



Understanding Mesothelioma

A guide for people with cancer,
their families and friends

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Note to reader

Always consult your doctor about matters that affect your health. This booklet is intended as a general introduction to the topic and should not be seen as a substitute for medical, legal or financial advice. You should obtain independent advice relevant to your specific situation from appropriate professionals and you may wish to discuss issues raised in this book with them.

All care is taken to ensure that the information in this booklet is accurate at the time of publication. Please note that information on cancer, including the diagnosis, treatment and prevention of cancer, is constantly being updated and revised by medical professionals and the research community. Cancer Council Australia and its members exclude all liability for any injury, loss or damage incurred by use of or reliance on the information provided in this booklet.

Cancer Council

Cancer Council is Australia's peak non-government cancer control organisation. Through the eight state and territory Cancer Councils, we provide a broad range of programs and services to help improve the quality of life of people living with cancer, their families and friends. Cancer Councils also invest heavily in research and prevention. To make a donation and help us beat cancer, visit cancer.org.au or call your local Cancer Council.



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Introduction

This booklet has been prepared to help you understand how mesothelioma is diagnosed and treated. The chapters cover both pleural mesothelioma and peritoneal mesothelioma.

As the experience for every person with mesothelioma is different, you need to discuss your treatment options with your doctor. However, we hope the information in this booklet will answer some of your questions and help you think about other questions to ask your treatment team.

This booklet does not need to be read from cover to cover – just read the parts that are useful to you. Some medical terms that may be unfamiliar are explained in the glossary. You may also like to pass this booklet to your family and friends for their information.

How this booklet was developed

This booklet was developed with help from a range of health professionals and people affected by mesothelioma. The information on pleural mesothelioma is based on clinical practice guidelines¹ developed with the support of the Asbestos Diseases Research Institute (ADRI) and approved by the National Health and Medical Research Council (NHMRC).

If you or your family have any questions, call Cancer Council **13 11 20**. We can send you more information and connect you with support services in your area. Turn to the last page of this book for more details.



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What is cancer?

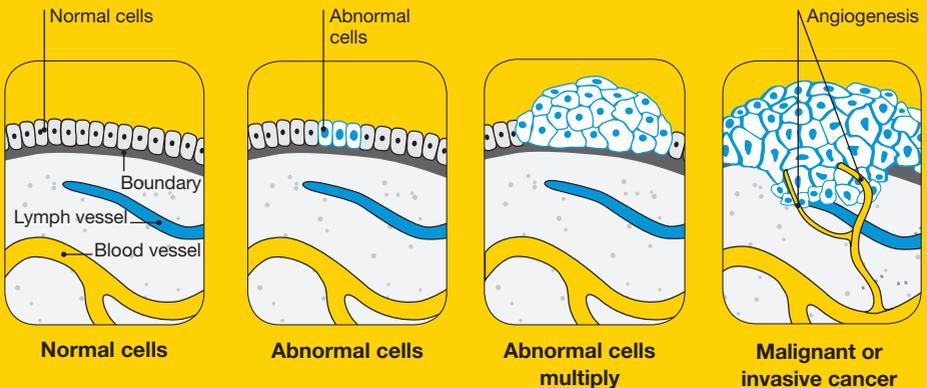
Cancer is a disease of the cells, which are the body's basic building blocks. The body constantly makes new cells to help us grow, replace worn-out tissue and heal injuries. Normally, cells multiply and die in an orderly way.

Sometimes cells don't grow, divide and die in the usual way. This may cause blood or lymph fluid in the body to become abnormal, or form a lump called a tumour. A tumour can be benign or malignant.

Benign tumour – Cells are confined to one area and are not able to spread to other parts of the body. This is not cancer.

Malignant tumour – This is made up of cancerous cells, which have the ability to spread by travelling through the bloodstream or lymphatic system (lymph fluid).

How cancer starts



The cancer that first develops in a tissue or organ is called the primary cancer. A malignant tumour is usually named after the organ or type of cell affected.

A malignant tumour that has not spread to other parts of the body is called localised cancer. A tumour may invade deeper into surrounding tissue and can grow its own blood vessels in a process known as angiogenesis.

If cancerous cells grow and form another tumour at a new site, it is called a secondary cancer or metastasis. A metastasis keeps the name of the original cancer. Mesotheliomas form metastases only in the later stages of the disease process. They usually spread by invading nearby organs and structures in the chest and abdomen, and spreading to the lymph nodes in the chest.

How cancer spreads

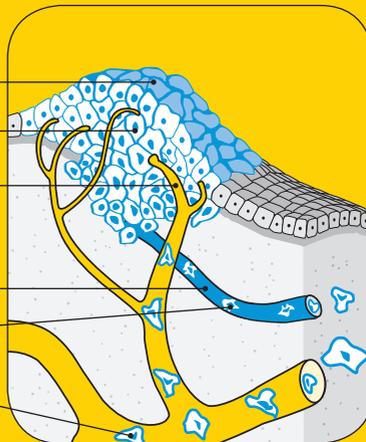
Primary cancer

Local invasion

Angiogenesis –
tumours grow their
own blood vessels

Lymph vessel

Metastasis –
cells invade other
parts of the body via
blood vessels and
lymph vessels





What is mesothelioma?

Mesothelioma is a type of cancer that starts from mesothelial cells. These cells line the outer surface of most of the body's internal organs, forming a protective membrane called the mesothelium.

