Patients:
Get answers to questions you may not even know to ask.
Overview

Whether you were recently diagnosed with mesothelioma or have known about your illness for some time, the information in this booklet is designed to help you and your family navigate this difficult journey.

What you need to know now

Mesothelioma is a complex, fast-moving disease. While we encourage you to learn everything about it on our website—MesotheliomaHelpNow.com—this booklet provides patients with concise, handy information they need to know in order to make smart decisions now.

What you’ll find in this booklet

Within these pages you will find such topics as what to expect in the weeks and months following your diagnosis, how to find the best care possible, and practical, “how to” advice on questions you’ll want to be sure to ask your doctor. You’ll find these questions on page 6. We recommend printing this page and bringing it with you to your next doctor’s appointment.

It is our sincere hope that the time you spend reviewing this information will prove invaluable to your overall health and well-being. If you need help right away, please call one of our highly trained Claim Advocates at 866-533-3564.
Understanding Mesothelioma

What it is, how you got it, and what you can do about it

If you’re like most patients, you probably hadn’t even heard the word “mesothelioma” before you were diagnosed. That’s not surprising, given that there are only about 3,200 documented new cases of this aggressive cancer each year.

What is Mesothelioma?
Mesothelioma is a rare type of cancer occurring in the lining—or mesothelium—of the lungs, abdomen, or heart.

The 3 Main Types of Mesothelioma

- Pleural (lungs)
- Peritoneal (abdomen)
- Pericardial (heart)

Pleural mesothelioma is the most common type and accounts for roughly 75% of all cases.

It can take years, even decades, for mesothelioma symptoms to develop. And those symptoms are, initially at least, easily mistaken for common illnesses such as a bad cold or flu.

Mesothelioma symptoms can easily be mistaken.
How did I get mesothelioma?

Medical and scientific experts agree that exposure to asbestos is the only way people can get mesothelioma.

Up until the late 1970s, asbestos was commonly used in many everyday products such as floor tiles, wallboard, and insulation. Its durability and heat resistance made it especially ideal for use on ships and in other places where fire was of great concern. Asbestos was even used in Hollywood movies as a substitute for snow.

However asbestos is used, and in whatever product, any damage or disturbance to the tiny asbestos fibers can cause them to become airborne. Then, these fibers may be inhaled or swallowed and lodge in a person’s lungs, abdomen, or heart. Over time, mesothelioma, lung cancer, or asbestosis could develop.

Fortunately, today we know a lot more about the dangers of asbestos, but that knowledge doesn’t help all the people who were unnecessarily exposed to this deadly mineral. It is hard to believe that many manufacturers knew about the dangers of asbestos and still chose to put people at risk—but that’s exactly what happened.

What can I do after diagnosis?

Once you get over the shock of your diagnosis, you will want to start to think strategically. Here are some important questions to consider: How can I get the best care possible? Which medical centers offer the most advanced treatment options? Who can I count on to be part of my support network? Your primary care physician as well as the specialist who diagnosed your illness can be great resources, but you should also dig in on your own and learn everything you can about this disease. The more you know, the more you’ll be ready to make the best possible treatment choices. Our website, MesotheliomaHelpNow.com offers a lot of helpful, detailed information.

Consult these resources for more information

- Cancer.gov
- Cancer.org
- Curemeso.org
- MesotheliomaHelpNow.com
Many patients and families report feeling overwhelmed following a mesothelioma diagnosis. This is certainly understandable. Suddenly you and your family are hit with a flood of new information and strange medical terms, and you are asked to make medical decisions that you may not fully understand. It can be a real whirlwind.

**What to expect immediately after diagnosis**

Patients diagnosed with mesothelioma typically are referred to a mesothelioma specialist. Once the specialist has completed all the necessary tests to confirm the diagnosis, he or she will recommend a course of treatment. There are four stages of mesothelioma. In general, each of the four stages calls for a different type of treatment. Treatment options may include surgery, radiation, chemotherapy or a combination of procedures. There are more treatment options available for mesothelioma if it is detected in its earlier stages.

