test results and suggests a treatment plan. Copies of the pathology report, imaging, and other test results need to be sent to the doctor who's giving the second opinion. Some people feel uneasy asking for copies from their doctors. However, a second opinion is a normal part of cancer care. Even doctors get second opinions!

Some health plans even require a second opinion. If your health plan doesn't cover the cost of a second opinion, you have the choice of paying for it yourself.

If the two opinions are the same, you may feel more at peace about treatment. If the two opinions differ, think about getting a third opinion. A third opinion may help you decide between your options.

Things you can do to prepare for a second opinion:

- Check with your insurance company about its rules on second opinions. There may be out-of-pocket costs to see doctors who are not part of your insurance plan.
- Make plans to have copies of all your records sent to the doctor you will see for your second opinion.
- Compare benefits and downsides. Every option has benefits and downsides. Consider both when deciding which option is best for you. Talking to others can help identify benefits and downsides you haven't thought of. Scoring each factor from 0 to 10 can also help because some factors may be more important to you than others.

Questions to ask your doctors

Possible questions to ask your doctors are listed on the following pages. Feel free to use these questions or come up with your own. Be clear about your goals for treatment and find out what to expect from treatment.



Get group support

Many people with cancer find a lot of value in a support group. In support groups, you can ask questions and hear about the experiences of other people with cancer. Some people may be newly diagnosed, while others may be finished with treatment.

A support group can help with emotional and psychological needs. A support group can also be a good source of practical advice and helpful tips. People with common ground can share information on their experiences, financial and emotional burdens, coping strategies, and knowledge about research and treatments.

Ask your doctors or supportive care team about finding a mesothelioma or cancer support community. Support groups can be found online and in-person groups are often available in larger communities.

Questions to ask about testing

1. Can this cancer be cured? If not, how well can treatment stop it from growing?
2. What tests will I have?
3. Will I have more than one biopsy?
4. How do I prepare for testing?
5. Where do I go to get tested? How long will the tests take? Will any test hurt?
6. How often are these tests wrong?
7. Should I bring someone with me?
8. Should I bring a list of my medications?
9. How soon will I know the results and who will explain them to me?
10. Would you give me a copy of the pathology report and other test results?
11. Who will talk with me about the next steps? When?
12. Who can I call if I need help immediately?
13. Can I get a second opinion? Who would you recommend I see for a second opinion?

Questions to ask about treatment options

1. What are my treatment options? Are you suggesting options from the NCCN Guidelines, or have you modified the standard approach in my situation?
2. How many patients with mesothelioma have you treated?
3. Will the treatment hurt?
4. What will happen if I do nothing?
5. How do my age, overall health, and other factors affect my options?
6. Does any option offer a cure or long-term cancer control? Are my chances any better for one option than another? Less time-consuming? Less expensive?
7. Do your suggested options include clinical trials?
8. How do you know if my treatment is working, and how long does it usually take?
9. What are my options if treatment stops working?
10. What are the possible complications? What are the short- and long-term side effects of treatment?
11. How will treatment affect me? Will my hair fall out?
12. How soon will I need to make my treatment decisions?
13. What can be done to prevent or relieve the side effects of treatment?
14. Can I stop treatment at any time? What will happen if I stop treatment?

Questions to ask about getting treatment

1. Do I have to go to the hospital or elsewhere? How often? How long is each visit?
2. What do I need to think about if I will travel for treatment?
3. Do I have a choice of when to begin treatment? Can I choose the days and times of treatment?
4. How do I prepare for treatment? Do I have to stop taking any of my medicines? Are there foods I should avoid?
5. Should I bring someone with me when I get treated?
6. How much will the treatment cost me? What does my insurance cover? Are there any grants available to me?
7. Will I miss work or school? Will I be able to drive?
8. Who can I call on weekends or non-office hours if I have an urgent problem with my cancer or my cancer treatment?
9. Is home care after treatment needed? If yes, what type?
10. Will I be able to manage my own health?
11. Will I be able to return to my normal activities? If so, when?
12. What supportive care services are available for me and those taking care of me during and after treatment?

