



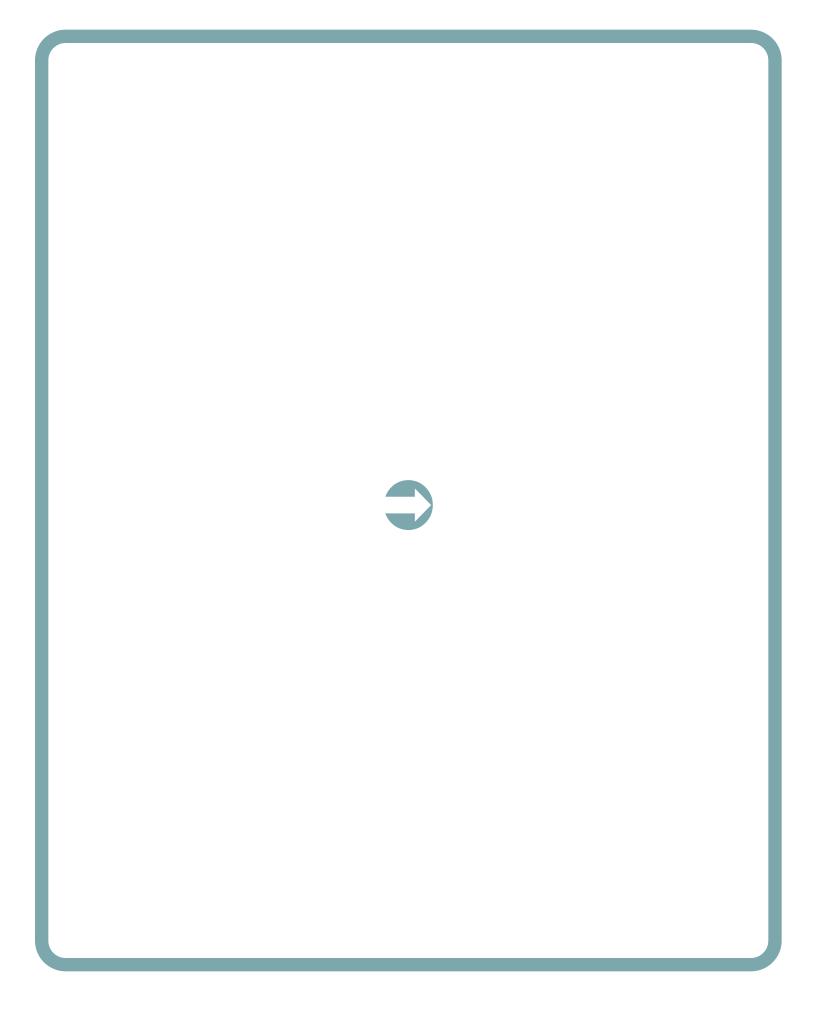
Pleural Mesothelioma



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About the NCCN Guidelines for Patients®



National Comprehensive Cancer Network®

Did you know that top cancer centers across the United States work together to improve cancer care? This alliance of leading cancer centers is called the National Comprehensive Cancer Network[®] (NCCN[®]).



Cancer care is always changing. NCCN develops

evidence-based cancer care recommendations used by health care providers worldwide. These frequently updated recommendations are the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®). The NCCN Guidelines for Patients plainly explain these expert recommendations for people with cancer and caregivers.

These NCCN Guidelines for Patients are based on the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines[®]) for Mesothelioma: Pleural Version 2.2025 — January 14, 2025.

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Contents

- 4 About pleural mesothelioma
- 8 Testing for mesothelioma
- 15 Treating mesothelioma
- 25 Improving life with supportive care
- 30 Other resources
- 33 Words to know
- 35 NCCN Contributors
- 36 NCCN Cancer Centers
- 38 Index

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1

About pleural mesothelioma

- 5 What is pleural mesothelioma?
- 5 How is mesothelioma found?
- 6 How is mesothelioma treated?
- 7 What can you do to get the best care?

Learning you have mesothelioma can be frightening and overwhelming. Mesothelioma is a cancer that is challenging to treat. This book describes the best options for treatment to help you make well-informed decisions.

What is pleural mesothelioma?

Pleural mesothelioma is a cancer that develops in the thin layers of tissue that surround the lungs.

The term pleural mesothelioma requires more explanation, though. Let's break it down to figure out exactly what it means:

Pleural – This word refers to the pleura. The pleura is a tissue that surrounds each lung. It has 2 thin layers made of mesothelium and connective tissue. There is fluid between the pleural layers that lets them slide easily against one another. This sliding ability allows the lungs to move smoothly during breathing.

Mesothelioma – A mesothelioma is a cancer of cells from the mesothelium. The pleural mesothelium is a thin but strong membrane that surrounds the lungs. The cancer cells grow out of control and may become a tumor. They also may spread to other areas of the body. The pleural mesothelium is not the only mesothelium in the body. There are other areas of mesothelium, so there are other types of mesothelioma. Pleural mesothelioma is the most common type.

From this point on, we'll refer to pleural mesothelioma in this book simply as mesothelioma.

How is mesothelioma found?

Mesothelioma is usually found after a person develops certain symptoms. Some common symptoms are shortness of breath, chest wall pain, fever, extreme tiredness, and unexplained weight loss.

Diagnosing mesothelioma can be a lengthy and worrisome experience. Because mesothelioma is rare, it can be mistaken for other conditions that are more common.

Mesothelioma is also difficult to distinguish from other cancers. That's why your care team will request several tests to learn about the cancer you have.

The tests needed to confirm mesothelioma and plan treatment are discussed in *Chapter 2: Testing for mesothelioma*.

How is mesothelioma treated?

The most common treatment for mesothelioma is prescribed drugs called systemic therapy. These drugs treat cancer throughout the body, including cancer that's in hard-to-reach places and in many places. Treatment may continue, off and on, for the rest of your life.