**You may want a second opinion**

Mesothelioma is a complex disease, so your specialist or insurance company may recommend getting a second opinion. This is a smart step to take. A confirmed second opinion will give you more confidence in your medical team’s recommended course of action.

**It may be possible to enroll in a research study**

The specialist may also recommend you enroll in a research study or clinical trial. By doing so you will have the benefit of receiving new types of treatment, while also having the satisfaction of knowing you’re helping other patients like you by participating in cutting-edge medical research.

**What to expect in the months following diagnosis**

Depending on your doctor’s recommended plan, you can expect treatment to last anywhere from a few weeks to several months. After the initial procedure is complete and you are well enough to be released from the hospital, you should be able to live at home and return to the hospital or doctor’s office for any follow-up procedures.
Mesothelioma is a complex and rare disease that requires unique treatment. Only 3,200 people in the U.S. are diagnosed with mesothelioma each year, so it is not guaranteed that your local medical facilities will have much, if any, experience treating this disease. You absolutely must work with a specialist who has considerable experience treating your specific type of mesothelioma.

Finding a mesothelioma specialist

Fortunately, the National Cancer Institute (NCI) at the National Institutes of Health (cancer.gov) has designated certain stellar hospitals across the country as NCI-designated cancer centers. These hospitals hire top faculty and have leading research programs and treatment facilities. In order to be labeled an NCI cancer center, a medical facility must offer “world class, state-of-the-art programs in multidisciplinary research.”

As of today, there are 68 NCI-designated cancer centers, most of which are associated with a university. In addition, U.S. News & World Report recently published its annual ranking of top cancer care facilities.

It’s worth checking several sources to find the best mesothelioma care facility in your area. In addition to the National Cancer Institute and U.S. News & World Report recommendations, see these trusted resources:

The Mesothelioma Applied Research Foundation (MARF) has a medical liaison on staff to help patients find the specialist best suited to meet their needs. MARF is a nonprofit organization, and this service is free.

www.curemeso.org  |  877-363-6376

The American College of Surgeons Commission on Cancer (CoC) offers a list of accredited cancer diagnosis and treatment centers. There are more than 1,500 CoC-approved cancer centers across the U.S, which include major treatment centers and community hospitals. The CoC is constantly monitoring these institutions to ensure they continue to offer the highest-quality cancer care.

www.facs.org
Once you are diagnosed with mesothelioma, you will have a lot of questions and may not have the mental and emotional stamina to remember everything you’d like to ask your doctor. Most doctors recommend you bring a close friend or family member to appointments to take notes and help you keep track of all the information doctors and nursing staff will share with you. Taking an active role in your treatment will help to ensure you have the best outcome possible. With this in mind, print out our list of must-ask questions and bring it with you on your next visit to the doctor. We encourage you to add your own questions to this list.

- Based on what you know about my cancer so far, what is my prognosis?
- What are my treatment options?
- What can I expect from the treatment?
- Should I get a second opinion? If so, can you recommend another specialist?
- Where do you recommend I go for treatment?
- What risks are associated with the treatments you suggest? Do the benefits outweigh these risks?
- Do I have a choice about whether to accept certain forms of treatment?
- What kinds of side effects can I expect?
- How will I know if my side effects are normal or require immediate medical attention?
- How will this treatment affect my daily life?
- Are there steps I should take to get ready for my treatment?
- How will we know if the treatment is working?
- Will my health insurance cover the cost of treatment?
- At what point should I consider participating in a clinical trial?
- Will I be able to care for myself during treatment?
- Will I have to stay in the hospital or cancer facility while I am being treated, or will my family be able to take care of me?
- Will I be able to resume my normal activities, such as going to work, exercising, and participating in my hobbies?
There is no way around it: it is difficult to share the bad news of a mesothelioma diagnosis with friends and family. But you may find that preparing for and having these important conversations will bring a sense of relief.

