

Understanding Pleural Mesothelioma

A Patient's Guide

Mesothelioma Hope

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What Is Pleural Mesothelioma?

Pleural mesothelioma is the most common type of mesothelioma. It develops in the pleura, which is the thin lining of tissue surrounding the lungs.

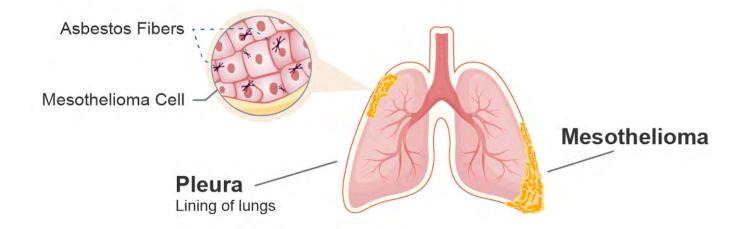
The only known cause of pleural mesothelioma is exposure to asbestos, a mineral widely used in construction, shipbuilding, and other industries until the early 1980s.

The average life expectancy with pleural mesothelioma is about 1.5 years or 18 months. However, many patients have lived 10 years or more with specialized treatment. A pleural mesothelioma specialist can determine the best treatments to help manage your cancer and reduce symptoms.

"You might not win the war, but you must fight like you can. You might even surprise yourself with how strong you are. I've been fighting nonstop for more than a decade."



- John Panza, 12+ year pleural mesothelioma survivor



Causes and **Risk Factors**

Asbestos exposure causes pleural mesothelioma. When asbestos is breathed in or swallowed, the tiny fibers can lodge in the delicate tissue around the lungs and never leave.

Over time, these asbestos fibers irritate healthy pleural tissue, causing inflammation and scarring. There's usually a latency period of 10-50 years for pleural mesothelioma to develop and for cancerous cells to become detectable.

Who's at Risk for Pleural Mesothelioma?

Some people are at a higher risk of pleural 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, account for 33% of mesothelioma patients.
- 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 contained asbestos.

"I was exposed to asbestos through Sheetrock® products, the mud, through gaskets, in piping, through respirators," said John Stahl, a retired construction worker and stage 4 mesothelioma survivor. "The cartridges and the filters had asbestos in them throughout my career."



John, 5+ year pleural mesothelioma survivor

Signs and Symptoms

Because of how slowly pleural mesothelioma develops, patients may not have any symptoms for decades after they're exposed to asbestos.

The most common symptom is fluid buildup around the lungs, also known as pleural effusion. According to a 2022 report in *Pathology International*, more than **80%** of cases start with pleural effusion.

People with pleural effusion usually experience **shortness of breath** that worsens when lying down or during physical activity.

The symptoms of mesothelioma become more severe as the cancer spreads.

Other warning signs include:

- Chest pain
- Difficulty swallowing (dysphagia)
- Fatigue
- Hoarseness
- Night sweats
- Pain near the rib cage
- Weight loss
- Worsening cough

Highlighting Hope: Arthur



- Still thriving: 6+ year survivor
- Symptoms: Hacking cough
- Treatments received: Chemotherapy, immunotherapy, and alternative medicine

"I survived mesothelioma because of my wife talking me into getting my treatment, which I wasn't going to do."



How Is Pleural Mesothelioma Diagnosed?

Pleural mesothelioma can only be diagnosed through a biopsy, but doctors may perform multiple tests and procedures along the way.

In 2021, the World Health Organization (WHO) introduced two new classifications for pleural mesothelioma:

- Diffuse mesothelioma: The more common and aggressive cancer that has spread widely beyond the lung lining.
- Mesothelioma in situ: Early-stage cancer that stays localized in one area and hasn't spread.

A timely and accurate diagnosis is key to determining the best treatment plan for your cancer.

Imaging Scans

When doctors suspect pleural mesothelioma, they begin with imaging scans to get a detailed look inside your body.