There's no single treatment plan that's best for everyone. Some people don't start treatment right away. Systemic therapy differs between people. And certain types of treatments may be used with systemic therapy to improve results. Learn about your treatment options in *Chapter 3: Treating mesothelioma.*

People with mesothelioma face many challenges. They often have distressing symptoms from the cancer and treatment. Many also have spiritual, emotional, and social concerns. It's important to tell your team about the challenges you face and get the supportive care you need. More information is in *Chapter 4: Improving life with supportive care.*

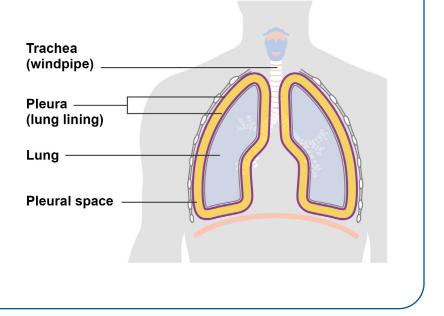
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I think the absolute best thing you can do as a mesothelioma patient is seek out the oncologists who specialize in this field. Pick their brains, ask questions, ask more questions, and get comfortable with their expertise leading the plan. Stay involved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

The pleura

The pleura is made of two layers of mesothelium tissue. The inner layer (the visceral pleura) covers the lung. 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 that's filled with fluid.

Credit: Cancer Research UK, CC BY-SA 4.0, via Wikimedia Commons



What can you do to get the best care?

Advocate for yourself. You have an important role to play in your care. In fact, you're more likely to get the care you want by asking questions and making shared decisions with your care team.

The NCCN Guidelines for Patients will help you understand cancer care. With better understanding, you'll be more prepared to discuss your care with your team and share your concerns. Many people feel more satisfied when they play an active role in their care.

You may not know what to ask your care team. That's common. Each chapter in this book ends with an important section called *Questions to ask*. These suggested questions will help you get more information on all aspects of your care.

Take the next step and keep reading to learn what is the best care for you!

Why you should read this book

Making decisions about cancer care can be stressful. You may need to make tough decisions under pressure about complex choices.

The NCCN Guidelines for Patients are trusted by patients and providers. They clearly explain current care recommendations made by respected experts in the field. Recommendations are based on the latest research and practices at leading cancer centers.

Cancer care is not the same for everyone. By following expert recommendations for your situation, you are more likely to improve your care and have better outcomes as a result. Use this book as your guide to find the information you need to make important decisions.

2 Testing for mesothelioma

- 9 Reasons to suspect mesothelioma
- 10 Confirming mesothelioma
- 12 Types of mesothelioma
- 13 Planning treatment
- 14 Key points
- 14 Questions to ask

This chapter explains the variety of tests used to confirm mesothelioma and plan treatment. Testing will show how much cancer there is and correctly identify the type of cancer.

Reasons to suspect mesothelioma

Asbestos is the main cause of mesothelioma. Most people with mesothelioma have been around or worked with asbestos.

Yet some people with mesothelioma haven't had any contact with asbestos that they're aware of. This suggests that there are other causes of mesothelioma.

Your care team will suspect mesothelioma if you have pleural effusion or thickening.

Pleural effusion

Fluid that builds up around the lung is called pleural effusion. This excess fluid puts pressure on the lungs, making it more difficult to breathe. Other symptoms are cough and chest pain.

Pleural effusion is often the earliest sign of asbestos-related disease. However, not everyone who has pleural effusion will have mesothelioma.

How asbestos is linked to mesothelioma

Asbestos is a group of naturally occurring minerals. It's found in rocks and soil in many parts of the world.

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. Workers who use, install, or remove asbestos as part of their jobs are much more likely to get mesothelioma than other workers.

Asbestos can break into tiny pieces that can become airborne. These particles can be inhaled or even swallowed. In the lungs, some of the fibers travel to the lining of the lungs called the pleura. Asbestos will irritate the tissue and cause swelling and scarring.

Many scientists think asbestos causes changes in pleural cells, which result in cancer.

These changes don't happen quickly. Mesothelioma develops over many years, even decades.

Pleural thickening

Pleural thickening is what happens when there's widespread scarring of the pleural tissue. Asbestos is one cause of pleural thickening. Over time, the irritation and inflammation caused by asbestos in the pleura creates scar tissue.

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.

Confirming mesothelioma

Several steps are required to reach a final diagnosis of mesothelioma. Testing begins with an examination of your general health and an evaluation of your symptoms.

Health history

Your care team needs to have all of your health information. They'll ask you about health issues and treatments you've had.

Mesothelioma mainly occurs in people who've been exposed to asbestos. You'll be asked whether you've worked with asbestos or lived with someone who worked with asbestos.

Physical exam

A team member will also perform a thorough physical exam of your body. This allows your

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.



team to look for any signs of cancer and assess your overall health.

CT scan of the chest

If your symptoms suggest mesothelioma, you'll need to have computed tomography (CT) of the chest. A CT scan creates pictures (images) of the insides of the body. It's a more detailed kind of x-ray.

You'll receive an injection of contrast if it's safe for you. Contrast is a substance that makes images clearer.

After the scan, your images will be studied by a thoracic radiologist. A thoracic radiologist is an expert in reading images of inside the chest.

A CT can show if you have pleural effusion or pleural thickening. It can also detect tumors.

Your team will see where tumors have formed and the size of the tumors.

Blood test

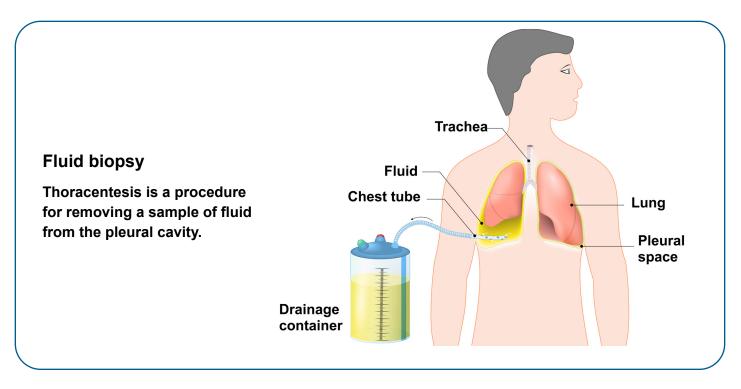
Mesothelioma cells release molecules called soluble mesothelin-related peptides into the bloodstream. Although not done often, a sample of your blood may be tested for these molecules to help with diagnosis.