Online resources

American Cancer Society (ACS)
cancer.org/cancer/malignant-mesothelioma.html

American Lung Association
lung.org/lung-health-diseases/lung-disease-lookup/mesothelioma

Asbestos Disease Awareness Organization
asbestosdiseaseawareness.org

CancerCare
cancercares.org

Cancer Hope Network
cancerhopenetwork.org

Cancer Support Community
cancersupportcommunity.org

Center to Advance Palliative Care
getpalliativecare.org

National Cancer Institute (NCI)
cancer.gov/types/mesothelioma

National Hospice and Palliative Care Organization
caringinfo.org

NCCN Patient and Caregiver Resources

[NCCN.org/patientresources/patient-resources/support-for-patients-caregivers](https://www.nccn.org/patientresources/patient-resources/support-for-patients-caregivers)

U.S. National Library of Medicine Clinical Trials Database

clinicaltrials.gov



With the help of trusted organizations, you can find and learn about treatments that are best suited for you. From my experience, finding trusted organizations may be made easier with the help of other patients who have been treated successfully and can steer you toward those groups. Patients who share best practices can also help you understand what decisions you need to make. ”

– Bill, mesothelioma patient



Words to know

advance care planning

The process of deciding what you would want if you become too sick to make medical decisions for yourself.

asbestos

A group of naturally occurring minerals found in rocks and soil and used for many industrial and commercial products. It is the main cause of mesothelioma.

biopsy

A procedure that removes tissue or fluid samples to be tested for disease.

chemotherapy

Cancer drugs that stop the cell life cycle so cells don't increase in number.

clinical trial

A type of research that assesses investigational tests or treatments in people.

computed tomography (CT)

A test that uses x-rays from many angles to make a picture of the inside of the body.

diagnosis

The identification of an illness based on tests.

first-line therapy

The first type of treatment given for a condition or disease. First-line therapy is the one considered to be the best treatment.

genetic abnormality (mutation)

An abnormal change in the genetic code (DNA) of a gene within cells.

genetic test

A lab test that looks for abnormal changes in the coded instructions within cells.

histology

The study of cell and tissue structures viewed under a microscope.

imaging

A test that makes pictures (images) of the insides of the body.

immune system

The body's natural defense against infection and disease.

immunohistochemistry

A lab test of cancer cells to find specific cell traits involved in abnormal cell growth.

immunotherapy

A drug treatment that helps a patient's own immune system find and destroy cancer cells.

infusion

A method of giving drugs slowly through a needle into a vein.

lymph node

A small, bean-shaped, disease-fighting structure in the immune system.

lymphatic system

A network of organs and vessels that fights infections and transports a fluid called lymph.

malignant pleural mesothelioma

A rare cancer that develops in the thin layers of tissue that surround the lungs. Often simply called mesothelioma.

multidisciplinary care

A treatment method where doctors, specialists, and other health providers work and communicate as a team to provide expert care for the patient.

observation

A period of watching for cancer growth or occurrence while not receiving treatment.

palliative therapy

Health care that includes symptom relief but not cancer treatment. Also sometimes called supportive care.

pathologist

A doctor who specializes in testing cells and tissue to find disease.

performance status

A rating of a person's overall health and ability to do ordinary activities.

pleura

Two thin layers of tissue that surround and protect the lungs and the inside of the chest.

pleural effusion

An unusual buildup of extra fluid in the pleural cavity.

pleural thickening

Widespread scarring of the tissue surrounding the lungs (pleura).

prognosis

The likely course and outcome of a disease based on tests and response to treatment.

progressive disease

The growth or spread of cancer after being tested or treated.

quality of life

The state of a person's overall enjoyment of life, including their sense of well-being and ability to participate in regular activities.

radiation therapy

A treatment that uses high-energy rays (radiation) to kill cancer cells.

regimen

A plan that defines the dosage, schedule, and duration of a treatment.

risk factor

Something that increases the chance of getting a disease.

second-line therapy

The second type of treatment given if the first treatment doesn't work or stops working.

second opinion

An evaluation of a patient's diagnosis or treatment given by a doctor who isn't the patient's current doctor.

secondary exposure

An exposure to asbestos that occurs when family members or others come into contact with asbestos fibers brought home on work clothes or other workplace items.

side effect

An unhealthy or unpleasant physical or emotional response to treatment.

staging

The process of rating the extent of cancer in the body.

supportive care

Health care for the symptoms of cancer or the side effects of cancer treatment. Also sometimes called palliative care.

symptom

A feeling or problem that can indicate a disease or condition.

systemic therapy

A treatment (such as chemotherapy) that affects the whole body.

treatment response

An evaluation of how well the body reacts to a therapy.