Some mesotheliomas form a mass (tumour), while others grow along the mesothelium and form a thick covering. In later stages, mesothelioma may spread (metastasise) to other parts of the body.

Pleural mesothelioma

The mesothelium that covers the lungs is called the pleura. Mesothelioma that develops in the pleura is known as malignant pleural mesothelioma or, simply, pleural mesothelioma. It accounts for more than 90% of all mesotheliomas.

Although pleural mesothelioma involves the lining of the lungs, it is not lung cancer and is diagnosed and treated differently.

The pleura

There are two layers in the pleura. The inner layer lines the surface of the lungs and is called the visceral pleura. The outer layer lines the chest wall and the diaphragm, and is called the parietal pleura.

Between the two layers is the pleural cavity (also called the pleural space), which normally contains a small amount of fluid. This fluid allows the two layers of pleura to slide over each other so the lungs move smoothly against the chest wall when you breathe. When mesothelioma develops in the pleura, the delicate layers of the pleura thicken and may press on the lung, preventing it

from expanding when breathing in (inhaling). Excess fluid often collects between the two layers – this is called a pleural effusion.

Peritoneal mesothelioma

The mesothelium that lines the walls and organs of the abdomen and pelvis is called the peritoneum. Mesothelioma that develops in the peritoneum is known as malignant peritoneal mesothelioma or, simply, peritoneal mesothelioma. It accounts for less than 10% of all mesotheliomas.

The peritoneum

The peritoneum has two layers. The inner layer lines the surface of organs such as the bowel, liver and ovaries and is called the visceral peritoneum. The outer layer lines the walls of the abdomen and pelvis, and is called the parietal peritoneum.

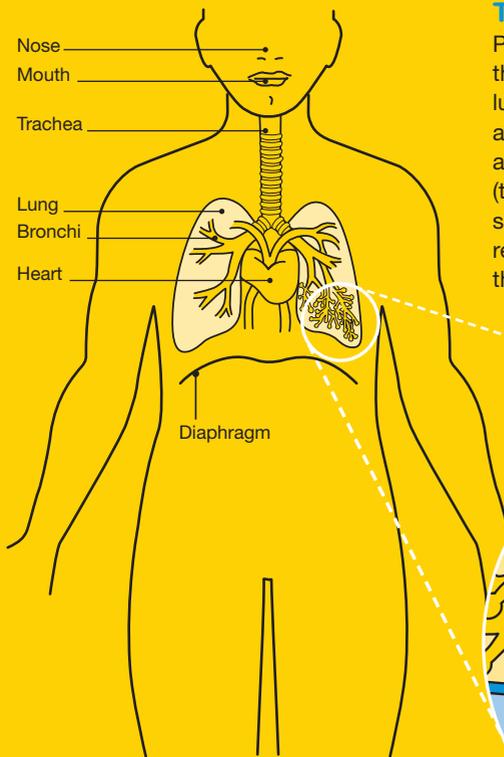
Between the two layers is the peritoneal cavity, which normally contains a small amount of fluid. This fluid allows the two layers to slide over each other as you move around. In people with peritoneal mesothelioma, excess fluid often collects between the two layers – this is known as ascites or peritoneal effusion.

Rarely, mesothelioma occurs in the pericardium, the mesothelium covering the heart. This is called pericardial mesothelioma. Even more rarely, mesothelioma can occur in the membrane around the testicles, the tunica vaginalis. This is called testicular mesothelioma.



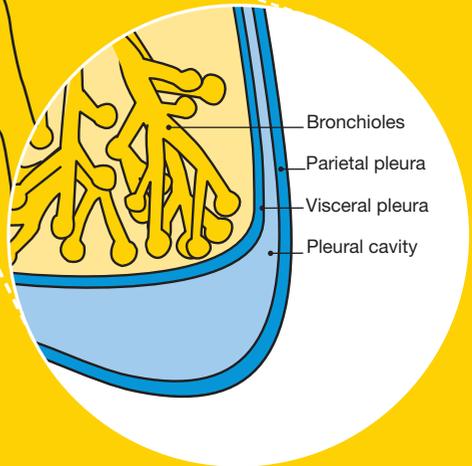
The pleura and the peritoneum

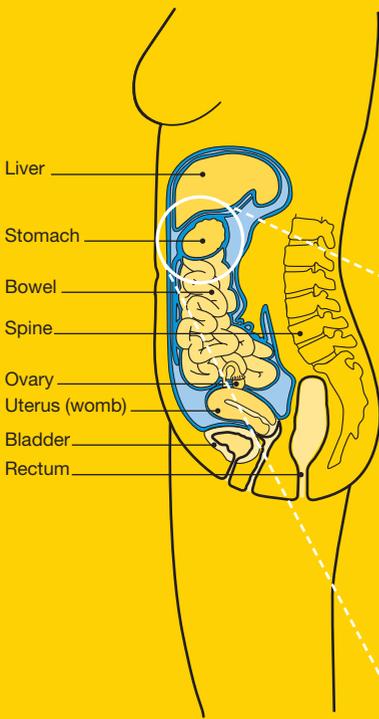
This booklet discusses pleural mesothelioma (lungs) and peritoneal mesothelioma (abdomen and pelvis). It is rare for mesothelioma to start in more than one area of the body.