Because mesothelioma is such a rare disease and such a big, scientific-sounding word, explaining what it is and how it’s affecting your health can be difficult, especially when speaking with children. It helps to simplify the language. For example, you could say that mesothelioma is a type of cancer that developed in your body over a long period of time because you were exposed to asbestos. Your conversations will vary depending on whether you’re speaking with adults, teenagers, children, or grandchildren.

These tips from the National Cancer Institute and MesotheliomaHelpNow.com will ensure conversations about your illness with friends and family are thoughtful, productive and helpful for everyone.

**Speaking with young children about your diagnosis**

Young children will not fully understand the seriousness of your illness or the potential consequences.

- Keep your tone simple and loving.
- Explain that you have a sickness in your body, but don’t offer many details.
- Reassure children that they are not at risk of “catching” the disease from you, and that you will always love them.

**Mesothelioma**

Mesothelioma is a type of cancer that develops in a person’s body over a long period of time after he or she has been exposed to asbestos.
Speaking with teens about your mesothelioma diagnosis
Older children are often smarter than adults give them credit for. The tone you take with them will not differ substantially from that you would take with an adult.

- Tell them that you’ve been diagnosed with mesothelioma.
- Tell them what the disease is and how you got it.
- Say that you plan to fight this disease as hard as you can, but be honest about your prognosis. There is no point trying to shield them from the facts—and you can bet that their next step will be to go online to research the disease to find their own information.

Speaking with adults about your mesothelioma diagnosis
Whether speaking with adult friends or adult family members, expect that they will have many questions.

- Explain what mesothelioma is and how it is linked to exposure to asbestos at some point in your past.
- Share details about your course of treatment, but also share your prognosis.
- Let them know how they can help and be involved in your care.
- Promise to keep them updated on your progress.

End every conversation, no matter the age of the audience, by saying that you are always willing to answer any questions they may have.
Making Your Home Safe and Comfortable

Making your home an accident-free space during and after treatment

Once you begin mesothelioma treatment, you may need to rely on a wheelchair or walker. You may also need to use a portable oxygen tank. To make sure you can safely move around your home, ask family members and friends to help make some extra space by moving furniture and clearing hallways. Checking that each room is adequately lit, so you can see where you’re going, is also a smart step toward creating a safer home.

Home safety tips

☐ Add a rubber threshold ramp at every doorway. These are inexpensive and can be cut to size.

☐ Rent or buy a chair with a built-in lift that raises and lowers the seat.

☐ Install bed rails to ease the difficulty of getting into and out of bed.

☐ Install a second stairway railing so there is one on either side of the stairs for extra support.

Bathroom safety tips

☐ Place a plastic seat right in the shower.

☐ Install a rubber bath mat or rubber treads inside and outside the shower.

☐ Use carpet tape or other heavy-duty tape to keep the bathmat outside the shower from slipping.

☐ Install an elevated toilet seat with armrests.

☐ Install a handrail or grab bar in the shower to help with balance.

☐ Add nightlights in bathrooms and along hallways that lead to them.

MESOTHELIOMA HELP NOW
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Call our Claim Advocates at 866-533-3564. We’re here to help – now.
Creating Your Support Network
Finding helpful resources

Research shows that patients who regularly participate in support groups have an improved quality of life. The simple act of connecting with others who are going through or who have gone through similar experiences may help lift your spirits and minimize the feelings of sadness and isolation you may have following your diagnosis.

There are several different types of support groups. Some meet weekly in hospitals, libraries, or community centers; others have regular “meet ups” in online chat forums. Some organizations, such as the Mesothelioma Applied Research Foundation (MARF) offer support groups through Facebook. There are dedicated support groups for patients, for caregivers, and for family and friends, and some groups are a combination of all of the above.

Even if you’re unsure whether a support group is right for you, you owe it to yourself to give it a try, at least once—then decide whether it makes a difference in your life.

