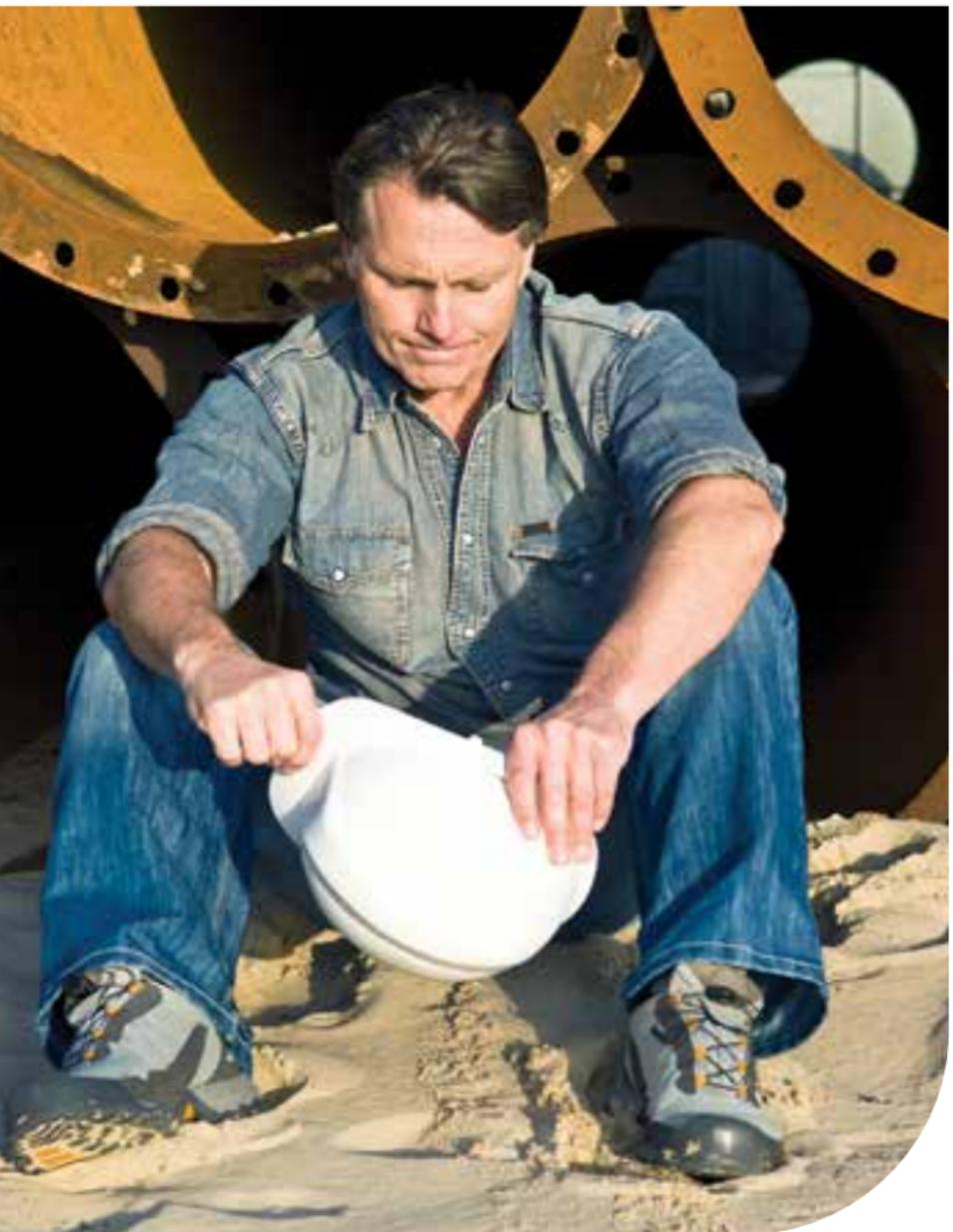




Canadian
Cancer
Society

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 have to take in and the decisions you need to make.

