

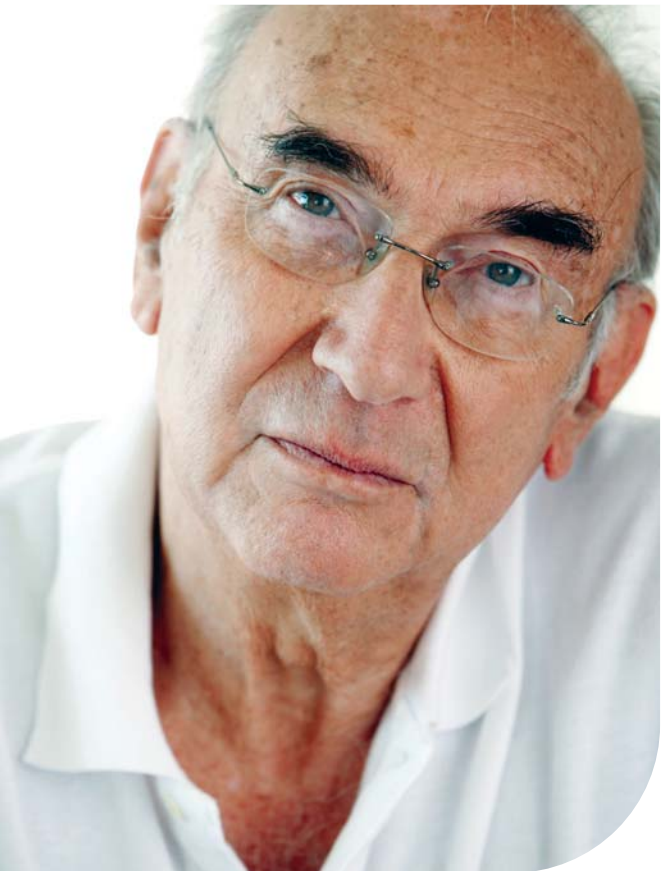


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# Mesothelioma

*Understanding your diagnosis*



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# Mesothelioma

## *Understanding your diagnosis*

When you first hear that you have cancer, you may feel alone and afraid. You may be overwhelmed by the large amount of information you will have to take in and the decisions you will need to make.

The introductory information in this brochure can help you and your family take the first step in learning about mesothelioma. A better understanding may give you a sense of control and help you work with your healthcare team to choose the best care for you.

## What is cancer?

Cancer is a disease that starts in our cells. Our bodies are made up of millions of cells, grouped together to form tissues and organs such as muscles and bones, the lungs and the liver. Genes inside each cell order it to grow, work, reproduce and die. Normally, our cells obey these orders and we remain healthy.

But sometimes the instructions in some cells get mixed up, causing them to behave abnormally. These cells grow and divide uncontrollably. After a while, groups of abnormal cells form lumps, or tumours.

Tumours can be either *benign* (non-cancerous) or *malignant* (cancerous). Benign tumour cells stay in one place in the body and are not usually life-threatening.

Malignant tumour cells are able to invade nearby tissues and spread to other parts of the body. Cancer cells that spread to other parts of the body are called *metastases*.

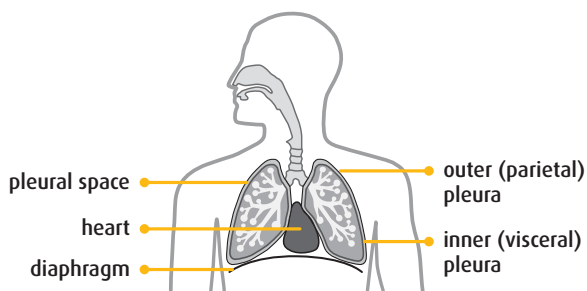
The first sign that a malignant tumour has spread (metastasized) is often swelling of nearby lymph nodes, but cancer can spread to almost any part of the body. It is important to find and treat malignant tumours as early as possible.

Cancers are named after the part of the body where they start. For example, cancer that starts in the covering of the lungs but spreads to the liver is called pleural mesothelioma with liver metastases.