Biopsy of pleural fluid or tissue

A biopsy is a procedure that removes a small amount of fluid or tissue for testing. If your CT scan shows excess pleural fluid or a mass, your team will want to take a sample of the fluid or the tissue.

Fluid biopsy

Taking fluid out of the pleural space is called a thoracentesis. After your skin is cleaned and



numbed, a needle will be inserted between your ribs into your chest to get the fluid.

Tissue biopsy

A pleural biopsy is when samples of pleural tissue are removed. A pleural biopsy can be done in several ways:

- A thoracoscopic biopsy removes tissue with medical tools inserted through small cuts made in the chest. A thoracoscopic biopsy is preferred over other methods because it can obtain enough tissue for an accurate diagnosis.
- An image-guided core biopsy uses a CT scan or ultrasound to guide a needle through your skin and into a tumor. The needle will remove samples of tissue.
- An open biopsy involves making a large cut into your chest through which the surgeon can see and remove tissue.

Lab tests

The biopsy samples will be sent to a lab for testing by a pathologist. A pathologist is an expert in tissue and cells and confirming cancer.

Because mesothelioma is hard to identify, several tests will be performed:

- The pathologist will use a microscope to examine the biopsy samples. The size, shape, and structure of the cells can tell the pathologist whether there is cancer and its outlook.
- The pathologist will use a lab method called immunohistochemistry to identify the type of cancer. Immunohistochemistry

detects specific proteins linked with mesothelioma and its outlook.

 Cytogenetic and molecular testing looks for abnormal changes in the genes of cells. These tests can lead to a more precise prognosis.

The results of lab tests used for diagnosis are recorded in a pathology report.

Types of mesothelioma

Mesothelioma affects more than one type of pleural cell. Knowing the cell type of your cancer is important because sometimes treatment options differ between them. The cell types of mesothelioma are:

- Epithelioid is the most common subtype of mesothelioma. Epithelioid cells are uniform and arranged in organized patterns.
- Sarcomatoid is the least common subtype. Sarcomatoid cells are rodshaped and found in disorganized patterns.
- The **biphasic** subtype has a mix of epithelial cells and sarcomatoid cells.

Planning treatment

Your care team will plan treatment using diagnostic tests and the tests in this section. A list of common tests for mesothelioma is in **Guide 1.**

They'll need to know how far the mesothelioma has grown and spread in your body. This is called cancer staging.

After testing is completed, your team will explain the results to you and what they recommend for cancer care.

Performance status

Performance status is your ability to do day-today activities. It's based on your health history and physical exam. Your team will use your performance status to decide if your body can endure intense treatment.

CT scan of the chest and abdomen

To stage mesothelioma, a CT scan of your chest and abdomen is needed. Contrast should be used if it's safe for you.

Cancer stages

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. A lower number means the cancer has grown less, and a higher number means it has grown more.

Surgical evaluation

Surgery to remove the cancer is sometimes used to treat stage 1 epithelioid mesothelioma.

Guide 1

Common tests for mesothelioma

- · CT of the chest and abdomen with contrast
- Performance status evaluation
- Review of biopsy by pathologist, immunohistochemistry, cytogenetic testing, and molecular testing
- Thoracentesis and pleural biopsy

If surgery may be an option, you will need additional tests to confirm the cancer stage and learn more about your health. This evaluation may include:

Heart and lung tests

Your heart and lungs need to be healthy enough for surgery. Pulmonary function tests show how well your lungs are working. A cardiac stress test measures how well your heart works during exercise.

PET/CT and MRI scans

You'll have more scans to assess if the cancer has spread. Positron emission tomography (PET) combined with a CT scan is necessary. PET highlights tissue in your body that may be cancerous using a sugar radiotracer. You may have an MRI (magnetic resonance imaging) scan of the chest as well.

Biopsy of lymph nodes

When mesothelioma spreads, it usually travels to tiny structures, called lymph nodes, that are between your lungs. Your care team will biopsy these nodes using a thin scope that has a camera. The scope is guided down your throat or through a small cut into your body.

Biopsy methods include endobronchial ultrasound fine-needle aspiration (FNA), endoscopic ultrasound FNA, and mediastinoscopy.

Additional biopsies

Other biopsies may be done if your team suspects that cancer has spread to the other side of the chest or to your abdomen. Your team will biopsy inside your chest using videoassisted thoracoscopic surgery. To biopsy inside your abdomen, laparoscopy is needed.

Key points

- Asbestos is the main cause of mesothelioma.
- Excess fluid and scar tissue in the pleura are signs of mesothelioma.
- A CT scan can show if there are tumors and where they are located.
- To confirm mesothelioma, a sample of pleural fluid or tissue must be removed from your body and tested.
- The 3 types of mesothelioma are epithelioid, sarcomatoid, and biphasic.
- Your care team will plan treatment based on the cancer type and stage, and other factors.

Questions to ask

- What are the most common ways to be exposed to asbestos?
- Do the tests for mesothelioma have any risks?
- > Will I need to pay any costs for the tests?
- How can I get a copy of the test results in case I want a second opinion?
- What do I need to do to prepare for testing?



Treating mesothelioma

- 16 A team approach to care
- 16 Treatment options
- 17 What is systemic therapy?
- 18 First-line systemic therapy
- 21 Second-line systemic therapy
- 22 What is observation?
- 22 A surgical approach to treatment
- 22 What is a clinical trial?
- 24 Key points
- 24 Questions to ask

Treatment for mesothelioma varies from person to person. Your care team will work with you to plan the best treatment. Central to treatment is systemic therapy. It treats mesothelioma wherever it is in the body.

A team approach to care

NCCN recommends that a multidisciplinary team manage treatment of mesothelioma.

A multidisciplinary team is made up of specialists from different fields of medicine. By working together, the team brings the best knowledge from all sides to plan the best treatment.

Each member of your multidisciplinary team should have experience with mesothelioma, if possible.

