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**Learn About Mesothelioma**

Mesothelioma is a rare type of cancer that develops in the pleura, a thin membrane that separates the lung from the chest wall. As it progresses along the membrane, it results in breathing difficulties, chest pain, and fever. It usually occurs from prior exposure to asbestos, a type of mineral fiber used in the insulation industry. Mesothelioma can also arise, less commonly, along the lining of the abdomen.

**Key Facts**

- Mesothelioma is a rare type of cancer that usually arises from the lining of the lung (pleura) and less commonly the lining of abdomen (peritoneum).
- Although patients with mesothelioma have been exposed to asbestos, only a small fraction of patients with exposure develop the disease.
- Mesothelioma is not caused by smoking.
- Other causes have been identified, and sometimes it is unclear what causes a person to get mesothelioma.

**What Is Mesothelioma?**

There are approximately 3,500 new cases of mesothelioma every year in the United States. This is a very small number compared with lung cancer (220,000 new cases per year in the United States). It is caused by exposure to asbestos in at least 80% of the cases, and in some, there is probably exposure that a patient may not know about. When asbestos fibers are inhaled into the lung, they can penetrate very deeply due to their small size and accumulate near the lining of the lung, or pleura. These fibers can irritate the pleura resulting in inflammation and abnormal growth of mesothelial (surface lining) cells, which can eventually lead to cancer. The abnormally growing mesothelial cells produce tumor nodules on the surface of the lung and cause fluid accumulation (pleural effusion) between the lung and the chest wall, resulting in pain and shortness of breath. There are other areas in the body with a lining similar to the pleura that can also be affected, although much less commonly.

**How Mesothelioma Affects Your Body**

Mesothelioma, unlike other cancers, tends to grow mainly along the surface of the lung and other surfaces of the chest resulting in pain from invasion of nerves, and shortness of breath from compression of the lungs or restriction of lung expansion. Tumor nodules and fluid accumulates along the pleural space between the lung and the chest wall. Sometimes the growth of the tumor leads to fever. Though mesothelioma can spread to chest lymph nodes and invade into the lung, it is rare for it to spread to the rest of the body. Left untreated, mesothelioma worsens and can cause death.

**How Serious Is Mesothelioma?**

Mesothelioma is a very serious disease. While promising research efforts are underway, there is currently no consistently effective treatment for this disease. However, treatment to ease symptoms, sometimes called palliative or supportive care, can often control debilitating symptoms. The severity of mesothelioma can vary from person to person.
Mesothelioma Symptoms, Causes, and Risk Factors

Mesothelioma generally occurs in people who have previously been exposed to asbestos, sometimes 40 to 60 years prior to the diagnosis. In most cases, mesothelioma occurs at least 20 years after asbestos exposure. Those who get mesothelioma are usually exposed to higher levels of asbestos than those who get other asbestos-related disease, including lung scarring (fibrosis) and lung cancer.

What Are the Symptoms of Mesothelioma?
Less than 5% of individuals exposed to asbestos will eventually develop mesothelioma. Sometimes, the diagnosis is discovered on a chest-X-ray for other reasons.

The most common symptoms are:
- Shortness of breath
- Chest pain, increased during breathing efforts
- Dry, persistent cough
- Frequent chest cold symptoms

The progression of the cancer can also result in general symptoms such as:
- Weight loss with low appetite
- Generalized fatigue
- Low grade fever

When other areas of the body are affected by mesothelioma, other localized symptoms may occur:
- When the peritoneum (lining on the abdomen) is involved, abdominal swelling, constipation, intestinal obstruction, and pain and nausea may occur.
- An abnormal mass or swelling may be felt in the scrotum when its lining is involved.

Rarely, the defense mechanisms of the body may try to control the disease by producing antibodies aimed at fighting the cancer that can themselves lead to symptoms, such as hypoglycemia, blood clots in the legs or the lungs, and various neurological symptoms. These symptoms are called “paraneoplastic,” which means “associated with cancer.”

