

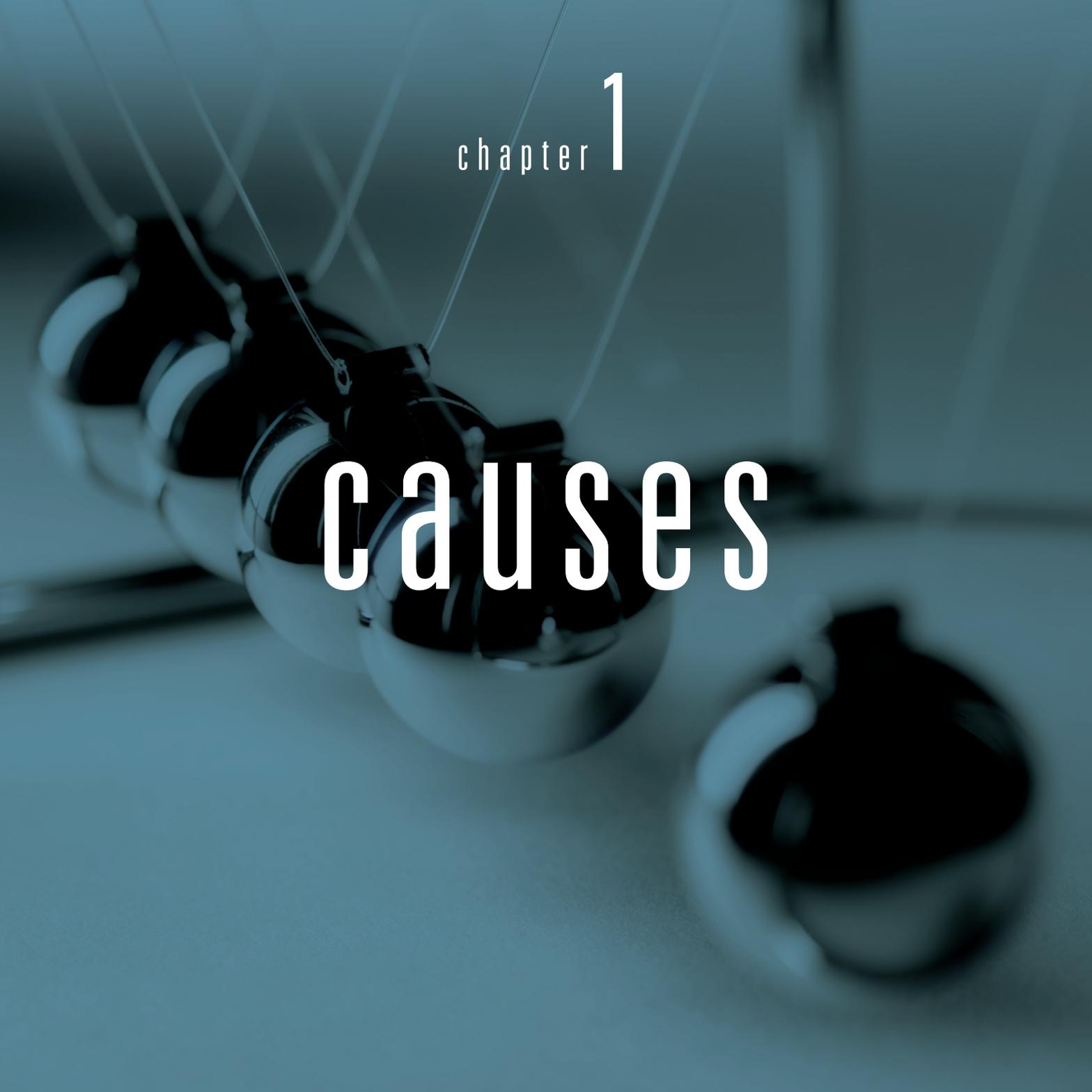


understanding  
mesothelioma

*{ second edition }*

presented by **cure**



A Newton's cradle with five silver spheres hanging from thin wires. The spheres are in motion, with one sphere in the foreground and others in the background. The background is a soft, out-of-focus light blue.

chapter 1

# causes

# causes of mesothelioma

**W**HILE asbestos is far and away the most common cause of mesothelioma, there are theories of other causes or cofactors of the disease, such as viruses, alternate mineral fiber exposure, radiation exposure and genetic predisposition. Asbestos can also cause other thoracic diseases, some with symptoms similar to mesothelioma.



## Asbestos >

The majority of patients with pleural mesothelioma have a history of asbestos exposure. Six minerals, all of which are present in nature as bundles of fibrous crystals, comprise asbestos. The favorable properties of these crystals—heat and chemical resistance, strength, flexibility and low electrical conductivity—make them useful in numerous residential and commercial applications, such as roofing materials, ship insulation, pipe insulation and acoustic ceiling tiles. These are just some of the 3,000 estimated products manufactured during the peak of asbestos usage in the late 1960s and early 1970s.

Three types of asbestos are commonly used in the United States. Chrysotile, or white asbestos, is the most widely used. Its fibers are curled, a property that makes them easier to be cleared from the lungs through coughing if inhaled. The other two types of fibers, crocidolite (blue asbestos) and amosite (brown asbestos), are typically used in limited, specialized applications due to their brittle, needle-like structure, which makes them harder to dislodge from the lungs and respiratory tract.

### **Asbestos-Related Mesothelioma**

Asbestos is categorized as a carcinogen (a substance that

causes cancer) by the U.S. Department of Health and Human Services, the U.S. Environmental Protection Agency and the International Agency for Research on Cancer. Studies have shown that asbestos exposure may increase the risk of mesothelioma and lung cancer. Although asbestos-related mesothelioma is most often attributed to occupational asbestos exposure, this is not always the case; there are also cases of asbestos-induced mesothelioma in women who laundered the work clothes of their husbands who were exposed to asbestos and cases of other environmental exposures. In addition, some people who live or lived near sites where asbestos was once mined may have an increased risk of developing the disease.

Generally, it takes 20 to 50 years for mesothelioma to develop following exposure. The association between asbestos exposure and both pleural and peritoneal mesotheliomas has been well established. Since pericardial and testicular mesotheliomas are rare, their linkage to asbestos exposure is unclear.

### **How Asbestos Causes Mesothelioma**

The exact means by which asbestos causes cancer has not yet been fully determined, but it is known when asbestos is inhaled, about two-thirds of the fibers are eliminated from the body by coughing or swallowing.

The remaining fibers travel through the airways, and some may reach the alveoli, the tiny air sacs in the lungs. Although the method by which asbestos fibers arrive at the mesothelium is not certain, it is likely that this journey takes years.

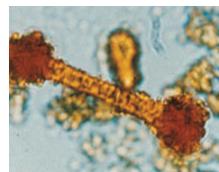
One theory is that the size and shape of the fibers affects the ability to cause mesothelioma. This theory proposes that longer fibers are too big to be eliminated through the actions of certain immune system cells called macrophages. Mesothelial cells may take in asbestos fibers, and the presence of fibers inside the cells can interfere with chromosomal division that takes place as cells reproduce. This interference may be the cause of the chromosomal abnormalities that are frequently documented in mesothelioma cells. Asbestos fibers can also initiate numerous cellular events, including the generation of free radicals, the initiation of inflammation and other signals of cellular distress. Taken together, these processes likely induce genetic changes, which ultimately lead to the development of mesothelioma.

### Asbestos Safety

While the World Health Organization states there is no safe threshold of asbestos exposure, the Occupational Safety and Health Administration sets the permissible level of asbestos exposure requiring no protective gear for employees at 0.1 fiber per cubic centimeter of air per eight-hour day. This standard covers only those fibers that are equal to or greater than 5 micrometers in length, as fibers shorter than this are believed to be cleared easily from the body. Research on the duration

## Mesothelioma: Cause & Effect

CAUSES

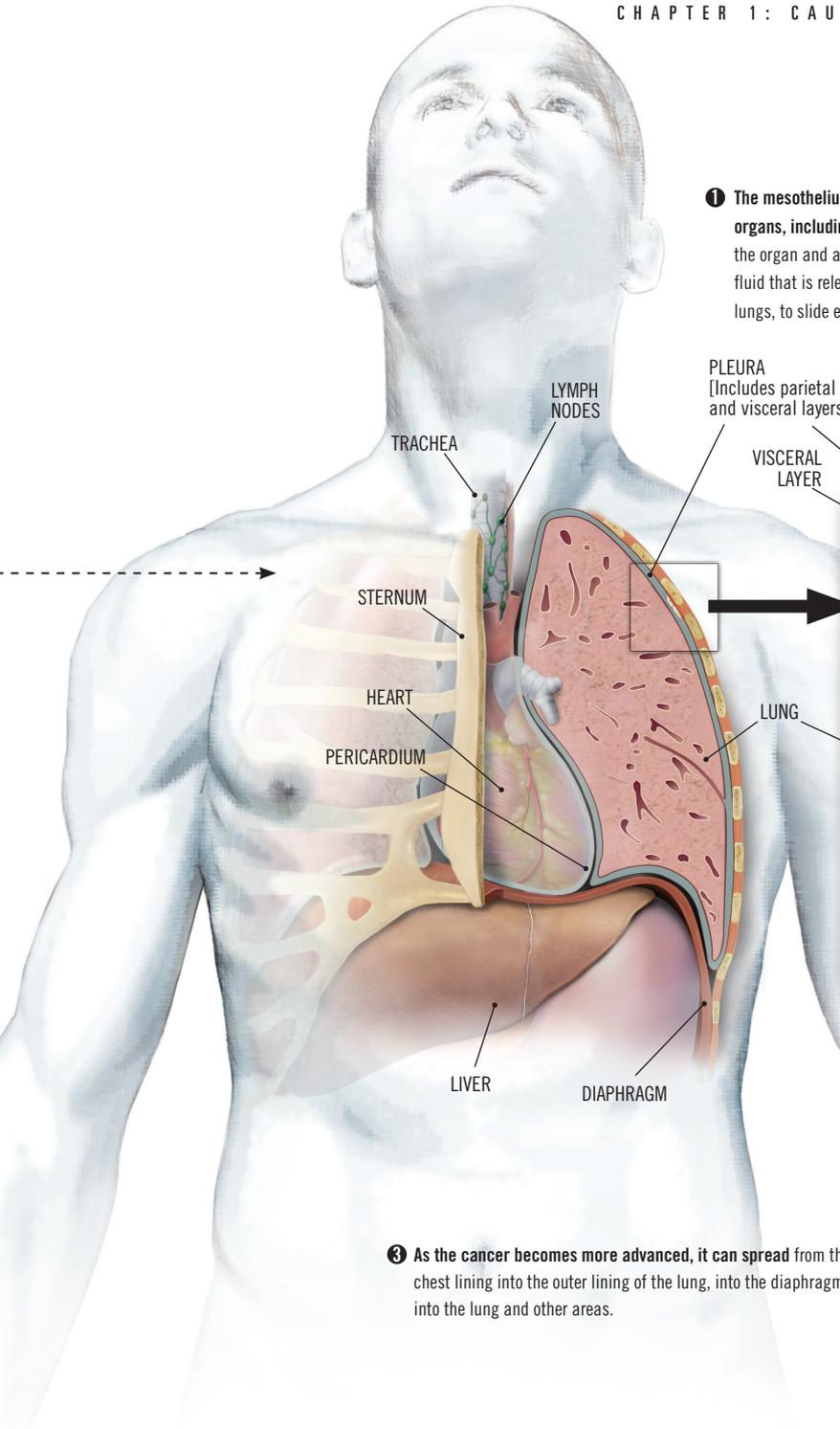


While **asbestos** is estimated to cause up to 80 percent of mesothelioma cases, other causes are being studied.

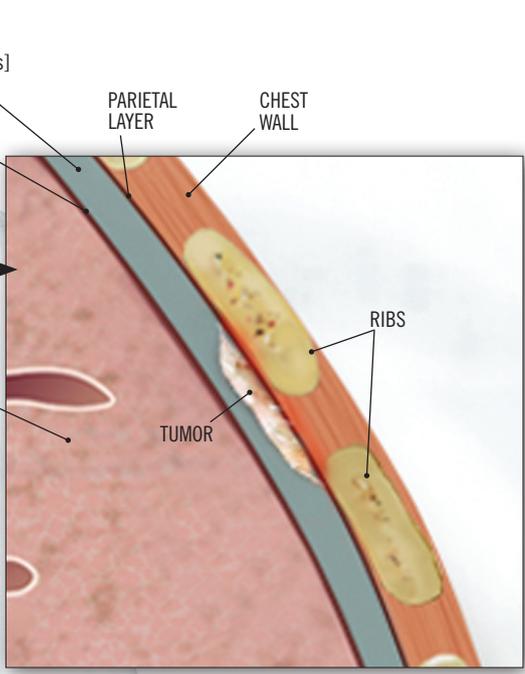
DIAGNOSTIC



**Positron emission tomography (PET) scan** of a patient with stage 4 mesothelioma showing disease in the superior part of the lung (orange arrows) and a metastatic lesion in the abdomen (green arrow).



**1** The mesothelium is a membrane that covers and protects most of the body's internal organs, including the lungs. It is composed of two layers—one that immediately surrounds the organ and another that forms a sac around it. The mesothelium produces a lubricating fluid that is released between the layers, allowing moving organs, such as the heart and lungs, to slide easily against bordering structures.



**2** The mesothelium that surrounds the lungs and lines the wall of the chest cavity is called the pleura. In its early stage, mesothelioma is contained within the pleura.

**3** As the cancer becomes more advanced, it can spread from the chest lining into the outer lining of the lung, into the diaphragm or into the lung and other areas.

of asbestos exposure and the risk of mesothelioma development has been mixed. Studies have shown that people with long exposure durations have an increased risk of mesothelioma relative to those with short exposure. Other studies have reported no difference in the incidence of mesothelioma in those with long versus those with short exposure times. However, there is at least circumstantial evidence that even low environmental levels of asbestos exposure can increase the risk of mesothelioma.

Although the risk of mesothelioma in the U.S. general population is small (less than 1 percent), the risk skyrockets to 8 to 13 percent for asbestos workers. Smoking has no impact on the development of mesothelioma. However, smoking does increase the risk of non-small cell lung cancer and small cell lung cancer, which are frequent in patients with asbestos exposure. Thus, people with both a history of smoking and asbestos exposure have an elevated risk of developing lung cancer—about 60-fold higher than nonsmokers with no asbestos exposure. Asbestos-related lung cancer accounts for a similar number of deaths in the U.S. to mesothelioma at about 2,000 to 3,000 per year.

### **Other Asbestos-Related Diseases**

Aside from mesothelioma and lung cancer, asbestos is associated with a number of other thoracic diseases, including benign pleural effusions, pleural plaques and asbestosis. Benign pleural effusions occur when excess fluid accumulates within the pleural lining of the lungs and are often the earliest sign of asbestos-related disease, developing within

10 to 20 years of asbestos exposure. They typically cause no symptoms and disappear without treatment, but do require monitoring to rule out the development of mesothelioma. Pleural plaques are patches of scar tissue on the surface of the pleural membrane and are the most common manifestation of asbestos-related disease. Pleural plaques also produce no symptoms and require no treatment; furthermore, they are not believed to lead to malignant disease. Asbestosis is the most serious of the thoracic diseases discussed here. It is a chronic lung disease characterized by scarring of the lung tissue. Patients generally have only minor symptoms at diagnosis, including shortness of breath and dry cough. However, this is a slow-progressing disease, and of the 200,000 Americans currently suffering from asbestosis, about 2,000 are expected to die from the disease each year.

### **Other Causes >**

Although asbestos is clearly linked to mesothelioma, certain characteristics of the disease suggest that asbestos exposure is not the only cause. First, people with no apparent lifetime exposure to asbestos occasionally develop mesothelioma. Second, asbestos workers only have an 8 to 13 percent risk of developing the disease, indicating that other factors may be present in certain people that make them susceptible to the disease. Third, mesothelioma takes approximately 20 to 50 years to develop following asbestos exposure, suggesting that there are certain additional factors that may either promote or inhibit the process.

# Jocelyn Farrar, DNP, ACNP

## Helping Those on a Similar Journey

**J**OCelyn FARRAR'S GRANDFATHER was a pipe fitter who worked with asbestos insulation. When her grandmother used to shake out his work clothes in the laundry room, asbestos particles would drift down like snow next to where Farrar played as an infant.

Farrar, who is now 60, first exhibited symptoms in March, 2008. She thought she had a bad cold, but a dry cough persisted despite two rounds of antibiotics. A positron emission tomography (PET) scan suggested pleural mesothelioma, and the diagnosis was confirmed in June. Farrar received chemotherapy infusions and underwent an extrapleural pneumonectomy in November.

After a few weeks of recuperation at home, Farrar enrolled in a pulmonary rehabilitation program. "That was one of the best decisions I made because the respiratory therapists and exercise specialists helped me regain my strength," she says. During this period Farrar also received six weeks of tomotherapy, a form of radiation therapy, at The Johns Hopkins Hospital in Baltimore.

Farrar remained tumor-free for two years, but experienced a recurrence in 2010. She underwent 11 months of chemotherapy, then opted out due to nausea. Her mesothelioma stabilized until the summer of 2012 when a computed tomography (CT) scan revealed resumed growth. She enrolled in a clinical trial at Johns Hopkins involving the chemotherapy drug Gemzar (gemcitabine), which she is still participating in today.

"I take pride in not letting this disease control my life," says



PHOTO BY COLBY WARE

Farrar, an assistant professor at the University of Maryland School of Nursing. "My motto is: I might have meso, but it doesn't have me."

Farrar has learned much during her cancer journey and is eager to help others. "Attempt to find an oncology and pulmonary surgeon specialist to provide your therapy," she advises. "If a physician tells you that he has limited experience with mesothelioma, find another source of care, even if you have to leave the state.

"And never hesitate to be a full partner in your care. Choose providers who treat you as part of the team and are open to your questions and direction." ❁

*"My motto is: I might have meso, but it doesn't have me."*

# Who is at risk?

The occurrence of mesothelioma in multiple family members has led researchers to ask whether it has a genetic component. However, family members often share more than just genetics—they also share environmental exposures, such as the same water supply or proximity to power lines—making it difficult to determine the factors that affect the likelihood of developing mesothelioma.

## SV40 Exposure

Perhaps the most controversial link to mesothelioma is exposure to Simian virus 40 (SV40), a virus known to infect monkeys and apes. In the 1950s, monkeys were used to develop a vaccine against polio. In 1961, it was discovered that the polio vaccines may have contained SV40 from some infected monkeys. By the time SV40 was removed from the polio vaccine supply, 62 percent of the American population had been inoculated with potentially contaminated vaccines.

Shortly thereafter, animal studies showed that SV40 was highly carcinogenic (capable of causing cancer). In 1993, researchers discovered that infecting hamsters with SV40 in the pleural space caused mesothelioma in 100 percent of the infected animals, prompting further study of this potential link in humans.

Despite the fact that the United States failed to experience an explosion of new cancer diagnoses, as might be expected if SV40 were capable of causing cancer, concern has been kept alive by a few smaller studies reporting that a portion of mesothelioma tumors contain SV40. In addition to the proposition that SV40 may encourage the development of asbestos-induced

**C**ancer patients often wonder why they got the disease. Most cases of mesothelioma involve asbestos exposure, but a patient may be unsure when, or even how, his or her exposure occurred. Although minute levels of asbestos exist in the air, water and soil, most people do not develop mesothelioma from this type of exposure. People who develop the disease generally have regular asbestos exposure, such as from a job.

While the use of asbestos is still currently not banned in the U.S. and asbestos continues to be imported, regulations are in place to protect the public when it comes to its safe removal from buildings and homes. Legislation was enacted in the 1970s to protect workers from asbestos exposure. Prior to that, workers in certain industries may have had regular exposure to asbestos. Some of these occupations are:

- > **Workers involved in manufacturing of asbestos products, such as insulation and plumbing supplies**
- > **Insulation workers in buildings and structures**
- > **Demolition workers, especially in older buildings**
- > **Drywall workers**
- > **Oil refinery workers**
- > **Power plant workers**
- > **Chemical plant workers**
- > **Railroad workers**
- > **Firefighters**
- > **Automobile mechanics**
- > **Steel mill workers**
- > **Paper mill workers**
- > **Shipyards and shipbuilding workers**
- > **Navy veterans**

In addition, individuals who were involved with the recovery, rescue and cleanup of the 9/11 attacks are also at risk for developing an asbestos-related disease because the mineral was used in construction of the World Trade Center's North Tower. When the building was destroyed, tons of asbestos were released in the air exposing police officers, firefighters, paramedics, volunteers, residents and other people in the area. Also, family members of asbestos-exposed workers may develop mesothelioma because of regular exposure to the fibers brought home on clothing, shoes and hair. Regular exposure may have occurred from tasks such as washing work clothes that contained asbestos fibers.