“ *All I could hear was ‘cancer.’ I heard my doctor say something like, ‘We’re going to start your treatment as soon as possible.’ I didn’t hear one word after that.* ”

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

For more information

You can find more in-depth information about mesothelioma on cancer.ca. Or call us at 1-888-939-3333 to learn more about cancer, diagnosis, treatment, support and services near you.

Check out our video series on common cancer topics. These short, simple videos cover subjects like *What is cancer?* and *Coping when you’re first diagnosed*.

Find the series at cancer.ca/cancerbasics.

What is cancer?

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

But sometimes the instructions in some cells get mixed up and the cells behave abnormally. These cells start to grow and divide uncontrollably. After a while, a group of abnormal cells forms a lump, or tumour.

Tumours can be either non-cancerous (benign) or cancerous (malignant). Non-cancerous tumour cells stay in one place in the body and are not usually life-threatening. Cancerous tumour cells can grow into nearby tissues and spread to other parts of the body. It's important to find and treat cancerous tumours as early as possible. In most cases, finding cancer early increases the chances of successful treatment.

Cancer cells that spread to other parts of the body are called metastases. The first sign that a tumour has spread (metastasized) is often swelling of nearby lymph nodes, but cancer can spread to almost any part of the body.

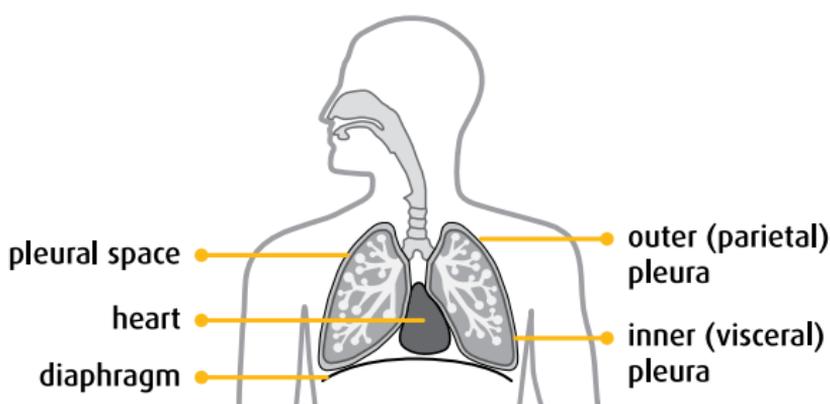
Cancers are named after the part of the body where they start. For example, cancer that starts in the lining of the lungs but spreads to the liver is called pleural mesothelioma with liver metastases.

What is mesothelioma?

Mesothelioma is cancer that starts in the cells of the mesothelium. The mesothelium is a lining (membrane) that covers and protects most organs in your body, such as the lungs, heart or stomach. It is made up of 2 layers. The inner layer wraps around the organs. The outer layer forms a sac around the inner layer. There is a small amount of fluid between the 2 layers so that the organs can move easily.

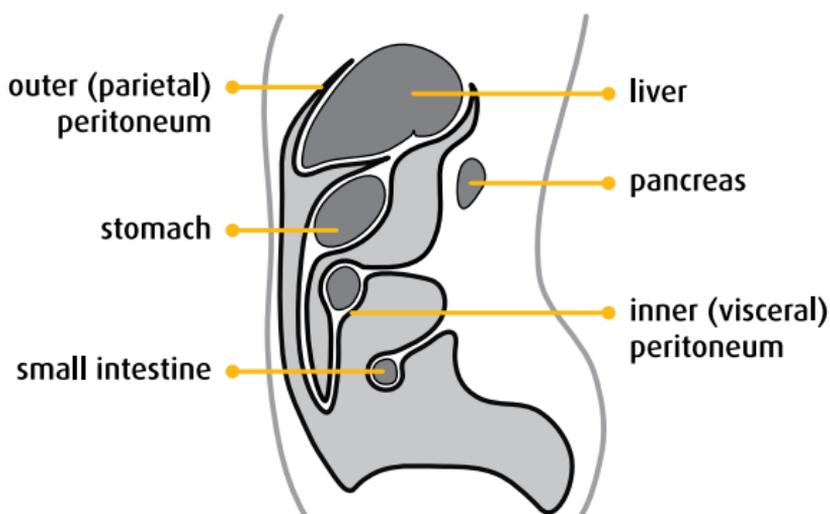
The mesothelium has different names, depending on where it is in the body. The mesothelium that protects and cushions the lungs is called the pleura. The inner layer that covers the lungs is the visceral pleura. The outer layer that lines the inside wall of the chest is called the parietal pleura. The space between the 2 layers (called the pleural space) is filled with pleural fluid. Pleural fluid allows the layers to slide over each other as you breathe.

