

# Understanding Peritoneal Mesothelioma

A Patient's Guide

## **Mesothelioma Hope**

1330 Boylston Street Suite 400  
Chestnut Hill, MA 02467

**MesotheliomaHope.com**



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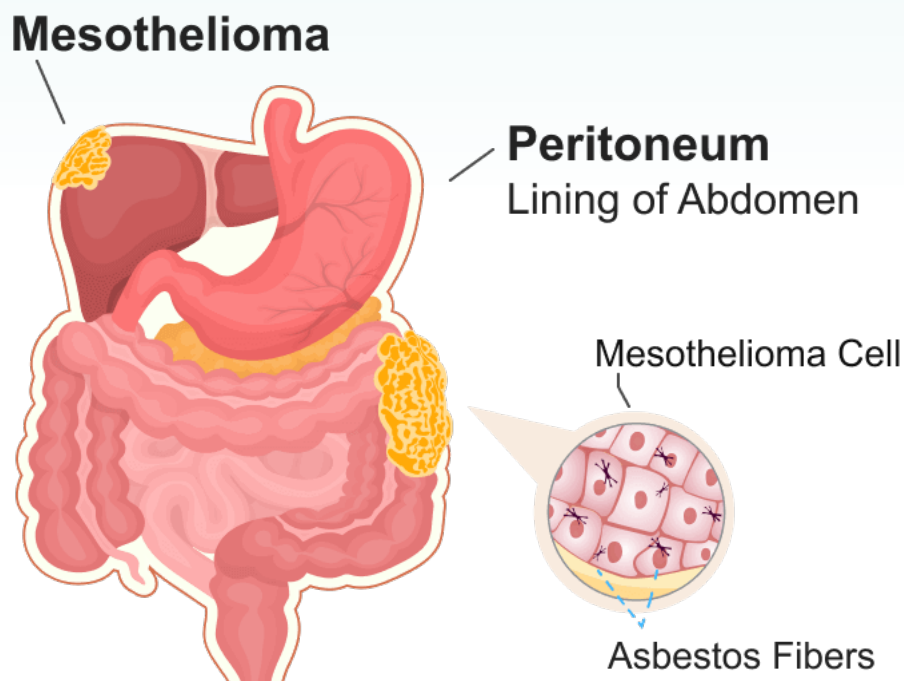
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# What Is Peritoneal Mesothelioma?

Peritoneal mesothelioma is a type of cancer that develops in the peritoneum, the thin membrane covering the abdominal cavity.

It is the second most common type of mesothelioma and makes up 10–15% of all diagnosed cases. The most common type is pleural mesothelioma, which affects the lining of the lungs.

The average life expectancy with peritoneal mesothelioma is about 4.5 years or 53 months. However, many patients have **survived 15 years or more** with specialized treatment.



Because peritoneal mesothelioma doesn't directly affect the heart or lungs, patients have higher survival rates than those diagnosed with pleural mesothelioma.

# Causes and Risk Factors

**Asbestos exposure is the primary cause of peritoneal mesothelioma. When asbestos is inhaled or swallowed, the tiny fibers can lodge themselves in the peritoneum and never leave.**

Once inside the body, asbestos fibers irritate healthy tissue for decades. After 10–50 years, the damage from asbestos can cause mesothelioma cells to form.

## Who's at Risk for Peritoneal Mesothelioma?

Some people are more prone to developing peritoneal mesothelioma because of certain factors like occupation, genetics, and prolonged asbestos exposure.



### High-risk groups include:

- **Military veterans**, especially those who served in the U.S. Navy and worked on ships and submarines before the early 1980s
- **Workers in certain blue-collar occupations** like construction, shipbuilding, and automotive repair
- **Families of veterans and blue-collar workers** who were exposed to asbestos brought home on their loved ones' uniforms, tools, or equipment
- **People with a family history of genetic mutations**, specifically in the BAP1 gene, which helps control cell growth and prevent tumors from forming
- **Regular users of talcum powder products** that may have been contaminated with asbestos

One-third of mesothelioma patients are **military veterans**.