In September 2012, mesothelioma was one of some 50 cancers added to the list of World Trade Center-related health conditions for those exposed to toxins in the area.

mesothelioma, it has also been suggested that SV40 may be responsible for mesothelioma found in patients with no asbestos exposure.

While all of this may seem alarming, it must be counterbalanced by the knowledge that some studies have found no SV40 in mesothelioma tumors and, more importantly, it has been suggested that, in at least some studies, the molecule used to identify SV40's presence within the body might actually have identified viruses that have similar structures to that of SV40 and are commonly present in humans. Furthermore, although an explanation has been proposed regarding the relationship between SV40 and asbestos, there is no evidence to date in humans that supports such a theory.

### **Erionite Exposure**

Erionite is a non-asbestos mineral fiber that is similar in physical characteristics to crocidolite. Erionite has been identified as a cause of mesothelioma based on studies of mesothelioma rates among residents of Cappadocia, Turkey, where erionite has been used in building materials. According to a survey of 141 deaths in four villages during a four-year period, 24 percent of deaths were due to mesothelioma. Interestingly, animal studies have shown that, just as with asbestos, long erionite fibers are highly carcinogenic, whereas short fibers are relatively inactive. Erionite deposits can be found throughout the western United States, primarily in areas with a low population density. To date, there are no cases of mesothelioma attributed to erionite exposure in the

United States, although studies are ongoing as high levels of exposure occurred in the 1980s. In Mexico, at least more than one case has been reported.

### **Genetic Predisposition**

Further examination of the link between erionite exposure in Turkey and the high mesothelioma death rate produced evidence that genetic predisposition might also be a factor in the development of this disease. Although all homes in that region contained similar amounts of erionite, mesothelioma occurred in some homes and not in others. Furthermore, no increased incidence of mesothelioma was found in a nearby village, despite the fact that the homes there contained the same types of erionite fibers. Even more interesting is that mesothelioma development followed a dominant genetic inheritance pattern, in which half of the children of parents with mesothelioma also developed mesothelioma. This pattern is consistent with a single genetic mutation from one of the parents causing the disease. Furthermore, marriage of unaffected people into such families also produced the same pattern of mesothelioma development. While these observations cannot be considered conclusive evidence for a genetic predisposition to mesothelioma, they do provide reason to further study genetics for risk factors.

More recently, information gained from studying seven unrelated families with an increased risk of mesothelioma has provided even stronger evidence for a genetic link to this disease. The high incidence among these family members has been explained

by the presence of an inherited mutation in the BRCA1-associated protein 1 (BAP1) gene, which is associated with mesothelioma, along with other cancers. Normally, this gene inhibits tumor development; mutated BAP1 is hypothesized to encourage the growth of tumors.

### **Radiation Exposure**

Exposure to ionizing radiation is a well-established risk factor for the development of a number of different cancers. This type of exposure frequently occurs as a result of radiation therapy, often used to treat cancer. While the incidence of secondary cancers due to radiation therapy is low, there is a link between radiation therapy and the development of a secondary malignancy. Little has been published on the potential link between radiation therapy and mesothelioma, but a recent retrospective report shows that mesothelioma rates are significantly increased in lymphoma patients who have a history of radiation therapy.

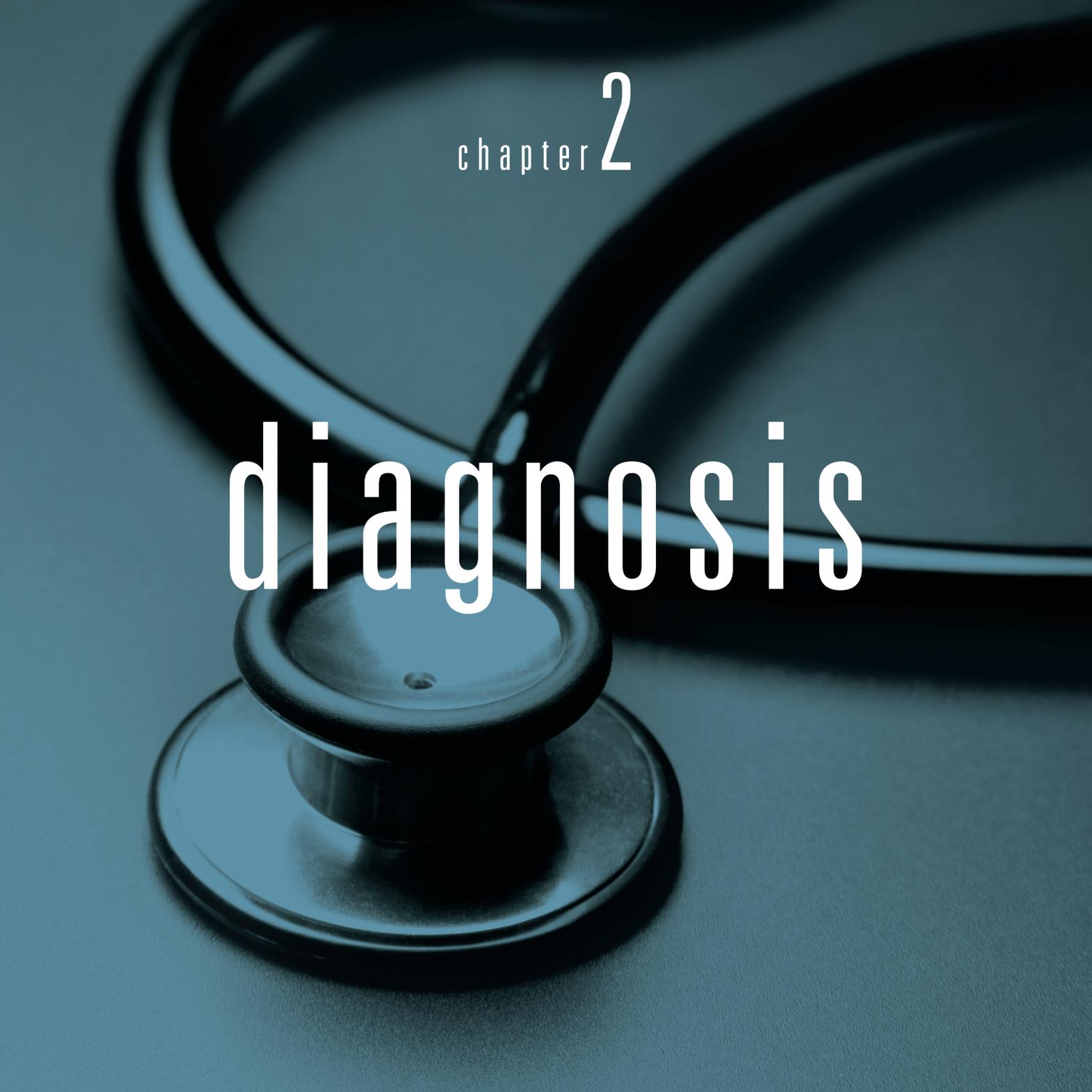
A link between mesothelioma and ionizing radiation has also been observed in patients who received Thorotrast, a now-defunct contrast material that was used with X-rays in the 1930s through the 1950s. Contrast materials are injected into patients prior to imaging in order to enhance X-ray resolution. Contrast mediums used today, such as barium and iodine, are relatively harmless, but Thorotrast is very harmful, although this was not known at the time of its use. Following a Thorotrast injection, the drug was absorbed by many organs and then decayed over

time. Unfortunately, these cancer-causing particles were present in the tissues for decades; Thorotrast's half-life, or the time it takes for half of its quantity to decay, is estimated to be 22 years. It has been associated with cancer of the bile duct and leukemia; three retrospective studies have identified a link between Thorotrast radiation exposure and mesothelioma development.

### **Chronic Inflammation**

Circumstantial evidence suggests that chronic inflammation may also increase the risk of mesothelioma. Peritoneal mesothelioma has been reported in several patients with familial Mediterranean fever (FMF) and no known exposure to asbestos. FMF is characterized by long periods of inflammation of the chest and joints, as well as the peritoneum, the same tissue where peritoneal mesothelioma is localized.

Associations between chronic inflammation and the presence of mesothelioma have led some researchers to postulate that repeated inflammatory episodes might predispose patients to the development of malignant tumors. Finally, there is concern that tiny artificial particles called nanoparticles, which have recently been developed for medical and material sciences research, might carry the potential to cause mesothelioma. ❁



chapter 2

# diagnosis

# diagnosis

## D IAGNOSING

mesothelioma can be a complicated process. Symptoms are vague, and many tests may be needed to reach a proper diagnosis. Once a final diagnosis is made, the stage of the disease will be determined, and a course of treatment can be decided.



## Symptoms >

Symptoms of mesothelioma do not typically arise until the disease has reached later stages. When they do arise, most are nonspecific in nature, including weight loss, fatigue and night sweats. Depending on the type of mesothelioma, other organ-specific symptoms may be present. For example, most patients with pleural mesothelioma begin to experience lung-related symptoms, such as consistent chest pain and progressively worsening shortness of breath. The pain is typically caused by invasion of cancer into the chest wall, and the shortness of breath is often caused by pleural effusion (excess fluid in the pleural linings of the lungs). The presence of cough, or coughing up blood, can occasionally occur with pleural mesothelioma.

Patients with peritoneal mesothelioma often report abdominal pain or bloating, which is caused by the accumulation of ascites, or fluid in the abdomen. A change in bowel habits (diarrhea or constipation), nausea and vomiting can also develop.

Even fewer symptoms are present in pericardial mesothelioma, making it more difficult to diagnose. Because the tumor is present in the linings of the heart, patients with pericardial mesothelioma generally have symptoms related to cardiac function, including chest pain, heart palpitations and difficulty breathing.

The only known symptom of testicular mesothelioma is testicular lumps.

## Diagnosis >

Because of the nonspecific nature of mesothelioma symptoms, proper diagnosis requires a combination of physical, radiological and pathological examinations, as well as obtaining an accurate patient history, including potential asbestos exposure and identification of asbestos-related occupations.

For those patients with pleural effusions, a sample of the pleural fluid is taken and sent to a pathologist, who examines the sample for the presence of malignant cells. Pleural fluid is not as sensitive as tissue and may result in a false negative. Therefore, even when a pleural fluid sample is available, a biopsy of the pleural tissue is also required in most cases to make a diagnosis. A biopsy can be obtained by needling the pleural mass. The optimal method, however, involves surgical biopsy, such as with a thoracoscopy, a procedure in which a tube with a camera on the end is inserted into the chest.

Radiological analysis using a contrast-enhanced computed tomography (CT) scan provides a three-dimensional view of the entire pleural surface. This

can help determine the extent of disease and can aid the physician in finding the desired tissue for biopsy. Two other radiological tests, magnetic resonance imaging (MRI) and positron emission tomography (PET) scans, may also be used to evaluate patients with mesothelioma. PET scans provide information regarding how active the tumor is by measuring its metabolic activity and can also assess whether the cancer has spread to other parts of the body. Recently, several studies have demonstrated that an integrated approach using both PET and CT scanning produces the best images with which to diagnose pleural mesothelioma, second only to surgical biopsy and subsequent examination of the tissue. Although combined PET/CT scanning also shows promise in the diagnosis of peritoneal mesothelioma, and is less invasive than a biopsy, it remains to be thoroughly evaluated in this rare disease.

The pathological examination of the biopsy samples includes immunohistochemistry tests, in which the samples are processed in a way that allows the pathologist to look for specific signs, called markers, of mesothelioma. There is no known singular marker that points to mesothelioma, so in order to diagnose this disease, the pathologist generally evaluates the presence or absence of several different markers. The pathologist also uses the biopsy samples to classify the type of mesothelioma: epithelioid, sarcomatoid or biphasic. About 60 percent of mesotheliomas are of epithelioid origin, and these tend to be associated with better outcomes than the other two types. Approximately 10 to 20 percent of mesotheliomas are sarcomatoid, or fibrous, in nature, and the remaining

tumors are biphasic, or mixed, containing both epithelioid and sarcomatoid areas.

## Staging >

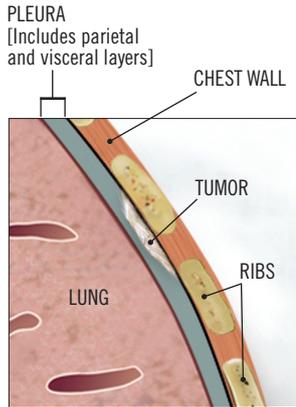
After a diagnosis of mesothelioma has been reached, staging of the disease is the next step. As with any type of cancer, mesothelioma staging, or determining the extent of the disease, is used both to predict a patient's outcome and to determine the best course of treatment.

Several types of staging systems are used to evaluate pleural mesothelioma, but the one used by most major cancer centers in the United States is the TNM staging system. Developed by the American Joint Committee on Cancer, it takes into account **T**umor location and involvement with surrounding tissues, disease spread to **l**ymph **N**odes, and presence or absence of **M**etastases (disease spread to other organs). There are four possible stages of pleural mesothelioma based on the TNM classification system.

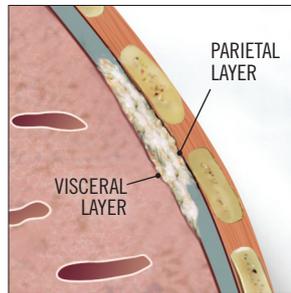
In stage 1, the disease may be present in one or more spots but is confined to the mesothelium (disease has not spread to either the lymph nodes or any other organs); stage 1A refers to a tumor in the outer layer of the mesothelium, whereas stage 1B refers to a tumor that has reached both the outer and inner layers. This stage of disease is the most easily treatable and, as such, patients with stage 1 disease have the best prognosis (expected outcome).

Stage 2 disease is characterized by the spread of cancer beyond the mesothelium and into the lung tissue and/or diaphragm but not yet into the lymph nodes.

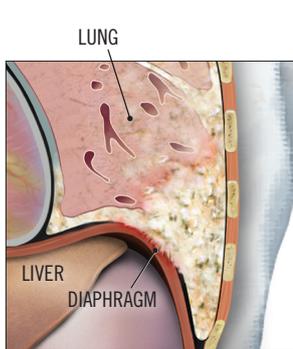
## Stages of Pleural Mesothelioma



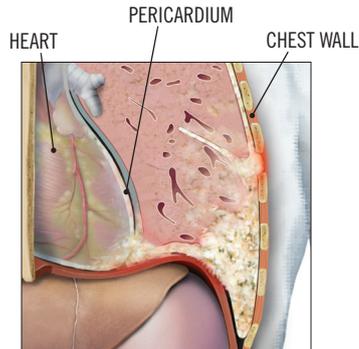
**STAGE 1A:** Tumor is confined to the parietal pleura, the external layer of the pleura.



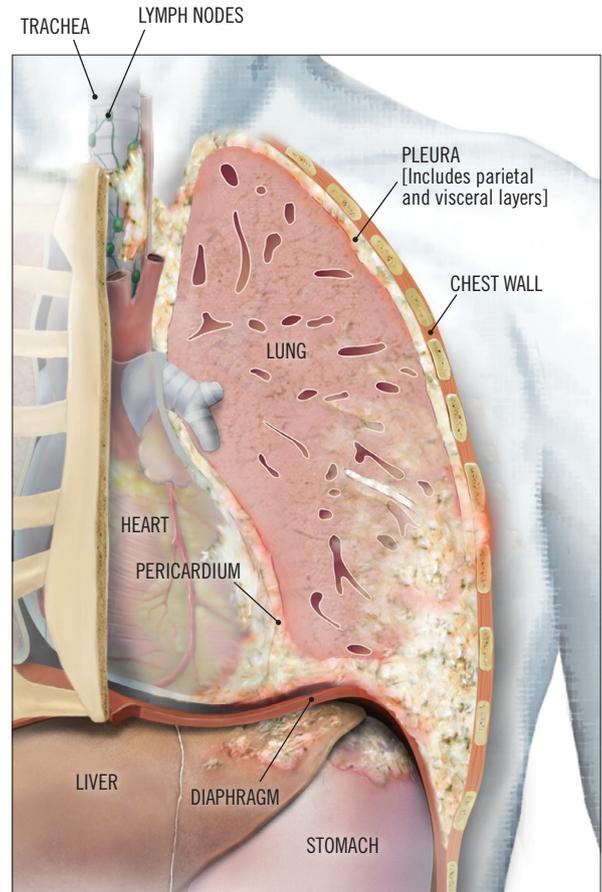
**STAGE 1B:** Tumor occupies the parietal pleura and the visceral pleura, the internal layer of the pleura that covers the lung.



**STAGE 2:** Tumor expands into the lung or diaphragm.



**STAGE 3:** Tumor expands into the chest wall, the tissue surrounding the heart (pericardium) and/or the lymph nodes in the chest.



**STAGE 4:** Tumor invades multiple areas, penetrates the pericardium or diaphragm, extends into lymph nodes outside the chest, and/or spreads to at least one other organ, such as the heart, esophagus, liver or opposite lung.

ILLUSTRATION BY PAM CURRY

As in stage 1 disease, patients with stage 2 mesothelioma may be able to have their entire tumor removed surgically.

In stage 3, the malignancy has spread into the fatty part of the mediastinum (the space behind the breastbone and between the lungs) and/or into the lymph nodes within the thorax.

Stage 4 is metastatic disease, where the cancer has spread to at least one other organ (aside from the lungs) or in which multiple tumors have invaded the chest wall. Malignancy may also have spread into the peritoneum or the lining of the abdominal wall.

Unfortunately, peritoneal mesothelioma has no accepted staging system, partly because the disease is rare and partly because, until recently, no effective treatments had been available that would necessitate knowing a patient's stage in order to make a treatment decision. However, in recent years, treatments using a combination of surgery and chemotherapy have prolonged survival and more physicians have begun employing these techniques. This uniform treatment of patients allows for the identification of factors that may affect patient outcomes.

Factors associated with improved survival include being under the age of 50, being a female and having a limited extent of disease throughout the abdomen and no disease in the lymph nodes. Other favorable factors include having no disease outside of the abdomen as well as an epithelial type of tumor. Patients who had surgery to remove tumors did best when there were either no tumors or very small tumors ( $\leq 2.5$  millimeters diameter) remaining.

Using this information, a staging system for peritoneal disease has been proposed with the goal of predicting a patient's outcome and identifying appropriate treatment options, including surgery for qualified candidates. Under this proposed system, stage 1 disease is the most limited (in terms of size and extent of tumor deposits) with no spread beyond the abdomen. Stage 2 disease is more extensive but still limited to the abdomen, and stage 3 disease occurs when any disease is found in the lymph nodes or elsewhere outside the abdomen or if the disease is spread extensively throughout the abdomen.