The respiratory system

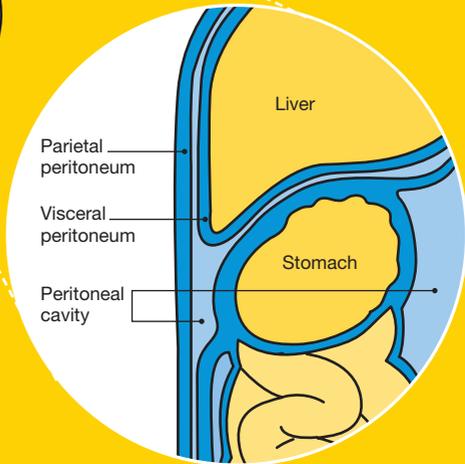
Pleural mesothelioma affects the pleura, the membrane that covers the lungs. The lungs are the main organs for breathing and are part of the respiratory system, along with the nose, mouth, windpipe (trachea), large airways (bronchi) and smaller airways (bronchioles). The lungs rest on the diaphragm, which is a wide, thin muscle that helps with breathing.





The abdomen and pelvis

Peritoneal mesothelioma affects the peritoneum, the membrane that lines the walls and covers the organs of the abdomen and pelvis. These organs include the stomach, bowel, liver, kidneys and, in women, the uterus and ovaries.





Key questions

Q: What causes mesothelioma?

A: Exposure to asbestos is the main cause of mesothelioma. Very rarely, mesothelioma has been linked with previous radiotherapy to the chest.

Asbestos is the name of a group of naturally occurring minerals that are resistant to high temperatures and humidity. It was used in many building products in Australia from the 1940s until 1987. Since 2004, Australia has had a ban on asbestos being sold, reused and/or imported. It is still present in many older buildings, so special precautions must be taken when renovating or demolishing. It has also been found in some recently imported products despite the ban.

People most likely to have been exposed to asbestos at work include asbestos miners and millers, asbestos cement manufacturing workers, ladders and insulators, builders, plumbers and electricians, automotive industry workers, mechanics, transport workers (especially waterside workers), and textile workers. People who haven't worked directly with asbestos but have been exposed to it can also develop mesothelioma. These can include people cleaning work clothes with asbestos fibres on them or people disturbing asbestos during home renovations or maintenance.

It can take many years for mesothelioma to develop after a person is exposed to asbestos. This is called the latency period or interval – it is usually between 20 and 60 years (most commonly around 40 years) after exposure.

Q: Can I seek compensation?

A: People who develop mesothelioma due to asbestos exposure may be able to claim compensation. Start making notes and talking to family and friends about when you may have been exposed to asbestos. It is important to get advice from an experienced lawyer as soon as possible after diagnosis. See pages 62–67 to read more about seeking compensation.

Q: How common is mesothelioma?

A: Australia has one of the highest rates of mesothelioma in the world, with 732 Australians diagnosed in 2014. Of these, more than 93% had pleural mesothelioma, about 6% had peritoneal mesothelioma, and about 1% had a rarer type.²

Men are over three times more likely than women to be diagnosed with mesothelioma, probably because many cases have been caused by exposure to asbestos at work. Western Australia has the most cases per population due to past asbestos mining. Mesothelioma is more common in people over the age of 65, but can occur in younger people.

The Australian Mesothelioma Registry monitors new cases of mesothelioma and collects information about asbestos exposure to help reduce mesothelioma in the future. Health professionals may tell the registry about new cases, or you can self-notify by visiting mesothelioma-australia.com or calling **1800 378 861**.



Q: What are the symptoms?

A: The first signs of mesothelioma are often vague and similar to other conditions. If you are concerned, see your general practitioner (GP). It may take some time to be diagnosed, as the symptoms may come and go, and more common conditions are likely to be investigated first. Let your GP know if you may have been exposed to asbestos in the past.

Symptoms will depend on where the mesothelioma has developed. Pleural mesothelioma may cause:

- **Shortness of breath (breathlessness)** – This common symptom usually feels worse with activity or when you are lying down. It is often caused by a build-up of fluid in the chest called pleural effusion (see *Draining fluid*, page 21).
- **Pain** – This can occur in the chest around the ribs or in the shoulder. It may be sharp and stabbing, made worse by breathing in deeply, or dull and persistent. You may also have a change in skin sensation or sensitivity to touch.
- **Other general symptoms** – Some people experience loss of appetite with weight loss, loss of muscle bulk, loss of energy, a persistent cough or a change in coughing pattern. Some people also experience night sweats.

Peritoneal mesothelioma may cause: abdominal pain; a swollen abdomen; poor appetite, nausea and vomiting; night sweats or fever; and bowel or urinary problems.

Q: What can I expect after diagnosis?

A: You are likely to feel shocked and upset when told you may have mesothelioma. It's common to have many questions and concerns about what the diagnosis will mean for you.

Diagnosis stage (pages 16–26)



You will have various tests to confirm that you have mesothelioma and work out how far it has progressed. The results will allow you and your health professionals to make decisions about the best approach to treatment.

Treating symptoms (pages 29–44)



Mesothelioma is often diagnosed at an advanced stage. For most people, the main goal of treatment is to manage symptoms and improve quality of life.

Active treatment (pages 45–55)



Depending on how advanced the mesothelioma is and other factors, you may be offered active cancer treatments to achieve a longer period of disease control and improve quality of life.