# Signs and Symptoms

Peritoneal mesothelioma symptoms may not appear until **10–50 years after asbestos exposure**.

If the cancer is advanced, it may spread from the abdominal area into the lining of the lungs and cause pleural effusion, which is a buildup of fluid around the lungs.

“My father was exposed to asbestos through his work as a union insulator. He was just doing his job and providing for his family. Later in life, at the age of 79, he was diagnosed as having peritoneal mesothelioma.”



– Jeff, son of a peritoneal mesothelioma patient who served in U.S. Army.

## Common warning signs to watch for include:

- Abdominal fluid buildup (ascites)
- Bloating and discomfort
- Nonspecific pain
- Shortness of breath
- Unexplained weight loss

The average time between the first appearance of symptoms and a peritoneal mesothelioma diagnosis is about **5 months**.

## Highlighting Hope: Julie



- **Still thriving:** 17+ year survivor
- **Symptoms:** Digestive problems and constipation
- **Treatments received:** Chemotherapy and cytoreductive surgery with HIPEC

“Keep the faith and keep putting one foot in front of the other.”



# How Is Peritoneal Mesothelioma Diagnosed?

Peritoneal mesothelioma can only be diagnosed through a biopsy, but multiple tests and procedures are performed along the way.

These procedures include:

- **CT Scans:** X-rays are combined with computer technology to create detailed cross-sectional images of the abdomen. CT scans help doctors see the size, shape, and position of peritoneal mesothelioma tumors.
- **MRIs:** Powerful magnets and radio waves are used to create detailed images of the inside of the body. An MRI can provide more detailed information about tumor location and cancer spread than a CT scan.
- **Paracentesis:** A small needle is used to remove fluid that has built up in the abdomen. A lab will then analyze the fluid to see if it contains cancer cells.
- **PET Scans:** A special dye containing radioactive tracers is given orally or through an IV to highlight areas of increased cell activity associated with cancer.

If your doctor suspects you may have mesothelioma, they'll take a tissue biopsy using a small camera (laparoscope) and instruments inserted through small incisions in the abdomen. The tissue sample will then be sent to a lab and examined under a microscope to look for mesothelioma cells.

Because the symptoms of peritoneal mesothelioma can be mild or nonspecific, this type of cancer is often misdiagnosed as irritable bowel syndrome (IBS), gallstones, hernias, or ovarian cancer.

"It was very hard for me to get a full breath, and I got scared. I thought I was having a heart attack. The hospital said I could have Crohn's disease, so they wanted to narrow it down with a CT scan. We found out later that day that it was peritoneal mesothelioma."



– Brenda, 6-year peritoneal mesothelioma survivor





## Determining Peritoneal Mesothelioma Cancer Stage

Mesothelioma staging refers to **how far the cancer has spread from its original location**. Peritoneal mesothelioma does not have a formal staging system. However, doctors use the peritoneal cancer index (PCI) to analyze this cancer.

The PCI divides the abdomen into 13 sections, giving each section a score of 0–3. Zero means there is no cancer, while 3 indicates cancer is present. PCI scores provide a standard for oncologists and surgeons to measure the extent of the cancer and tailor treatment plans to each patient.

### The 4 PCI Stages

- **Stage 1:** PCI score of 1–10
- **Stage 2:** PCI score of 11–20
- **Stage 3:** PCI score of 21–30
- **Stage 4:** PCI score of 31–39



Reach out to our team anytime so we can help you find a peritoneal specialist in your area and schedule your first appointment. **(800) 943-0050.**

### Survivor Spotlight: Jill



- **Year diagnosed:** 2009
- **Symptoms:** Heavy menstrual cycle
- **Treatments received:** Chemotherapy and cytoreductive surgery with HIPEC

*“My family needs me, and I have to keep living my best so I can take care of them.”*

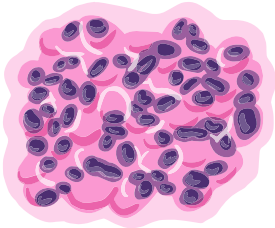




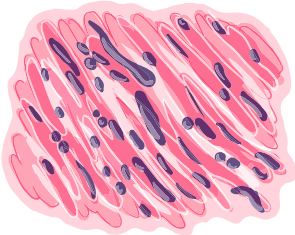
# Identifying Peritoneal Mesothelioma Cell Type

There are variations of cells that make up mesothelioma tumors. Cell type is an important part of a peritoneal mesothelioma diagnosis since it can affect your treatment options.