Support group resources

**American Cancer Society’s online & support communities**
Join an online support community for cancer patients and family members.
www.cancer.org/treatment/supportprogramsservices/onlinecommunities

**CancerCare**
Find an online, telephone, or face-to-face support group for cancer patients and their families.
www.cancercare.org/support_groups

**Mesothelioma Applied Research Foundation support groups**
Connects patients and their families to online and telephone support groups.
www.curemeso.org  |  703-879-3820

Check with the patient’s medical care team as well as your local community center and places of worship for additional listings of support groups in your area.
We have done the legwork and research for you and developed this list of organizations whose sole reason for existence is to help patients and families get the care and help they deserve.

Travel and transportation assistance

Getting the best care possible means working with a medical team that is highly skilled and experienced in treating your type of mesothelioma. Because the disease is so rare, your local hospitals may not have experts on staff. You may need to travel far from home to receive treatment from one of the leading cancer centers (refer to Cancer Centers of Excellence in section 4 for more information).

Fortunately, there is financial assistance available to help patients and their families pay for travel and lodging.

Travel

The American Cancer Society’s road to recovery
Provides local rides to doctors’ appointments for patients who do not have their own transportation.
www.cancer.org/treatment/supportprogramsservices/road-to-recovery

Corporate Angel Network
Arranges free travel on corporate jets for cancer patients.
www.corpangelnetwork.org | 914-328-1313

Mercy Medical Angels
Offers assistance for patients and families who cannot afford to travel for treatment.
www.mercymedical.org | 1-888-675-1405

Mesothelioma Applied Research Foundation
Has a grant program providing up to $1,000 for travel for expert mesothelioma consultations.
www.curemeso.org | 703-879-3820
**Lodging**

Where you stay while undergoing treatment is more than just a place to lay your head at night; it is your home away from home. Contact these organizations to find comfortable lodging for you and your family that is offered free or at greatly reduced rates.

**The American Cancer Society’s Hope Lodge**
Has 31 locations throughout the U.S. offering free lodging near cancer treatment centers.
www.cancer.org/treatment/supportprogramsservices/hopelodge/index

**The American Cancer Society’s Lodging Program**
Connects patients and their families with places to stay during treatment.
www.cancer.org/treatment/supportprogramsservices/patientlodging/index

**Joe’s House**
Lists various types of lodging throughout the U.S. near hospitals and treatment centers.
www.joeshouse.org

**Mesothelioma advocacy organizations**

These nonprofit organizations are dedicated to advocating for the rights of asbestos victims and are working hard to raise money to find a cure for asbestos-related diseases. Join the cause. By helping them, you may wind up helping yourself.

**Mesothelioma Applied Research Foundation**
This national organization is dedicated to finding a cure and eradicating mesothelioma as a life-ending disease.
www.curemeso.org

**Asbestos Disease Awareness Organization (ADAO)**
The largest independent asbestos victims’ organization in the U.S., ADAO is dedicated to preventing asbestos-caused diseases through national and international education, advocacy, and community initiatives.
www.asbestosdiseaseawareness.org
Financial assistance & legal support

These organizations have a proven track record of assisting mesothelioma victims and their families. Whether you need help paying your medical bills or are in search of an attorney to pursue your legal rights, you can rely on the trusted sources listed here.

CancerCare Co-Payment Assistance Foundation
This nonprofit organization is dedicated to helping patients afford co-payments for chemotherapy and targeted treatment drugs.
www.cancercarecopay.org | 866-55-COPAY

Patient Access Network Foundation
This independent organization is dedicated to providing people with chronic or life-threatening illnesses access to breakthrough medical treatments.
www.panfoundation.org | 866-316-7263

Patient Services Incorporated
Provides a “safety net” for patients with chronic illnesses struggling to pay insurance premiums and co-payments.
www.patientservicesinc.org | 800-366-7741

Veterans Disability
Provides compensation for veterans with disabilities related to military service.
www.vba.va.gov/bln/21/compensation

Sokolove Law
An experienced mesothelioma law firm. Compensation may be available for qualified mesothelioma victims and their families. When you are ready to learn more about the legal claims process, contact a highly trained case manager.
www.sokolovelaw.com | 800-579-5189