Depending on the impact of mesothelioma on your health, you may experience periods of relatively good health when symptoms are under control or less active. You may also experience periods when symptoms need more intensive treatment. For information about living with mesothelioma, see pages 56–61. For questions you may want to ask your doctor, see page 69.

Q: Which health professionals will I see?

A: If you have mesothelioma, you will be cared for by a range of health professionals who specialise in different aspects of your treatment. This is known as a multidisciplinary team (MDT) and may include some or all of the health professionals described in the table below.

MDT health professionals

general practitioner (GP)	assists with treatment decisions and works with your specialist to provide ongoing care
respiratory physician*	specialises in diseases of the lungs; may investigate symptoms of pleural mesothelioma and suggest initial treatments
gastroenterologist*	specialises in diseases of the digestive system; may investigate symptoms of peritoneal mesothelioma and suggest initial treatments
radiologist*	specialises in reading chest x-rays, CT scans and other scans
interventional radiologist*	may drain fluid and remove tissue for diagnosis using CT scans as a guide
pathologist*	examines cells and tissue under the microscope to determine the type and extent of mesothelioma
thoracic surgeon*	conducts some biopsy procedures and performs surgery to prevent and treat symptoms of pleural mesothelioma, including radical surgery
surgical oncologist/ general surgeon*	performs surgery to prevent and treat symptoms of peritoneal mesothelioma
medical oncologist*	prescribes and coordinates drug therapies such as chemotherapy, immunotherapy and targeted therapy

Some people are diagnosed and treated in specialist centres in major cities around Australia. To find out if there is a specialist unit near you, ask your doctor or call Cancer Council 13 11 20. If you live in a rural or regional area, or find it difficult to travel far, your GP can provide care and discuss further options with an MDT from a specialist centre.

radiation oncologist*	prescribes and coordinates the course of radiotherapy
palliative or supportive medical specialist*	manages pain and other symptoms to improve quality of life and wellbeing; usually works as part of a palliative care team
palliative care team (doctors, nurses and other health professionals)	assist with control of symptoms such as pain, breathlessness, nausea and anxiety, as well as offering emotional and spiritual support
nurses and nurse care coordinator	administer drugs and provide care, support and information throughout treatment
community nurses	visit you at home to supervise treatment, assess needs, and liaise with your GP or MDT
dietitian	recommends an eating plan to follow during and after treatment
physiotherapist, occupational therapist	help with maintaining and restoring strength and mobility during and after your treatment and may recommend equipment
social worker	provides counselling and support, links to services and helps with practical issues
psychologist	provides emotional support and strategies to help deal with the impact of the disease

* Specialist doctor



Diagnosis

Mesothelioma can be challenging to diagnose. The symptoms are often the same as those of other diseases and mesothelioma cells can look similar to other types of cancer cells.

The path to diagnosis usually begins with seeing your GP or going to a hospital emergency room, perhaps for shortness of breath, pain or another symptom. The doctor will examine you and take a history of your general health. If you think you may have been exposed to asbestos in the past, it is important to raise it at this time as many doctors won't automatically look for mesothelioma. The doctor will arrange some initial tests and probably refer you to a specialist, usually a respiratory physician (for chest symptoms) or a gastroenterologist (for abdominal symptoms).

You are likely to have quite a few tests and see several different health professionals (see pages 14–15) before a diagnosis of mesothelioma is confirmed.

General tests

Blood tests and x-rays can provide information about your overall health and help to rule out other conditions.

Blood test

You will have blood taken to check your overall health and let your doctors know how your blood cells, liver and kidneys are working. This helps them judge your fitness for treatment. A blood test will not usually show up mesothelioma, but can sometimes reveal certain markers that suggest the presence of the disease.

X-ray

If pleural mesothelioma is suspected, you will have a chest x-ray to look for any abnormalities in the lungs, thickening of the pleura, and fluid in the space between the lungs and the chest wall. For peritoneal mesothelioma, an x-ray will look for abnormalities in the abdomen, such as fluid and thickening in the peritoneum.

If abnormal growth or other changes are found, you will need more tests to check whether mesothelioma or another condition is the cause. Sometimes mesothelioma will not show up on an x-ray but can be seen in a CT scan.

Waiting for test results

Waiting for test results can be a difficult time. It's common to feel anxious about what will happen if you do have mesothelioma. It may help to focus on recovering from the test procedures and any improvements in symptoms.

Some results are available within a few days, but others take several weeks. In some cases, it may be necessary to have more tests before a definitive diagnosis can be

made. Ask your doctor or nurse how long the test results will take. It may help to talk to a family member or friend about how you're feeling. They're probably experiencing similar emotions.

If you need support or want to learn more about what a mesothelioma diagnosis will mean for you, call Cancer Council **13 11 20** or contact one of the organisations listed on page 72.

CT scan

A CT (computerised tomography) scan uses x-rays and a computer to create a detailed picture of an area inside the body.

Before the scan, you will be given an iodine contrast dye to make the scan pictures clearer. This is usually injected into a vein in your arm, but is sometimes given as a drink. If you have had an allergic reaction to iodine or dyes during a previous scan, tell your medical team beforehand. Also let them know if you have diabetes or kidney problems or are pregnant.