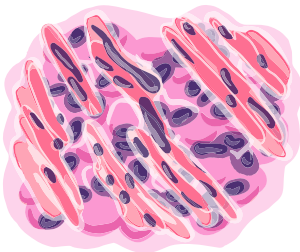
## Epithelioid Cells



## Sarcomatoid Cells



## Biphasic Cells



“The epithelioid cell type tends to have a better outlook than other cell types. That means there’s more reason to stay positive and hopeful about treatment possibilities.”



– Jenna Tozzi, RN,  
Chief Patient Care Advisor

The three main mesothelioma cell types are:

1

**Epithelioid:** The epithelioid cell type is the most responsive to treatment and has a better prognosis (health outlook) and survival rate than the other cell types. Surgery, chemotherapy, and immunotherapy are often recommended treatment options for this cell type.

2

**Sarcomatoid:** These rare mesothelioma cells are recognized by their large size and spindle shape. Only 10–20% of patients have sarcomatoid tumors. Chemotherapy and immunotherapy are the recommended treatment options for this cell type.

3

**Biphasic:** Biphasic tumors contain both the sarcomatoid and epithelioid mesothelioma cell types and account for 20–30% of cases. Depending on the ratio of epithelioid to sarcomatoid cells, surgery may be recommended as a treatment option.

There are also two less common cell subtypes:

- **Well-differentiated papillary mesothelioma** grows slowly and is usually less aggressive. It forms small, finger-like projections in the peritoneum. Because this subtype grows slowly, the prognosis for these patients is generally better, and it can often be managed successfully with aggressive treatments.
- **Multicystic mesothelioma** creates small cysts (fluid-filled sacs) in the abdomen. It’s also less aggressive and usually has a better prognosis. Treatment typically involves surgery to remove the cysts, but they can return over time.



# Treatment Options and What to Expect

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**Peritoneal mesothelioma treatment typically involves a combination of surgery and chemotherapy. Other treatment options include immunotherapy, new therapies being tested in clinical trials, and palliative care to manage symptoms and improve quality of life.**

The choice of treatment depends on the stage and cell type of the disease, your overall health, age, and other factors.

## **Cytoreductive Surgery with HIPEC**

Cytoreductive surgery with hyperthermic intraperitoneal chemotherapy (HIPEC) is the gold standard surgery for patients with peritoneal mesothelioma.

To qualify for this surgery, you must be in good overall health with early-stage cancer that hasn't spread past the abdomen. Your doctor may also order new imaging scans or perform a laparoscopic procedure to confirm your tumors can be safely and completely removed with surgery.

**More than 69% of patients are still alive 5 years after receiving cytoreductive surgery with HIPEC.**

## This two-part surgery involves:

### 1 Removing visible tumors from the peritoneum and abdomen.

Organs or parts of organs close to the peritoneum, such as the omentum, gallbladder, spleen, or large intestine, may also need to be removed.