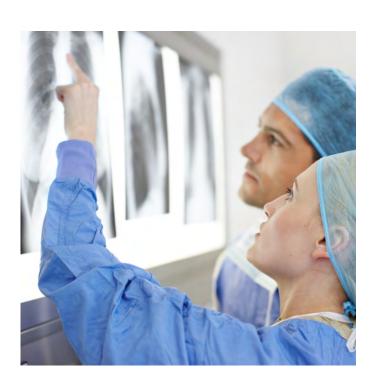
There are 3 main types of imaging tests used:

- X-rays: Low doses of radiation create pictures of the inside of your chest, helping doctors spot any abnormalities
- CT or CAT scans: Advanced X-rays that provide detailed, crosssectional images of your chest
- PET scans: A test that uses a small amount of radioactive material to find cancer in the body

These scans reveal tumors, abnormal growths, and other key indicators of pleural mesothelioma.

Some of the most common signs include:

- Calcification: Hard calcium deposits in the lung lining
- Pleural effusion: Extra fluid between the lungs and chest wall
- Pleural plaques: Pearly white, rubbery, or hard areas on the lung lining
- Pleural thickening: Thickening of the lung lining, which can make breathing more difficult



Fluid vs. Tissue Biopsy

To confirm a pleural mesothelioma diagnosis, doctors must examine cells from your body under a microscope.

This can be done in one of two ways:

- Fluid biopsy: While this method is less invasive, it may not provide a definitive diagnosis if there aren't enough cancerous cells in the fluid.
- **Tissue biopsy:** This involves taking a small piece of tissue from the affected area, often using a procedure called video-assisted thoracoscopic surgery (VATS). It is the gold standard for getting an accurate diagnosis.

"They started out with X-rays, which showed some fluid in the lung. Then we went to a CAT scan, then we went to a PET scan. The radiation department suggested that I have biopsy surgery, and that's when I found out that I had mesothelioma."



Ernie, 7-year pleural mesothelioma survivor

Preventing Misdiagnosis

Since pleural mesothelioma is so rare, it's often mistaken for other lung-related illnesses, which can delay proper treatment.

Common misdiagnoses include:

- Adenocarcinoma (another type of cancer)
- **Bronchitis**
- Chronic obstructive pulmonary disease (COPD)
- Lung cancer
- Pneumonia

A fluid or tissue biopsy is essential to avoid being misdiagnosed. Cancerous mesothelial cells can be found in fluid samples, and immunohistochemical staining on biopsy tissue helps identify specific proteins and biomarkers expressed by the tumor that can confirm whether you have mesothelioma.

It's also important to get a second opinion from a specialist to ensure you've been correctly diagnosed before starting treatment.

Nearly 1 in 4 pleural mesothelioma patients are misdiagnosed at first, according to a report in The Open Epidemiology Journal.



Identifying Cell Type

Mesothelioma tumors are made up of different types of cancer cells. Cell type is an important part of a pleural mesothelioma diagnosis since it can affect your treatment options and provide you with a better understanding of your prognosis.

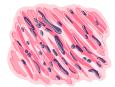
Your mesothelioma cell type is identified through a tissue biopsy and shown on the pathology report after immunohistochemical staining is done. This is a special lab test that uses dyes to help doctors see specific types of cells under a microscope.

Epithelioid Cells



Average prognosis: 14 months

Sarcomatoid Cells



Average prognosis: 4 months

Biphasic Cells



Average prognosis: 10 months

"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."



The three main mesothelioma cell types are:

- **Epithelioid:** Making up around 70% of cases, this cell type is the easiest to treat and has the best prognosis (health outlook). Surgery, chemotherapy, and immunotherapy can be used to treat epithelioid mesothelioma.
- 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.
- Biphasic: Biphasic tumors contain both sarcomatoid and epithelioid mesothelioma cells and make up 20-30% of cases. Surgery may be recommended as a treatment option depending on the ratio of epithelioid to sarcomatoid cells.

There are two less common cell variants of pleural mesothelioma that include:

- **Desmoplastic mesothelioma** is a rare subtype of sarcomatoid mesothelioma made up of thick, fibrous tissue. It tends to grow slowly but is still difficult to treat. Treatment options may include surgery, chemotherapy, or radiation, depending on how advanced the cancer is.
- Multicystic mesothelioma creates small cysts (fluid-filled sacs) in the lung lining. It's less aggressive than other types and usually has a better prognosis. Surgery is often used to remove the cysts, but they may come back over time.