For the scan, you will need to lie flat on a table that slides in and out of a large, doughnut-shaped scanner. The procedure takes about 30 minutes. Although the test itself is painless, lying flat and still can be uncomfortable if you already have breathlessness or pain. Discuss any concerns with your medical team.

The CT scan provides accurate information about the location and thickness of the tumour(s) in the chest or abdomen. It can also show if the mesothelioma has spread to other organs. The information gathered by the CT scan is used to work out the best way of obtaining tissue for testing (see *Biopsy* below).

Biopsy

A biopsy is the main test used to diagnose mesothelioma. A doctor will remove a sample of tissue for a specialist called a pathologist to examine under a microscope. The pathologist can then determine if the tumour is mesothelioma and, if so,

the type of mesothelioma cells present. Mesothelioma is usually classified according to the appearance of the cells (although in about 25% of cases, no classification has been recorded):

- **Epithelioid** – cells look similar to normal mesothelial cells. This is the most common type, making up about 50% of cases.
- **Sarcomatoid** – cells have changed and look like cells from fibrous tissue. This type accounts for about 13% of cases.
- **Mixed or biphasic** – has epithelioid and sarcomatoid cells. This type makes up about 12% of all cases.²

Obtaining a biopsy for diagnosis can be challenging, so a respiratory physician or gastroenterologist, radiologist, surgeon and pathologist may all be involved.

Ways to take a biopsy for mesothelioma

A biopsy can be taken in different ways. Keyhole surgery, such as VATS or laparoscopy, is usually the preferred biopsy technique as several tissue samples can be taken and fluid can be removed. However, the choice will depend on your general health and fitness, and how suitable the tumour is for sampling using this method. An alternative method is CT-guided core biopsy.

Video-assisted thoracoscopic surgery (VATS) – To get a tissue sample from the lining of the lungs (pleura), your doctor may suggest VATS. You will be given a general anaesthetic, then a thin tube with a light and camera will be inserted through several

small cuts in your body. Tissue samples can be removed through the tube and sent to a laboratory for analysis. If fluid has built up around the lungs and is causing breathlessness, it can be drained during the VATS.

Laparoscopy – To get a tissue sample from the lining of the abdomen (peritoneum), your doctor may suggest a laparoscopy. You will be given a general anaesthetic, then a thin tube with a light and camera will be inserted through small cuts on your abdomen. Tissue samples can be removed through the tube and sent to a laboratory for analysis. Fluid that has built up in the abdomen can be drained during the laparoscopy.

CT-guided core biopsy – A CT-guided core biopsy may be used instead of VATS or laparoscopy. You will have a local anaesthetic and the biopsy will be taken from the lining of the lungs or abdomen with a needle that has a tip for cutting out tissue. A CT scan will be used to guide the needle into position.

During a CT-guided core biopsy, you will need to lie still on a table for about 30 minutes. Afterwards you will stay in the radiology suite for a couple of hours so you can be watched for potential complications (such as bleeding or a collapsed lung).

Special stains

Sometimes to confirm a diagnosis of mesothelioma, the pathologist needs to do further tests on the tissue sample using special stains. These look for specific molecules that may help to distinguish mesothelioma from other cancers.

Draining fluid

When you first experience symptoms of mesothelioma, there is likely to be a build-up of fluid in the space around your lungs or in your abdomen. Fluid around the lungs (pleural effusion) can make it hard to breathe. Fluid in the abdomen (ascites) may cause abdominal swelling, shortness of breath and pain.

Your doctor may drain some fluid to provide relief before suggesting further tests or treatment. A sample of the fluid may be sent to a

laboratory for testing to see whether cancer cells are present or whether the effusion is caused by another disease.

When fluid is drained from the pleura, it is called a pleural tap, pleurocentesis or thoracentesis; when it is drained from the peritoneum, it is called a peritoneal tap or paracentesis. To prevent fluid building up around the lungs again, you may have a talc pleurodesis at the same time. You can read more about these procedures on pages 30–31.

Other ways to diagnose mesothelioma

The current clinical practice guidelines recognise that the diagnosis of pleural mesothelioma can be difficult. They recommend CT scan and a biopsy guided by VATS or CT as the most reliable tests. The following techniques are considered less reliable for diagnosing this disease and are not recommended:

- fine needle aspiration, which uses a fine needle to extract a sample of cells
- core biopsy (using a needle to remove a sample of tissue) without the guidance of a scan, such as a CT or ultrasound.

Diagnosis from fluid samples

In some cases, a fluid sample rather than a tissue sample may be used to make a diagnosis because it's easy to collect fluid when draining the pleural or peritoneal cavity. However, it can be harder to diagnose mesothelioma with fluid samples, especially as abnormal mesothelioma cells can look similar to cells found in other conditions.

Some specialist centres have developed a high level of expertise in diagnosing mesothelioma using fluid samples. For this method to provide a reliable diagnosis, it's important that the tests are done at a specialist centre, a large volume of fluid has been collected, and the results are combined with information from an x-ray and CT scan. Your doctors may suggest this method of diagnosing mesothelioma if you are not well enough for a biopsy.

Staging mesothelioma

After mesothelioma has been diagnosed, your specialist will order further tests to find out if the disease has spread to other parts of the body and, if so, by how much and how far. This process is called staging. Knowing the stage helps doctors to work out your treatment options.