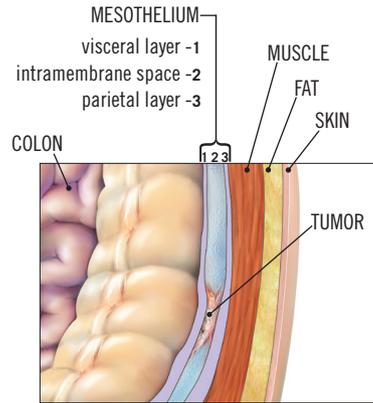
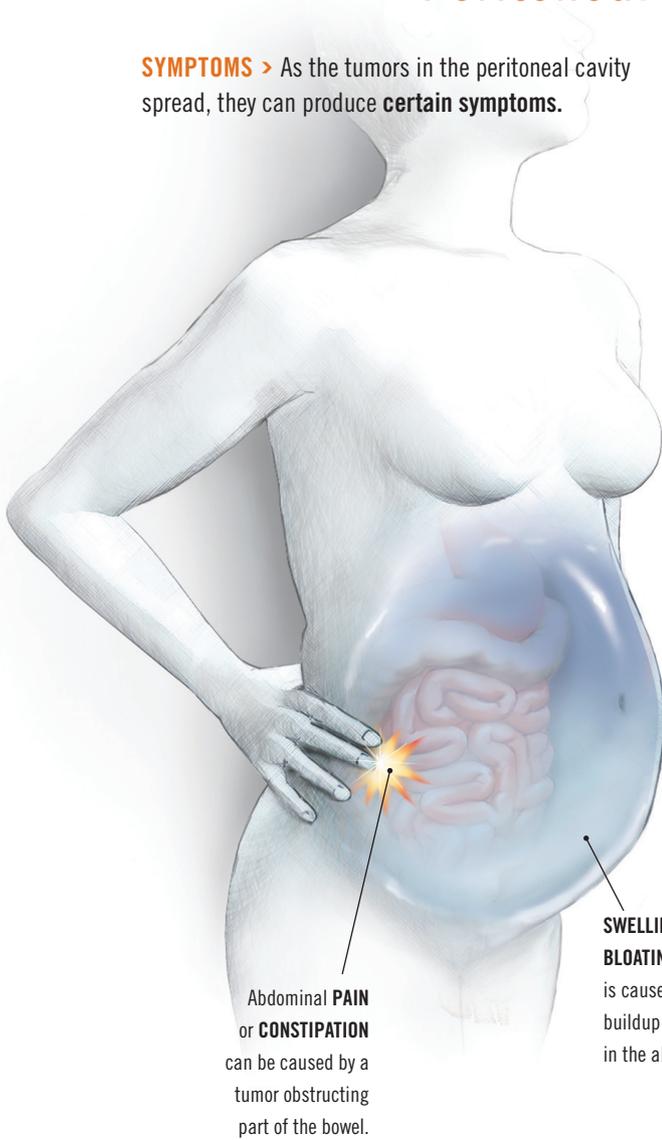
## Prognosis >

Because mesothelioma is rare, it is difficult to obtain accurate survival rates based on disease stage; however, it is generally true that patients diagnosed with early-stage pleural mesothelioma have a better prognosis and a small possibility of cure with surgery (and the expectation of living about three or more years, although that length can be variable) than those diagnosed with advanced disease (most of whom will live less than one year). Other factors have been identified by their ability to predict an improved outcome for patients with mesothelioma. Some of these prognostic factors are patient characteristics, such as younger age, female gender and good performance status (being able to perform normal tasks of daily life). Some are symptom-related, such as the absence of chest pain and a lack of significant weight loss; others are related to laboratory tests, including normal blood counts (red

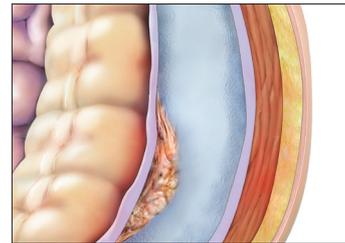
# Peritoneal Mesothelioma

**SYMPTOMS** > As the tumors in the peritoneal cavity spread, they can produce **certain symptoms**.

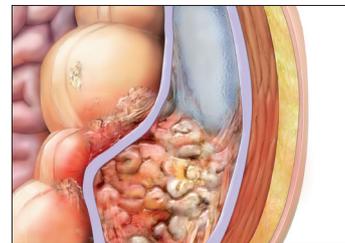
**DISEASE PROGRESSION** > While no established staging system exists at this time for peritoneal mesothelioma, here is **how the disease may progress**.



Tumor begins in the lining (mesothelium) covering the abdomen's internal organs. The tumor causes a thickening and an irritation of the lining.



Tumor expands and results in fluid build-up in the abdomen.



Tumor grows and penetrates the bowel, which can cause bowel obstruction and pain.

blood cells, white blood cells and platelets) and normal levels of a substance in the blood called lactate dehydrogenase (LDH).

Although the average pleural mesothelioma patient survives four to 18 months after diagnosis and less than 10 percent of patients survive at least five years, there have been reports of long-term survivors who have no evidence of disease many years after treatment. Many of these survivors are women, and they have even longer survival times than male long-term survivors. The reason for this is unclear, but most women with mesothelioma have no history of asbestos exposure, raising the possibility that their disease may be very different (and have a more favorable prognosis) than that of men who were exposed to asbestos.

Before any effective treatments had been developed for peritoneal mesothelioma, the expected survival of someone with this disease was approximately one year. However, recent improvements in therapy (which will be discussed in Chapter 4: Treatment Options) have produced anticipated survival times ranging from 2.4 years to more than eight years across different clinical trials. Women with peritoneal mesothelioma have a better prognosis than men with the same disease, having a median survival time that is years longer. This advantage, however, seems to hold only for younger women, leading researchers to question whether premenopausal status may play a protective role against this disease. There is interest in studying estrogen and estrogen receptors further in the hopes of understanding the development of mesothelioma and in potentially developing therapies to take advantage of this characteristic. 🌱

# The Checklist I Wish I'd Had

## By Linda Reinstein, President & CEO of the Asbestos Disease Awareness Organization

**I**n 2003, my husband, Alan, was diagnosed with mesothelioma. Three years later, Alan died with our then 13-year-old daughter and me by his side. During my journey, I have learned that each mesothelioma patient and family must be committed to finding balance. Below are 10 tips for mesothelioma patients and families.

### ACCEPT THE NEW NORMAL

- **Build an expert medical team** that the patient and family can trust.
- **Designate an advocate** who will assist the patient with understanding his or her options and coordinating both appointment and treatment schedules.
- **Understand LIFE:** Legal, Insurance, Financial and End-of-life requests (including advance directives such as a living will, power of attorney and healthcare proxy).

### EMBRACE COMMUNITY

- **Join a network, online or otherwise,** of patients or caregivers.
- **Share the care.** Patients and caregivers are not alone. Family and friends want to help—let them. Reach out for their support.
- **Share fears** with a spouse, family and friends.

### PRACTICE SELF-CARE

- **Caregivers are co-patients.** Design and honor a wellness program to take care of mind, body and spirit. Caregivers should schedule at least 15 minutes a day for themselves.
- **Make time for fun activities and, yes, plan for the future.** Buy a movie ticket, book a trip with travel insurance or have dinner with friends.
- **Trust instincts.** Once a patient or caregiver has made a decision, they should release themselves from self-doubt and criticism.
- **Create inspiration.** Hope and faith will fuel this journey.

chapter 3



finding a  
specialist

# finding a specialist

**T**HE PROCESS of choosing a doctor should never be taken lightly, especially when dealing with cancer treatment. Treatment for mesothelioma can be complex and may require finding more than one specialist, such as an oncologist, a radiologist or a surgeon. All will be instrumental for immediate and long-term treatment and subsequent follow-up.



## Starting the Search >

Before beginning a search, patients should think of the qualities their doctor should possess. Here are a few suggestions to consider:

- > Patients should choose a doctor who has experience with mesothelioma. It is a rare type of cancer and requires disease-specific expertise.
- > Patients should determine if the doctor is part of their health plan and accepts their health insurance. If not, patients will need to be prepared to pay out of pocket.
- > Patients should choose a doctor who is able to practice at a hospital where comprehensive services for mesothelioma are available. Since traveling to receive treatment may be required, having as many services as possible in one location is important.
- > Patients should choose a doctor they feel comfortable with. Patients should interview the doctor, if possible, and check out his or her background. Patients should also determine personal preferences about bedside manner, gender, language and personality. These traits may be as important as education and expertise when choosing a specialist.
- > Patients should get referrals from their primary care doctor, other patients in their community and mesothelioma advocacy and support groups.

- > Patients should check if the doctor is board certified. Certification involves additional training and passing an examination to treat special conditions or perform special procedures, as in medical oncology.

The treatment of mesothelioma may require the services of several specialists. Finding a specialist for a particular mesothelioma treatment may be difficult because many are affiliated with large metropolitan teaching hospitals and cancer specialty centers. Here are some places to go to find a specialist:

- > Local hospital referral services
- > National Cancer Institute-designated cancer centers (search by state at [cancer.gov/researchandfunding/extramural/cancercenters/find-a-cancer-center](http://cancer.gov/researchandfunding/extramural/cancercenters/find-a-cancer-center))
- > The American Board of Medical Specialties at [www.abms.org](http://www.abms.org)
- > The American Medical Association DoctorFinder at [extapps.ama-assn.org/doctorfinder/recaptcha.jsp](http://extapps.ama-assn.org/doctorfinder/recaptcha.jsp)
- > The American Society of Clinical Oncology's patient site at [cancer.net/all-about-cancer/newly-diagnosed/find-oncologist](http://cancer.net/all-about-cancer/newly-diagnosed/find-oncologist)
- > The American College of Surgeons at [facs.org/patienteducation](http://facs.org/patienteducation)

- › The Mesothelioma Applied Research Foundation at [marf.org](http://marf.org)
- › National Comprehensive Cancer Network at [nccn.org/members/network.asp](http://nccn.org/members/network.asp)

Once several doctors have been identified who seem like a good fit, patients should call and ask a few questions, such as does the doctor take their insurance and with which hospital is he or she affiliated, before scheduling an appointment to meet and interview the doctor/surgeon.

It is important that patients feels comfortable with their choice of doctors and trust the healthcare team that is planning and conducting their treatment. Patients may use the information provided here, but should also trust their feelings and observations to make the best decision. Any relationship takes time to build, and making the best choice helps to build a solid foundation for the doctor-patient relationship.

## Traveling for Treatment ›

The National Cancer Institute has designated 40 cancer centers throughout the United States as comprehensive centers. These elite facilities are recognized for their focus on scientific research, excellence and dedication to the prevention, treatment and cure of cancer, including mesothelioma. The Department of Veterans Affairs (VA) medical system has also designated comprehensive cancer centers at some of their VA Medical Centers.

Traveling to a comprehensive center for treatment gives patients access to mesothelioma experts and a team of healthcare professionals to assist them and their family

during all phases of treatment. Besides medical specialists, a team for mesothelioma patients may include the following:

- › Oncology nurses are specially trained in cancer management, administering medication (chemotherapy), monitoring for side effects and conducting routine tests.
- › Oncology/clinical social workers specialize in helping cancer patients and their families in the decision-making process. Many are certified to provide family therapy and counseling for patients coping with a serious illness.
- › Psychiatrists and psychologists are available to help with depression, anxiety and coping skills related to the diagnosis of cancer. Many conduct support groups for patients and family members.
- › Dietitians work with patients to maintain weight, deal with side effects and plan diets to treat other medical conditions, such as high cholesterol and heart disease.

Traveling for treatment and consultation can be a daunting task, but large cancer centers are equipped to help with planning, lodging and other services that may be required while patients are undergoing treatment. Medical facilities that are accustomed to patients traveling for care negotiate discounts with airlines, hotels and ground transportation for established patients and their caregivers.

There are other resources that can help with travel-related expenses. Medicaid, for example, covers travel expenses for recipients, and the American Cancer Society has a Road to Recovery program in some areas that has volunteers who provide transportation to appointments and gas reimbursement for travel.

Discounted and free airfare is available from nonprofit

# Paul Zygielbaum

## Looking Toward the Future

**RONICALLY, SUFFERING A HEART ATTACK** in his early 40s might be the reason why Paul Zygielbaum of Santa Rosa, California, is still alive today. Although the 62-year-old CEO of a medical device company began experiencing symptoms of peritoneal mesothelioma as early as 1998, it was an ultrasound for a routine stress echo-cardiogram performed in late 2003, which detected the some 30 pounds of fluid he was carrying around his waist.

“I had the warning signals,” says Zygielbaum, who was also experiencing a lot of fatigue. “It’s just that they were subtle enough that nobody really noticed.”

When his doctor mentioned peritoneal mesothelioma as a possibility, Zygielbaum, married with three grown children and now five grandchildren, began researching the disease on the Internet.

“I couldn’t find very much information except that you could expect to be dead in six months to a year,” he says. “Yet, I knew I’d been developing these fluid symptoms for six years.”

When he went to see his local oncologist after receiving the diagnosis, he realized his doctor had gathered information from the same websites as he had.

“That’s when I made the decision that I needed to own this and be my own advocate,” says Zygielbaum. “I needed to learn everything I could about this disease and drive the treatment decision-making if I was going to survive.”

Research comes naturally to Zygielbaum, who has an



PHOTO BY ANTHONY DIMAANO

extensive background in the aerospace and electrical industry. Some of that work involved significant asbestos exposure.

His research led him to Creighton University Medical Center in Omaha, Nebraska, where he received a peritonectomy and intraperitoneal chemotherapy. He has had surgery since the initial peritonectomy for secondary tumors and, although monitored constantly, he is still going strong.

This is not the way Zygielbaum had expected his fate to unfold. In fact, when he first received his diagnosis, he decided to retire, although he agreed to help a

few college friends with their start-up company for as long as he could, maybe a couple of years.

“Here it is nine years later, and I’m the CEO,” he says. “There are no guarantees, but at this point I’ve done pretty well.” 🌱

**“I needed to learn everything I could about this disease and drive the treatment decision-making if I was going to survive.”**

organizations and commercial carriers. The Air Charity Network and Corporate Angel Network (see Resources chapter, page 81, for contact information) arrange and coordinate free airfare for cancer patients. The Mesothelioma Applied Research Foundation has established a grant program to help newly diagnosed patients travel to consult with an expert.

The most essential items patients will need to pack are their medical records, including doctor's notes, laboratory tests, X-rays, scans and any special diagnostic testing or evaluations that may have already been completed. A patient's primary care doctor's office can help with releases or paperwork to facilitate the transfer of records to the cancer center, especially if an electronic medical record is forwarded.

Any other items patients choose to bring will be based on their personal needs and comfort. Even though this is a medical trip, patients should plan as if they were going on a two-week vacation when deciding which items are essential to include.

Above all, patients should not be afraid to ask for advice or help from the cancer center staff and utilize services available for travel planning to make this difficult time an easier one. With appropriate preparation, attention can be focused on the evaluation appointment and not on the details of the trip.

## Seeking a Second Opinion >

Getting a second opinion is common, and several situations call for one. If patients have concerns about recommended treatments, a second opinion is

appropriate. A second opinion should also be considered if the pathologist is having difficulty making a diagnosis, if the patient's doctor is unfamiliar with mesothelioma, if the doctor underestimates the seriousness of the disease or if the patient's medical insurance plan requires it. For confirmation of a diagnosis, a patient can request a second review of tissue slides, and for another opinion on treatment, a simple consultation with an expert may make a patient feel more comfortable. In some cases, a second opinion could correct a misdiagnosis or provide additional treatment options.

### Finding Referrals

Patients should not worry about offending their doctors—most oncologists expect their patients to seek second opinions. Many suggest it themselves and give recommendations for specialists who are recognized experts in diagnosing and treating specific types of cancer. A physician should be open to discussion or confirmation of treatment options with other doctors. If not, a patient may want to consider finding another physician.

Many local hospitals and regional cancer centers, such as Memorial Sloan-Kettering Cancer Center in New York and M.D. Anderson Cancer Center in Houston, as well as institutions, including the National Cancer Institute and the National Comprehensive Cancer Network, have physician referral services that provide consultations for second opinions. An expert who specializes in mesothelioma can give a different viewpoint, suggest clinical trials other doctors may not know about or confirm a doctor's treatment recommendations.

# Linda Reinstein

## Sharing Hard-Earned Knowledge

**a** **S PRESIDENT AND CEO** of the Asbestos Disease Awareness Organization (ADAO), Linda Reinstein has a very personal connection to mesothelioma. Her husband, Alan, received a diagnosis of pleural mesothelioma in 2003, and she served as his caregiver until his death in 2006.

A year after her husband's diagnosis, she cofounded the ADAO, a group that serves as a platform for survivors of asbestos-related diseases to raise awareness of asbestos exposure and its deadly effects. Reinstein frequently serves as a Congressional witness and has organized the Asbestos Awareness Conference, now in its ninth year.

But like many who first hear the term "mesothelioma," Reinstein had never heard of the disease when her husband received his diagnosis. "I couldn't even pronounce it," she says. After Alan underwent an extrapleural pneumonectomy, Reinstein was then overwhelmed with the detail and level of care needed to tend to the needs of a mesothelioma patient.

"You get a driver's manual when you get a new car," she says. "With this disease, there's nothing. I didn't know what to do. I'm not a nurse." Reinstein now shares with others what she had to learn the hard way. "I'm a strong advocate for having a plan to navigate the medical maze."

She and her husband determined which doctor they would choose by creating a large spreadsheet to evaluate the six or seven opinions they had obtained. The Reinsteins measured

each doctor according to whether they were at a public or private hospital, their experience and their bedside manner, and then they voted. "Alan always had two votes, because he had cancer," says Reinstein.

Reinstein also found that recording their visits with the doctor to be helpful.

"I found that when I would listen to the doctor, I could hear and understand, but when we'd walk out I'd be so emotional that I couldn't commit it to memory." Playing back those appointments allowed her to access vital information that she missed.

Reinstein recommends that once patients and their families have arrived at a decision about treatment, they should try not to doubt that decision.

"Recognize that is the best decision at that point in time," she advises, "and don't look back with any regret." 🌻



PHOTO BY GLENN ZAMORA

**"You get a driver's manual when you get a car. With this disease, there's nothing. I didn't know what to do."**

# Questions to Ask

Nurse coordinators at large medical centers can be particularly helpful in finding physicians who give second opinions. Support groups and other cancer survivors may also be good sources for recommending oncologists and specialists. Patients may want to inquire about online or phone referrals, especially if they want a second opinion from an expert at a large cancer center or one who practices far from where they live. Keep in mind that most of these consultations can be expensive and may not be covered by insurance.

For some insurance plans, second opinions are covered or even required before the plan approves payment for treatment. Patients may be limited to certain physicians or hospitals, so it is always best to consider their coverage plan when coordinating second opinion appointments.

## Weighing Options

If the second doctor recommends a different treatment than that of the first, the patient may become confused about what advice to take. In that case, the decision may depend on how the side effects of each treatment are weighed against a patient's own personal views and lifestyle. A primary care doctor may also have helpful advice about weighing the recommendations.

Patients may also want to seek a third opinion if they are still not comfortable with their diagnosis or treatment options. Sometimes it is helpful to get an opinion from a large cancer center or academic hospital, especially if the first two doctors recommend different therapies or have conflicting diagnoses.

After options are weighed, a patient must choose his or her medical team. Most go with their initial doctor, but the comfort level, treatment options proposed and medical expertise should all be evaluated when making a decision. 🌸

**A** **PATIENT** should prepare for an appointment by formulating a list of questions to ask. Here is a basic list to start with, divided into two categories:

### EXPERTISE & EDUCATION

- > **Does the doctor have experience** treating mesothelioma?
- > **What types of treatment** does he or she usually recommend?
- > **Is there a multidisciplinary team** that includes a surgeon and a medical oncologist, imaging and pathology experts, and a social worker or nurse navigator?
- > **If meeting a surgeon**, how many times has he or she performed the surgery needed, and at what success rate?
- > **Is the doctor** board certified?
- > **How long has the doctor** been in practice, and how many cases of mesothelioma has he or she treated?
- > **Is the doctor involved** in clinical trials and research?
- > **Is the doctor affiliated** with a medical school?

### QUALITIES

- > **Did the doctor** give the patient a chance to ask questions?
- > **Did the patient feel like** the doctor was listening to them?
- > **Did the doctor seem** comfortable answering the patient's questions?
- > **Did the doctor talk** to the patient in an understandable way?
- > **Does the patient feel** respect from the doctor?
- > **Did the doctor ask** the patient's treatment preferences?
- > **What are the doctor's office hours?** How can the doctor be reached after hours?
- > **Who will cover** for the patient's doctor when he or she is out of the office?
- > **Can family members** or friends be brought to appointments?

chapter 4

# treatment options



# treatment options

**T**HERE ARE a variety of treatment options for patients with mesothelioma, including surgery, chemotherapy and radiation therapy. Oftentimes, a combination of these therapies is used. The specific options chosen depend on factors related to both the patient (such as age and overall health) and the location and stage or extent of disease.



BECAUSE MESOTHELIOMA is so rare, few large clinical trials have been conducted to guide treatment recommendations. This limited amount of information has created some uncertainty regarding the best treatment approach in some situations. However, a number of investigational agents and therapies are continually being tested in smaller clinical trials. This type of research has provided valuable information regarding the management of mesothelioma patients, resulting in an improved understanding of current treatment options. Moreover, the ongoing evaluation of so many investigational therapies gives both researchers and patients a ray of hope for the future.