Genetic Testing

Your doctors may examine your biopsy sample to identify specific genetic mutations that can provide valuable insights into your diagnosis and treatment plan.

One of the most common mutations is a change in the BAP1 gene, which normally helps prevent tumors. When this gene is altered, it may lead to cancer.

Other genes that may be affected include:

- CDKN2A: Helps control cell growth
- NF2: Regulates cell growth and communication
- TP53: Protects against cancer
- SETD2 and SETDB1: Help control how DNA is organized and read by cells

Your doctor may suggest genetic testing as part of the diagnosis process, but it's not always necessary.

Staging the Disease

After a pleural mesothelioma diagnosis, the next step is to determine the stage of the cancer. Staging is crucial as it helps doctors develop the most effective treatment plan.

Pleural mesothelioma has four stages under the tumor-node-metastasis (TNM) staging system, the global standard for classifying cancer spread.

Four Stages

- Stage 1: The cancer is localized and confined to the lung lining.
- Stage 2: Tumors have spread to nearby lymph nodes and may affect nearby organs.
- **Stage 3:** The cancer has spread extensively to nearby organs and lymph nodes.
- **Stage 4:** The tumors have spread to distant organs throughout the body.

Imaging tests such as CT and PET scans are typically used to see how far the cancer has spread. If surgery is being considered, doctors can perform diagnostic surgery to determine if the tumors can be removed successfully.



Reach out to our team so we can help you find a pleural mesothelioma specialist in your area and schedule your first appointment. Call (800) 943-0050 now.

Treatment Options and What to Expect

Pleural mesothelioma treatment typically involves a combination of surgery, chemotherapy, immunotherapy, and radiation.

Other treatment options include new therapies being tested in clinical trials and palliative care to manage symptoms and improve quality of life.

"I come up with a plan with our medical oncologists and radiation oncologists, and we all talk together about what the best treatments might be. We also consider what goals the patient may have — if they favor more aggressive or less aggressive options."



- Dr. Matthew Steliga, pleural mesothelioma specialist at UAMS Winthrop P. Rockefeller Cancer Institute

Pleurectomy With Decortication Surgery

Pleurectomy with decortication (P/D) is a two-part surgery that can help control the spread of pleural mesothelioma while relieving shortness of breath and other symptoms.

- **Pleurectomy** removes part or all of the pleura.
- **Decortication** removes visible tumors from the chest cavity.

An expanded pleurectomy/decortication (eP/D) goes a step further by removing additional tissue beyond the pleura and visible tumors.

This might include parts of:

- The diaphragm (muscle below lungs)
- The pericardium (lining around heart)
- Other affected tissues in the chest cavity

The surgery usually lasts **5-6 hours**, followed by a hospital stay of about 5-7 days. Some patients are sent home with a drainage tube until their lung is healed.

P/D Surgery With HITHOC

After P/D surgery but while still in the operating room, some patients may undergo hyperthermic intrathoracic chemotherapy (HITHOC). The surgeon will apply heated chemotherapy into the chest cavity to kill any remaining mesothelioma cells and keep the cancer from returning.

A pleurectomy/decortication has been shown to double the life expectancy of patients with pleural mesothelioma.

Extrapleural Pneumonectomy Surgery

Extrapleural pneumonectomy (EPP) is a more aggressive surgery used to treat pleural mesothelioma.

During an EPP, the surgeon removes the:

- Entire affected lung
- Pleura
- Diaphragm
- Pericardium

Patients undergoing an EPP usually stay in the hospital for up to 10 days, and full recovery takes 6 to 8 weeks.

Some doctors prefer to use an EPP over a P/D because it allows more cancer to be removed. However, an EPP may come with a higher risk of complications since patients will only be left with one lung.

Consult a mesothelioma specialist to find out if an EPP or P/D may be better in your case.