The main test to stage mesothelioma is a CT scan. You may have had a CT scan earlier when mesothelioma was suspected (see page 18), or during a CT-guided core biopsy (see page 20). If this CT scan showed advanced disease, a further CT scan may not be necessary.

Staging systems for mesothelioma

Staging is a way to describe the size of the cancer and whether and how far it has spread beyond its original site. Doctors use particular systems when staging different types of mesothelioma.

TNM staging system for pleural mesothelioma

The staging system recommended for pleural mesothelioma is the international tumour–node–metastasis or TNM staging system

T (tumour) 1–4	Describes if the pleural mesothelioma has grown in and beyond the pleural cavity. The higher the number, the further it has grown. If limited to the pleura on one side of the chest, it is T1. If it has grown into the lung or beyond, it is T2, T3 or T4.
N (node) 0–3	Describes if the pleural mesothelioma has spread to the lymph nodes. No lymph nodes affected is N0; spread only to lymph nodes on the same side of the chest is N1; spread to lymph nodes on the other side of the chest or in the neck is N2 or N3.
M (metastasis) 0–1	Shows if pleural mesothelioma has spread to other parts of the body. M0 means no spread to distant organs; M1 means it has spread to the bones, liver or other distant organs.

PCI system for peritoneal mesothelioma

Peritoneal mesothelioma is usually staged using the peritoneal cancer index (PCI). This gives a score out of 3 for the size of any tumours in 13 regions of the abdomen and pelvis, and then adds the scores together, with a maximum score of 39. The higher the PCI, the further the cancer has spread.

Tests before surgery

If radical surgery is being considered as a treatment option (see pages 50–53), you may have other scans and procedures to check whether mesothelioma has spread to other areas of the body.

FDG-PET – A positron emission tomography (PET) scan detects radiation from a low-level radioactive drug that is injected into the body. In an FDG-PET, the drug used is called fluorodeoxyglucose (FDG). The FDG shows up areas of abnormal tissue.

MRI scan – A magnetic resonance imaging (MRI) scan uses magnetic waves to create detailed cross-sectional pictures of the soft tissues in your body.

Mediastinoscopy – This procedure is used to sample the lymph nodes at the centre of the chest. A small cut is made in the lower neck, and an instrument is inserted to remove some lymph node tissue from the area between the lungs (mediastinum).

Endobronchial ultrasound (EBUS) – This procedure may be used along with, or instead of, mediastinoscopy. A tube called a bronchoscope, which has a small ultrasound probe on the end, will be put down your throat into your trachea. This allows the respiratory physician to target lymph nodes for biopsy.

Surgical staging – Before radical surgery for pleural mesothelioma, a less extensive operation may sample lymph nodes and other areas of the body. Surgical staging is not advised before a peritonectomy for peritoneal mesothelioma (see page 53).

Prognosis

Prognosis means the expected outcome of a disease. You may wish to discuss your prognosis with your doctor, but it is not possible for anyone to predict the exact course of the illness.

Mesothelioma behaves differently in different people. It is often present for many months before being diagnosed at an advanced stage, which will affect prognosis. After diagnosis, mesothelioma may progress quickly or more slowly. If it progresses slowly, some people may live for several years.

Your doctor will consider several factors when discussing prognosis with you, including:

- the appearance of the mesothelioma cells (see page 19)
- the stage (see page 23)
- the type of treatment you are able to have
- your symptoms, such as weight loss or pain
- your white blood cell count – people with normal levels usually have a better prognosis
- your overall health – recovering quickly after procedures tends to suggest a better outcome.

While knowing the stage helps doctors plan treatment, it is not always useful for working out prognosis for people with mesothelioma. This is partly because it is hard to predict how quickly mesothelioma will grow. In general, the earlier cancer is diagnosed, the better. If the cancer has advanced to a point where it is difficult to treat successfully, the priority will be to relieve symptoms and improve your quality of life.



Key points

- Mesothelioma can be very difficult to diagnose since many other diseases have similar symptoms.
- Various tests are used to diagnose mesothelioma. You are likely to need a number of tests before a diagnosis can be confirmed.
- Initial tests usually include a blood test, x-ray and CT scan.
- The main test to diagnose mesothelioma is a biopsy to collect tissue samples. This may be done using keyhole surgery, such as VATS or laparoscopy, or a CT-guided core biopsy. Your specialist will recommend the best technique for you.
- Fluid that has built up in the lungs or abdomen can be drained, either during tests to take a biopsy or as a separate procedure. It is possible to test a sample of this fluid for mesothelioma, but the results may not be reliable unless the test is done in a specialist mesothelioma centre and combined with other tests.
- The main test to see if mesothelioma has spread is a CT scan. If radical surgery is being considered, you may have other types of scans and surgical procedures to work out more precisely how far the cancer has spread (the stage).
- Pleural mesothelioma is staged using the TNM system. Peritoneal mesothelioma uses the PCI system.
- You may wish to talk to your doctor about your prognosis. Prognosis is the expected outcome of a disease.



Making treatment decisions

Sometimes it is difficult to decide on the type of treatment to have. You may feel that everything is happening too fast. Check with your doctor how soon your treatment should start, and take as much time as you need before making a decision.

Understanding the disease, the available treatments and possible side effects can help you weigh up the pros and cons of different treatments and make well-informed decisions that are based on your personal values. You may also want to discuss the options with your usual doctor, family and friends.