## What is mesothelioma?

Mesothelioma starts in the mesothelial cells, which form a membrane (lining) that covers and protects most internal organs in your body. This is called the *mesothelium*. It is made up of two layers. The inner (visceral) layer wraps around organs such as the lung, heart or stomach. The outer (parietal) layer forms a sac around the inner layer. The mesothelium makes fluid to fill the space between the two layers so that the organs can move easily. The mesothelium has different names, depending on where it is in the body.

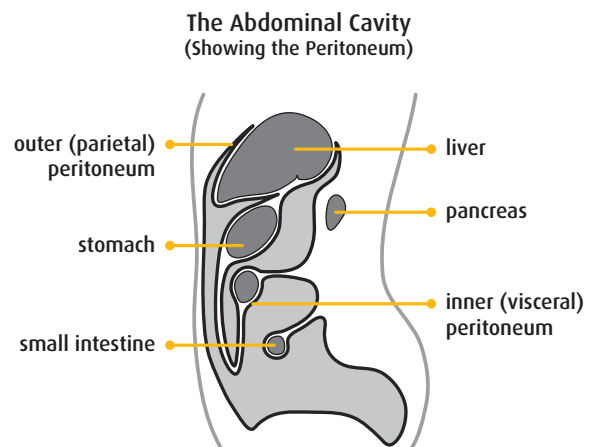
The *pleura* is the mesothelial membrane that protects and cushions the lungs. The inner layer covers the lungs, and the outer layer lines the inside wall of the chest. The space between the two layers (called the *pleural space*) is filled with pleural fluid. The pleural fluid allows the layers to slide over each other as you breathe.



The *peritoneum* is the mesothelial membrane that protects and cushions the organs in the abdomen, such as the liver, stomach and intestines. The inner layer covers the abdominal

organs and the outer layer lines the wall of the abdomen. The peritoneum fluid fills the space between the two layers and helps the organs move smoothly inside your abdomen.

Mesothelioma is a very rare form of cancer. Mesothelioma usually develops in the pleura or the peritoneum.



- *Pleural mesothelioma* starts in the pleura. (It is sometimes mistakenly called a lung cancer.) As the cancer cells grow, the membranes thicken and press on the lung. Sometimes fluid collects between the two layers of the pleura. This is called a *pleural effusion*. Changes to the pleura or pleural fluid can make breathing difficult.
- *Peritoneal mesothelioma* starts in the peritoneum. It causes the membranes to thicken. Fluid may collect in the abdomen. This is called *ascites* and it causes the abdomen to swell.

## Causes of mesothelioma

Exposure to asbestos is the main cause of mesothelioma. Asbestos fibres are very fine. If you breathe them in, they can make their way deep into the smallest airways of your lungs. Once lodged deep in the lungs, the fibres do not escape when you breathe out and can't be coughed out. The fibres sometimes make their way through the lung and settle in the pleura. This can cause pleural mesothelioma or other lung diseases, such as asbestosis. The fine asbestos fibres can also be swallowed and settle in the digestive system. From there, they can move into the peritoneum, causing peritoneal mesothelioma.

You can be exposed to asbestos either:

- *directly*, working with asbestos, or living or working where asbestos was released from building materials or other asbestos products
- *indirectly*, living with an asbestos worker and being exposed to the asbestos dust that is brought home on clothing and hair

Mesothelioma may not appear until 15 to 40 years after exposure to asbestos. Some people develop mesothelioma without knowing they've been exposed to asbestos. Other possible risk factors, such as family history, genetics and personal health history, are being studied to see if they increase the risk of getting mesothelioma.

## If you've been exposed to asbestos in the workplace

In some provinces, there are special services or benefits to help workers (and their families) who have developed mesothelioma from workplace exposure to asbestos. Ask your doctor about these programs or check with the workers' compensation or health insurance agency in your province.

## Symptoms of mesothelioma

Mesothelioma often does not cause any symptoms in its early stages. Symptoms may appear as the cancer grows. General symptoms may include night sweats and weight loss.