Chemotherapy

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

Doctors select chemotherapy drugs based on the mesothelioma cell type:

- Epithelioid mesothelioma: Pemetrexed (Alimta®) with cisplatin or carboplatin is the primary treatment. Bevacizumab may be added for patients who don't qualify for surgery.
- Sarcomatoid and biphasic mesothelioma: Similar to epithelioid, pemetrexed with cisplatin or carboplatin is recommended.

When undergoing chemotherapy for pleural 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.

Highlighting Hope: Bonnie



- **Still thriving:** 3-time cancer survivor
- Symptoms: Difficulty breathing, fluid
- around the lungs (pleural effusion)

Treatments received: Chemotherapy and alternative treatment

"It's most important for any mesothelioma patient to take charge of their own choices and decisions about treatment."



Immunotherapy

Immunotherapy drugs use the body's immune system to target and destroy cancer cells.

Nivolumab (Opdivo®), ipilimumab (Yervoy®), and pembrolizumab (Keytruda®) are three immunotherapies approved for pleural mesothelioma that can't be removed with surgery.

"Immunotherapy and the combination of Opdivo and Yervoy was found to be effective for the sarcomatoid cell type, and it was really a game changer."



- Dr. Andrea Wolf, pleural mesothelioma specialist at Mount Sinai Hospital

One benefit of immunotherapy is that patients can receive it even in advanced stages of pleural mesothelioma, regardless of their cell type.

Like chemotherapy, immunotherapy is typically administered through an IV infusion. Patients usually undergo several cycles or rounds of treatment, with sessions spaced a few weeks apart to give the body time to recover.

Radiation Therapy

Radiation therapy uses high-energy particles or waves to destroy or damage cancer cells. It can also manage pain by shrinking any tumors that are pressing on vital organs or nerves.

There are two main types of mesothelioma radiation:

- External beam radiation therapy (EBRT): This is the most common type and is administered through the skin from outside the body.
 - Proton therapy is a more advanced form of EBRT that allows doctors to precisely target tumors while minimizing damage to healthy tissue.
- **Brachytherapy:** This internal radiation therapy works by placing a radioactive device inside the tumor, allowing higher doses of radiation to target more specific places than EBRT.

Radiation can be administered before, during, or after surgery or chemotherapy. The standard course of radiation treatment is 5 days a week for 5-6 weeks, with each session lasting 15-30 minutes on average.



Palliative Care

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

Palliative care for pleural 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
- Thoracentesis: Drains excess fluid from around the lungs
- Physical therapy: Exercises and activities to maintain your mobility
- **Pleurodesis:** Seals the space between the lung and chest wall to prevent fluid buildup

Palliative care provides 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 side effects from treatment, and you can enhance your quality of life by taking charge of it."



Jenna Tozzi, RN, Chief Patient Care Advisor

Early palliative care for mesothelioma can lead to a 25% improvement in overall quality of life, according to an April 2024 peer-reviewed study.

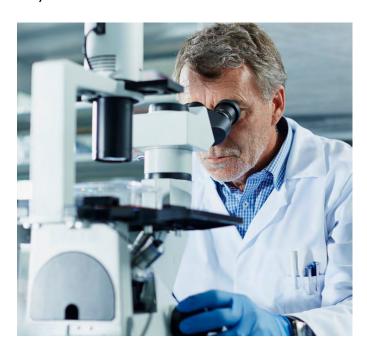
Clinical Trials

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

New treatments being studied for pleural mesothelioma include:

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

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





Finding a Mesothelioma **Specialist for Treatment**

Mesothelioma Hope is dedicated to helping people access the best medical care. One way we do that is by matching patients with doctors who meet their needs, location, and financial situation.

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

Some of the top doctors for pleural mesothelioma include:



Dr. Raphael Bueno Thoracic surgeon

Brigham and Women's Hospital in Boston, MA



Dr. Robert Cameron Thoracic surgeon

UCLA Medical Center in Los Angeles, CA



Dr. David Harpole Jr. Thoracic surgeon

Duke Cancer Center in Durham, NC



Dr. Hedy Lee Kindler Medical oncologist

University of Chicago Comprehensive Cancer Center in Chicago, IL



Dr. Taylor Ripley Thoracic surgeon

Baylor Lung Institute in Houston, TX



Dr. James Stevenson Medical oncologist

Cleveland Clinic in Cleveland, OH



Call (800) 943-0050 anytime so we can help you find a pleural mesothelioma specialist in your area and schedule your first appointment.