You have the right to accept or refuse any treatment offered. Some people with more advanced cancer choose treatment even if it offers only a small benefit for a short period of time. Others want to make sure the benefits outweigh the side effects so that they have the best possible quality of life.

Talking with doctors

When your doctor first tells you that you have mesothelioma, you may not remember the details about what you are told. Taking notes or recording the discussion may help. Many people like to have a family member or friend go with them to take part in the discussion, take notes or simply listen.

If you are confused or want clarification, you can ask questions – see page 69 for a list of suggested questions. If you have several questions, you may want to talk to a nurse or ask the office manager if it is possible to book a longer appointment.

A second opinion

You may want to get a second opinion from another specialist to confirm or clarify your doctor's recommendations or reassure you that you have explored all of your options. Specialists are used to people doing this.

Your doctor can refer you to another specialist and send your initial results to that person. You can get a second opinion even if you have started treatment or still want to be treated by the first doctor. You might decide you would prefer to be treated by the doctor who provided the second opinion.

Taking part in a clinical trial

Your doctor or nurse may suggest you take part in a clinical trial. Doctors run clinical trials to test new or modified treatments and ways of diagnosing disease to see if they are better than current methods. For example, if you join a randomised trial for a new treatment, you will be chosen at random to receive either the best existing treatment or the modified new treatment.

Over the years, trials have improved treatments and led to better outcomes for people diagnosed with cancer.

It may be helpful to talk to your specialist or clinical trials nurse, or to get a second opinion. If you decide to take part in a trial, you can withdraw at any time. For more information, call Cancer Council 13 11 20 and ask for a free copy of *Understanding Clinical Trials and Research*, or visit australiancancertrials.gov.au.



Treatment for symptoms

For many people, mesothelioma is diagnosed at an advanced stage, and the main goal of treatment is to manage and control your symptoms. Although there is usually no cure for mesothelioma, treatment may make you feel better and help you live longer. This is called palliative treatment.

It is often assumed that palliative care is only for people at the end of life; however, it is beneficial for people at any stage of a mesothelioma diagnosis. It does not mean giving up hope – rather it is about living for as long as possible in the most satisfying way you can and managing symptoms as they occur. Early palliative care is sometimes also called supportive care.

This chapter describes treatments and strategies for managing some common symptoms of mesothelioma. As you may be experiencing a number of symptoms, you may have a combination of treatments. Keep in mind, however, that you won't necessarily experience every symptom listed here.

If symptoms return after a period of relatively good health, you may be offered a different combination of treatments.

Breathlessness

Breathlessness is the most common symptom of pleural mesothelioma and is often caused by a build-up of pleural fluid around the lungs. In the earlier stages of pleural mesothelioma, controlling this fluid build-up will improve breathlessness. The level of improvement will depend on how healthy your lungs

were before you developed pleural mesothelioma, and the level of lung function after surgery. You may also feel breathless because of the cancer itself not allowing the lung to work properly – this is known as a trapped lung.

In peritoneal mesothelioma, a build-up of fluid (ascites) can cause the abdomen to swell. This can be painful, but also puts pressure on the diaphragm and can make you feel breathless.

Infection or a low level of red blood cells (anaemia) can also cause breathlessness. Your doctor can manage this with medication.

Although living with breathlessness can be difficult, there are ways to reduce its impact on your life (see pages 34–35). For some people, there are surgical options to control the build-up of fluid.

Ways to drain fluid around the lungs or abdomen

You may have a procedure to drain the fluid from around the lungs or abdomen. If you have gone to the doctor with symptoms, this may be done before mesothelioma is diagnosed. Sometimes it is done at the same time as the biopsy (see pages 18–21).

Pleural tap – Also known as pleurocentesis or thoracentesis, a pleural tap drains fluid from around the lungs. To drain the fluid, your doctor can numb the area with a local anaesthetic and insert a needle through the skin. An ultrasound scan is used to help the doctor guide the needle to where the fluid is. A pleural tap can also be done when a biopsy is taken during the keyhole surgery called VATS (see pages 19–20).



As well as surgical options, there are a number of ways you can manage breathlessness at home. See pages 34–35 for some strategies. You can also watch Lung Foundation Australia’s video *Managing your breathlessness*, which is available online at lungfoundation.com.au/patient-support under “Self-management”.

Peritoneal tap – In peritoneal mesothelioma, fluid that has built up in the abdomen (ascites) can be drained with a needle guided by ultrasound. This procedure is called a peritoneal tap or paracentesis and may be done while you are still having tests.

Ways to control fluid around the lungs

Talc pleurodesis – To prevent fluid building up again in the lining of the lungs, you may have a talc pleurodesis. This is best done when you are having a pleural tap during VATS, but may also be done under local anaesthetic by a respiratory physician.

Pleurodesis means closing the pleural space. The doctor inserts sterile talcum powder (talc slurry) into the pleural cavity. The talc slurry causes an inflammatory reaction that helps to fuse the two layers of the pleura together. After pleurodesis, some people experience a burning pain in the chest for 24–48 hours. This pain can be eased with medication.

Talc pleurodesis is sometimes done during the process of diagnosing pleural mesothelioma. If you haven’t already had this procedure, your surgeon may suggest it now.