Other symptoms of **pleural mesothelioma** include:

- breathing problems, such as shortness of breath or wheezing
- a cough that gets worse or does not go away
- pain in the lower back or side of the chest
- a hoarse voice
- difficulty swallowing

Other symptoms of **peritoneal mesothelioma** include:

- pain in the abdomen
- changes to digestion, such as nausea, vomiting or a loss of appetite
- changes in bowel habits, such as constipation or diarrhea
- a lump that can be felt in the abdomen
- swelling in the abdomen (ascites)

Other health problems can cause some of the same symptoms. More testing is needed to make a diagnosis.

## Diagnosing mesothelioma

After taking your medical history and completing a physical examination, your doctor may suspect you have mesothelioma. To confirm the diagnosis, your doctor will arrange special tests. These tests may also be used to “stage” the cancer. You may have one or more of the following tests.

**Imaging studies:** Imaging studies allow tissues, organs and bones to be looked at in more detail. Using x-rays, ultrasounds, CT scans or MRIs, your healthcare team can get a picture of the size of the tumour and see if it has spread. The pictures may also show an abnormal buildup of fluid or swollen lymph nodes. These tests are usually painless and do not require an anesthetic.

**Blood tests:** Blood is taken and studied to see if the different types of blood cells are normal in number and appearance. The results show how well your organs are working and may suggest whether or not you have cancer.

**Biopsy:** A biopsy is usually necessary to make a definite diagnosis of cancer. Cells are removed from the body and checked under a microscope. If the cells are cancerous, they may be studied further to see how fast they are growing. There are many ways to do a

biopsy. For mesothelioma, cells may be taken from the pleura or peritoneum during endoscopy.

An endoscopy lets your doctor look inside certain parts of your body using an endoscope. An endoscope is a thin, flexible tube with a light and sometimes a tiny camera at the end.

To diagnose **pleural mesothelioma**, you may have one of the following endoscopic procedures:

- **Bronchoscopy** uses a bronchoscope to look at the trachea (windpipe) and the large air passages in the lungs. The tube is inserted through your nose or throat and passed down to your lungs. You will be given a mild sedative and an anesthetic to numb your throat. If an abnormal area is found, the doctor can take several samples of tissue through the bronchoscope. If tissue samples are taken, you may need a general anesthetic (you will be unconscious). You may have a sore throat afterwards. This is normal and should disappear after a couple of days.
- For a **thoracoscopy**, the endoscope is inserted through a small cut in the chest between two ribs. A thoracoscopy lets your doctor look inside your chest and take tissue samples (biopsies). A local anesthetic (freezing) will be used to numb the area or you may be given a general anesthetic.

To diagnose **peritoneal mesothelioma**, you may have one of the following endoscopic procedures:

- For a *laparoscopy*, the endoscope is inserted through a small cut in the abdomen. This procedure lets your doctor look inside the abdomen to examine the internal organs and the peritoneum and take tissue samples. A local anesthetic will be used to numb the area or you may be given a general anesthetic.
- A *laparotomy* is sometimes done if a laparoscopy did not allow the doctor to get enough tissue samples. A *laparotomy* is an operation used to look inside the abdomen. A surgical cut is made through the wall of the abdomen. The organs are examined and samples of tissue are taken. Nearby lymph nodes may be removed. A laparotomy is done in the hospital under a general anesthetic, and you will stay in the hospital for several days after the surgery.

Another way to do a biopsy is to take cells from the pleural or peritoneal fluid. A local anesthetic is used to numb the area of the chest. The doctor uses a needle to remove a small amount of fluid or cells from the space around the lungs or abdomen. Taking a sample of fluid from between the layers of the pleura is called a *pleural aspiration*. Taking fluid from the abdomen is called a *peritoneal aspiration*.

**Further testing:** If the initial diagnostic tests show that you have mesothelioma, your doctor may order more imaging studies or other tests to find out if the cancer has spread.

## Staging

Once a definite diagnosis of cancer has been made and your healthcare team has the information it needs, the cancer will be given a stage.

The cancer stage describes the tumour size and tells whether it has spread beyond the place where it started to grow.