## Surgery >

Complete surgical removal of the mesothelioma tumor is always preferred but is only possible for selected patients with early-stage disease, whereas most patients are diagnosed with advanced disease. For only a tiny fraction of patients with stage 1 or 2 disease, surgical removal of the tumor can be potentially curative. Most often, visible or microscopic tumor tissue is left behind during surgery, leading to inevitable progression of the disease. This fact, however, does not negate the usefulness of this approach,

and it is often performed to treat mesothelioma. Other surgical procedures are performed purely for symptom relief and are less involved than the former surgeries. The different types of surgical procedures are described below.

### **Cytoreductive Surgery**

Because of the advanced stage of disease of most mesothelioma patients and its diffuse (widespread) presentation throughout the pleura or peritoneum, removing 100 percent of the tumors is rarely achievable. However, surgical removal of as much of the disease as possible (called debulking or cytoreductive surgery) may still be desired for patients with good overall health and an epithelioid type of tumor, as it may provide symptom relief, improve quality of life, and in some cases, prolong survival. Patients must be selected carefully for maximal debulking surgery because it carries substantial risk of morbidity (surgical or postoperative complications) and mortality (death). These are major surgeries requiring hospitalization.

### **Pleurectomy/Decortication**

The first type of cytoreductive surgery for pleural mesothelioma is called pleurectomy/decortication (P/D), where the surgeon removes the pleura (pleurectomy)

and the fibrous covering of the lungs (decortication), which can restrict expansion of the lungs and may also harbor tumor cells. The more involved version of this surgery is known as extended (or radical) P/D, in which the diaphragm and pericardium, the thin sac that surrounds the heart, are removed as well. Typically, 80 to 90 percent of patients have local recurrence following the P/D procedure, which is not surprising given that visible tumor remains after surgery in the majority of cases. Thus, this procedure is not considered curative. Rather, the removal of the fibrous covering often relieves the patient's breathing symptoms and prevents future pleural effusions. In some cases, the removal of the bulk of the disease may extend the patient's survival when combined with other therapies, which will be discussed later in this chapter.

This procedure is associated with a number of postoperative complications, including air leak, bleeding and infection. Another disadvantage of this surgery is the difficulty in performing postoperative radiation therapy, which risks lung-related side effects because the involved lung is preserved.

In its guidelines for pleural mesothelioma, the National Comprehensive Cancer Network (NCCN), an alliance of the country's top 21 cancer centers, recommends P/D as the first option for patients with operable stage 1 disease with little to no lymph node involvement.

### **Extrapleural Pneumonectomy**

EPP is the second, and most aggressive, type of cytoreductive surgery performed on pleural mesothelioma

patients. It involves the removal of the entire diseased lung and the pleura. This is possible because mesothelioma is usually restricted to one side of the body and involves only one lung. EPP surgery also involves the removal of some lymph nodes, and, most often, the diaphragm and the pericardium. If removed, these last two structures need to be reconstructed using a mesh fiber. The lymph nodes are sent for analysis for staging purposes.

Because of the radical nature of this procedure, patients can expect to stay in intensive care for several days after surgery and will likely be hospitalized for a week beyond that. Even with experienced surgeons, approximately 4 percent of patients will die as a result of this surgery, and 60 percent may experience postoperative complications, some of which will be rare but life threatening (such as cardiac arrest or pulmonary embolism, which is a blockage of one or more arteries in the lung).

Because of the serious risks associated with this procedure, potential surgical candidates must meet a strict set of eligibility criteria, including having early-stage disease, good performance status and adequate kidney, liver, heart and lung function. Because most patients are diagnosed with advanced, or late-stage, disease, few patients are eligible to have this type of surgery. For those who are, it can provide a chance for longer survival, especially when combined with other therapies.

There is much debate over which debulking surgery is better for pleural mesothelioma patients, with some surgeons preferring the less aggressive P/D

surgery because it can provide symptom relief with less risk to the patient, whereas other surgeons prefer the more aggressive EPP because it is associated with a lower rate of recurrence and may provide longer survival, although the risk of serious health complications or even death is high. However, since healthier patients tend to be selected for surgery, the extent to which more aggressive surgery improves survival is uncertain.

Regardless of which procedure is chosen, it has finally been demonstrated that cytoreductive surgery is associated with prolonged survival among eligible patients. A recent study found an average survival of 18 months for cytoreductive surgery as compared with 12 months for those who had surgery performed for palliative treatment but without an intent to cure. Long-term complications for both surgery techniques can include chronic pain as well as scarring of the pleura, both of which can cause breathing impairment.

For patients with peritoneal mesothelioma, debulking surgery is called peritonectomy and includes the removal of all diseased peritoneum and the stripping of visible tumors on the surface of all internal organs involved. Surgery is typically combined with intraperitoneal chemotherapy, which, unlike traditional intravenous or oral chemotherapies that deliver cancer-fighting drugs through the bloodstream, delivers chemotherapy directly to the abdominal cavity through a thin tube. Deaths due to treatment range from 3 to 8 percent and serious complications, including bleeding or infection that might necessitate a second operation, range from 25 to 40 percent. The combination of

surgery and intraperitoneal chemotherapy is considered the standard treatment for this disease.

### Symptom Management

Patients with pleural mesothelioma often develop pleural effusions, or fluid accumulation in the pleural cavity. This impairs the ability of the lungs to expand during inhalation and produces shortness of breath. To make breathing easier, a thoracentesis can be performed by inserting a needle into the pleural space and draining the excess fluid. Sometimes this can be repeated, as needed, if fluid continues to build up.

Another option is a device known as the PleurX catheter, which is a thin, flexible tube that is inserted into the pleural space to drain fluid build-up. This device can stay in for longer periods of time and be emptied periodically by the patient, which can allow patients to manage their pleural effusions from home.

Pleural effusions may also be treated with video-assisted thoracoscopic (VATS) talc pleurodesis, which involves the insertion of both a camera and surgical instruments into the pleural space through small incisions in the chest. The camera allows the surgeon to maneuver the instruments to first drain the excess fluid and then to blow sterilized talc (similar to talcum powder) into the pleural space, causing an inflammatory reaction that literally glues the lung to the inner surface of the rib cage. Eventually, scar tissue forms, creating permanent bonds that eliminate the space in which fluid can develop. Typically, this procedure does not need to be repeated. Because it can be painful, patients are premedicated or sedated before the

procedure is performed. Due to its invasive nature, it is usually reserved for patients with recurrent effusions that are causing shortness of breath. Although pleurodesis is performed primarily to ease breathing difficulties caused by the fluid accumulation, it may permit a frail patient who was too symptomatic to receive further treatment to undergo additional therapy once the shortness of breath has subsided.

In some cases, a partial pleurectomy is performed for symptomatic relief. As with P/D, partial pleurectomy involves partial removal of the pleura, but it is less extensive and is not intended to improve survival. Rather, the stripping of the pleura with the tumor serves to re-expand the lung and ease breathing.

For patients with peritoneal mesothelioma, fluid (ascites) may accumulate in the abdomen; in these cases, a paracentesis, similar to a thoracentesis, is performed to drain the excess fluid. A doctor may perform an ultrasound prior to the procedure in order to determine the best location for needle insertion.

## Radiation Therapy >

Unlike most tumors, which grow as a sphere or ball of tumor cells, mesothelioma typically develops into a diffuse sheet of tumor cells, blanketing the lung or abdomen. This characteristic makes it difficult to treat mesothelioma with radiation therapy, which works best when it is targeted to a defined area. With mesothelioma, the challenge is to deliver enough radioactivity to the sheet of tumors to destroy it without damaging underlying structures, such as the lungs,

heart, liver and spinal cord. For this reason, radiation therapy is generally used to treat localized patches of tumor recurrence or small areas of tumor left behind after surgery. However, it can be used to treat larger areas following EPP because the lung has been removed. There is no evidence to suggest that radiation therapy alone improves survival in mesothelioma patients, but it does alleviate pain for approximately half of the patients receiving it. Radiation therapy may also be used to treat chest wall wounds caused by a biopsy or drainage procedure.

## Chemotherapy >

Since a cure is rarely possible in mesothelioma patients, the goals of current chemotherapy regimens are to prolong the survival of these patients and improve their quality of life by relieving some of their disease-related symptoms. Ideally, a chemotherapy regimen will be able to achieve both goals simultaneously. Chemotherapy is traditionally given systemically; that is, the drugs enter the body orally or intravenously and subsequently travel throughout the body via the bloodstream. This type of administration is responsible for many of the side effects of these drugs because the entire body is exposed to chemotherapy. Unlike many other cancers, however, peritoneal mesothelioma is often treated with intraperitoneal administration.

### Intravenous Administration

Approval by the U.S. Food and Drug Administration (FDA) of the intravenously administered chemotherapy

drug Alimta (pemetrexed) in 2004 has led to the largest improvement ever in the outcomes of pleural mesothelioma patients. Alimta acts as an antifolate drug; that is, it disrupts the metabolism of folic acid in cancer cells. When added to another chemotherapy drug called cisplatin in a clinical trial, Alimta prolonged the average survival of mesothelioma patients by almost three months. In addition, Alimta also relieved pain and shortness of breath and improved lung function in some patients. Because of these encouraging results, the combined administration of Alimta and cisplatin given intravenously once every three weeks has become standard therapy for the treatment of newly diagnosed pleural mesothelioma patients.

Premedication with folic acid and vitamin B12 is necessary when taking Alimta in order to reduce the frequency of side effects, which can include fatigue, rash, nausea, vomiting, anorexia (loss of appetite), constipation, mouth sores and myelosuppression (low blood cell counts). Other severe side effects, including renal failure, neuropathy and hearing loss, can occur from cisplatin.

To reduce the risk of these toxicities, particularly in elderly or frail patients, some physicians combine Alimta with carboplatin, an agent similar to cisplatin. Carboplatin has a reduced risk of renal dysfunction, hearing loss, vomiting and peripheral neuropathy (tingling, numbness or pain in the arms and/or legs), although it does more commonly lower blood counts. For newly diagnosed patients who cannot tolerate the toxicity of either cisplatin or carboplatin, a single alternative chemotherapy agent, such as Alimta or another

drug called vinorelbine, is a reasonable treatment.

Mesothelioma patients tend to remain on a chemotherapy regimen until the cancer worsens or chemotherapy-related toxicity requires discontinuation. At that point, the patient can be given a different chemotherapy drug, assuming he or she is not too frail. There are a number of chemotherapy drugs that have been shown to shrink mesothelioma tumors, and all produce the risk of certain side effects. Thus, in the absence of compelling data showing superiority of one or more of these drugs, all are considered reasonable treatment options, and physicians rely on their clinical judgment, knowledge of side effects and patient input when choosing subsequent chemotherapy treatment.

### **Intraperitoneal Administration**

Particularly with peritoneal mesothelioma, chemotherapy is often delivered directly to the site of disease. Called intraperitoneal administration, it immediately follows debulking surgery. With peritoneal mesothelioma, tubes are placed inside the abdomen. The tubes are connected to a machine outside the body that circulates a chemotherapy solution, effectively bathing the surfaces of the abdomen with chemotherapy in an attempt to destroy any tumor cells remaining after surgery, even if they cannot be seen.

Intraperitoneal chemotherapy has two theoretical advantages over systemic chemotherapy: 1) side effects, such as vomiting, fatigue and peripheral neuropathy, should be reduced since the chemotherapy is not traveling throughout the body; and 2) higher doses

of the drug reach the site of disease, possibly increasing its effectiveness.

However, this treatment comes with a risk of complications arising from the tube, or catheter, used to deliver the chemotherapy, including abdominal pain, infection at the site of catheter placement and catheter blockage, leakage or dislocation. Also, some chemotherapy is absorbed into the bloodstream and can lead to intravenous chemotherapy side effects. Chemotherapy is sometimes also administered for several days following surgery via a catheter that remains in the patient's abdomen, providing the opportunity to administer additional chemotherapy postoperatively.

Oftentimes, the intraperitoneal, circulating chemotherapy solution is heated to 104-108°F (called hyperthermic administration). At this temperature, not only does the chemotherapy more easily kill cancer cells, but the higher temperature may permit the chemotherapy to penetrate into the tissues, potentially killing cancer cells just below the surface.

## Current Combination Treatment Approaches >

Aside from the rare patient with early-stage disease who receives curative surgery, none of the therapies alone can produce substantial improvements in patient survival. However, certain combination approaches are believed to produce survival advantages, and many are currently in use.

Although the specifics differ for pleural and peritoneal diseases, the strategy for all combination regimens

is usually to use surgery to remove the largest amount of tumor possible and then to use other methods to reduce or (ideally) eliminate the remaining disease. Consideration of this approach merits an in-depth discussion between patient and surgeon, in which the risks and the potential benefits can be weighed. Any combination treatment approach should be undertaken by a team of specialists to ensure that the patient receives the best possible care.

### Pleural Mesothelioma

For patients with operable pleural mesothelioma, postoperative chemotherapy, radiation therapy or a combination is generally recommended, although in some cases the chemotherapy is administered prior to surgery and in others chemotherapy is delivered during surgery, or intraoperatively. Clinical trials have not adequately studied all the various regimens, so it is impossible to know for certain if any of these approaches improve survival.

Providing radiation after EPP surgery appears to reduce the risk of developing a recurrence where the radiation therapy was given. In one study, only 13 percent of patients developed recurrence in the chest following EPP and radiation. In addition, more precise forms of radiation therapy, called intensity-modulated radiation therapy (IMRT) and proton therapy, have been studied. IMRT can change the intensity of the radiation delivered to different parts of the body so that radiation is focused more on the diseased area and less on the surrounding tissues. However, it has been associated with a high rate of fatal

## Marc Ladanyi, MD

### Finding Hope through Science

**M**ARC LADANYI, MD, joined Memorial Sloan-Kettering Cancer Center in 1987 as a trainee in cancer pathology, then stayed on as a member of the professional staff. On the research side, his group works in three main areas: mesothelioma, lung cancer and sarcomas.

“Our laboratory has maintained a focus on improving the understanding of mesothelioma through the study of human mesothelioma tumor tissues and mesothelioma cells lines in order to raise diagnostic accuracy, refine the assessment of prognosis and drive the development of new therapeutic strategies,” says Ladanyi, who is MSKCC’s William J. Ruane Chair in Molecular Oncology. “More recently, we have been applying new genomic technologies and drug screening approaches to continue to attack this important clinical problem. For example, as a result of these long-standing efforts, we recently discovered that many mesotheliomas contain mutations of the BAP1 gene, a major tumor suppressor.”

Ladanyi also is leading the effort to analyze mesothelioma tumor samples for The Cancer Genome Atlas (TCGA), a network of cancer centers and investigators who are using state-of-the-art technologies to provide an integrated, in-depth analysis of the genetic abnormalities among certain tumor types.

Ladanyi’s involvement in TCGA began in 2006 when MSKCC was picked to be one of the pilot phase Cancer Genome Characterization Centers under his leadership. Today, Ladanyi



PHOTO BY RITA ROSENBLIT

is codirector of the TCGA Genome Data Analysis Center at MSKCC.

“Given my long-standing involvement in TCGA and my own laboratory experience with mesothelioma, when TCGA leaders at the National Cancer Institute proposed in 2011 to extend the project to less common cancers, I felt well-placed to advocate for mesothelioma,” Ladanyi says.

Ladanyi has high hopes for the ongoing research into mesothelioma. “In coming years I think we will see advances in risk assessment, meaning the identification of predisposing [inherited] conditions such as the germline BAP1

cancer syndrome,” he says, adding that this could lead to the prevention or early detection of some mesotheliomas. On the treatment front, Ladanyi sees much hope in multimodality therapy that delivers a “double punch” to mesothelioma cells. “A combination of approaches, such as targeted therapies together with immunotherapies, might eventually result in real clinical benefits, including cures.”

**On the treatment front, Ladanyi sees much hope in multimodality therapy that delivers a “double punch” to mesothelioma cells.**

pneumonitis (inflammation of the lungs) when used after EPP. Proton therapy can likewise minimize toxicity to nearby organs and is undergoing further study.

Trimodality therapy, which consists of some combination of cytoreductive surgery (EPP or P/D surgery), chemotherapy (before, during or after surgery) and postoperative radiation therapy, has produced promising results. Although not all studies examining this approach have shown a benefit to trimodality therapy, most studies have reported encouraging survival times, from a little over a year to up to about two years. Even more impressive is that, when looking only at patients with early-stage disease who completed all three treatments, one study reported that survival was nearly five years. This suggests that trimodality therapy may be highly advantageous, but only for a select group of patients who have favorable characteristics, like early-stage disease.

### **Peritoneal Mesothelioma**

The greatest strides made in mesothelioma in recent years have been in the treatment of peritoneal disease. A combination approach using cytoreductive surgery, intraperitoneal heated chemotherapy and postoperative intraperitoneal chemotherapy (via a surgically implanted tube) has produced median survival times from nearly three years to more than seven years according to several studies. This is far beyond the approximately six month- to one-year survival that has been typically expected for peritoneal mesothelioma patients. This has led many physicians to consider this to be a potential standard therapy for any patients

who can tolerate such a rigorous treatment. For those patients who cannot tolerate surgery, an Alimta-based chemotherapy regimen is a reasonable option that may produce improvement in survival.

## **Investigational Therapies >**

Investigational therapies describe a wide variety of treatments. They can refer to new surgical techniques, new ways of chemotherapy administration, new radiation protocols, new drugs that have not yet been approved by the FDA, approved drugs that are being tested for a different disease or even a combination of approved therapies that have not been tested concurrently with one another.

### **Clinical Trial System for Testing Investigational Therapies**

Clinical research is performed to improve the prevention, screening, diagnosis, prognosis and treatment of a disease. For treatment-focused research, investigators use a tiered clinical trial system that minimizes the number of patients exposed to the potential dangers of an untested drug or other therapeutic regimen.

Clinical trials are classified by phase, which defines the purpose of the trial. Phase I trials are designed to evaluate how a new treatment should be given, how often it should be administered, and the most effective and tolerable dose. Because the potential dangers of a new treatment are relatively unknown, phase I trials are small studies enrolling few patients who are carefully monitored for the development of side effects.

Dosages are often increased or decreased based on the frequency and severity of side effects observed, and if the side effects are deemed too severe, the trial is terminated.

Typically, patients with different types of cancer are enrolled in phase 1 studies. If the safety of a treatment is considered acceptable in phase 1 trials, it can move to phase 2 testing in a single disease.

A phase 2 trial may have more patients enrolled than a phase 1 trial and, while safety is still carefully monitored, the effectiveness of a treatment is an equally important focus at this stage. However, rarely can any conclusions about a treatment's impact on survival be drawn from a phase 2 study.

Phase 3 clinical trials are specifically designed to carefully test whether a new treatment is more effective than what is currently considered standard therapy. This is typically done by controlling as many variables as possible (such as previous treatment received, size of tumor and stage of disease) and conducting the trial in such a way that the only difference between the two groups of patients is the different drug regimens they receive.

Once the phase 3 trial is complete, statistics are used to determine if the results achieved by both groups (i.e., average survival time, rate of response to therapy) are different enough to claim that one treatment is superior to the other. In order to accomplish this goal, typically hundreds, and in some cases thousands, of patients must participate in a phase 3 trial. This also provides an excellent opportunity to confirm the safety of a treatment in a larger patient population.

When a treatment shows both superior efficacy and good safety in a phase 3 trial, it often changes the way physicians treat patients and may also lead the FDA to approve a new treatment for a specific use.

The problem with performing phase 3 clinical trials in mesothelioma is the rarity of the disease, which makes it exceedingly difficult to accrue hundreds of patients matching particular eligibility criteria to a specific trial.

### **Update of Recently Completed Phase 3 Clinical Trials**

Two of the largest phase 3 trials to be conducted thus far with mesothelioma patients examined two promising investigational agents: Zolanza (vorinostat) and Onconase (ranpirnase). Both drugs are considered targeted agents. Targeted agents are named for their ability to more directly attack tumor cells rather than indiscriminately attacking all rapidly dividing cells, as chemotherapy does. This targeted approach, in theory, should produce fewer side effects, and in general, it is true that they induce fewer chemotherapy-related side effects, such as hair loss and nausea/vomiting, than traditional treatments. However, experience has proven that these targeted agents are not without side effects, some of which can be severe, and thus require careful examination to determine how to administer these agents in the safest possible way.