Your team may include these experts:

- A medical oncologist treats cancer with drugs.
- A radiation oncologist treats cancer with radiation.
- A thoracic surgical oncologist removes cancer from the chest during an operation.
- A pulmonologist is an expert in lung diseases.

Many people also have team members who provide supportive care, which is discussed in *Chapter 4: Improving life with supportive care.*

You're an important part of the team. Your input will help shape your treatment plan.

Treatment options

Your team will assess which treatments of mesothelioma are options for you. They will plan treatment based on many factors, including your overall health.

Performance status

First, your team will assess if you are healthy enough to have cancer treatment. Treatment of mesothelioma can be tough on the body.

High scores of 3 or 4 on the Eastern Cooperative Oncology Group (ECOG) Performance Status system reflect poorer overall health. Cancer treatment may not be safe if your scores are high.

If treatment may seriously harm you, NCCN experts recommend only receiving supportive care. More information is in *Chapter 4: Improving life with supportive care*.

Options by cancer type and stage

If you are fairly healthy, cancer treatment is likely to be safe. Low performance scores of 0, 1, and 2 reflect better overall health. You should receive supportive care in addition to treatment. NCCN recommendations for treatment are based on the types and stages of mesothelioma. **See Guide 2.**

The 2 main approaches to treatment are:

- Whole-body drug treatment called systemic therapy
- A watch-and-wait phase called observation

Surgery may be a third option for stage 1 epithelioid mesothelioma, but its benefits are unclear. There aren't any data that show it prolongs life when added to systemic therapy.

What is systemic therapy?

Systemic therapy consists of prescribed drugs that treat cancer throughout the body. Your medical oncologist will prescribe a regimen for you. A regimen consists of one or more drugs that are taken at a specific dose, schedule, and length of time.

You'll need to go to a health care center to receive systemic therapy. It is given through a slow drip from a needle into a vein. This method is called an infusion. The drugs travel in the bloodstream to reach cancer cells throughout the body.

Systemic therapy is given in cycles of treatment days, followed by rest days. One cycle typically lasts for several weeks.

NCCN levels of preference

The next 2 sections discuss regimens for mesothelioma. NCCN experts recommend these regimens based on science and safety.

Guide 2 Treatment options for meso	othelioma
Stage 1 epithelioid type	 Systemic therapy (preferred) with or without intensity- modulated radiation therapy (IMRT) Observation Surgery
Stage 2, stage 3, and stage 4 epithelioid type All stages of sarcomatoid and biphasic types	Systemic therapyObservation

When helpful, they assign a level of preference to their recommendations:

- Preferred therapies have the most evidence they work better and may be safer than other therapies.
- Other recommended therapies may not work quite as well as preferred therapies, but they can still help treat cancer.
- Therapies used in certain cases work best for people with specific cancer features or health circumstances.

First-line systemic therapy

The first treatment you will receive is referred to as first-line therapy. It is often

a chemotherapy-based regimen or a combination of immune checkpoint inhibitors. A list of regimens for epithelioid mesothelioma is in **Guide 3** and regimens for biphasic or sarcomatoid mesothelioma can be found in **Guide 4.**

Platinum-doublet chemotherapy

Chemotherapy kills fast-growing cells including cancer cells. Platinum-doublet chemotherapy is commonly used for treatment. It's a combination of 2 types of chemotherapy that work in different ways to kill cancer cells.

Platinum-doublet chemotherapy consists of either cisplatin or carboplatin and a second chemotherapy. Most often, the second chemotherapy is pemetrexed (Alimta, Pemfexy). But gemcitabine (Gemzar, Infugem) is sometimes used.

Guide 3 First-line therapy for epithelioid mesothelioma	
Preferred therapies	 Chemotherapy-based therapy Cisplatin and pemetrexed Cisplatin and pemetrexed with bevacizumab Cisplatin and pemetrexed with pembrolizumab Carboplatin and pemetrexed Carboplatin and pemetrexed with bevacizumab Carboplatin and pemetrexed with pembrolizumab Carboplatin and pemetrexed with pembrolizumab Nivolumab and ipilimumab
Therapies used in certain cases	 Chemotherapy Cisplatin and gemcitabine Carboplatin and gemcitabine Pemetrexed Vinorelbine

Platinum-doublet chemotherapy with targeted therapy

Targeted therapy works by stopping the specific ways cancer cells grow. Bevacizumab (Avastin) is a type of targeted therapy called a VEGF antibody. It blocks a protein called VEGF, which stops the growth of blood vessels on tumors. Without blood, cancer cells die.

- For epithelioid mesothelioma, platinumdoublet chemotherapy with bevacizumab is one of the preferred options.
- For biphasic or sarcomatoid mesothelioma, platinum-doublet chemotherapy with bevacizumab is an option for other recommended therapies.

An FDA-approved biosimilar can be taken instead of bevacizumab. A biosimilar is almost an identical drug made by another company.

Platinum-doublet chemotherapy with an immune checkpoint inhibitor

Immune checkpoint inhibitors restore the ability of immune T cells to kill cancer cells. Pembrolizumab (Keytruda) is an immune checkpoint inhibitor. The combination of pembrolizumab and platinum-doublet chemotherapy is a preferred regimen for all types of mesothelioma.

Guide 4 First-line therapy for biphasic or sarcomatoid mesothelioma		
Preferred therapies	 Chemotherapy-based therapies Cisplatin and pemetrexed with pembrolizumab Carboplatin and pemetrexed with pembrolizumab 	
	Immune checkpoint inhibitors	
	 Nivolumab and ipilimumab 	
Other recommended therapies	Chemotherapy-based therapies	
	Cisplatin and pemetrexed	
	Cisplatin and pemetrexed with bevacizumab	
	Carboplatin and pemetrexedCarboplatin and pemetrexed with bevacizumab	
	Chemotherapy	
Therapies used in certain cases	Cisplatin and gemcitabine	
	Carboplatin and gemcitabine	
	Pemetrexed	
	Vinorelbine	

Combined immune checkpoint inhibitors

The combination of nivolumab (Opdivo) and ipilimumab (Yervoy) is also a preferred regimen for all types of mesothelioma. Both drugs are immune checkpoint inhibitors but work in different ways to kill cancer cells.