What Causes Mesothelioma?
Researchers are still trying to understand what causes mesothelioma, other than as a response to asbestos fibers over a long period of time.

What Is Asbestos?
When an individual is exposed to asbestos, the small fibers can easily be inhaled into the lungs, increasing the risk of developing mesothelioma, lung cancer, and a type of scarring lung disease called asbestosis.

What Are the Risk Factors?
- **Asbestos exposure:** Asbestos is a mineral fiber that resists fire and heat, and has been used in insulation and fire-retardant materials. Concerns over human safety appeared at the beginning of the 20th century, and its use was finally banned or tightly regulated in most countries 30 years ago. Most individuals who develop mesothelioma due to asbestos were exposed during their work, called an “occupational exposure.” The typical occupations associated with exposure to asbestos include miners or millers, electricians, plumbers, pipe-fitters, insulators, and even individuals who have remodeled older homes or lived with workers exposed to asbestos. Living in a house that contains asbestos is not generally considered to be a cause of mesothelioma when the asbestos is enclosed in walls and ceilings, and not directly breathed by individuals.

- **Smoking is not a risk factor for mesothelioma; however, quitting smoking is extremely important:** Asbestos exposure does not increase the risk of mesothelioma, but does increase the risk of lung cancer in general.
Other types of fibers, such as erionite, are thought to be responsible for mesothelioma as well. Erionite has been identified in a specific region in Turkey called Cappadocia and is thought to be responsible for the high rate of mesotheliomas observed in that area.

Age: The risk of developing mesothelioma increases with age. This is due to the fact that it takes a long time for mesothelioma to develop after asbestos exposure, usually at least 20 years. This length of time from exposure to malignancy is called latency.

Other causes have been discovered, including prior radiation therapy, particularly in patients who have received high doses of radiation therapy to the chest for cancer, such as in the treatment of lymphoma, and certain rare genetic mutations. These causes are much less common than asbestos exposure.

Sometimes, no cause can be identified at all.

When to See Your Doctor
If you have been exposed to asbestos at work or somewhere else, have been diagnosed with frequent pneumonias, or experience the symptoms listed previously, you should consult your healthcare provider.

Diagnosing and Treating Mesothelioma

What to Expect
In general, individuals at risk and with a suspicion of mesothelioma should be referred to a specialist in lung diseases. That physician will order a series of one or more tests to prove the diagnosis of mesothelioma.

How Mesothelioma Is Diagnosed

Chest X-ray: A chest X-ray is usually ordered as a first step, but a chest computed tomography scan (or chest CT) will be needed in most cases. The chest X-ray may be normal or reveal signs of prior exposure to asbestos, called pleural plaques (thickened pleura with calcium deposits). Sometimes, the chest X-ray may reveal accumulation of fluid between the lung and the chest wall, or pleural effusion. These abnormalities, however, may only mean that the patient has been exposed to asbestos and do not establish the diagnosis of mesothelioma. A definitive diagnosis of mesothelioma cannot be rendered radiologically, it can only be confirmed by pathologic examination of tissue.

Fluid drainage or thoracentesis: When pleural fluid is identified, the next best step is to drain the fluid with an ultrasound-guided needle aspiration. This procedure is primarily performed to exclude other causes of pleural effusion (there are many) and is not usually sufficient to establish mesothelioma. Biopsies are needed.

Chest CT scan: This test allows a more detailed examination of the chest and may allow selection of a best site to biopsy. In addition, it can determine the extent of the disease. A needle biopsy may be performed guided by CT images in the same procedure.