Living With Pleural Mesothelioma

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

With advances in treatment and an emphasis on holistic care, patients are finding new ways to regain control of their health and improve their 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 pleural 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. These provide 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

Navigating life with pleural mesothelioma can be challenging, so it's crucial to have mental and emotional support. A recent mental health study found that half of mesothelioma patients struggle with anxiety while awaiting scan results or worrying about the possibility of their cancer spreading or returning.

Below are some support options that can help you:

- Peer mentors: Peer mentorship programs allow you to connect with survivors and caregivers impacted by mesothelioma and other rare cancers.
- Professional counseling: A therapist or counselor can help you navigate the emotional aspects of your diagnosis and treatment.
- Support groups: In-person and online groups allow you to share your feelings and challenges with others who understand what you are going through.

A mesothelioma diagnosis can be overwhelming, but you're 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. 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 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.

Moving your body can also improve muscle mass, strength, and overall physical well-being while fighting mesothelioma, according to a 2024 report in Current Oncology.

Remember to communicate openly with your health care 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

Highlighting Hope: John



- Still thriving: 5+ years with stage 4 mesothelioma
- **Symptoms:** Fatigue, trouble breathing
- Treatments received: Chemotherapy

"I'm doing very well. I play golf twice a week. I go hang out with my friends when they're around. I'm pretty well back to normal."



Pursuing Financial Compensation

A pleural 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 pleural 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 pleural mesothelioma.

Nearly all mesothelioma lawsuits or legal claims are settled out of court, with average settlements awarding 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.

Our legal partners have secured **over \$9.6 billion in mesothelioma compensation** for families nationwide, including:

- \$250 million for an Indiana steelworker with pleural mesothelioma (largest asbestos verdict for a single plaintiff in the U.S.)
- \$34 million for a California auto mechanic who developed pleural mesothelioma
- **\$24.4 million** for an Illinois janitor with pleural mesothelioma
- \$8 million for a Louisiana mechanic who developed pleural mesothelioma
- \$6.88 million for an auto mechanic in Florida with pleural mesothelioma
- \$4 million for a U.S. Navy veteran & boiler operator from Kansas with pleural mesothelioma
- \$3.8 million for the wife of a Pennsylvania maintenance worker who passed away from pleural mesothelioma
- \$3.35 million for a U.S. Air Force veteran from Nevada with pleural mesothelioma
- \$15 million for the family of a New York construction worker who passed away from pleural mesothelioma

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

Accessing Asbestos Trust Funds

In the late 1980s, U.S. courts required asbestos product manufacturers that filed for bankruptcy to set aside money in special trusts. These trusts were created to compensate 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.

"The Simmons difference is that those people are absolutely top shelf. I didn't have to do anything except make a phone call."



- Howard, Simmons Hanly Conroy client & spouse of a pleural mesothelioma patient

Increasing Your Veterans Benefits

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

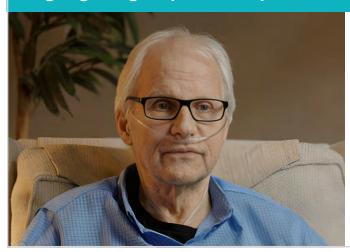
Married veterans with mesothelioma may qualify for 100% disability benefits worth nearly **\$4,000 a month**.

Other key VA benefits for pleural mesothelioma patients include:

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

You can still file for VA benefits even if you pursue compensation through mesothelioma lawsuits or asbestos trust fund claims. These other options don't involve suing the U.S. military or government.

Highlighting Hope: Jimmy



- Still thriving: 2+ year survivor
- Symptoms: Fatigue, shortness of breath
- Treatments received: Chemotherapy and immunotherapy

"One check showed up, and then another check showed up, and then another, and they're still coming in now. It's been very satisfying."

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 pleural 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.



Your Mesothelioma Lifeline



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

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