The Chest
(Showing the Pleura)



The mesothelium that protects and cushions the organs in the abdomen, such as the liver, stomach and intestines, is called the peritoneum. The inner layer that covers the abdominal organs is the visceral peritoneum. The outer layer that lines the walls of the abdomen and pelvis is called the parietal peritoneum. Peritoneum fluid fills the space between the 2 layers and helps the organs move inside your abdomen.

The Abdomen
(Showing the Peritoneum)



Mesothelioma is a very rare form of cancer.

It usually starts in the pleura or the peritoneum.

- Pleural mesothelioma starts in the pleura. As the cancer cells grow, the lining thickens and presses on the lung. Sometimes too much fluid builds up between the 2 layers of the pleura. These changes can make it hard to breathe.
- Peritoneal mesothelioma starts in the peritoneum. It causes the lining to thicken. Fluid may build up in the abdomen causing it to swell. This is called ascites.

Diagnosing mesothelioma

Your doctor may suspect you have mesothelioma after hearing about your symptoms, taking your medical history and doing a physical exam. To find out for sure, your doctor will arrange special tests. These tests may also be used to help plan treatment.

Signs and symptoms of **pleural mesothelioma** include:

- pain in the side of the chest or under the ribs
- 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
- difficulty swallowing
- a hoarse voice
- swelling of the face and arms
- weight loss
- loss of appetite
- fever
- sweating
- feeling generally unwell

Signs and symptoms of **peritoneal mesothelioma** include:

- swelling in the abdomen
- pain in the abdomen
- a lump that can be felt in the abdomen or pelvis
- nausea, vomiting or loss of appetite
- changes in bowel habits, such as constipation
- blockage of the bowel (bowel obstruction)

The process of diagnosing cancer may seem long and frustrating. But other health problems can cause some of the same symptoms. The doctor has to make sure there are no other possible reasons for a health problem.

Your doctor will do one or more of the following tests to make a diagnosis.

Imaging tests: The healthcare team uses x-rays, ultrasounds, CT scans, MRIs or PET scans to look at your tissues, organs and bones in more detail. They can see the amount of cancer and if it has spread.

Blood tests: Blood is taken to see if the different types of blood cells are normal in number and how they look. Blood tests are also done to show how well your organs are working and may suggest whether you have cancer and if it has spread.

Biopsy: A biopsy is usually needed to make a definite diagnosis of cancer. The doctor removes cells or tissues from the body to be checked under a microscope. A biopsy is usually done using a hollow needle that is inserted through the skin. It may also be done using an endoscope or surgery. If the cells are cancerous, they will be studied to see how fast they are growing.

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 often a tiny camera at the end. It can be inserted through a small

cut in the chest or abdomen or through the nose or throat. The doctor may take samples of tissue or fluid through the endoscope.

Pulmonary function tests: These tests check how well the lungs are working. They are important if surgery is being considered as a treatment for mesothelioma.

Further testing: Your doctor may order other tests to find out if the cancer has spread and to help plan your treatment.

Will I be OK?

Most people with cancer want to know what to expect. Can they be cured?

A prognosis is your doctor's best estimate of how cancer will affect you and how it will respond to treatment. It looks at many factors including:

- the type and stage of the cancer
- the location of the cancer and whether it has spread
- your age, sex and overall health

Even with all this information, it can still be very hard for your doctor to say exactly what will happen. Each person's situation is different.

Your doctor is the only person who can give a prognosis. Ask your doctor about the factors that affect your prognosis and what they mean for you.

Staging

Once a diagnosis of cancer has been made, the cancer is given a stage. This information helps you and your healthcare team choose the best treatment for you and helps your doctor give a prognosis.