Single-agent chemotherapy

Pemetrexed is sometimes used by itself to treat mesothelioma. Another option is vinorelbine.

Radiation therapy for stage 1 epithelioid type

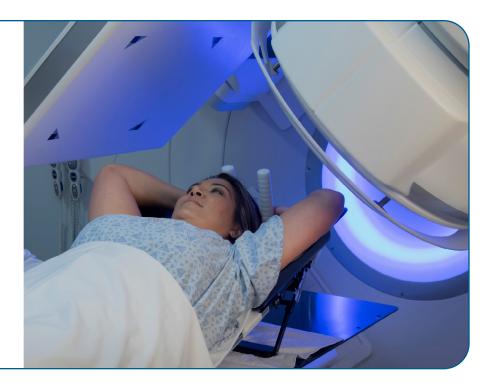
If you have stage 1 epithelioid mesothelioma, your care team may consider adding intensitymodulated radiation therapy (IMRT) to systemic therapy. IMRT is a type of radiation therapy. It delivers x-ray beams that very closely match the shape of the tumor and spare more normal tissue around the tumor. The x-rays damage cancer cells, which either die or stop making new cancer cells.

During treatment, you will be lying down on a table. A large machine makes the radiation beams and will aim the highest radiation dose at the tumor. Nearby tissue will receive a much lower dose.

A tumor in the chest is hard to target because it often moves when you breathe. To account for this challenge, your team will use advanced methods. You may need to hold your breath for 15 to 20 seconds at a time to better target the tumor.

What is radiation therapy?

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



Second-line systemic therapy

If the cancer grows during or after first-line therapy, another regimen may be started. This is called second-line therapy. The goal of second-line therapy is to stop the growth of the cancer. Second-line options can be found in **Guide 5.**

Second-line options are based on your prior treatment:

If you had chemotherapy, nivolumab with or without ipilimumab is the preferred therapy. Nivolumab with hyaluronidasenvhy (Opdivo Qvantig) injections into the skin may be given instead of nivolumab infused into a vein. It's not an option if ipilimumab is used with nivolumab.

- Some people have a second option after prior chemotherapy. If a regimen with pemetrexed stopped cancer growth before, another regimen with pemetrexed may be given.
- If you had nivolumab and ipilimumab, platinum-doublet chemotherapy and pemetrexed with or without bevacizumab is preferred. Pemetrexed can also be given by itself.

Other recommended therapies include gemcitabine with or without ramucirumab (Cyramza). Ramucirumab is a VEGF antibody. In addition to gemcitabine, vinorelbine is an option.

Guide 5 Second-line therapy for all types of mesothelioma	
Preferred therapies	If you had chemotherapy, your options are:Nivolumab with or without ipilimumab
	 If you had nivolumab and ipilimumab, your options are: Cisplatin and pemetrexed Cisplatin and pemetrexed with bevacizumab Carboplatin and pemetrexed Carboplatin and pemetrexed with bevacizumab Pemetrexed
Other recommended therapies	 Chemotherapy-based therapy Gemcitabine with or without ramucirumab Vinorelbine

What is observation?

Observation is a watch-and-wait approach to treatment. Because mesothelioma takes decades to develop, it may continue to grow very slowly after it has been found.

During observation, you'll see your care team often. You won't receive any treatment unless you begin to have symptoms or until a scan shows that the mesothelioma is growing.

A surgical approach to treatment

If you have stage 1 epithelioid mesothelioma, surgery with systemic therapy may be an option.

Systemic therapy

You may receive systemic therapy either before or after surgery. Systemic therapy before surgery may shrink the tumor and make surgery easier. Systemic therapy given after surgery is meant to kill any cancer cells that were left behind.

Types of surgery

There are 2 types of surgery for mesothelioma:

Pleurectomy/decortication 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 removes both pleural layers and the lung. This procedure may also remove part of the diaphragm and often the pericardium.

Surgeons most often perform pleurectomy/ decortication, but extrapleural pneumonectomy is sometimes done. Your team will consider a number of factors before recommending which operation is best for you. Sometimes, the surgeon has to begin operating first to see what's going on inside your chest before deciding on the type of surgery.

The surgeon will also take samples of the lymph nodes in between your lungs. This is done to find out if the cancer has spread outside the pleura.

Radiation therapy after surgery

Some people receive IMRT after pleurectomy/ decortication. IMRT may help you live longer by killing any cancer cells that weren't removed by surgery.

It can be difficult to give IMRT after surgery. IMRT may be an option at a treatment center that has experienced and trained staff.

What is a clinical trial?

You may be able to receive therapy that you can't get elsewhere by joining a clinical trial.

A clinical trial is a type of medical research study. After being developed and tested in a lab, 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).

Everyone with cancer should carefully consider all of the treatment options available for their cancer type, including standard treatments and clinical trials. Talk to your doctor about whether a clinical trial may make sense for you.

Phases

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

- Phase 1 trials study the safety and side effects of an investigational drug or treatment approach.
- Phase 2 trials study how well the drug or approach works against a specific type of cancer.
- Phase 3 trials test the drug or approach against a standard treatment. If the results are good, it may be approved by the FDA.
- Phase 4 trials study the safety and benefit of an FDA-approved treatment.

Who can enroll?

It depends on the clinical trial's rules, called eligibility criteria. The rules may be about age, cancer type and stage, treatment history, or general health. They ensure that participants are alike in specific ways and that the trial is as safe as possible for the participants.



Finding a clinical trial

In the United States

NCCN Cancer Centers NCCN.org/cancercenters

The National Cancer Institute (NCI) cancer.gov/about-cancer/treatment/clinicaltrials/search

Worldwide

The U.S. National Library of Medicine (NLM) <u>clinicaltrials.gov</u>

Need help finding a clinical trial?

NCI's Cancer Information Service (CIS) 1.800.4.CANCER (1.800.422.6237) cancer.gov/contact

Informed consent

Clinical trials are managed by a research team. This group of experts 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 it with people you trust. Keep in mind that you can leave and seek treatment outside of the clinical trial at any time.