Zolanza, an oral histone deacetylase inhibitor that impacts how genes are expressed, showed some promise in a phase 1 study, which led to a large phase 3 trial. The phase 3 trial with Zolanza enrolled 660 patients

with pleural mesothelioma who had already received Alimta combination therapy. These patients were then given the best standard of care with either Zolinz or placebo. However, the patients receiving Zolinz showed no improvement in survival; thus, this drug is no longer under consideration as a potential mesothelioma treatment.

Onconase is a novel agent that degrades RNA in cancer cells. Onconase in combination with doxorubicin was compared with treatment with doxorubicin alone in 413 patients with mesothelioma. Unfortunately, this trial also showed no improvement in survival when Onconase was added to chemotherapy; both groups had approximately 11 months survival. These studies highlight the difficulties that researchers have encountered in trying to find effective new therapies for this disease. Nonetheless, research continues to search for better ways to treat mesothelioma, and some of the most promising therapies are discussed below.

### **Ongoing Phase 3 Clinical Trials**

As of early 2013, there were around 80 ongoing clinical trials to improve the diagnosis, screening and

treatment of mesothelioma. A few are phase 3 trials focused on mesothelioma treatment; one compares surgical procedures and two examine targeted agents added to chemotherapy. The surgical clinical trial examines two surgical procedures commonly used in patients with mesothelioma. To be enrolled in this trial, patients must have suspected or proven mesothelioma; one group will undergo a VATS pleurectomy to remove the diseased pleural membranes, and the other group will have talc pleurodesis to glue the pleural membranes together. Survival of both patient groups will be the primary measure of interest, but surgical complications, control of pleural effusions and quality of life will be examined as well.

A French trial is currently examining the effectiveness and safety of adding the targeted agent Avastin (bevacizumab) to a chemotherapy combination of Alimta and cisplatin in patients with pleural mesothelioma. Avastin is a cancer drug that has been widely used in colorectal, kidney and non-small cell lung cancer, as well as a certain type of brain cancer. It works by disrupting a tumor's blood supply, effectively starving the tumor. Given its success in improving the survival of patients with other types of cancers, including lung cancer, researchers are hopeful it can produce similar results in mesothelioma patients.

Previously, a randomized phase 2 trial of Avastin with a slightly different chemotherapy combination of gemcitabine and cisplatin in 115 mesothelioma patients demonstrated no benefit. There is reason to believe that Avastin added to Alimta might produce better results. The French Avastin study should

Experience has proven that these targeted agents are not without side effects, some of which can be severe.

provide those answers. Target enrollment for that study is 445 patients, and results are expected by the end of 2014.

The third phase 3 mesothelioma trial is testing another agent, asparagine-glycine-arginine-human tumor necrosis factor (NGR-hTNF), which targets the tumor blood supply. This trial is enrolling patients with pleural mesothelioma who have already been treated with an Alimta-based chemotherapy regimen. NGR-hTNF is an intravenously administered drug that has already demonstrated the ability to slow disease progression in a phase 2 mesothelioma trial. Because no standard therapy exists for mesothelioma patients after treatment with Alimta, this investigational agent will be added to any of three different chemotherapy drugs, doxorubicin, gemcitabine or vinorelbine (the investigator will decide which one the patient receives) in one group of patients, and placebo will be added to the investigator's choice of chemotherapy in the other group of patients. Approximately 400 patients have enrolled in this study, and results are expected in 2013.

### **Other Investigational Therapies to Watch**

A number of investigational therapies that have not yet reached phase 3 testing are of interest and may end up being used successfully to treat mesothelioma patients in the future. Amatuximab is an antibody designed to target the growth of mesothelioma tumor cells. It is currently undergoing phase 2 testing for pleural mesothelioma when combined with chemotherapy. Interim results (made public while the study

is still ongoing) showed that this drug appears well-tolerated and the combination of amatuximab and chemotherapy is associated with a median overall survival time of more than 14 months. Perhaps more interesting is the fact that researchers discovered that certain laboratory tests may be able to potentially identify patients who respond particularly well to this treatment, information which will likely be used in the next clinical trial to better select patients for this therapy.

Another investigational therapy is CBP501, a new chemotherapy drug that affects cell division and enhances the toxic effects of cisplatin on cancer cells. In phase 2 testing of CBP501 in combination with Alimta and cisplatin, those pleural mesothelioma patients who received all three drugs experienced a longer time until their disease progressed compared with those patients receiving only Alimta and cisplatin, although both arms of the trial experienced the same median overall survival of 13 months.

It has long been known that pleural mesothelioma patients who have immune cells in close proximity to their tumors may have better outcomes. For this reason, researchers have sought ways to harness the immune system to more effectively fight mesothelioma. Tremelimumab is one such example of an investigational immunotherapy; it works by boosting the immune system to more aggressively attack tumor cells. Preliminary results from phase 2 testing in patients who have already progressed after receiving standard chemotherapy showed that tremelimumab could slow down the disease and has led to another

phase 2 trial, which will investigate a more intense administration schedule of the drug.

Several drugs that have been used for other cancers and conditions are currently being investigated for treating mesothelioma. Erbitux (cetuximab), an FDA-approved drug for colorectal and head and neck cancers, is an example. It binds to the epidermal growth factor receptor (EGFR), which is found in abundance on the surface of many tumor cells. Because EGFR is also present on many mesothelioma cells, a clinical trial is studying the drug's effectiveness when combined with chemotherapy. Results are expected in 2013.

Already an established treatment in some lung cancers, photodynamic therapy is also currently being studied as a treatment for mesothelioma. In this therapy, a drug called a photosensitizing agent is injected into the bloodstream. The agent is absorbed by all cells, both healthy and cancerous, but the cancerous cells retain the drug longer. Roughly 24 to 72 hours later, when the agent is no longer in healthy cells, the tumor is exposed to a special light, activating the agent and killing the cancer cells.

While the only large study conducted to evaluate this light-based approach showed no improvement when photodynamic therapy was administered following surgical debulking and immunochemotherapy in pleural mesothelioma patients, many of those patients had significant tumors remaining after surgery, which might have compromised the results of the study. Recent research from the University of Pennsylvania suggests that photodynamic therapy can

be used in combination with P/D surgery in patients with advanced-stage pleural mesothelioma to produce a median survival time of 2.6 years. These researchers are now considering studying this combination therapy in a large phase 3 trial, which would provide more definitive results regarding the effectiveness of this approach.

Whereas intraperitoneal administration of chemotherapy is part of a standard regimen for peritoneal mesothelioma, hyperthermic intrathoracic chemotherapy administration for pleural mesothelioma is investigational. In a small 2012 study of eight mesothelioma patients, using this approach in combination with P/D, intravenous chemotherapy and radiation therapy resulted in a median survival of 18 months, with no deaths 30 days after treatment. Given the success of intraperitoneal administration of chemotherapy for peritoneal disease, intrathoracic administration is of interest for pleural disease to determine if it can produce similar benefit.

For peritoneal mesothelioma, ongoing research is exploring the possibility of simultaneously using two methods of chemotherapy, with some drugs being injected intravenously and others injected directly into the abdomen (intraperitoneal administration) in an approach called bidirectional chemotherapy. The phase 2 results of this approach following debulking surgery plus intraperitoneal heated chemotherapy suggests that bidirectional chemotherapy can be performed safely.

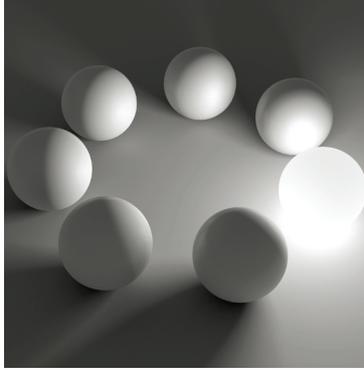
For a complete list of ongoing mesothelioma clinical trials, go to [clinicaltrials.gov](http://clinicaltrials.gov). 🌐

chapter 5

side effects  
& coping  
strategies

# side effects & coping strategies

**A**LMOST all cancer treatments have side effects. Physicians should discuss with their patients the expected benefits of therapy with the expected side effects when choosing a particular approach. Side effects can often be effectively treated and managed, but this requires good communication about these side effects between patients and their healthcare provider.



## Surgery >

In general, recovery from surgery for pleural mesothelioma depends upon the type of procedure received. Recovery from P/D surgery (four to six weeks) is shorter than the recovery period for the more aggressive EPP surgery (six weeks to as much as four months). For patients undergoing peritonectomy for peritoneal mesothelioma, recovery may be even longer, with hospitalization alone required for an average of three weeks.

Regardless of the surgery, some side effects and complications are common. Patients may experience nausea from the anesthesia, and they may have difficulty dealing with the various tubes coming out of their bodies (such as I.V., catheter, chest tube, breathing tube and feeding tube). Pain, swelling, drainage and some bleeding at the incision site is normal, but excessive swelling, foul-smelling drainage, redness, a warm or tingling sensation, fever and extensive bleeding are all reasons to seek medical care.

After either type of debulking surgery for pleural mesothelioma, air and fluid may collect in the chest. Although this condition makes it difficult to turn over, cough and breathe deeply, these activities are important to aid in the expansion of remaining lung tissue and the elimination of the excess air and fluid. Patients

often experience shortness of breath following surgery, a feeling that subsides over time as lung tissue expands. Pain or weakness in the chest and arm is another common surgical complication, but can be managed with physical therapy, which can help restore strength and range of motion.

For patients receiving a peritonectomy, the biggest challenge is getting the gastrointestinal tract to function postoperatively. This temporary dysfunction is caused by the large amount of bowel manipulation required during surgery, as well as the trauma caused by stripping the tumor from intra-abdominal surfaces. Until the gastrointestinal tract regains function, a nasogastric tube, which runs through the nose into the stomach, will remain in order to drain the stomach's contents. This can take roughly three to four

Patients often experience shortness of breath following surgery, a feeling that subsides over time as lung tissue expands.

Many mild side effects can be managed by behavioral or dietary changes and over-the-counter medications, whereas severe side effects may be treated with prescription medications.

weeks. Once the bowels are functioning, intravenous nutrition may need to be continued even longer until adequate nutrition can be taken by mouth.

## Chemotherapy >

Chemotherapy causes a number of well-established side effects, but not all patients will experience all side effects, nor will all side effects be severe. Also, side effects vary significantly between different chemotherapy drugs. Common side effects include nausea, vomiting, fatigue, mouth sores, dry mouth, loss of appetite, low white blood cell counts (which can increase the risk of infection), diarrhea, constipation, rash, hair loss, body aches and peripheral neuropathy (tingling, numbness or pain in the hands and/or feet).

Management of side effects often depends on the severity. Many mild side effects can be managed by behavioral or dietary changes and over-the-counter medications, whereas severe side effects may be treated with prescription medications. For instance, mild diarrhea management is typically started with a diet of bananas, rice, applesauce and toast (BRAT) and increased fluids to prevent dehydration.

Medication for mild diarrhea is most often over-the-counter Imodium (loperamide), to which prescription Lomotil (atropine-diphenoxylate) can be added if no improvement in the condition is observed. Severe diarrhea is treated with the prescription medicine Sandostatin (octreotide).

Mouth sores can be debilitating due to pain and can cause difficulty in talking, swallowing and eating. Behavioral modifications include careful oral hygiene, use of a soft-bristle toothbrush and frequent application of lip moisturizer. Magic mouthwash, often prescribed for the management of mouth sores, is a generic term for a mouthwash that contains a variety of active ingredients, often including a pain reliever, an antibiotic and an anti-inflammatory, but may also include an antacid or an antifungal agent.

Management of dry mouth relies primarily on behavioral modifications, such as using humidifiers, rinsing one's mouth frequently with water, drinking at least 64 ounces of water each day and avoiding alcohol-based mouthwashes and dry, sticky or spicy foods. Saliva substitutes can be purchased over the counter and can be in gel, gum, mouthwash and toothpaste forms. If those provide no improvement of dry

## Mary Hesdorffer

### Growing Education, Research and Support

**M**ARY HESDORFFER, MS, APRN, had an association with the Mesothelioma Applied Research Foundation long before becoming its executive director in 2012. As a nurse practitioner, she's been working with the foundation as a medical liaison since 2007. Before then, she customarily spoke at the Meso Foundation's conferences as a mesothelioma clinician.

Services for patients and their families, including disease management and clinical trial guidance, have always been at the heart of the Meso Foundation's mission, making Hesdorffer's skills an obvious fit for the nonprofit organization.

"My strength is that I am a clinician," Hesdorffer explains. "I have been treating patients with mesothelioma for more than 14 years. I discuss options with patients, and I make appropriate referrals to physicians who have a good knowledge of mesothelioma and a good track record."

Hesdorffer also places much emphasis on clinical trials, which she believes are very important for mesothelioma.

"I view clinical trials as opportunities for patients to try new drugs that may be better than the currently available drugs, and it is my mission to educate all patients about all options," Hesdorffer adds.

According to Hesdorffer, this specific combination of expertise and services is what sets the Mesothelioma Applied Research Foundation apart from other entities claiming to provide similar services but that are neither nonprofits nor have

any expertise in mesothelioma treatment.

Established in 1999, the Meso Foundation is dedicated to offering support and education to families affected by mesothelioma and to providing peer-reviewed funding for mesothelioma research with over \$7.6 million funded to date. The Meso Foundation also does advocacy work, including ongoing efforts to obtain more federal research funding on behalf of veterans affected by mesothelioma.

"About 30 percent of all patients diagnosed with mesothelioma are veterans," Hesdorffer says. "We feel that the government has an obligation to provide more funds for research." 🌻

**"My strength is that I am a clinician. I have been treating patients with mesothelioma for more than 14 years."**



PHOTO BY COLBY WARE

mouth, prescription medications, such as Salagen (pilocarpine) and Exovac (cevimeline), may be used.

Some side effects are treated primarily without prescription medications. Constipation is initially managed with dietary changes, such as increasing fiber and water intake and avoiding dairy products and processed foods. Behavioral modifications include establishing a regular bathroom routine and increasing physical activity. Several over-the-counter remedies can be used to effectively treat constipation, including Colace (docusate), Senokot (senna), MiraLAX (polyethylene glycol) and Milk of Magnesia (magnesium hydroxide). Persistent constipation may require suppositories or enemas.

Nausea and vomiting, which are, unfortunately, common with chemotherapy, can be managed successfully by a number of prescription medications. Not only are there more than a dozen drugs available to treat nausea and vomiting, but many of them can be used in anticipation of these conditions, which can be

Not only are there more than a dozen drugs available to treat nausea and vomiting, but many of them can be used in anticipation of these conditions.

prevented when the drugs are taken prior to chemotherapy.

Peripheral neuropathy is best avoided rather than treated. Although behavioral modifications can prevent the exacerbation of this problem (avoiding excessive heat or cold and wearing protective clothing, such as gloves and thick socks), little can be done to eliminate the problem. Mild peripheral neuropathy (characterized by tingling or numbness) is often tolerated, but if it becomes severe (characterized by pain), the dosage of the chemotherapy is typically reduced; if that does not alleviate the peripheral neuropathy, the chemotherapy may be discontinued.

## Radiation Therapy >

Radiation therapy can cause pain, nausea, vomiting, fatigue, loss of appetite, low blood cell counts and diarrhea. However, side effects are usually related to the areas treated, such as redness, peeling, irritation or dryness of the skin, and hair loss at the radiation site.

Radiation to the lungs can cause fibrosis or a stiffening or scarring of tissue that may result in shortness of breath. If radiation is close to the esophagus, the patient may have swallowing difficulties. These can be managed using a number of behavioral modifications, including altering food consistency or modifying head or body position to make it easier to swallow. Training can also be provided to patients in order to teach them to swallow differently, using biofeedback or techniques such as holding one's breath while swallowing.

A nutrition plan should be devised that has a number of goals: to minimize nutrition-related side effects, to prevent nutrient deficiencies, to preserve lean body mass and to maximize quality of life.

### Dietary Changes >

Cancer can cause changes within the body that alter nutritional requirements for vitamins, minerals, protein, carbohydrates and fat, while at the same time producing a loss of appetite in many patients. This is certainly true for mesothelioma patients, many of whom experience unexplained weight loss as one of the symptoms leading them to seek out medical attention for what is ultimately diagnosed as mesothelioma.

Once mesothelioma treatment begins, maintaining proper nutrition becomes even more challenging, as both chemotherapy and radiation therapy can cause a number of symptoms that adversely affect nutritional intake, such as taste or smell changes, nausea, vomiting, diarrhea, constipation and loss of appetite. Furthermore, mesothelioma patients who undergo radiation therapy may have difficulty swallowing, making it difficult to eat solid foods. The danger for patients with these symptoms is that poor diet will lead to malnutrition, which is associated with shorter survival times.

There are interventions that can minimize or avoid these negative outcomes associated with poor

nutrition. Most importantly, a nutritional assessment should be performed prior to beginning mesothelioma treatment. This assessment should take into account current nutritional status and physical condition, as well as anticipated side effects from upcoming therapy that may negatively affect the patient's nutrition. A nutrition plan should be devised that has a number of goals: to minimize nutrition-related side effects, to prevent or reverse nutrient deficiencies, to preserve lean body mass and to maximize quality of life.

Studies have shown that dietary counseling does improve patient outcomes, including enhanced nutrition, fewer treatment-related symptoms and improved quality of life.

For patients with a loss of appetite, eating smaller, more frequent meals may help increase food intake. Nutrient-dense foods or beverages should be encouraged so patients can make the most of their calorie intake. For those patients unable to improve nutrition using these techniques, short-term nutritional support may be needed in the form of appetite-stimulating medications and intravenous or feeding tube administration of nutrients. The use of nutritional supplements, either as liquids or pills (such as

Evidence suggests that exercise produces a number of additional benefits, including increases in physical function, muscle strength and self-esteem, as well as reductions in anxiety and depression.

vitamins), by cancer patients is controversial, despite their appearance as a healthful approach to maintaining proper nutrition. The reason for the controversy is the belief by some experts that it may be counterproductive to supplementally provide nutrients that can inhibit the function of the cancer treatments. It should be noted, however, that patients treated with Alimta are required to take folic acid and B12 supplements to reduce treatment-related toxicity.

Although antioxidants are widely perceived to produce health benefits due to their ability to protect cells from cellular damage caused by free radicals, these substances may be harmful to cancer patients because they may prevent the cellular damage to the tumor caused by chemotherapy or radiation therapy. These beliefs are primarily theories, with little research conducted to test their effectiveness.

However, in the absence of compelling evidence regarding the harm or benefit of nutritional supplements, the American Cancer Society recommends that cancer patients receiving chemotherapy or radiation therapy not exceed the 100 percent recommended

daily allowance of certain antioxidants. Similarly, most cancer experts recommend avoiding supplements, unless instructed by the doctor, containing high concentrations of antioxidants.

## Physical Activity >

Nearly all patients with cancer, including those with mesothelioma, experience fatigue at some point during their disease. This may be caused by cancer treatment, the cancer itself or both. Cancer-related fatigue is different from feeling tired; it is a feeling of exhaustion that does not improve with sleep. Although patients who are fatigued may not feel that exercise is possible or even desirable, an analysis of about 2,000 cancer patients has shown that exercise can reduce fatigue. Evidence suggests that exercise produces a number of additional benefits, including increases in physical function, muscle strength and self-esteem, as well as reductions in anxiety and depression.

The appropriate type and intensity of exercise should be individualized to each patient's physical condition and personal preference, taking into account

both pre-existing diseases, such as rheumatoid arthritis, and physical limitations caused by the disease or treatment, such as reduced lung capacity. However, in many cases, taking a short walk each day can produce substantial health benefits and is encouraged as an excellent way to improve physical fitness and emotional wellness. For those patients on bed rest, declines in muscle strength, endurance and overall fitness are inevitable, and physical therapy can help maintain strength and fight fatigue.

## Integrative Medicine >

Integrative medicine is an approach in which traditional therapies, including surgery, chemotherapy and radiation therapy, are combined with complementary therapies, such as homeopathic medicines, herbal therapy, acupuncture, massage therapy, chiropractic treatment, hypnosis, meditation and yoga. Integrative medicine extends traditional medicine from treatment of the body to that of the mind and spirit. Many major cancer centers offer some level of integrative medicine.