### 2 Using catheters to administer a chemotherapy solution heated to 107 degrees.

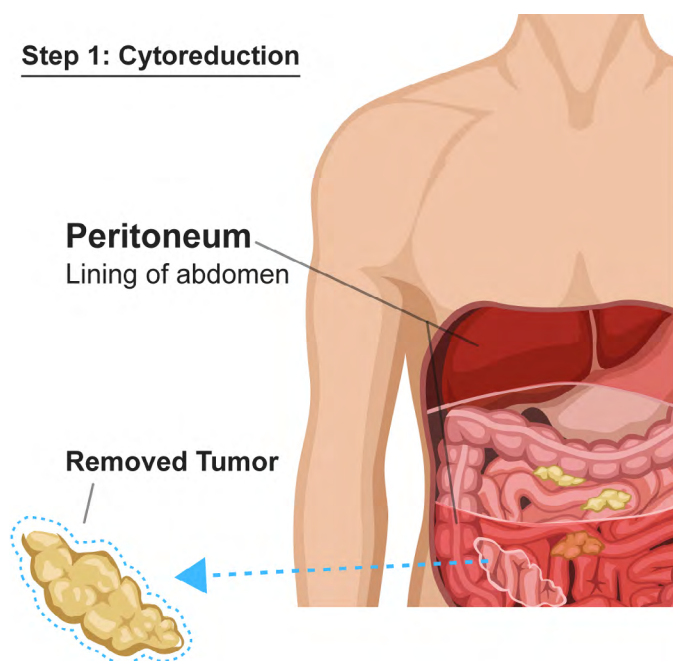
The liquid solution is circulated through the abdomen for 30–90 minutes to kill any remaining cancer cells.

Administering HIPEC after surgery allows for a higher concentration of the drugs to reach any remaining cancer with fewer side effects than standard chemotherapy.

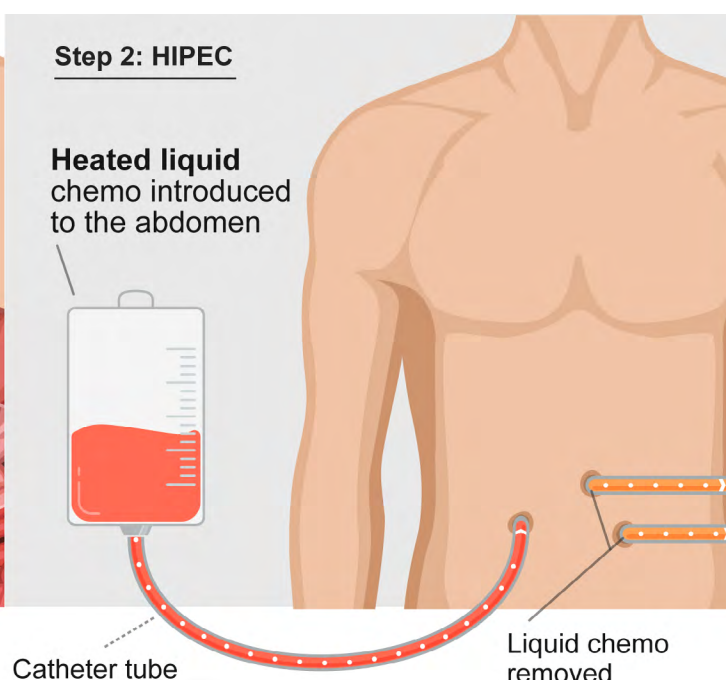
After surgery, patients are typically moved to a regular hospital floor for about **7–10 days**. During this time, they receive IV nutrition and follow a pain management protocol.

Physical exercise is encouraged as soon as possible to aid recovery. It may take a few weeks for bowel function to return to normal, and many patients experience fatigue for several weeks after returning home.

#### Step 1: Cytoreduction



#### Step 2: HIPEC



Cytoreduction with HIPEC takes between **8–12 hours**. Most patients stay in the intensive care unit for 1–2 days for close monitoring.

## Chemotherapy

Chemotherapy is the recommended treatment for peritoneal mesothelioma patients who are not candidates for surgery.

During chemotherapy, cancer-fighting drugs are administered through an IV to shrink peritoneal mesothelioma tumors and kill cancerous cells throughout the body.

**The main chemotherapy drugs used to treat peritoneal mesothelioma are:**

- Alimta® (pemetrexed)
- Cisplatin or carboplatin

Peritoneal mesothelioma patients can receive chemotherapy as a standalone treatment or in addition to cytoreductive surgery.

When undergoing chemotherapy for peritoneal mesothelioma, patients typically receive **treatments every 21 days**. Each chemotherapy cycle is followed by a rest period so the body has time to recover between sessions.