Biopsy: There are many causes of disease of the pleura, so getting a tissue sample (biopsy) is usually required for diagnosis. A biopsy sample can be obtained from the outside, with CT or ultrasound guidance, under local anesthesia, or from the inside with the use of a small camera introduced between the lung and the chest wall (thoracoscopy or pleuroscopy), under general anesthesia. Both ways have advantages and disadvantages, but usually thoracoscopy or pleuroscopy are preferred as they allow deep sampling of larger areas, often needed to establish the diagnosis with certainty. Biopsy samples are often difficult to interpret under the microscope, and pathologists are often required to do additional testing on biopsy specimens to reach a definitive conclusion.
**Additional testing:** A breathing test (pulmonary function studies) and other tests such as blood workup are typically obtained to determine what kind of treatment the patient should receive. If the disease is advanced, an evaluation is done at rest and with activity to determine whether supplemental oxygen is required.

**Staging of the disease:** If mesothelioma is diagnosed, the extent of the disease needs to be determined, as this will guide treatment decisions. In addition to the chest CT, a positron-emission tomography scan (PET scan) is generally obtained to identify other areas involved with cancer, which may need to be biopsied, as well. Biopsies of suspicious areas may be performed.

**How Mesothelioma Is Treated**

Although some patients may be suitable for surgery, the results of treatment of mesothelioma with surgery, radiation and chemotherapy have so far been disappointing. It is important that patients with mesothelioma be referred to centers with experience in treating this rare disease who are familiar with modern approaches and who may be able to offer patients enrollment in research studies.

**Living With Mesothelioma**

Mesothelioma is usually diagnosed when the disease is advanced enough to cause symptoms. While treatments aimed at curing the disease are limited, most of these symptoms can be effectively managed to improve quality of life.

**What to Expect**

Shortness of breath is a common problem that interferes with quality of life in patients with mesothelioma. Depending on individual factors, shortness of breath may be addressed by removing fluid from the pleural space with a needle, placement of a drain, or sometimes surgery. Oxygen and narcotics like morphine may also improve shortness of breath.

There may be severe pain caused by progression of the cancer into the chest wall and nerve fibers, which may also lead to poor sleep. Pain is usually treated with medications, either orally, with a patch, or intravenously. Poor nutrition and fatigue are often present because of appetite loss, nausea, progression of the cancer, or chemotherapy.

Palliative care to control these distressing symptoms is a key component of the multidisciplinary care of patients with mesothelioma. Physicians specialized in the palliative management of patients with mesothelioma could be of great value in treating symptoms and assisting patients and their loved ones about make plans for the end of life. They should become part of the team as soon as possible after the diagnosis is established.

**Finding Support**

Being diagnosed with mesothelioma is a life-changing event with emotional, physical, familial, and, often, financial consequences. It is very important to establish strong relationships with a team of experts able to provide support and guidance in all aspects of the management of mesothelioma.

The Lung Association recommends patients and caregivers join our Living with Lung Disease Support Community to connect with others facing this disease. You can also call the Lung Association’s Lung HelpLine at 1-800-LUNGUSA to talk to a trained respiratory professional who can help answer your questions and connect you with additional support.
Questions to Ask Your Doctor About Mesothelioma

The diagnosis of mesothelioma is very serious and may be overwhelming and affects all aspects of life in a profound way. In order to make the best use of your limited time with health-care providers involved in your care, it might be useful to consider the following questions, as well as questions of your own, and we recommend actively preparing for each health-care visit by writing them down ahead of time.

You should feel comfortable asking all these questions and other ones that may be relevant to you. Important questions to ask after being diagnosed with mesothelioma may include:

- How do we know I have mesothelioma?
- Should I have a biopsy, and if so, what kind of biopsy should it be?
- How will we know how extensive the disease is, and what does that mean for me?
- How much experience do you and your colleagues have in treating mesothelioma?
- If you don’t have much experience, can you refer me to a center that does?
- Will my case be discussed in a group of experts from different specialties?
- What is the goal of the treatment you are proposing? Is the intent to cure me from the disease or manage its symptoms? What are the side effects of the proposed treatment and how will they affect my quality of life?
- How much will this cost for me? Can you help me identify somebody who might be able to answer these questions?
- Am I a candidate for any clinical trial?
- What are my options for palliative care to address management of my shortness of breath and pain?
- Can you help me and my family make decisions about how I will be treated at the end of my life?

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