Will I get a placebo?

Placebos (inactive versions of real medicines) are almost never used alone in cancer clinical trials. It is common to receive either a placebo with a standard treatment, or a new drug with a standard treatment. You will be informed, verbally and in writing, if a placebo is part of a clinical trial before you enroll.

Are clinical trials free?

There is no fee to enroll in a clinical trial. The study sponsor pays for research-related costs, including the study drug. But you may need to pay for other services, like transportation or childcare, due to extra appointments. During the trial, you will continue to receive standard cancer care. This care is often covered by insurance.

Key points

- A multidisciplinary team will work together with you to create a treatment plan. The treatment plan will be based on many factors including the type and stage of mesothelioma.
- Systemic therapy treats cancer wherever it is in the body. Chemotherapy, targeted therapy, and immune checkpoint inhibitors are types of systemic therapy. Radiation therapy may also be part of treatment for stage 1 epithelioid mesothelioma.
- Observation is a watch-and-wait strategy for people with slow-growing mesothelioma.
- Stage 1 epithelioid mesothelioma may be surgically removed and treated with systemic therapy. Radiation therapy is sometimes part of treatment.

 Clinical trials study new ways of fighting cancer in people. A clinical trial may be an option in addition to standard treatment.

Questions to ask

- > Do I need to start treatment right away?
- How did you decide what treatment is best for me?
- What is the schedule, or cycles, of the systemic therapy?
- What are the common and serious side effects of my treatments?
- Is there a clinical trial that's a good fit for me?



There's more hope now than there ever was. So don't give up. When hope is in the equation, the odds don't matter."

4 Improving life with supportive care

- 26 What is supportive care?
- 26 Mesothelioma complications
- 27 Common cancer effects
- 28 Help to quit smoking
- 28 End-of-life concerns
- 29 Key points
- 29 Questions to ask

The main concern for most people with cancer is to find treatment that works. Having cancer is not only about cancer treatment, though. Cancer care includes many additional challenges that may affect your life in unexpected ways. This chapter addresses some of the challenges you may face and how supportive care can help.

What is supportive care?

Supportive care helps improve your quality of life during and after cancer treatment. The goal is to prevent or manage side effects and symptoms, like pain and cancer-related fatigue. It also addresses the mental, social, and spiritual concerns faced by those with cancer.

Supportive care is available to everyone with cancer and their families, not just those at the end of life. Palliative care is another name for supportive care.

Supportive care can also help with:

- Making treatment decisions
- Coordinating your care
- Paying for care
- > Planning for advance care and end of life

It's important to know that you can get support for the challenges caused by cancer. Your care team will help you get the supportive care you need.

Mesothelioma complications

People with mesothelioma often have health issues, called complications, that are caused by the cancer. Your care team will create a management plan based on your needs. This section addresses 3 complications of mesothelioma.

Pleural effusion

Pleural effusion is the buildup of extra fluid in the space between the 2 pleural layers. This space is called the pleural cavity. This can result in shortness of breath. There are 2 treatment options.

Pleural catheter

One treatment for pleural effusion is a pleural catheter. A pleural catheter is a thin, flexible tube that's placed in your chest. The catheter drains the buildup of fluid in the pleural cavity.

Talc pleurodesis

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 or heat

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or cold therapy (thermal ablation) may be used to ease chest pain. Other ways to manage chest pain are with pain medications or chemotherapy.

Bronchial or esophageal obstruction

For some people, mesothelioma grows and causes a blockage (obstruction). An obstruction can block your airway or your digestive tract. If this happens, radiation therapy may be used to shrink the tumor. Other less common treatment options are laser treatment or thermal ablation.

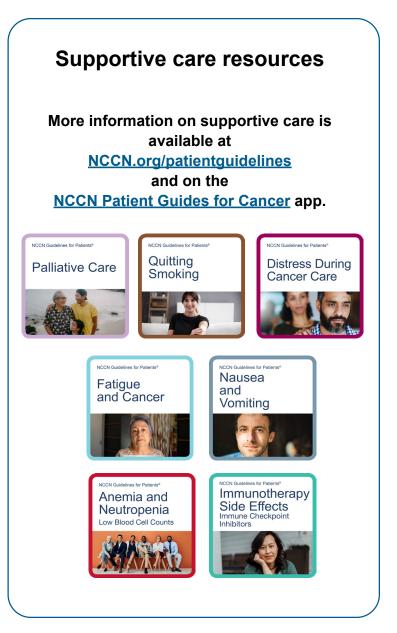
Common cancer effects

People with different types of cancer experience common health issues. Cancers share some common symptoms because they disrupt the body in similar ways. Treatment is similar for different cancers and causes common side effects.

Information on managing common effects can be found in the library of NCCN Guidelines for Patients. Books from the supportive care series are briefly described next so that you can find the information you need.

Distress

Everyone with cancer feels distressed at some point. It is normal to feel worried, sad, helpless, or angry. *NCCN Guidelines for Patients: Distress During Cancer Care* empowers people to get help for distress.



Fatigue

Cancer-related fatigue is not the typical tiredness that follows an active or long day. It's a lack of energy that's distressing, doesn't improve with normal rest or sleep, and disrupts life. Read the NCCN book on fatigue to learn about physical activity and other methods that reduce cancer-related fatigue.

Nausea and vomiting

Both chemotherapy and radiation therapy can cause nausea and vomiting. Nausea is the feeling that you are going to throw up. Vomiting is forcefully throwing up what's in your stomach. Treatments that prevent and manage both conditions are discussed in *NCCN Guidelines for Patients: Nausea and Vomiting*.

Anemia and neutropenia

Chemotherapy often causes a drop in red and white blood cells. A low number of red blood cells, called anemia, may cause fatigue. A low white blood cell count, called neutropenia, raises your risk of infections. Treatment for low blood cells is described in *NCCN Guidelines for Patients: Anemia and Neutropenia*.

Immunotherapy side effects

Immune checkpoint inhibitors are used to treat all types of mesothelioma. This treatment may cause your immune cells to attack your healthy cells.