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This patient guide is based on the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®) for Malignant Pleural Mesothelioma, Version 1.2022. It was adapted, reviewed, and published with help from the following people:

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NCCN Cancer Centers

Abramson Cancer Center
at the University of Pennsylvania
Philadelphia, Pennsylvania
800.789.7366 • penncancer.org/cancer

Case Comprehensive Cancer Center/
University Hospitals Seidman Cancer
Center and Cleveland Clinic Taussig
Cancer Institute
Cleveland, Ohio
800.641.2422 • UHSeidmanCancerCenter.org/services/cancer-services
866.223.8100 • [CC Taussig Cancer Institute my.clevelandclinic.org/departments/cancer](http://CCTaussigCancerInstitute.org/my.clevelandclinic.org/departments/cancer)
216.844.8797 • [Case CCC case.edu/cancer](http://CaseCCC.case.edu/cancer)

City of Hope National Medical Center
Los Angeles, California
800.826.4673 • cityofhope.org

Dana-Farber/Brigham and Women's
Cancer Center | Massachusetts General
Hospital Cancer Center
Boston, Massachusetts
617.732.5500 • youhaveus.org
617.726.5130
massgeneral.org/cancer-center

Duke Cancer Institute
Durham, North Carolina
888.275.3853 • dukecancerinstitute.org

Fox Chase Cancer Center
Philadelphia, Pennsylvania
888.369.2427 • foxchase.org

Fred & Pamela Buffett Cancer Center
Omaha, Nebraska
402.559.5600 • unmc.edu/cancercenter

Fred Hutchinson Cancer
Research Center/Seattle
Cancer Care Alliance
Seattle, Washington
206.606.7222 • seattlecca.org
206.667.5000 • fredhutch.org

Huntsman Cancer Institute
at the University of Utah
Salt Lake City, Utah
800.824.2073 • huntsmancancer.org

Indiana University
Melvin and Bren Simon
Comprehensive Cancer Center
Indianapolis, Indiana
www.cancer.iu.edu

Mayo Clinic Cancer Center
Phoenix/Scottsdale, Arizona
Jacksonville, Florida
Rochester, Minnesota
480.301.8000 • Arizona
904.953.0853 • Florida
507.538.3270 • Minnesota
mayoclinic.org/cancercenter

Memorial Sloan Kettering
Cancer Center
New York, New York
800.525.2225 • mskcc.org

Moffitt Cancer Center
Tampa, Florida
888.663.3488 • moffitt.org

O'Neal Comprehensive
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Birmingham, Alabama
800.822.0933 • uab.edu/onealcancercenter

Robert H. Lurie Comprehensive Cancer
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Chicago, Illinois
866.587.4322 • cancer.northwestern.edu

Roswell Park Comprehensive
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Siteman Cancer Center at Barnes-
Jewish Hospital and Washington
University School of Medicine
St. Louis, Missouri
800.600.3606 • siteman.wustl.edu

St. Jude Children's
Research Hospital/
The University of Tennessee
Health Science Center
Memphis, Tennessee
866.278.5833 • stjude.org
901.448.5500 • uthsc.edu

Stanford Cancer Institute
Stanford, California
877.668.7535 • cancer.stanford.edu

The Ohio State University
Comprehensive Cancer Center -
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Solove Research Institute
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800.293.5066 • cancer.osu.edu

The Sidney Kimmel Comprehensive
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www.hopkinskimmelcancercenter.org

The University of Texas
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Houston, Texas
844.269.5922 • mdanderson.org

UC Davis
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Sacramento, California
916.734.5959 • 800.770.9261
health.ucdavis.edu/cancer

UC San Diego Moores Cancer Center
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858.822.6100 • cancer.ucsd.edu

UCLA Jonsson
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Los Angeles, California
310.825.5268 • cancer.ucla.edu

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San Francisco, California
800.689.8273 • cancer.ucsf.edu

University of Colorado Cancer Center
Aurora, Colorado
720.848.0300 • coloradocancercenter.org

University of Michigan
Rogel Cancer Center
Ann Arbor, Michigan
800.865.1125 • rogelcancercenter.org

University of Wisconsin
Carbone Cancer Center
Madison, Wisconsin
608.265.1700 • uwhealth.org/cancer

UT Southwestern Simmons
Comprehensive Cancer Center
Dallas, Texas
214.648.3111 • utsouthwestern.edu/simmons

Vanderbilt-Ingram Cancer Center
Nashville, Tennessee
877.936.8422 • vicc.org

Yale Cancer Center/
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855.4.SMILOW • yalecancercenter.org

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Suvarna Hospital (Borivali):

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