Chemotherapy medications can cause fatigue and nausea, but your doctor will prescribe folic acid and vitamin B12 to help combat these side effects.

## Immunotherapy

Immunotherapy is a newer type of cancer treatment that has many mesothelioma specialists feeling hopeful because of its potential to slow the spread of the disease and improve survival rates.

Immunotherapy drugs **reprogram the immune system to find and kill cancer cells**. The role of immunotherapy in peritoneal mesothelioma treatment is expanding as doctors learn from its success in treating pleural mesothelioma.

“Immunotherapy drugs like Keytruda®, Opdivo®, and Yervoy® are commonly used medications in peritoneal mesothelioma.”



– Jenna Tozzi, RN, Chief Patient Care Advisor

Immunotherapy is often used as a second-line treatment option for peritoneal mesothelioma. This means it is used if standard treatments like surgery or chemotherapy aren't an option or have stopped working.

## Survivor Spotlight: Alexis



- **Year diagnosed:** 2007
- **Symptoms:** Abdominal pain
- **Treatments received:** Chemotherapy and cytoreductive surgery with HIPEC

“If I can help give even one person a small bit of hope, then this life of mine is worth something.”



## Palliative Care

Patients can receive palliative care at any point during treatment to manage symptoms and improve their quality of life.

**Palliative care for peritoneal mesothelioma can include:**

- **Complementary therapies:** Acupuncture, massage, and relaxation techniques like yoga or meditation to enhance well-being
- **Nutritional support:** Maintaining strength and energy by optimizing your diet
- **Pain management:** Medications and therapies to control pain and discomfort
- **Paracentesis:** A procedure that removes excess fluid from the abdominal cavity (ascites) to reduce bloating and improve breathing
- **Physical therapy:** Exercises and activities to maintain your mobility

The goal of palliative care is to provide holistic support that **addresses each patient's physical, mental, and emotional needs** throughout their treatment journey.

“Palliative care is your best friend through this process. You may experience unwanted long-term effects from treatment and you can enhance your quality of life by taking charge of it.”



– Jenna Tozzi, RN, Chief Patient Care Advisor

## Clinical Trials

Clinical trials offer peritoneal mesothelioma patients access to cutting-edge treatments that are not widely available to the public.

**Various emerging treatments are being studied for peritoneal mesothelioma:**

- **Experimental vaccines** are being developed to stimulate the immune system to recognize and attack mesothelioma cells. These vaccines are designed to boost the body's natural defenses against cancer.
- **Gene therapy** involves modifying the patient's own genes to fight cancer. Scientists are exploring ways to correct genetic defects or introduce new genes that can improve the body's ability to combat mesothelioma.
- **Targeted therapy** focuses on specific genetic mutations or proteins that drive cancer growth. Targeted therapies can target cancer cells without harming healthy tissue, potentially reducing side effects compared to traditional chemotherapy.

Participating in a clinical trial provides an opportunity to benefit from the latest advancements in cancer therapy at no cost to you.

Clinical trials for mesothelioma are highly regulated by the U.S. Food and Drug Administration (FDA) to protect patients' health and safety.



# Finding a Mesothelioma Specialist for Treatment

Mesothelioma Hope is dedicated to helping patients get the very best medical care. One of the ways we do that is by matching them with doctors who meet their needs, location, and financial situation.

Our Patient Advocates can connect you with peritoneal mesothelioma specialists for an initial diagnosis, second opinion, treatment, or ongoing care.

Some of the top doctors for peritoneal mesothelioma include:



**Dr. Daniel M. Labow**

Nuvance Health  
Praxair Cancer  
Center in  
Danbury, CT



**Dr. Hedy Lee Kindler**

University  
of Chicago  
Comprehensive  
Cancer Center in  
Chicago, IL



**Dr. Joel Baumgartner**

Moore's Cancer  
Center at UC San  
Diego in  
San Diego, CA



**Dr. Richard N. Berri**

Van Elslander  
Cancer Center  
in Grosse Pointe  
Woods, MI



**Dr. Travis Grotz**

Mayo Clinic in  
Rochester, MN



Reach out to our team anytime so we can help you find a peritoneal specialist in your area and schedule your first appointment. **(800) 943-0050**.