There is no established staging system for peritoneal mesothelioma. For pleural mesothelioma, there are several different staging systems. Four stages are often used. The different stages describe how far the cancer has spread.

| Stage | Description   |
|-------|---|
| 1     | Cancer is found in the outer pleura on one side of the body. There may also be small tumours in the inner pleura.   |
| 2     | Cancer is found in the outer pleura on one side of the body with one or both of the following: <ul style="list-style-type: none"> <li>• large tumour in the inner pleura</li> <li>• cancer in the diaphragm (a sheet of muscle separating your chest and abdomen) or lung</li> </ul>  |
| 3     | Cancer is found in the outer pleura on one side of the body, and it has spread to one or more of the following areas: <ul style="list-style-type: none"> <li>• nearby lymph nodes</li> <li>• outer lining of the heart</li> <li>• chest wall</li> </ul>   |
| 4     | Cancer has spread to one or more of the following areas: <ul style="list-style-type: none"> <li>• distant lymph nodes</li> <li>• distant organs</li> <li>• ribs, spine or nearby nerves</li> <li>• diaphragm</li> <li>• into the heart</li> <li>• the pleura on the other side of the body</li> <li>• chest wall</li> </ul> |

It is important to know the stage of the cancer. This information helps you and your healthcare team choose the best treatment for you.

### Treatments for mesothelioma

Your healthcare team will consider your general health and the type and stage of the cancer to recommend what treatments will be best for you. You will work together with your healthcare team to make the final treatment choices. Talk to them if you have questions or concerns.

Treatments affect everyone in different ways. It's hard to predict which side effects you will have. Your healthcare team will tell you what to expect with each treatment. They will also let you know which side effects you should report right away and which ones you can wait to tell them about at your next appointment. If you notice any side effects or symptoms that you did not expect, talk to a member of your healthcare team as soon as possible.

Patients often worry about the side effects of cancer treatment. However, side effects can often be well managed and even prevented with medicine. Be open with your healthcare team. Tell them your concerns and ask questions. They will help you get the care and information you need.

For mesothelioma, you might receive one or more of the following treatments.

**Surgery:** A decision to have surgery depends on the size of the tumour and where it is. During the operation, all or part of the tumour and some healthy tissue around the tumour are removed. Surgery is done under general anesthetic (you will be unconscious), and you will stay in the hospital for several days after the surgery.

Surgery is sometimes used to remove as much of the tumour as possible before using other treatments. Both pleural and peritoneal mesothelioma are often diagnosed when they have already spread and can no longer be removed surgically. In this situation, surgery may be used to relieve symptoms, such as pain or a buildup of fluid.

Surgery for **pleural mesothelioma:**

- **Extrapleural pneumonectomy:** The surgeon removes the lung, the outer layer of the pleura, the pericardium (covering of the heart) and part of the diaphragm on the side of the chest affected by mesothelioma. You will be able to breathe with your remaining lung.

It can take many weeks to recover fully from a lung operation. It is normal to have some pain or discomfort after your operation. Air and fluid may also collect in the chest. These side effects are temporary and can be controlled. Sometimes a tube is inserted in the chest temporarily to drain fluid and to inject drugs into the pleural space.

**Surgery for peritoneal mesothelioma:**

- **Peritonectomy:** The surgeon removes the part of the peritoneum where the tumour is growing. This surgery can be done only if the mesothelioma is found very early.
- **Paracentesis:** Paracentesis is done to drain fluid that has built up in the abdomen. You will be given a local anesthetic to numb the area. A tube is inserted through a small cut in the abdomen.
- **Surgical resection:** The surgeon removes a large tumour or a bowel obstruction.

**Radiation therapy:** In *external beam radiation therapy*, a large machine is used to carefully aim a beam of radiation at the tumour. The radiation damages the cells in the path of the beam – normal cells as well as cancer cells. Radiation therapy is most often used to relieve pain or to control the symptoms of advanced mesothelioma. It may also be given after surgery to destroy cancer cells that may have been left behind.

Radiation side effects are usually mild. Side effects will be different depending on what part of the body receives the radiation. You may feel more tired than usual, have some diarrhea or notice changes to the skin (it may be red or tender) where the treatment was given.

**Chemotherapy:** Chemotherapy may be given as pills or by injection. It may be used before surgery or radiation therapy to shrink a tumour or after surgery to destroy cancer cells that may have been left behind. More commonly it is used to relieve pain or to control the symptoms of advanced mesothelioma.