The following stages for pleural mesothelioma describe the amount of cancer and if it has spread.* There is no staging system for peritoneal mesothelioma.

Stage	Description
1	Cancer is found in the outer pleura. There may also be a small amount of cancer in the inner pleura.
2	Cancer is found in the outer pleura. The cancer may also have spread to the inner pleura, chest wall, diaphragm, lung or lymph nodes.
3	The cancer has usually spread to lymph nodes close to the lungs. It may have spread to the space between the lungs or to the heart.
4	The cancer has spread to the lung on the other side of the chest from where it started or to distant organs, such as the liver or kidney.

* This table summarizes the stages of pleural mesothelioma according to the Union for International Cancer Control (UICC). For more in-depth information, visit cancer.ca.

Treatments for mesothelioma

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

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

Surgery: A decision to have surgery depends on the amount of cancer and where it is. During the operation, all or part of the cancer and some healthy tissue around it are removed. Surgery to treat the cancer is an option for only a small number of people with mesothelioma. It may include removing the pleura or peritoneum.

It can take many weeks to recover fully from surgery for mesothelioma. It is normal to have some pain or discomfort after surgery. You may also have nausea and vomiting. Air and fluid may collect in the chest. These side effects are usually temporary and can be controlled.

In other cases, surgery may be done to relieve symptoms caused by the cancer. If you are having trouble breathing, your doctor may be able to drain fluid from the lungs or abdomen so that it becomes easier. You may also have surgery to remove an obstruction from the large or small intestine (called a bowel obstruction).

Chemotherapy: Chemotherapy uses drugs to treat cancer. Chemotherapy may be given as pills or injected with a needle into a vein. It may be the main treatment to help control the cancer when surgery is not possible. Or it may be given before surgery to shrink the cancer or after surgery to kill any cancer that remains. It may also be used to relieve the symptoms of mesothelioma. You may experience side effects from chemotherapy, like fatigue, nausea, vomiting, loss of appetite or an increased risk of infection.

Radiation therapy: External beam radiation therapy uses a large machine to carefully aim a beam of radiation at the tumour. The radiation damages cells that are in the path of the beam – both cancer cells and normal cells. Radiation therapy may also be used to help destroy any cancer that remains after surgery. And it may be used to relieve pain when surgery is not possible.

The side effects of radiation therapy depend on what part of the body receives the radiation. You may feel more tired than usual, have nausea or vomiting, or notice changes to the skin (it may be red or tender) where the treatment was given.

For more information on treatment, you may want to read our booklets *Chemotherapy and Other Drug Therapies* and *Radiation Therapy*.

Clinical trials: Clinical trials test new ways to treat cancer, such as new drugs, types of treatments or combinations of treatments. They provide information about the safety and effectiveness of new approaches to see if they should become widely available. Ask your doctor if any clinical trials are available that could be a treatment option for you.

Our brochure *Clinical Trials* has more information, including how to find a clinical trial.

Complementary therapies: Complementary therapies – for example, massage therapy or acupuncture – are used *together with* conventional cancer treatments, often to help ease tension, stress and other side effects of treatment. They don't treat the cancer itself.

If you're thinking about using a complementary therapy, learn as much as you can about the therapy and talk to your healthcare team. It's possible that the therapy might affect other treatments or test results.

Alternative therapies are used *instead of* conventional treatments. Alternative therapies haven't been tested enough for safety or effectiveness. Using alternative treatments alone for cancer may have serious health effects. Talk to your healthcare team before you try an alternative therapy.

Side effects of treatments

Some cancer treatments cause side effects, such as fatigue, hair loss or nausea. Because treatments affect everyone differently, it's hard to predict which side effects – if any – you may have.

Side effects can often be well managed and even prevented. If you're worried about side effects, tell your healthcare team about your concerns and ask questions. They can tell you which side effects you should report right away and which ones can wait until your next visit.

If you notice any side effects or symptoms that you didn't expect, talk to a member of your healthcare team as soon as possible. They'll help you get the care and information you need.