Because physicians traditionally have been skeptical of the usefulness of integrative therapies, patients who use them may hide this fact from their doctors. Patients should always disclose this information for a variety of reasons: 1) certain herbs or substances may directly harm the patient; 2) they may increase the toxicities of conventional approaches; and 3) they may inhibit the ability of traditional medicine to be effective. Thus, the safest and most effective use of

integrative therapies is within the context of a program in which physicians can help patients choose a complementary approach most likely to benefit them as well as monitor the effects of therapies to ensure they do not negatively impact the outcomes of conventional approaches.

Another benefit to an integrative medicine program is the ability to recommend or employ trained practitioners to ensure that patients are treated with techniques in a safe, professional manner. There are a number of integrative approaches that mesothelioma patients may consider, some with potential benefits and others with risks (see chart on page 52). Finally, whether the patient participates in an integrative medicine program or not, it is important to discuss integrative treatments with a physician. ❁

Integrative medicine extends traditional medicine from treatment of the body to that of the mind and spirit. Many major cancer centers offer some level of integrative medicine.



**COMMON INTEGRATIVE APPROACHES USED TO TREAT MESOTHELIOMA >**

Below is an abbreviated list of integrative therapies, with their potential benefits and risks, that patients may consider. Before starting any integrative therapy, discuss it with the physician first.

INTEGRATIVE APPROACH	DEFINITION	POTENTIAL BENEFIT	POTENTIAL RISK
<b>Acupuncture/acupressure</b>	Acupuncture is the treatment of pain or disease by inserting the tips of needles at specific points on the skin. Acupressure is the treatment of pain or disease by applying pressure with the fingers to specific pressure points on the body.	Reduction in cancer pain, fatigue and chemotherapy-associated nausea	Increased risk of infection or bleeding in patients with low white blood cell or platelet counts
<b>Biofeedback</b>	Technique in which a patient is given information about certain bodily processes (heart rate or blood pressure) that is not normally available, with the goal of gaining conscious control of them	Reduction in cancer pain, stress and insomnia	None identified
<b>Guided imagery</b>	Relaxation technique in which a patient uses positive visualizations and thoughts	Reduction in cancer pain, anxiety and stress; promotion of healing	None identified
<b>Hypnosis</b>	An induced trance or sleeplike state, in which a patient is more susceptible to suggestion	Reduction in cancer pain, chemotherapy-associated nausea, anxiety and stress	Can be risky if performed by inadequately trained individuals
<b>Massage</b>	Manual manipulation of a patient's body that promotes relaxation, relieves tension and stimulates circulation	Reduction in cancer pain, anxiety and stress; increase in relaxation and circulation; improvement in mood	Increased risk of bruising in patients undergoing chemotherapy; increased irritation to irradiated skin in patients undergoing radiation therapy
<b>Reflexology</b>	Manual therapy using applied pressure to reflex zones on the feet and hands that correspond to other body areas	Reduction in cancer pain and stress; increase in relaxation and circulation	Not recommended for patients with low platelet counts, arthritis or osteoporosis
<b>Supplemental nutrition</b>	Use of nutritional supplements	May alleviate some cancer-related symptoms	May interfere with traditional cancer therapies
<b>Tai chi/Yoga</b>	Use of breathing techniques, movement, stretching and meditation	Reduction in fatigue, stress	Not recommended for patients with arthritis

chapter 6

legal  
issues &  
legislation

# legal issues & legislation

**C**OMPANIES involved in the manufacture and distribution of products containing asbestos can be held liable for the resulting harm, such as the development of mesothelioma in workers who were exposed to asbestos. Even though many companies removed asbestos from their products as far back as the 1970s, people are being diagnosed today with mesothelioma because of the long latency period between exposure and diagnosis.



## Legal Issues >

Patients who have a mesothelioma diagnosis and believe they had asbestos exposure in the past may be entitled to bring legal action to seek compensation for their injuries. If they file such a lawsuit, their rights and eligibility for legal compensation vary depending on the state in which the lawsuit is filed.

Asbestos lawsuits require a patient to provide evidence of asbestos-containing products to which they were exposed and work sites where they were exposed to asbestos. An attorney can assist patients on the investigation to understand how they were exposed to asbestos. The type and amount of damages that can be recovered depend not only on the laws of the particular state in which a patient filed but also on the individual facts of each case.

The law provides a maximum time to pursue a case, which is called the statute of limitations and varies from state to state. In most cases, the limitation period is two years from diagnosis, but it can be as short as a year or as long as three or more years depending on the state.

Most attorneys recommend pursuing compensation as soon as possible after diagnosis for several reasons. First, patients will need to provide details about their exposure to asbestos, symptoms, diagnosis

and treatment. If they are fatigued or ill from treatment, this process may be difficult. They will want to get the details recorded when their mind and health are at an optimum. Second, their case may be expedited depending on their symptoms and the stage of the disease. If patients pass away before a trial date is set, it can delay their case. Third, the point of compensation is to obtain money to help with medical bills and other expenses. The sooner the legal process is started, the sooner a patient may be able to recover compensation.

Each case is unique and it is difficult to determine how long the legal process will last. If a trial is not expedited, it may take two or more years before resolution. These are the most common types of lawsuits:

> **Personal injury lawsuits** are filed for personal suffering and pain associated with the illness, which can occur from direct or secondhand exposure to asbestos. Compensation is based on the degree of incapacity, loss of income and quality of life related to a patient's mesothelioma symptoms and treatment. Damages are awarded for medical expenses, lost wages, travel expenses for treatment, pain and suffering.

> **Wrongful death lawsuits** are filed on behalf of the family after the death of a person with mesothelioma. The damages awarded are for payment of

mesothelioma-related medical bills, lost income, counsel related to the death of a loved one and loss of care and companionship.

As with any other legal services, patients should obtain an attorney who specializes in mesothelioma and asbestos-related illnesses. Choosing an attorney is a personal decision, just as when choosing a medical team. Individuals should feel comfortable with the answers provided to their questions, the way they are treated by the attorney and staff, and the level of experience and positive outcomes the law firm has had with other cases. A word of caution: Watch out for law firms that merely advertise for cases and then send them to another lawyer to handle the case. Patients should ask the law firm they are interviewing if it actually prosecutes mesothelioma cases. If the answer is “yes” but the firm wants to refer the case, make sure the referral is based upon a decision to provide the patient with an optimum legal team. A firm should also never promise a specific amount of compensation. There are no guarantees; each case is unique.

Patients should also be aware that there is an abundance of websites, campaigns and social networking pages dedicated to mesothelioma. While some of these sites and initiatives appear to be nonprofits, many are created or sponsored by law firms or other for-profit institutions in order to reach victims of asbestos-related diseases and gain new clients.

Legal advice and the process of filing a lawsuit is an expensive undertaking. Therefore, most attorneys accept a case based on a contingency fee. This means

patients will have no out-of-pocket expenses and the attorney will receive a percentage of the settlement money as payment. The contingency fee pays for legal work done on the behalf of patients, court filing fees, expert witness fees and legal representation in court. Some patients’ claims may proceed outside the court system. Specifically, although some manufacturers of asbestos and asbestos-containing products have filed for bankruptcy, trust funds have been set up in many cases to compensate victims.

Once a person decides to hire an attorney, it is important to know what is expected. At first, patients will meet with the legal staff to gather the facts of the case. Patients will be asked to provide information about their work and personal history to determine the type and degree of asbestos exposure sustained. Authorizations for copies of medical records will be obtained, and patients should not have to undergo any further medical testing for the purposes of the lawsuit.

Next, patients will be asked to give a deposition (a testimony on tape). Some attorneys also have a videographer follow patients for a day to document what a typical day with mesothelioma is like for them. This can be shown in court to support their case.

To help expedite the case, patients will want to have the following documentation for their attorneys:

- › Pathology reports
- › Cytology reports
- › Surgery reports, if applicable
- › Diagnostic scans and reports if patients have not had

a biopsy or fluid sample taken

- > Documentation related to the patient's asbestos exposure
- > Names of coworkers or individuals who can verify the patient's exposure
- > A copy of the patient's will, living will and advanced directives
- > If this is a wrongful death lawsuit, a copy of the death certificate

Many worry that with a lengthy litigation, they may die before the case is settled. If patients pass away, their loved ones can continue to litigate in their place if patients have designated an executor of their estate and beneficiaries in their will.

Patients have a legal right to seek compensation for the toll of this disease. If individuals choose to move forward with litigation, they should do research and select a law firm that meets their needs. An attorney can be an important part of a patient's team, along with healthcare providers and family.

## Legislation >

According to the National Cancer Institute, no federal legislation has been enacted to compensate victims of asbestos-related diseases or to protect people from asbestos exposure. The recognition of asbestos as a cancer-causing agent and the effort to have asbestos products banned has been ongoing for decades.

The inhalation of asbestos fibers was first linked to

lung disease in 1890, and the first deaths attributable to asbestos exposure were reported in 1907. In 1927, physicians began to refer to the lung scarring caused by asbestos exposure as asbestosis. It was not until 1955 that Richard Doll, MD, published data from studies that linked asbestos exposure to lung cancer.

Beginning in the 1960s, professional organizations and advocacy groups spoke about the dangers of asbestos exposure, resulting in the establishment of standards and regulations. Here are a few highlights:

**[1964]** Irving Selikoff, MD, shows that asbestos causes mesothelioma at the New York Academy of Sciences Conference, "Biological Effects of Asbestos."

**[1970]** The Occupational Health and Safety Act is passed, resulting in the first standards for asbestos in the workplace.

**[1971]** The Environmental Protection Agency determines asbestos is a hazardous air pollutant.

**[1976]** The National Institute for Occupational Health and Safety calls for a ban on asbestos in the workplace.

**[1989]** The Environmental Protection Agency issues the "Asbestos Ban and Phase-Out Rule." The 5th U.S. Circuit Court of Appeals overturns it in 1991.

**[1998]** The International Programme for Chemical Safety determines there is no safe exposure for chrysotile asbestos.

**[2002]** U.S. Sen. Patty Murray (D-Wash.) introduces the Ban Asbestos in America Act of 2002.

**[2006]** The World Health Organization and the International Labor Organization agree that all forms of asbestos are carcinogens, there is no safe threshold for exposure and the elimination of asbestos is essential to stop asbestos-related diseases.

**[2007]** The Senate unanimously passes the Ban Asbestos in America Act of 2007. U.S. Rep. Betty McCollum (D-Minn.) introduces the Bruce Vento Ban Asbestos and Prevent Mesothelioma Act (HR 6903).

No action was taken after Rep. McCollum's bill was introduced, and in 2008, the Committee on Energy and Commerce, with sponsorship from U.S. Rep. Gene Green (D-Texas), re-introduced the legislation. In 2009, U.S. Rep. Henry Waxman (D-Calif.) took over as chairman of the Committee on Energy and Commerce. With a new administration, restructuring took place, and the subcommittee on Environment and

Hazardous Materials was split into the Environment and Energy subcommittee and the Commerce, Trade, and Consumer Protection subcommittee.

Survivors of mesothelioma are protected under the Americans with Disabilities Act (ADA), which was created to protect against discrimination in the workplace. Employers with more than 15 employees are required by law to make reasonable accommodations for cancer patients and survivors. These accommodations may include a change in job duties, flex time, longer lunch hours, adaptive equipment to facilitate an employee's job duties, ergonomic chairs and work breaks.

The Family and Medical Leave Act (FMLA) protects jobs of cancer survivors at companies with more than 50 employees. It allows for up to 12 weeks of unpaid leave and guarantees the continuation of benefits and health insurance during that time. The leave does not have to be taken in any specific increments, thereby allowing flexibility for medical procedures and treatment. Caregivers can also take advantage of the FMLA for extended travel for medical appointments and caregiving duties.

Patients have the right to keep their diagnosis a secret, but if they are concerned that it may affect their work performance or they ask for special accommodations or leave, it is recommended that they disclose their diagnosis to their employer. Employers may be receptive to meeting needs if patients are honest and forthcoming. Also, patients will not be covered by the ADA unless they notify their employer of their diagnosis. ❁

Survivors of mesothelioma are protected under the Americans with Disabilities Act (ADA), which was created to protect against discrimination in the workplace.

chapter 7

# survivorship



# survivorship

**T**HE transition into survivorship can be complex. Survivors often worry about recurrence or disease progression, may suffer from long-term side effects of treatment and can have emotional issues from having cancer. A survivorship plan can help organize follow-up care and provide patients with tools to ease into this next phase.



## Disease Progression >

Although mesothelioma tumors can be removed by surgery or shrunk using chemotherapy or radiation therapy, visible or microscopic tumors are left behind in the majority of cases. Most patients will experience disease progression, when tumors begin to grow again. Certain characteristics, such as early-stage disease, epithelioid subtype, young age and good performance status, may delay progression. Although treatment with Alimta and cisplatin produces a proven three-month improvement in survival, nearly all patients with pleural mesothelioma who are treated with this regimen will have progression within two years of treatment. Patients with peritoneal mesothelioma who are treated with cytoreductive surgery followed by intraperitoneal chemotherapy fare somewhat better, with approximately 40 percent living without disease progression at two years and 14 percent without disease progression at five years.

At the time of recurrence, patients must decide whether they wish to continue active treatment, either by one of the many chemotherapy agents currently in use or by participating in a clinical trial testing an experimental mesothelioma treatment. The other option they have is to receive only palliative care, in which patients are made as comfortable as possible

by managing disease-related symptoms as they arise. Although active treatment may be discontinued upon recurrence, palliative care continues. Not only do patients need continued management of pain and other symptoms, they also need social, emotional, psychological and spiritual support as they move to this new stage of survivorship.

## Long-Term Effects of Treatment >

Many of the side effects experienced during mesothelioma treatment disappear during or shortly after completion of treatment. However, some problems do linger, creating difficulty for those patients not undergoing active treatment.

Fatigue is a common side effect of cancer treatment, and 30 to 50 percent of cancer survivors experience fatigue that lasts for months, sometimes years, after treatment ends. Normal fatigue often gets better with rest, but cancer-related fatigue does not respond to sleep and can be distressing mentally and physically.

Exercise has been found to improve cancer-related fatigue. Doctors often start patients on a gentle exercise plan, such as a walking routine. Some medications can be helpful in treating fatigue. Physicians can determine appropriate exercises for their patients' individual

situations and prescribe medications if needed.

Pain is another long-term effect that can be caused by the cancer or from its treatment. It can result from surgery or can occur when tumors press on nerves or organs. Chronic pain often requires around-the-clock medication and can be treated with morphine or other opioids. Pain relief patches, which are applied to the skin for continuous high-dose pain medication over several days, may also be an option.

Peripheral neuropathy, which can be a result of damage to nerves by chemotherapy, causes symptoms of tingling, numbness or pain in the hands and feet. Although this type of neuropathy typically subsides after completion of chemotherapy, in some cases, it is irreversible. Physicians may prescribe certain antidepressants, anticonvulsants, steroids or pain medications to lessen the symptoms of this condition. In most cases, management of peripheral neuropathy primarily consists of behavioral modifications that are designed to prevent exacerbation of the problem, such as avoiding extremes in temperature, wearing protective clothing as needed (such as thick socks and gloves), and using only tepid water for bathing and other tasks, such as washing dishes.

Shortness of breath, particularly caused by radiation therapy to the lungs, is another example of a long-term effect of mesothelioma therapy. This may cause the patient to have difficulty breathing when exercising or during other strenuous activity. Radiation can also cause a thinning of the treated skin, and some patients may have difficulty healing a wound, especially if surgery was also performed on the same area.

## Emotional Aspects of Survivorship >

The experience of getting a cancer diagnosis, undergoing treatment and surviving is a roller coaster of emotions. Survivors realize that they are not the person they were before the diagnosis, find that relationships with friends and family have changed and may find that things that were important before diagnosis are no longer of value. It is not uncommon to be depressed; be anxious; be uncertain how to talk with friends, family and children; or become more spiritual.

Not all survivors experience the same emotions or respond to the same degree. Areas of concern include:

- > **Body Image:** Physical changes can occur in the body as a result of cancer, surgery and treatment. The way survivors see their bodies and feel about these changes can affect them emotionally. The responses of family and friends to those changes can also impact the ability to cope with them. Choosing well-fitted clothing, wearing a stylish wig or getting a makeover can start survivors on the road to accepting their new body image.
- > **Fear of Recurrence:** Fear that the cancer will return is a common response among survivors. Due diligence is required on their part to prevent this fear from leading to excessive worrying. Instead, survivors should focus on self-monitoring and follow-up.
- > **Finding Meaning:** A diagnosis of cancer is a life-altering event. As with any event of this magnitude, survivors may be exploring the purpose for their lives and the reasons for their survival. Many individuals turn to their spiritual side and meditate, pray or read.

# Janelle Bedel

## Getting Back into Life

**WHEN 31-YEAR-OLD** Janelle Bedel of Rushville, Indiana, asked her doctor if mesothelioma was a possibility when her symptoms—sensitivity by her left rib, a persistent cough and shortness of breath—kept getting progressively worse over the course of a year and a half, he laughed and told her that was doubtful. Indeed, Bedel didn't fit the typical profile of a pleural mesothelioma patient, who is male and over the age of 65.

But after a chest X-ray, a CT scan, a needle biopsy and finally a tissue biopsy, this young mother of a 4-year-old son received a diagnosis of mesothelioma in May 2007.

"My doctor was really shocked," says Bedel, now 36. "I'm from a small town, and they don't know much about [mesothelioma] around here. They'd never seen it in anybody."

Bedel's father was a firefighter, and her two uncles worked in factories in which asbestos was present, which makes secondhand exposure a likely cause.

She received chemotherapy followed by a pleurodesis, an extrapleural pneumonectomy and radiation. The road to recovery was long, leaving Bedel to battle chronic pain and, eventually, depression.

"I would lie in bed when I didn't feel good, so I was lying in bed every day," Bedel says. Her doctor sent her to a psychiatrist. "She told me no matter what I was feeling that day, to get up, get dressed and get outside the house. It took baby steps to get back into life."

But life delivered her another blow in 2010, when, with her



PHOTO BY CHARLES FARRIS

pleural mesothelioma holding steady, Bedel began noticing she would feel unusually bloated after she ate. She began carrying weight in her abdomen, so much that she thought she was pregnant. But when pregnancy tests came back negative, she began to worry.

Four years after receiving a diagnosis of pleural mesothelioma, Bedel was given a diagnosis of peritoneal mesothelioma. Once again, she endured a major surgery, which consisted of removing the tumor followed by heated chemotherapy delivered directly into her abdominal cavity. She endured another slow, arduous road to recovery.

Despite her difficult journey, Bedel has far surpassed the survival rates of both types of mesothelioma and has made the most of her diagnosis. She attends mesothelioma conferences yearly, reaches out to patients on social networking sites and participates in fund-

raisers to generate money for research. In August 2012, she took part in a 100-mile motorcycle race.

"Reaching out to others and going to conferences helped me go from getting mad to wanting to do what I could to help," Bedel says. 🌸

**"Reaching out to others and going to conferences helped me go from getting mad to wanting to do what I could to help."**

It is also helpful to keep a journal and discuss feelings with family or spiritual leaders.

> **Grief and Loss:** These emotions may result from what cancer has taken from a person's life. Individuals may feel a loss if they have had a change in body image, strength, family and career roles, relationships or sense of self. Grief progresses through stages, and survivors may need support to reach acceptance.

> **Doubt:** Even with a positive outcome from treatment, doubts may exist. It is important for survivors to look at ways to maintain a positive attitude and live each day to the fullest. Survivors should find activities and friends that help them maintain a sense of hope.

> **Living With Uncertainty:** Being a cancer survivor can intensify feelings of self-doubt, uncertainty and uneasiness about the future. Survivors should start by exploring why they feel this way and where they can turn for support. Setting goals and planning events for milestones and mundane activities can also help.

> **Sadness and Depression:** Feelings of sadness or situational depression are common with a life-changing event. These feelings are normal and can be managed by counseling, support and medications. If survivors find their sadness is not improving, they are not engaging in their daily routines or they have thoughts of suicide, they need to consult a mental health professional, as they may be experiencing depression.

> **Setting Priorities:** The things that are important in people's lives change as they go through different

phases and events. Throughout treatment, survivors were probably focused on the management of their illness, but now they need to get back to the business of life. Survivors should re-evaluate what their priorities are and communicate them to family and friends.