# Living With Peritoneal Mesothelioma

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If you've been diagnosed with peritoneal mesothelioma, focusing on self-care can help improve your quality of life.

## Balance Your Nutrition and Protein Intake

Maintaining a balanced diet is crucial for supporting your body's strength and immune function during treatment.

### Nutrition tips for peritoneal mesothelioma patients include:

- **Eating small, frequent meals:** Smaller but more regular meals can help manage appetite changes and reduce discomfort.
- **Following a balanced diet:** Ensure you consume a variety of vegetables, fruits, whole grains, and healthy fats. This provides essential vitamins and minerals that support overall health.
- **Increasing protein intake:** Protein helps repair tissues and maintain muscle mass. Incorporate high-protein foods like lean meats, fish, eggs, dairy products, beans, and legumes into your meals.
- **Staying hydrated:** Drink plenty of water throughout the day to stay hydrated, especially if you are experiencing side effects like nausea or vomiting.

## Build a Support System

Mental and emotional support is vital when navigating life with peritoneal mesothelioma.

### Below are some support options that can help you:

- **Peer mentors:** Peer mentorship programs allow you to connect with survivors and caregivers who have experience with mesothelioma.
- **Professional counseling:** A therapist or counselor can help you navigate the emotional aspects of your diagnosis and treatment.
- **Support groups:** There are in-person and online groups where you can share your feelings and challenge with others who understand what you are going through.

A mesothelioma diagnosis can be overwhelming, but you are not alone. Mesothelioma Hope's caring Patient Advocates are here to listen and help you find support.

## Managing Symptoms and Side Effects

Effectively managing symptoms and side effects can improve your comfort and well-being.

Focusing on nutrition, seeking support, and effectively managing symptoms can enhance your quality of life and help you navigate the challenges of peritoneal mesothelioma more effectively.

Remember to communicate openly with your healthcare team so they can provide the best possible care and support.

“Patients assume when they have the disease, that they can’t survive and can’t live with the disease, even though many of our patients are walking around living relatively normal lives.”



– Dr. Taylor Ripley, mesothelioma specialist at the Baylor Lung Institute in Houston

Here are some of the common side effects of treatment and potential ways to find relief:

- **Breathing difficulties:** Deep breathing exercises and relaxation techniques can help manage shortness of breath.
- **Fatigue:** Gentle exercise like walking or stretching can help increase your energy level. You can conserve energy by prioritizing activities — don’t feel bad saying “no” to things — and taking regular rest breaks.
- **Gastrointestinal issues:** Eating small, frequent meals throughout the day and in some cases, avoiding certain foods may be necessary. Your doctor can prescribe anti-nausea medications and refer you to a dietician to manage your nutritional needs.
- **Pain management:** Your health care team can develop a pain management plan that may include medications, physical therapy, and complementary therapies like acupuncture or massage.





# Pursuing Financial Assistance

A peritoneal mesothelioma diagnosis may leave you feeling scared for your future, wondering how you'll pay for treatment and take care of your loved ones.

A 2024 study in *Current Oncology* found that more than 50% of cancer patients experience financial distress. This stress can have a lasting impact on your physical and mental health as well as your family's.

"A peritoneal mesothelioma diagnosis can make you feel powerless, but one thing you can control is your ability to reduce financial distress for you and your family."



– Jenna Tozzi, RN, Chief Patient Care Advisor

Fortunately, several financial support options are available to help you pay for the treatment you need to live longer. Many patients start receiving their **first payouts within 90 days**.

## Filing Legal Claims

Filing a legal claim allows you to seek justice for yourself or on behalf of a loved one who developed peritoneal mesothelioma after exposure to asbestos products.

Nearly all mesothelioma claims are settled out of court, with an average settlement **between \$1 million and \$1.4 million**, allowing you to receive compensation without going to trial.