NCCN Guidelines for Patients: Immunotherapy Side Effects: Immune Checkpoint Inhibitors explains treatment for:

- Skin and mouth symptoms
- Bowel and liver symptoms
- Thyroid, pituitary, and pancreas symptoms
- Lung symptoms

Help to quit smoking

Smoking can limit how well cancer treatment works. It also can worsen your overall health and how well your lungs work. Plus, it increases your risk for lung cancer.

- If you don't smoke, it's important that you don't start now.
- If you do smoke, it is important to quit. It's never too late.

Nicotine addiction is one of the hardest addictions to stop. The stress of having cancer may make it harder to quit.

The NCCN Guidelines for Patients: Quitting Smoking provides critical support and guidance for people with cancer. This book explains how to best use the tools that exist to help you quit for good.

If you tried to quit before, try again. Most people slip or relapse before quitting for good.

End-of-life concerns

The NCCN Guidelines for Patients: Palliative Care helps people navigate the cancer experience across the spectrum of care. It describes care for physical and emotional symptoms. It also provides guidance on talking with your team about cancer treatment and advance care planning.

Advance care planning

When cancer keeps growing despite all treatment efforts, it may be time to set some new goals. Your new goals may involve

making the most of your time and ensuring that you can meet the end of life 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. You can set up an advance care plan early on to feel less stressed and better able to cope.

Hospice care

Hospice is a type of care designed to provide comfort to people who are close to the end of life as well as the people who love them. A major goal is to keep you pain-free and make sure that you can leave this world comfortably and with dignity.

Key points

- Supportive care aims to improve your quality of life, including preventing and relieving symptoms.
- Quitting smoking may improve treatment results.
- Advance care planning is done to ensure that your end-of-life wishes are understood and respected.

Questions to ask

- What should I say if health care providers ask if I'm getting supportive care? Some people think supportive care is hospice care.
- How will you prevent symptoms or relieve the symptoms I have?
- Who should I contact if my symptoms get worse?
- What are the best methods to help me quit smoking?
- What happens during end-of-life care and how can I prepare for it?



5 Other resources

- 31 What else to know
- 31 What else to do
- 31 Where to get help
- 31 Questions to ask

Want to learn more? Here's how you can get additional help.

What else to know

This book can help you improve your cancer care. It plainly explains expert recommendations and suggests questions to ask your care team. But it's not the only resource that you have.

You're welcome to receive as much information and help as you need. Many people are interested in learning more about:

- > The details of their health and treatment
- Finding a care provider who specializes in mesothelioma
- Being a part of a care team
- Getting financial and legal help
- Coping with health problems

What else to do

Your health care center can help you with next steps. They often have on-site resources to help meet your needs and find answers to your questions. Health care centers can also inform you of resources in your community.

In addition to help from your providers, the resources listed in the next section provide support for many people like yourself. Look through the list and visit the provided websites to learn more about these organizations.

Where to get help

CancerCare Cancercare.org

Imerman Angels Imermanangels.org

National Coalition for Cancer Survivorship canceradvocacy.org

U.S. National Library of Medicine Clinical Trials Database <u>clinicaltrials.gov</u>

Triage Cancer Triagecancer.org

Questions to ask

- How do I find a health care provider who's an expert in mesothelioma?
- What's my role in making decisions on the best cancer care for me?
- What are the steps to get a second opinion?
- How much will I have to pay for my treatment and what help is available for these costs?
- How can I connect with others and build a support system?



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.

cancer staging

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

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.

fine-needle aspiration (FNA)

Removal of a tiny sample of body tissue with a very thin needle.

first-line therapy

The first type of treatment given for a health condition or disease.

immune checkpoint inhibitors

A drug treatment that enables immune T cells to kill cancer cells.

immunohistochemistry

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

infusion

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

intensity-modulated radiation therapy (IMRT)

A type of external radiation therapy that uses many beams of different intensities.

lymph node

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

magnetic resonance imaging (MRI)

An imaging process that uses a magnetic field and radio waves to make pictures of the inside of the body.

multidisciplinary team

A group of health care providers who work together to give expert care.

observation

A period of watching for cancer growth or occurrence while not receiving treatment. Also called watch and wait.

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 daily 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 mesothelioma

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

pleural thickening

Widespread scarring of the tissue surrounding the lungs.

positron emission tomography/computed tomography (PET/CT)

A test that uses two picture-making methods to show the shape and function of tissue.

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.

second-line therapy

The second type of treatment given if the cancer grows.

second opinion

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

side effect

An unhealthy or unpleasant physical or emotional response to treatment.

supportive care

Interventions to improve quality of life. Also sometimes called palliative care.

systemic therapy

A drug treatment that travels in the bloodstream to reach cancer wherever it is.

NCCN Contributors

This patient guide is based on the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines[®]) for Mesothelioma: Pleural Version 2.2025. 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 • <u>pennmedicine.org/cancer</u>

Case Comprehensive Cancer Center/ University Hospitals Seidman Cancer Center and Cleveland Clinic Taussig Cancer Institute *Cleveland, Ohio UH Seidman Cancer Center* 800.641.2422 • <u>uhhospitals.org/services/cancer-services</u> *CC Taussig Cancer Institute* 866.223.8100 • <u>my.clevelandclinic.org/departments/cancer</u> *Case CCC* 216.844.8797 • <u>case.edu/cancer</u>

City of Hope National Medical Center Duarte, California 800.826.4673 • <u>cityofhope.org</u>

Dana-Farber/Brigham and Women's Cancer Center | Mass General Cancer Center Boston, Massachusetts 877.442.3324 • youhaveus.org 617.726.5130 • massgeneral.org/cancer-center

Duke Cancer Institute Durham, North Carolina 888.275.3853 • <u>dukecancerinstitute.org</u>

Fox Chase Cancer Center Philadelphia, Pennsylvania 888.369.2427 • <u>foxchase.org</u>

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

Fred Hutchinson Cancer Center Seattle, Washington 206.667.5000 • <u>fredhutch.org</u>

Huntsman Cancer Institute at the University of Utah Salt Lake City, Utah 800.824.2073 • <u>healthcare.utah.edu/huntsmancancerinstitute</u>