> **Stress:** A feeling of worry or constant tension brought on by trying to cope with everyday life causes stress. People cope with stress in different ways, and it is important to recognize what is causing that stress. Survivors should focus on ways to relax and not stress about things over which they have no control.

> **Relationships:** The key to good relationships is communication. Even if people have strong relationships prior to their diagnosis, the stress of treatment and survivorship can take a toll. Survivors should share their feelings and needs with their spouse, partner, family and friends. Keeping communication open will help everyone to feel supported and understood.

> **Telling Others:** Whether people choose to tell others they are a cancer survivor is a personal decision. They may need to explore whom they want to tell and for what reasons. Once they have decided, they should make a script of what they are going to say and practice with family if they feel uncomfortable with the topic.

All of these emotions and decisions can be overwhelming, but seeking counseling or support can help. Survivors should contact their healthcare team, primary care provider or the American Cancer Society for a list of programs and support groups near them. This is not a process that has to be handled alone.

## Survivorship Plan >

After treatment is completed, a survivor's medical team should provide a comprehensive care summary and follow-up plan, also known as a survivorship plan. This tool is designed to record the care patients received and the information they need to know as a cancer survivor. Without a survivorship plan, they may not get the necessary follow-up care or have the resources for the best quality of life and long-term survival. The Institute of Medicine of the National Academies says that a survivorship care plan should include:

- > Diagnostic tests performed and their results
  - > Tumor characteristics, including site, stage, grade and biomarker information
  - > Dates of treatment initiation and completion
  - > Surgery, chemotherapy, radiation therapy, transplant, gene therapy or other therapies provided
  - > Agents used in chemotherapy
  - > Treatment regimen and total dose
  - > Identifying number and title of any clinical trials in which the survivor participated
  - > Indicators of treatment response
  - > Toxicities experienced during treatment
  - > Psychosocial, nutritional and other supportive services
  - > Full contact information for the treating institution and key medical providers
  - > Identification of a point of contact and coordinator of continuing care
- The Institute of Medicine has established standards of care for cancer survivors. Before patients complete their treatment, their healthcare team should discuss the following with them:
- > Expected course of recovery from any treatment toxicities
  - > Recommended cancer screenings and follow-up testing that need to be scheduled
  - > Possible late and long-term side effects of treatment
  - > Possible signs of recurrence and metastasis
  - > The effects of cancer on emotions, relationships, sexual functioning, work and parenting
  - > The financial consequences of cancer and resources for dealing with insurance, employers and legal aid
  - > Recommendations for a healthy lifestyle, including weight, exercise, diet, smoking cessation, sunscreen use, vaccinations and osteoporosis prevention
  - > Referrals for follow-up with specialists and primary care providers
  - > A list of cancer survivor resources

Survivors should not be afraid to ask questions or be advocates for themselves. Survivorship brings the opportunity for more learning experiences and a period of transition back to a primary care provider. The better prepared survivors are, the easier that transition will be. 🌸

**A SURVIVORSHIP PLAN** should be given to the primary care provider and made a part of the patient's medical records. A survivorship plan may look something like this:

#### GENERAL INFORMATION

**Patient name and ID number:** John Doe #1234

**Date of birth:** 1/5/15

**Phone number:** 222-555-3579

**Medical oncology provider:**  
Dr. Bob Smith

**Primary care provider:** Dr. Mary Jones

**Support contact name, relationship:**  
Betty Doe, wife

**Symptoms/signs at diagnosis:** Cough, shortness of breath, frequent bouts of bronchitis

**Family history and predisposing conditions:** Family history non-significant, asbestos exposure during World War II as Navy shipbuilder

**Major co-morbid conditions:** COPD, heart disease, diabetes

**Tobacco use:** Yes, 40 years, no longer smokes

**Cancer type/location:** Mesothelioma/ chest and lungs

**Diagnosis date:** 10/23/08

**New or recurrence:** New

**Surgery:** Diagnosis and curative resection

**Surgical procedure:** Biopsy 10/23/08 and right lower lobectomy 11/4/08

**Tumor type, histology and grade:** G3

**Tumor marker:** See attached report

**Location of recurrence or metastasis if applicable:** None at present

**Height:** 6 foot

**Pretreatment weight:** 200 lbs.

**Name of chemotherapy regimen:** Drug XYZ for 6 weeks

**Start date and intent:** 11/1/08, cure

**Major side effects of regimen:** Fatigue, nausea and vomiting

**Post-treatment weight:** 180 lbs.

**Non-chemotherapeutic agents, route, purpose and response:** Zofran IV for nausea and vomiting, good response

**Radiation therapy:** 2 treatments on 11/10/08 and 11/12/08

**Names and phone numbers of oncology team members:** Dr. Bob Smith, medical oncologist, 222-565-2434

#### SCHEDULE OF FOLLOW-UP CARE

**Medical oncology visits:** every 3 months

**Lab tests:** CBC to be done at follow-up visit

**Imaging:** CT scan of chest in 6 months

**Potential late effects of treatment:**  
More frequent infections

**Signs/symptoms to report:** Cold that won't go away, unexplained cough, shortness of breath at rest, additional weight loss and loss of appetite

**Referrals provided:** Routine medical care to be provided by Dr. Mary Jones

#### NEEDS AND CONCERNS ADDRESSED

**Prevention and wellness:** Flu vaccine, PSA and routine colonoscopy

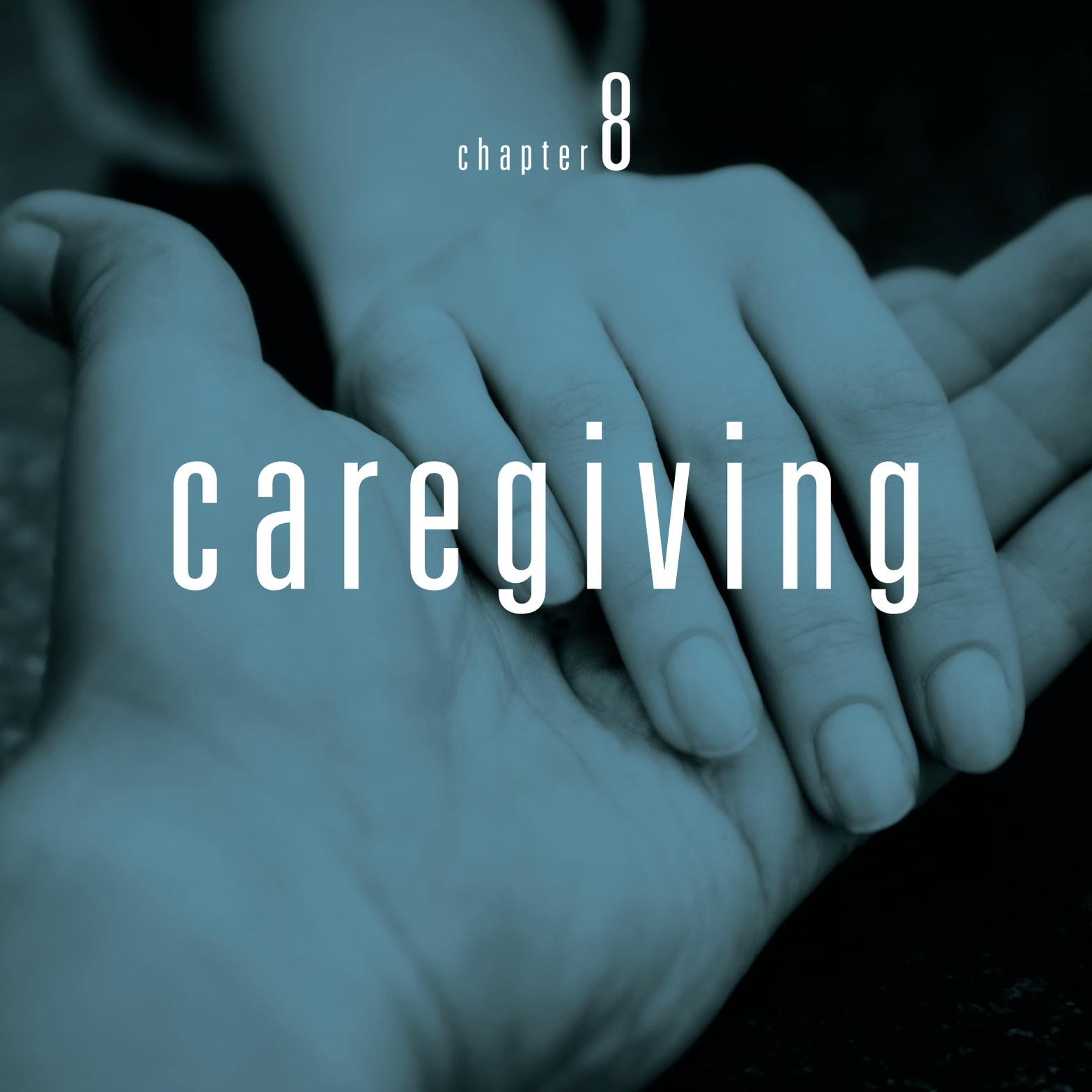
**Emotional or mental health:** Given list of support groups in area

**Personal relationships:** Married, wife given list of support groups and resources for caregiver

**Financial advice or assistance:**  
Continue to coordinate with VA benefits officer

**Other:** Visit with social worker for further assessment and needs

**Plan for referrals and needs/concerns:**  
VA for medical care and follow-up, support groups and other benefits



chapter 8

# caregiving

# caregiving

**B**EING a caregiver

is one of the most important—and loving—things a person can do for someone. However, it is important for caregivers to take care of themselves and not get stressed so that they have energy for the patient and their loved ones.



## Caring for Others >

Navigating the new terrain of caregiving isn't without its challenges, and while everyone's cancer experience is unique, there are some caregiving tips that apply to nearly everyone.

- > **Talk It Out:** It's important to take some time to process what's happened. Discuss with the patient the decisions that will need to be made quickly, including second opinions, treatment and where to be treated.
- > **Help with Research:** Learn about the disease and the range of potential treatment options and help the patient to understand and follow the treatment plan. The doctor should be able to help guide further education. To make the most out of the short time with the medical team, caregivers can help focus the patient's questions. For big decisions, talk with the patient a few days beforehand in case questions come up that require more research.
- > **Listen and Learn:** During appointments, listen carefully, take notes, or, with the doctor's permission, record the session. Unless the caregiver has permission from the patient to pursue a dialogue with the doctor, the patient should lead the conversation. Once the treatment plan has been determined by the medical team, get the plan in writing.

> **Be Realistic About What's Ahead:** Treatment can be very taxing, both emotionally and physically, so caregivers should not minimize what they or their loved one is going through. Keep in mind that people react differently to different treatments. Some patients will have more nausea or fatigue than others, or some patients may worry about losing their hair more than any other side effect. Also know that the toll chemotherapy takes can be cumulative. The patient may feel fine at the outset of treatment but may feel worse before he or she starts feeling better.

> **Kind Gestures Help:** Small gifts and cards can help lift a loved one's spirits. Experts say it's completely normal for patients to experience days when they feel dejected, lonely, afraid or depressed. Allow patients some time and space to be alone. Don't smother or shield them from finding their source of inner strength and balance.

> **Discuss Legal and Financial Issues:** If the patient hasn't already, he or she should take care of important affairs such as wills, living wills and medical power of attorney. Also, consider reviewing financial details, such as bank accounts, tax documents, stocks, bonds, mutual funds, CDs and contact information for financial advisers.

› **Allow Patients Their Feelings:** Caregivers want to be sure patients feel comfortable expressing how they feel. Patients should not feel pressure to be peppy and positive all the time.

› **Take a Step Back:** Conflicts about treatment are often more intense when the cancer recurs or is diagnosed at an advanced stage, experts say. The caregiver may want the patient to keep pushing and try everything possible to fight the cancer while the patient believes it's time to stop treatment. Or, a patient may want to pursue alternative treatments, upsetting caregivers who want him or her to stick to conventional medicine. Regardless of the scenario, caregivers should allow their loved ones to make choices that are right for them.

› **Call a Family Meeting:** Friends and family, regardless of distance, may want to be involved. Organize a family meeting, even by phone, to discuss who will do what. It's important for the patient to be involved in the dialogue. If outside help is needed, such as a home health aide or hospice care, be honest with the patient. Ultimately, patients should maintain as much independence as possible and control decisions about their care, within reason.

› **Help the Patient Set Up a Survivorship Plan:** The transition from active treatment to being a healthy survivor is important, including knowing what follow-up visits, long-term effects and limitations the patient will have in the years after treatment. A number of cancer survivorship plans have been developed (see page 66). A caregiver can help keep up

with the plan from day one and keep in touch with the medical team.

## Taking Care of the Caregiver ›

In the chaos and intensity that surrounds a new cancer diagnosis, people tend to focus all of their care and concern on the patient. While caregivers tend to brush their own needs aside, experts warn that selfless devotion can backfire.

The constant stress of caregiving can make a caregiver more vulnerable to getting sick or burned out. Caregivers should make a list of what triggers their stress, and then make another list of steps to reduce that stress. Here are some ways to prevent burnout:

› **Reach Out:** Caring for someone full-time can lead to feelings of panic, despair and isolation. Reach out to friends, family, online chat groups and support organizations to help reduce feelings of isolation.

Support groups for cancer patients and caregivers can be located through local hospitals, the American Cancer Society or other nonprofit organizations. It makes a huge difference for caregivers to feel they're not the only one having these feelings. Try exercise, meditation and other stress-reduction techniques. If nothing seems to help, it may be time to see a therapist or doctor.

› **Accept Help:** If friends or neighbors ask what they can do to help, a caregiver should tell them. Veteran caregivers suggest keeping a list in a pocket. That way, caregivers can pull it out and let people know exactly what they need. If friends or relatives are not available

## Kim Sebesta and Kristen Olson

### Working Side by Side

**W**HEN THEIR MOTHER, Lonna Morrison, received a diagnosis of mesothelioma in February 2007, twin sisters Kim Sebesta and Kristen Olson, both of Minneapolis, vowed to do everything they could to make their remaining time with her as enjoyable as possible.

Lonna was 65 when she started having difficulty breathing. The initial diagnosis was pneumonia, but additional tests confirmed pleural mesothelioma.

Lonna received chemotherapy, an extrapleural pneumonectomy and radiation, as well as dialysis when her kidneys failed. She passed away in 2009.

At first, Kim and Kristen primarily offered emotional support as Lonna underwent treatment. But as the disease progressed, their caregiving duties became more hands-on.

“As with most situations, we took on the things that related to our strengths,” observes Kim. “Kristen, who is a nutritionist, began regulating mom’s diet, fussing over how much she was eating and found ways to compensate for what she wasn’t getting with her restricted diet. And being the more organized sister, she created a folder containing doctors’ names, Mom’s medications and emergency contacts.”

Kim, meanwhile, was always there for moral support and to help lighten the mood. “She placed loving notes around the house for Mom to find, and even planned adventures for us to go on as a family,” Kristen notes. “She made sure Mom had



PHOTO BY DIANE HERNANDEZ

everything she needed at all times.”

Being sisters made caregiving a somewhat easier burden to bear, Kim adds. “We weren’t alone in the situation,” she explains. “We leaned on each other a lot. When one of us was feeling down, the other would pick up the slack without question.”

The caregiving experience also resulted in a deeper relationship with their mother. “I think it opened our eyes to many things,” Kim says.

“One of the biggest was that we realized Mom was human. She had fears and an understanding of the world that we didn’t know about. She opened up to us in a way I don’t think she would have if things had been different. We all became very close.” 🌸

---

**“We leaned on each other a lot. When one of us was feeling down, the other would pick up the slack without question.”**

---

to step in for a few hours, hire someone or find adult day care. The U.S. Administration on Aging offers a national database of elder care providers at [eldercare.gov](http://eldercare.gov).

> **Get Some Sleep:** To overcome insomnia, experts suggest everything from guided imagery and relaxation techniques to acupuncture and even warm milk. Cutting back on late afternoon caffeine and boosting exercise may also help caregivers sleep better. Sometimes it helps to write down worries and “release” them for the day, before heading to bed. If all else fails, it may be time to talk to the doctor about a nonaddictive sleep aid.

> **Communicate:** Most often, when a person is diagnosed with cancer, it's the spouse who takes over caregiving. American Cancer Society research shows husbands and wives can affect each other in profound ways in this new relationship. Wives hold themselves up to impossibly high standards as caregivers. They get stressed, try to do too much and rarely make time for themselves, which the study showed to have a negative effect on the husband's ability to heal. The husband absorbed these negative feelings and felt guilty about putting his wife through so much.

> **Maintain Health:** With everything they have to do in a day, caregivers often neglect basic health maintenance. Some simple things to keep in mind include eating regular meals that are rich in fruits and vegetables and staying hydrated. Exercise, even if it's a short walk each day. Line up help so regular appointments, such as dental cleanings, health screenings and annual checkups, can be kept.

> **Find Meaning:** If caregivers can take their experience with cancer and learn from it, they may have less depression and anxiety. Caregiving can help some people find more meaning in their lives and focus on their highest priorities. Work on personal growth. Participate in an art therapy workshop, begin a journal, talk with a counselor or lean on faith or a spiritual community. 🌸

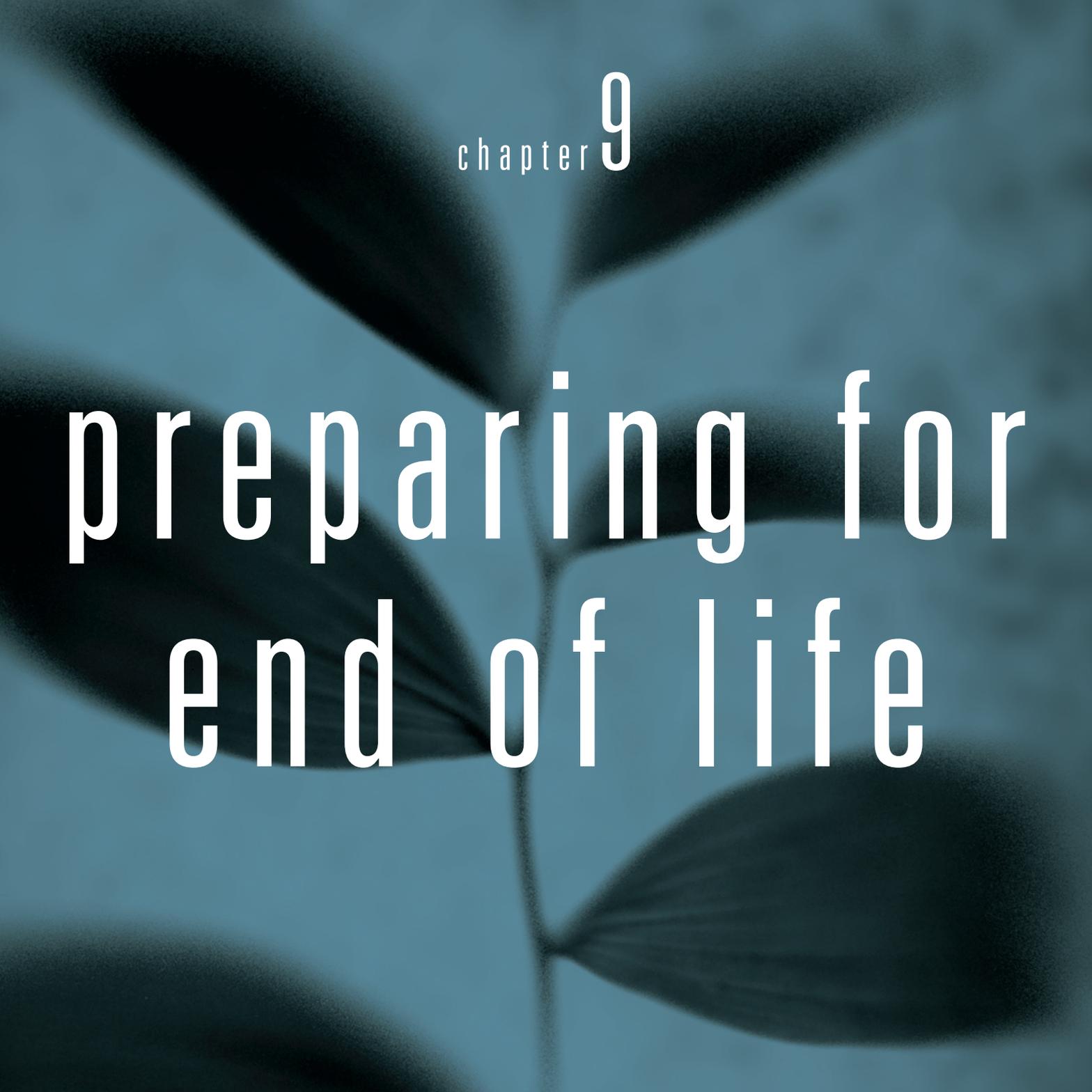
## **A** SSEMBLING A CREW of Helpful Friends and Family **Is Crucial** >

Caregivers should start by making a list of tasks they'll need help with and then think of family members, friends, neighbors or fellow congregants at their house of worship who can be a reliable source of support. They may want to identify a family member or friend who can take the lead in organizing what needs to be done and who will do it. Here are some tips for getting support:

**Call for Help** > If caregivers are in the thick of doctor visits and are overwhelmed, the laundry should be the last thing on their to-do list. They should not be afraid to ask for help. Often, friends and family want to help, but don't know what to offer. Most friends would gladly deliver a meal, do household chores or provide transportation.