Chemotherapy drugs interfere with the ability of cancer cells to grow and spread, but they also damage healthy cells. Although healthy cells can recover over time, you may experience side effects from your treatment like nausea, vomiting, loss of appetite, fatigue, hair loss and an increased risk of infection.

**Clinical treatment trials:** Clinical treatment trials investigate new approaches to treating cancer, such as new drugs, new types of treatments or combinations of existing treatments. They are closely monitored to make sure that they are safe for the participants. Ask your doctor if there is a clinical trial suitable as a treatment option for you. You may benefit and so may future cancer patients.

**Complementary therapies:** Complementary therapies are used *together with* conventional treatments. More research is needed to understand if these therapies are effective and how they work.

Alternative therapies are used *instead of* conventional treatments. Alternative therapies haven't been tested for safety or effectiveness. It is still unknown whether they will harm you or be effective in the treatment of cancer.

If you are thinking about using a complementary or alternative therapy, it is important to find out as much as you can about the therapy and talk to your healthcare team. It's possible that the therapy might interfere with test results or regular treatments.

## Treatments for symptoms caused by mesothelioma

There are a number of ways to help symptoms caused by mesothelioma.

### **Breathlessness or difficulty breathing:**

Breathlessness can sometimes be caused by a buildup of fluid around the lungs or fluid in the abdomen. Your doctor may be able to drain fluid from the lungs under a local anesthetic so that your breathing becomes easier. It may be necessary to have the fluid removed on a regular basis. Fluid in the abdomen can also be removed using a needle inserted under local anesthetic.

**Pain:** Pain is managed with medicines and sometimes with radiation therapy. Radiation therapy is helpful in managing chest pain, which is common in people with pleural mesothelioma.

**Bowel obstruction:** A bowel obstruction occurs when the large or small intestine becomes blocked and the intestinal contents are not able to pass through. It can occur in people with peritoneal mesothelioma. Surgery may be needed to remove the obstruction, or you may be given medicines to relieve pain and nausea.

If at any time you feel that your medicines are not working, let your doctor know as soon as possible.

## After treatment

Follow-up care helps you and your healthcare team monitor your progress and your recovery from treatment. At first, your follow-up care may be managed by one of the specialists from your healthcare team. Later on, it may be managed by your family doctor.

The schedule of follow-up visits is different for each person. You might see your doctor more often in the first year after treatment and less often after that. After treatment has ended, you should report to your doctor any new symptoms and symptoms that don't go away, such as breathlessness or a new cough or swelling of the abdomen. Don't wait for your next scheduled appointment.

The end of cancer treatment may bring mixed emotions. You may be glad the treatments are over and look forward to returning to your normal activities. But you could feel anxious as well. If you are worried about your treatment ending, talk to your healthcare team. They are there to help you through this transition period.

## Living with cancer

There are many sources of help available for people with cancer and for their caregivers.

**Your healthcare team:** If you need practical help or emotional support, members of your healthcare team may be able to suggest services in your community or refer you to cancer centre staff or mental health professionals.

**Family and friends:** Those closest to you can be very supportive. Accept offers of help. When someone says "Let me know how I can help," tell them what they can do. Maybe they can run errands, cook a meal or give you a ride to your doctor's office.

**People who have had a similar experience:** Consider visiting a support group or talking with a cancer survivor in person, over the telephone or online. Talking with and learning from others who have had similar experiences can be helpful. Try more than one option to see which one suits you best.

**Yourself:** Try to stay positive. Staying positive is about figuring out how to deal with cancer in the best way that you can – and everyone will do this their own way. It doesn't mean that you must seem happy or cheerful all the time or avoid talking or thinking about the difficulties of having cancer. But it can mean looking after yourself by finding relaxing, enjoyable activities that refresh you mentally, spiritually or physically.







## What we do

Thanks to the work of our volunteers and staff, and the generosity of our donors, the Canadian Cancer Society is leading the way in the fight against cancer. The Canadian Cancer Society:

- funds excellent research for all types of cancer
- advocates for healthy public policy
- promotes healthy lifestyles to help reduce cancer risk
- provides information about cancer
- supports people living with cancer

Contact us for up-to-date information about cancer, our services, or to make a donation.



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