Living with cancer

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

Our booklet *Coping When You Have Cancer* has more detailed information and resources.

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.

Family and friends: People 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 drive you to your doctor's office.

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

Yourself: Coping well with cancer doesn't mean that you have to be happy or cheerful all the time. But it can mean looking after yourself by finding relaxing, enjoyable activities that refresh you mentally, spiritually or physically. Take some time to find ways to cope. You may also want to talk to a counsellor for more help.

Talking to someone who's been there

If you would like to talk to someone who's had a similar cancer experience, you can connect by phone with a trained volunteer who will listen, provide hope and suggest ideas for coping – all from the shared perspective of someone who's been there.

Register for this free program at match.cancer.ca or call us at 1-888-939-3333.

Want to connect with people online?

If you'd like to join our online community, visit CancerConnection.ca. You can read news, join discussion group, get support and help others at the same time. You'll find caring, supportive people there.

After treatment

Follow-up care helps you and your healthcare team follow your progress and your recovery from treatment. At first, you might meet with one of the specialists from your healthcare team. Later on, it may be 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 new symptoms or symptoms that don't go away to your doctor right away, without waiting for your next scheduled visit.

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're worried about your treatment ending, talk to your healthcare team. They can help you through this transition period.

Eating well: After treatment for mesothelioma, you may need to make changes to your diet and your eating habits. Your body may have difficulty getting enough vitamins and minerals. It may be easier to eat small meals and snacks throughout the day, rather than eating 3 large meals. Getting enough calories and protein will help you stay at a healthy weight and maintain your strength during and after your cancer treatments.

Your doctor or dietitian can give you more information about supplements and how to maintain a healthy diet.

Self-esteem, body image and sexuality: It's natural to be concerned about the effects of mesothelioma and its treatment on your self-esteem, body image and sexuality. The cancer and its treatment may cause scars, hair loss or skin changes. You may be worried about how your body looks after treatment, about having sex with a partner or that you may be rejected. It may help to talk about these feelings with someone you trust. Your doctor can also refer you to specialists and counsellors who can help you with the emotional side effects of mesothelioma treatment.

What causes mesothelioma?

Exposure to asbestos is the main cause of mesothelioma. Asbestos fibres are very small. If you breathe them in, they can travel to the smallest airways of your lungs. The fibres sometimes travel through the lung to the pleura. This can cause pleural mesothelioma or other lung diseases. The 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 by working with it, for example, in the mining or construction industry, or when fibres are released from buildings or other asbestos products. You can also be exposed to asbestos dust on the clothes of someone who

works with asbestos. Some people develop mesothelioma without knowing they've been exposed to asbestos.

Mesothelioma may not appear until 15 to 40 years after being exposed to asbestos. It is uncommon in people under the age of 50.

Other risk factors include:

- exposure to erionite, a mineral found in the soil in certain parts of the world
- previous radiation therapy to the chest or abdomen
- exposure to thorium dioxide (Thorotrast), a substance that was sometimes used for imaging tests in the past

Researchers are studying other possible risk factors, such as family history, genetics and personal health history, to see if they increase the risk of getting mesothelioma.

If you've been exposed to asbestos at work

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

Canadian Cancer Society

We're here for you.

When you have questions about treatment, diagnosis, care or services, we will help you find answers.

Call our toll-free number 1 888 939-3333.



Ask a trained cancer information specialist your questions about cancer. Call us or email info@cis.cancer.ca.



Connect with people online to join discussions, get support and help others. Visit CancerConnection.ca.



Browse Canada's most trusted online source of information on all types of cancer. Visit cancer.ca.

Our services are free and confidential. Many are available in other languages through interpreters.

Tell us what you think

Email cancerinfo@cancer.ca and tell us how we can make this publication better.



What we do

The Canadian Cancer Society fights cancer by:

- doing everything we can to prevent cancer
- funding research to outsmart cancer
- empowering, informing and supporting Canadians living with cancer
- advocating for public policies to improve the health of Canadians
- rallying Canadians to get involved in the fight against cancer

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



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This is general information developed by the Canadian Cancer Society. It is not intended to replace the advice of a qualified healthcare provider.

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