Indiana University Melvin and Bren Simon Comprehensive Cancer Center Indianapolis, Indiana 888.600.4822 • www.cancer.iu.edu

Johns Hopkins Kimmel Cancer Center Baltimore, Maryland 410.955.8964 www.hopkinskimmelcancercenter.org Mayo Clinic Comprehensive 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 • <u>moffitt.org</u>

O'Neal Comprehensive Cancer Center at UAB Birmingham, Alabama 800.822.0933 • uab.edu/onealcancercenter

Robert H. Lurie Comprehensive Cancer Center of Northwestern University *Chicago, Illinois* 866.587.4322 • <u>cancer.northwestern.edu</u>

Roswell Park Comprehensive Cancer Center Buffalo, New York 877.275.7724 • roswellpark.org

Siteman Cancer Center at Barnes-Jewish Hospital and Washington University School of Medicine *St. Louis, Missouri* 800.600.3606 • <u>siteman.wustl.edu</u>

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

Stanford Cancer Institute Stanford, California 877.668.7535 • <u>cancer.stanford.edu</u>

The Ohio State University Comprehensive Cancer Center -James Cancer Hospital and Solove Research Institute *Columbus, Ohio* 800.293.5066 • <u>cancer.osu.edu</u>

The UChicago Medicine Comprehensive Cancer Center *Chicago, Illinois* 773.702.1000 • <u>uchicagomedicine.org/cancer</u>

The University of Texas MD Anderson Cancer Center Houston, Texas 844.269.5922 • <u>mdanderson.org</u>

NCCN Cancer Centers

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

UC San Diego Moores Cancer Center La Jolla, California 858.822.6100 • <u>cancer.ucsd.edu</u>

UCLA Jonsson Comprehensive Cancer Center Los Angeles, California 310.825.5268 • uclahealth.org/cancer

UCSF Helen Diller Family Comprehensive Cancer Center San Francisco, California 800.689.8273 • <u>cancer.ucsf.edu</u>

University of Colorado Cancer Center Aurora, Colorado 720.848.0300 • <u>coloradocancercenter.org</u>

University of Michigan Rogel Cancer Center Ann Arbor, Michigan 800.865.1125 • <u>rogelcancercenter.org</u>

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

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

Vanderbilt-Ingram Cancer Center Nashville, Tennessee 877.936.8422 • <u>vicc.org</u>

Yale Cancer Center/Smilow Cancer Hospital New Haven, Connecticut 855.4.SMILOW • <u>yalecancercenter.org</u>

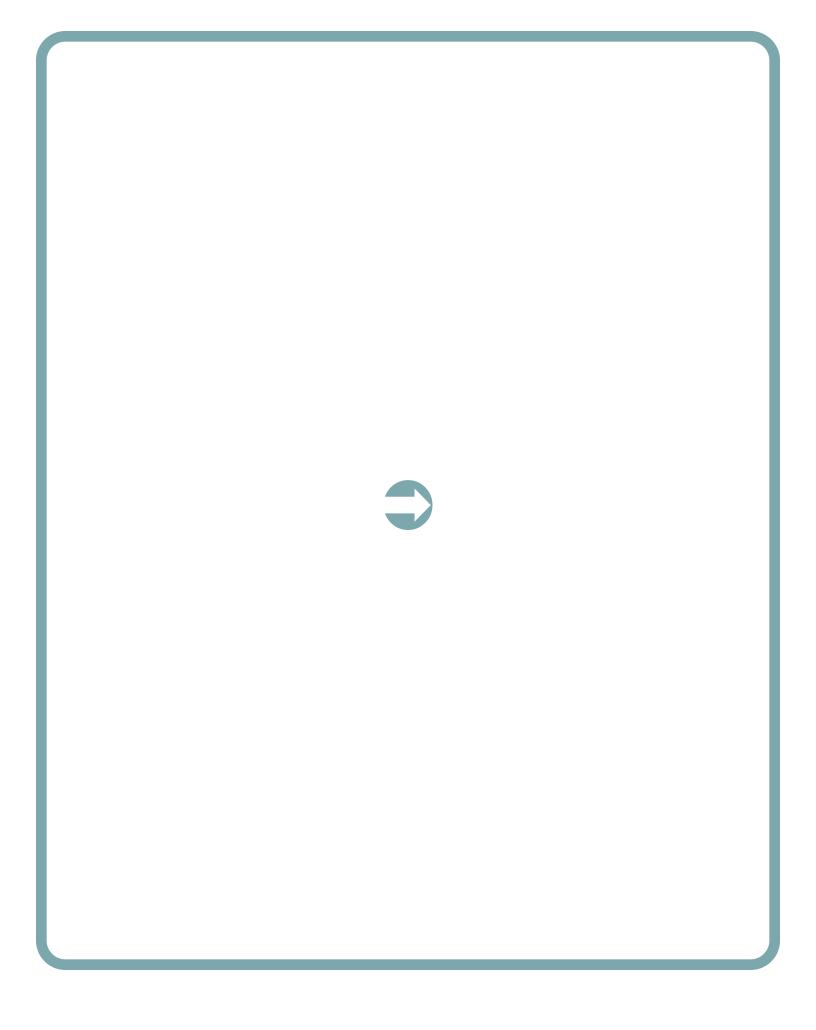


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Index

advance care planning 28-29 asbestos 9-10 biopsy 11–14 cancer staging 13 chemotherapy 18-21, 27-28 clinical trial 22-24 computed tomography (CT) 10–13 extrapleural pneumonectomy 22 first-line therapy 18–21 hospice 29 immune checkpoint inhibitors 18-20, 28 immunohistochemistry 12 infusion 17 lymph node 13, 22 multidisciplinary team 16 observation 17, 22 pathologist 12 performance status 13, 16 pleural effusion 9, 11, 26 pleural thickening 10–11 pleurectomy/decortication 22 radiation therapy 20, 22, 26-28 second-line therapy 21 side effect 23, 26–28 supportive care 16, 26–29 systemic therapy 6, 16-18, 20-22





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