Mesothelioma Hope has partnered with Simmons Hanly Conroy – a top asbestos law firm – to help victims and their loved ones get justice for their illnesses.

## In Memoriam: Mary Jane



- **Year diagnosed:** 2003 (passed away from Alzheimer's disease in 2018)
- **Symptoms:** Abdominal bloating, sweating, and weight loss
- **Treatments received:** Chemotherapy and cytoreductive surgery with HIPEC

"You need the compensation. You need it for your treatments. You need it for your transportation."



Our legal partners have secured **over \$9.3 billion in mesothelioma compensation** for families nationwide, including:

- **\$11.9 million** for a New York real estate investor with peritoneal mesothelioma
- **\$5.8 million** for a Florida man who developed peritoneal mesothelioma as a mechanic
- **\$4.9 million** for a peritoneal mesothelioma patient in Illinois who suffered secondhand asbestos exposure
- **\$4.5 million** for a U.S. Navy veteran in Florida who developed peritoneal mesothelioma
- **\$4.3 million** for a Missouri electrician with peritoneal mesothelioma
- **\$4.1 million** for a California electrician and laborer with peritoneal mesothelioma
- **\$3.8 million** for a U.S. Navy veteran from Illinois who developed peritoneal mesothelioma
- **\$6.4 million** for the family of a North Carolina peritoneal mesothelioma patient

A mesothelioma lawyer can handle every step of the legal process on your behalf while you focus on your health and well-being.

“Simmons made the legal process for my family and I very easy, and I was very comfortable.”



– Dennis, peritoneal mesothelioma patient & Simmons Hanly Conroy client

## Accessing Asbestos Trust Funds

Starting in the late 1980s, the U.S. court system forced asbestos product manufacturers – who avoided lawsuits by filing for bankruptcy – to deposit money in special trusts for current and future victims of asbestos-related diseases.

Today, **over \$30 billion** is set aside in asbestos trust funds. You may be able to access a portion of this money if you or a loved one was diagnosed with mesothelioma.

Asbestos victims usually qualify to file claims with multiple trusts, increasing their total compensation.

## Increasing Veterans Benefits

If you or a loved one developed mesothelioma cancer from service-related asbestos exposure, you can pursue financial support and free or low-cost medical care through the U.S. Department of Veterans Affairs (VA).

Veterans with mesothelioma almost always qualify for disability benefits, which pay almost **\$4,000 a month in tax-free compensation** if you're married.

### Other VA benefits that offer mesothelioma financial assistance include:

- Aid & Attendance
- Dependency and Indemnity Compensation (VA DIC)
- Funeral and burial allowances
- Pensions for victims and surviving loved ones
- Special Monthly Compensation (SMC)

Outside of VA benefits, you can work with a lawyer to pursue mesothelioma veterans compensation through asbestos trust fund claims and mesothelioma lawsuits. If you choose these options, you won't take legal action against the U.S. military or government.

Filing a legal claim won't affect your current or future veterans benefits – you can pursue both at the same time.

# Your Mesothelioma Lifeline: How We Can Help

**Mesothelioma Hope is here to serve patients, families, and caregivers who need help dealing with the challenges related to a cancer diagnosis.**

Think of us as an extra layer of personalized support throughout your journey with peritoneal mesothelioma.

## **Our experienced Patient Advocates can:**

- Listen to your story
- Help you understand your diagnosis
- Connect you with mesothelioma specialists in your area
- Empower you with information to make the most of your doctor's appointments
- Walk you through financial options to pay for treatment
- Share information on support groups and peer mentors
- And much more

*"Answering patient questions, explaining treatment options, and sometimes just listening to a patient and their loved one is the number one reason why I'm here."*



– Amy Fair, RN, Mesothelioma Hope  
Patient Advocate

Reach out for help today — **it's always free to speak with us. Call (800) 943-0050.**



# Your Mesothelioma Lifeline



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**Your Patient Advocate is standing by.  
Call (800) 943-0050 now!**

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MesotheliomaHope.com  
1330 Boylston Street, Suite 400, Chestnut Hill, MA 02467