**Seek Emotional Support** > Support can often come from established cancer communities, such as the Cancer Support Community ([cancersupportcommunity.org](http://cancersupportcommunity.org)) or online support groups. Finding community support helps to avoid feelings of isolation and allows members to share their experiences and collective wisdom with one another.

**Use Technology** > To update friends and extended family, caregivers may want to consider setting up a website. They'll receive support and inspiration by encouraging visitors to post messages and volunteer for tasks, and visitors can stay in the loop. Sites such as Care Central ([carecentral.com](http://carecentral.com)), Caring Bridge ([caringbridge.org](http://caringbridge.org)), Lotsa Helping Hands ([lotsahelpinghands.com](http://lotsahelpinghands.com)), Share the Care ([sharethecare.org](http://sharethecare.org)) and The Patient/Partner Project ([thepatientpartnerproject.org](http://thepatientpartnerproject.org)) make it easy to create a free website that will help connect friends and family. For those who are not web-savvy, ask a friend or family member for help.



chapter 9

# preparing for end of life

# preparing for end of life

**I**T is imperative that patients make their wishes known when they are dealing with a life-threatening illness like mesothelioma. They can do this at any time with a care plan. Advanced care planning is defined as planning for current and future medical care, assuring a patient's quality of life and allowing for a comfortable death.



## Having a Plan >

An advanced care plan has several components, which include:

**Designation of a Healthcare Power of Attorney (HCPOA):** Patients will want to choose a person to make medical decisions and initiate their care plan when they are no longer able to speak for themselves. Patients should choose wisely; sometimes close family members are not able to separate emotions from logic and may have difficulty carrying out wishes. Wishes should be discussed with an appointee to verify his or her cooperation and comfort with serving as an HCPOA.

**Code Status:** This designates whether patients want cardiopulmonary resuscitation (CPR) if their heart or breathing stops. If they choose not to have CPR initiated, they will need to have their physician complete a form referred to as an out-of-hospital Do Not Resuscitate (DNR) form. A copy should be placed in patients' medical records and kept in a prominent place in their home. If they choose to have CPR initiated, their status is designated as a "full code," and this is noted in their medical records; no special forms are needed.

**Living Will:** This document delineates wishes concerning common medical treatments for acute and

chronic illnesses and emergency treatment. Patients should record their choices based on whether or not they want the following:

- > **CPR:** Document the patient's code status.
- > **Intubation and Ventilation:** If breathing should stop, would patients want a breathing tube hooked to a machine to breathe for them?

## Hospice Services Covered *by* Medicare

- > Physician services
- > Nursing services
- > Home health aides
- > Medical appliances, supplies
- > Medications
- > Spiritual counseling
- > Dietary counseling
- > Continuous in-home or inpatient care during crisis periods
- > Trained volunteers
- > Bereavement services
- > Inpatient respite services
- > Social work services
- > 24/7 on-call support

**P**ATIENTS WILL be provided with any medical equipment needed, including a hospital bed, shower chair, grab bars, bedside commode and oxygen. A comfort kit of medications for nausea, pain, anxiety and excess secretions will be shipped to the patient's home within several days of the initiation of services. General supplies may include adult diapers, disposable bed pads, dressing supplies and catheter supplies.

# Choosing a Hospice Provider

- > **Dialysis:** If their kidneys should fail, would patients want to receive dialysis treatments to maintain kidney function? Dialysis involves having a shunt placed in the arm that is attached to a machine that filters the toxins out of the blood, normally a job performed by the kidneys. This may involve treatments several times a week or daily.
- > **Feeding Tube:** If patients are no longer able to take food or fluid by mouth, a permanent feeding tube is recommended to provide alternative nutrition. The tube is surgically inserted through the abdominal wall into the lower part of the stomach, and nutritional formula, along with water for hydration, is administered several times a day through the tube.
- > **Pacemaker:** If the patient's heart is no longer able to maintain an adequate heart rate, a pacemaker is recommended. This device is surgically inserted in the upper chest wall and has wires that attach to the heart muscle. When an individual's heart rate drops too low, the pacemaker fires an electrical pulse into the heart to stimulate the muscles to contract and raise the heart rate.
- > **Intravenous (I.V.) Fluids for Hydration:** If patients are unable to drink adequate fluids and do not have a feeding tube, poor fluid intake can lead to dehydration, which can result in organ failure. They may choose to have fluids administered on a case-by-case basis. There may be times when patients are ill from the effects

**D**EPENDING on where patients live, they may have multiple options in choosing a hospice provider. There can be variations in care and staffing based on core services, philosophy and location. Just as carefully as patients choose a healthcare team to treat their mesothelioma, they will want to do the same in selecting a hospice provider. Patients should set up an interview and start by asking the following:

- 
- |                                                                                                                                                        |                                                                                                                     |
|--------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------|
| > Does the provider serve the area in which the patient lives?                                                                                         | family member required for enrollment in services?                                                                  |
| > How long has the provider been in operation?                                                                                                         | > What is expected from the family caregiver?                                                                       |
| > Does Medicare certify the provider?                                                                                                                  | > What, if any, out-of-pocket charges can be expected?                                                              |
| > Does the provider accept Medicaid?                                                                                                                   | > How flexible is the schedule of visits?                                                                           |
| > Does the patient's insurance cover the provider?                                                                                                     | > Who provides the on-call coverage? Can the patient's regular doctor/oncologist be kept informed or provide input? |
| > Is the provider licensed by the state?                                                                                                               | > Does the provider have a residential facility?                                                                    |
| > What additional services does the provider cover, such as follow-up phone calls, mail-outs, support groups and retreats, or activities for families? | > What types of services are provided for funeral arrangement support?                                              |
| > What services, if any, are not provided?                                                                                                             | > How are bereavement services managed, and how long do they last?                                                  |
| > Is participation in care by a                                                                                                                        |                                                                                                                     |
- 

**After answering those questions**, if patients are still uncertain whether the agency is right for them, they can request an evaluation visit. This will give patients the chance to interact with the staff in a comfortable environment and get a better idea of how the services will work.

**It is also important to know if the agency is legitimate.** If patients are concerned, they should contact their state hospice association for verification. They may also want to research the reputation of the agency by asking their doctor, minister, other healthcare professionals and families of previous patients for advice and information.

**The opportunity** to have relief from pain, maintain quality of life and have a comfortable death is enhanced by utilizing hospice services. Patients should consider this option for themselves and their family, and make their wishes known to their healthcare team.

---

of chemotherapy or suffer from minor illness and are unable to eat and drink. Eventually, there will be a time when they are no longer able to drink, and if they have chosen not to have a feeding tube inserted, patients will need to decide if they want to be sustained on I.V. hydration. Contrary to common myths, dehydration is not painful and is actually a comfortable and humane way to die.

- > **Antibiotic Therapy:** Infections are common when the immune system is fighting an illness such as mesothelioma. Patients may need to be treated for pneumonia, skin infections or kidney infections. They can choose how aggressive they want their healthcare team to be in treating an infection and the route of administration of the prescribed antibiotics, by I.V. injection or by mouth.
- > **Hospitalization:** Medical care for the treatment and management of mesothelioma is commonly performed in a hospital setting. This choice allows patients to decide when they no longer wish to be hospitalized for treatment and care. This decision is tied closely to personal wishes for end-of-life care and whether patients want to die at home or in the hospital.
- > **Care Goals:** This decision can vary depending on the stage of mesothelioma, the current point in treatment and the patient's end-of-life care wishes. A patient may choose aggressive treatment and ask for any and all options and treatments to be considered, symptomatic treatment or palliative care for maintaining function and quality of life, or no treatment. This is the one decision that changes over

time and with the current situation. Patients should have open and honest discussions with their healthcare team to make their wishes known through every step in treatment.

These decisions can be documented on state-designated forms or recorded by an attorney.

### **The key ideas to take away from a discussion on advanced care planning are:**

- > **An advanced directive** is a communication tool for both patients' healthcare teams and their loved ones about their wishes and care goals.
- > **Planning in advance** decreases the burden on a family during health crises and at the end of life.
- > **Pain and other symptoms** can be managed to provide quality of life and a comfortable death.
- > **Decisions can be** changed by patients at any time.

## Hospice >

Hospice services are designed to provide palliative care and support to patients and their families at the end of life and afterward. The Hospice Foundation of America reports that one out of three Americans choose hospice care when they are dying. Hospice services began in the United States in the 1970s and were covered by Medicare in 1983. Since that time, hospice organizations, both nonprofit and proprietary, have opened in urban and rural areas. It is estimated that about 4,700 programs exist in the U.S.

Patients are referred to hospice services when their

life expectancy is less than six months and they are no longer responding to curative treatment. While medical science is not capable of predicting exact life expectancy, patients' doctors will take into consideration the stage of their disease, their response to treatment and their current level of function.

Hospice is not a brick and mortar place, although it can be a freestanding facility for care. Most hospice services take place in the patient's home, assisted living facilities or nursing homes. Hospice care neither prolongs life nor hastens death, but treats symptoms and provides for quality of life and a comfortable death. Unlike palliative care, which can begin at any time to manage pain and symptoms, patients receiving hospice care no longer get cancer therapy or experimental drugs. According to the Hospice Foundation of America, hospice encompasses a number of services:

- > **Care** is provided by a team of professionals and volunteers working together to provide comfort and support to patients and their families. The team consists of a physician, nurse, nursing assistant, social worker and chaplain.
- > **Hospice care addresses all symptoms** with special emphasis on pain management.
- > **Hospice care strives** to meet the emotional, social and spiritual needs of patients in addition to symptom management.
- > **Hospice professionals make routine visits** based on the needs of patients and their caregivers.
- > **Medicare and private insurance** cover hospice

services. Medicaid covers hospice care in 45 states and the District of Columbia.

- > **A variety of bereavement services** are offered to the family after the death of the patient.
- > **If a patient improves** or no longer desires services, hospice can be discontinued at any time.

Before hospice care is initiated, a patient's physician will provide a referral and discuss the reason for the referral and the patient's current prognosis with the hospice physician and team. The hospice team sets up an initial appointment with the patient and his or her caregiver to complete an evaluation and to explain the services they provide. The evaluation includes:

- |                                                                                                                                                                                                                                                                                                                                                             |                                                                                                                                                                                                                                                                                                                                                         |
|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <ul style="list-style-type: none"> <li>&gt; A review of medical history</li> <li>&gt; A review of medications: type, dose and schedule</li> <li>&gt; Allergies</li> <li>&gt; Vital signs</li> <li>&gt; Current weight</li> <li>&gt; Head-to-toe exam</li> <li>&gt; Pain assessment</li> <li>&gt; Functional assessment</li> <li>&gt; Home safety</li> </ul> | <ul style="list-style-type: none"> <li>assessment</li> <li>&gt; Medical equipment and supply needs assessment</li> <li>&gt; Verification of Medicare, Medicaid or insurance</li> <li>&gt; A review of the types of services available</li> <li>&gt; Development of a plan of care</li> <li>&gt; Establishing a schedule for nursing services</li> </ul> |
|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|

Once this initial visit is completed, services start immediately, along with 24-hours-a-day, seven-days-a-week phone access to the provider. 🌟



# resources

---

People with mesothelioma and their families need assistance coping with the emotional and practical aspects of the disease. For a complete list of cancer resources, visit [curetoday.com/toolbox](http://curetoday.com/toolbox). Those providing Spanish-language materials are marked with an **S**.

## GENERAL INFORMATION AND SUPPORT

### American Cancer Society (ACS)

800-ACS-2345 (800-227-2345)

[cancer.org](http://cancer.org)

Offers a variety of services to patients and their families through its Cancer Resource Network. The ACS also supports research, provides printed materials and conducts educational programs. **S**

### Association of Cancer Online Resources (ACOR)

212-226-5525

[acor.org](http://acor.org)

This website offers an expansive collection of online email lists organized by cancer type for patients and caregivers, as well as online resources the organization cultivates through credible content providers.

### Cancer.Net

888-651-3038

[cancer.net](http://cancer.net)

The patient information website of the American Society of Clinical Oncology, the leading professional organization representing oncologists. **S**

### CaringBridge

651-452-7940

[caringbridge.org](http://caringbridge.org)

A free Internet service that provides personalized web pages to help keep friends and family informed of life events. It also allows visitors to post encouraging messages and support on individualized password-protected websites.

### ChemoCare.com

[chemocare.com](http://chemocare.com)

Provides the latest information about chemotherapy to patients and their families, friends, and caregivers. It is designed to alleviate patient concerns about chemotherapy and outline everything they need to know in the following

sections: What is Chemotherapy?; Chemotherapy Drugs; Managing Side Effects; Eating Well During Chemotherapy; and Before and After Chemo.

### Coalition of Cancer Cooperative Groups

[cancertrialshelp.org](http://cancertrialshelp.org)

Contains a search engine to find cancer clinical trials closest to a patient's home, comprehensive self-study guide, patient discussion forum and helpful information for patients and caregivers.

### Commission on Cancer

312-202-5085

[facts.org/cancer](http://facts.org/cancer)

A consortium of professional organizations dedicated to improving survival and quality of life for cancer patients through standard setting, prevention, research, education and the monitoring of comprehensive quality care.

### Cancer Support Community

888-793-9355

[cancersupportcommunity.org](http://cancersupportcommunity.org)

Provides social and emotional support to cancer patients and their families and friends. Lectures, workshops, networking groups, special events and a children's program are available.

### LIVESTRONG Foundation

877-236-8820

[livestrong.org](http://livestrong.org)

Helps cancer patients and their loved ones live strong through advocacy, education, public health and research, as well as through the LIVESTRONG Resource for Cancer Survivors.

### Lotsa Helping Hands

[lotsahelpinghands.com](http://lotsahelpinghands.com)

Provides a simple way for friends, family, colleagues and neighbors to pitch in with meals, delivery, rides and other tasks necessary for life to run smoothly during a crisis. It uses a free and easy-to-use

private group calendar specifically designed for organizing helpers.

### National Cancer Institute

800-4-CANCER (800-422-6237)

[cancer.gov](http://cancer.gov)

[bethesdatrials.cancer.gov](http://bethesdatrials.cancer.gov)

An excellent and comprehensive site for people wanting to know more about cancer, including cancer prevention, definitions, clinical trial information, recipes, links to cancer centers and a whole lot more. The NCI's Center for Cancer Research also publishes a free quarterly e-newsletter, the Bethesda Trials News, designed to help community physicians stay informed of investigational approaches, including clinical trials and treating, diagnosing and preventing cancer. **S**

### National Coalition for Cancer Survivorship

877-622-7937

[canceradvocacy.org](http://canceradvocacy.org)

Offers support to cancer survivors and their loved ones. Provides information and resources on cancer support, advocacy and quality-of-life issues. **S**

### National Comprehensive Cancer Network

215-690-0300

[nccn.org](http://nccn.org)

A nonprofit alliance of 20 of the world's leading cancer centers, dedicated to improving the quality and effectiveness of care provided to cancer patients. NCCN develops resources that present valuable information to the numerous stakeholders in the healthcare delivery system. The primary goal of all NCCN initiatives is to improve the quality, effectiveness and efficiency of oncology practice.

### Strength for Caring

[strengthforcaring.com](http://strengthforcaring.com)

The first national program for cancer caregivers to address both the physical and psychosocial needs of the patient and caregiver. Free workshops, which

are facilitated by trained nurses and social workers, are held at healthcare facilities and advocacy organizations across the U.S. The website includes caregiving tips and resources, information about cancer side effects and caregiving training videos.

.....

## CLINICAL TRIALS

### **ClinicalTrials.gov**

888-346-3656

clinicaltrials.gov

Offers information for locating federally and privately supported clinical trials for a wide range of diseases and conditions, including cancer.

.....

## FINANCES AND INSURANCE

### **NeedyMeds**

needymeds.org

Offers information on patient-assistance programs for patients who can't afford their medications.

### **Partnership for Prescription Assistance**

888-477-2669

pparx.org

Helps qualifying patients without prescription drug coverage get medicines for free or at low cost.

.....

## HOSPICE & PALLIATIVE CARE

### **Center to Advance Palliative Care**

getpalliativecare.org

Provides information for patients and families coping with serious illnesses, a palliative care provider directory, a detailed description of palliative care and links to related organizations.

### **Hospice Foundation of America**

800-854-3402

hospicefoundation.org

Provides practical information about coping with death and grief, a blog and teleconferences.

### **National Association for Home Care & Hospice**

202-547-7424

nahc.org

Provides information on how to choose home care and hospice care providers.

### **National Hospice and Palliative Care Organization (NHPCO)**

800-658-8898

caringinfo.org

The NHPCO is an association of programs that provide hospice and palliative care. **S**

.....

## MESOTHELIOMA/ASBESTOS ORGANIZATIONS

### **Asbestos Disease Awareness Organization**

asbestosdiseaseawareness.org

A nonprofit volunteer group that provides education and advocacy on behalf of asbestos victims.

### **Mesothelioma Applied Research Foundation**

877-363-6376

marf.org

A national nonprofit organization dedicated to ending the suffering caused by mesothelioma.

.....

## PAIN

### **The Resource Center of The Alliance of State Pain Initiatives**

608-265-4013

trc.wisc.edu

Provides leadership and advocacy for state and regional pain initiatives.

### **Partners Against Pain**

partnersagainstpain.com

Includes news updates, pain control guides for patients, support groups, resources and additional information for healthcare professionals.

.....

## PATIENT ADVOCACY

### **Cancer Legal Resource Center**

866-THE-CLRC (843-2572)

cancerlegalresourcecenter.org

Provides information on cancer-related legal issues for cancer survivors, their families and others impacted by the disease.

### **Patient Advocate Foundation**

800-532-5274

patientadvocate.org

Provides education, legal counseling, and referrals

to cancer patients and survivors concerning managed care, insurance, financial issues, job discrimination and debt crisis matters.

.....

## TRAVEL AND HOUSING

### **Air Charity Network**

877-621-7177

aircharitynetwork.org

Network of seven organizations that provide transportation to patients traveling for treatment.

### **American Cancer Society Hope Lodge**

800-ACS-2345

cancer.org/hopelodge

Provides free, temporary housing in 28 locations across the U.S. for patients traveling for treatment. Accommodations and eligibility vary by location.

### **Corporate Angel Network, Inc.**

866-328-1313

corpangelnetwork.org

Finds free air transportation (on corporate planes) for cancer patients who need medical treatment. Patients must be ambulatory.

### **Joe's House**

877-JOES-HOU (563-7468)

joeshouse.org

A nationwide housing guide for patients and families when they travel for treatment. Directories of various places to stay near cancer treatment centers are available via the website or toll-free number.

### **National Association of Hospital Hospitality Houses**

800-542-9730

nahhh.org

Provides accommodations for families and patients receiving medical treatment away from home. Rates typically range from \$5-\$15 per day (sometimes free).

### **National Patient Travel Center**

800-296-1217

patienttravel.org

Locates the best available travel options for patients. Help available 24 hours a day.



*Understanding Mesothelioma*

is dedicated to the clients, past and present, whom we've had the honor of representing over the last 35 years.

Your fortitude, spirit and determination inspire us every day.



Protecting What's Right® for Asbestos Victims.