VATS with pleurectomy and pulmonary decortication –

When fluid is drained and talc pleurodesis is done during VATS, some of the outer lining of the chest wall and lung may also be removed. This is known as parietal pleurectomy (because only the outer pleura is removed) and pulmonary decortication.

Open surgery (thoracotomy) with pleurectomy and pulmonary decortication –

Following VATS and talc pleurodesis, the fluid build-up around the lungs may come back, making you feel breathless again. The surgeon may suggest more extensive surgery called thoracotomy with pleurectomy and pulmonary decortication. This surgery may also be recommended as a first option if the cancer has grown in a way that makes it difficult to perform VATS successfully.

Under a general anaesthetic, the surgeon will open the chest by making a cut from the back to the side of the chest, and between the ribs. The pleural fluid is drained and the part of the pleura most affected with cancer is removed. In some cases, all of the pleura may be removed. After this procedure, the anaesthetist inflates the lung and the surgeon closes the chest. Tubes are left in place in the chest for at least 48 hours to drain blood and any air that is leaking from the surface of the lung.

Open surgery helps to prevent fluid building up again in most cases. It also makes it easier for the lungs to expand and to transfer oxygen to the blood. Pain can last longer than after VATS, but the improvement in symptoms may make open surgery a worthwhile option if VATS has been unsuccessful or isn't possible.

Indwelling pleural catheter – Some people cannot have VATS or open surgery, either because they are too unwell or because the cancer has grown in a way that makes the surgery too difficult. In this case, you may be offered an indwelling pleural catheter (also known as a drain) to help your breathing. This can also be used if the pleural fluid builds up again after pleurodesis.

Under local anaesthetic, the specialist will insert a thin tube (the catheter) through the chest wall into the pleural cavity. You can manage the drain at home with the help of a community nurse, family member or friend. When you need to drain the fluid (usually once or twice a week), the catheter can be connected to a bottle.

Sometimes with an indwelling pleural catheter, the pleural cavity may close up over time and stop producing fluid. If this occurs, the drain will be removed.

Ways to control fluid in the abdomen

Indwelling peritoneal catheter – If fluid keeps building up around the abdomen, a small tube can be inserted to allow fluid to flow out of the body into a bottle. This is known as an indwelling peritoneal catheter or drain and is managed similarly to an indwelling pleural drain (see above).

Heated chemotherapy – To control ascites, your doctor may suggest a single dose of heated chemotherapy directly into the abdomen (HIPEC, see page 54). This can be given during laparoscopy (see page 20), and there is some evidence that it can help prevent fluid building up again.

Improving breathlessness at home

It can be distressing to feel short of breath, but a range of simple strategies and treatments can provide some relief at home.

Treat other conditions

Let your doctor know if you feel breathless. Other conditions, such as anaemia or a lung infection, may also make you feel short of breath, and these can often be treated.



Sleep in a chair

Use a recliner chair to help you sleep in a more upright position.

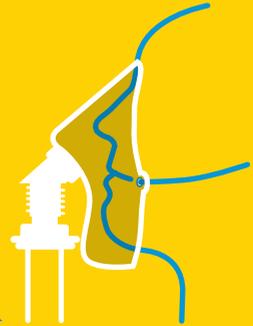


Ask about medicines

Talk to your doctor about medicines, such as a low dose of morphine, to manage feelings of distress. Make sure your chest pain is well controlled as pain may stop you breathing deeply.

Check if equipment could help

Ask your health care team about equipment to manage breathlessness. You may be able to use an oxygen concentrator at home to deliver oxygen to your lungs. For social outings and medical appointments, you can use a portable oxygen cylinder. If you have a cough or wheeze, you may benefit from a nebuliser, a device that delivers medicine into your lungs.





Modify your movement

Some types of gentle exercise can help, but check with your doctor first. A physiotherapist, exercise physiologist and/or occupational therapist from your treatment centre can explain how to modify your activities to improve breathlessness.



Create a breeze

Use a fan to direct a cool stream of air across your face if you experience breathlessness when you are not exerting yourself.

Relax on a pillow

Lean forward on a table with an arm crossed over a pillow to allow your breathing muscles to relax.



Explore options

Some people find breathing exercises, acupuncture and meditation helpful. Call **13 11 20** for a copy of *Understanding Complementary Therapies*, or find it on your local Cancer Council website.

Find ways to relax

Listen to a relaxation recording or learn other ways to relax. This can allow you to control anxiety and breathe more easily. In some states and territories, Cancer Council offers free relaxation CDs or has the recordings available on the website.



Difficulty sleeping

Getting a good night's sleep is important for maintaining your energy levels, reducing fatigue, and improving mood. Difficulty sleeping may be caused by pain, breathlessness, anxiety or depression. Some medicines can also disrupt sleep. If you already had sleep problems before the mesothelioma diagnosis, these can become worse.

Talk to your doctor about what might be helpful for you. Your medicines may need adjusting or sleep medication may be an option. There are also a number of strategies that other people with mesothelioma have found helpful (see below).



Getting a better night's sleep

- Try to do some gentle physical activity every day. This will help you sleep better. Talk to a physiotherapist, who can tailor an exercise program, and an occupational therapist, who can suggest equipment to help you move safely. You can also call Cancer Council **13 11 20** for a copy of the *Exercise for People Living with Cancer* booklet, or download it from your local Cancer Council website.
- Limit or cut out the use of alcohol, caffeine, nicotine and spicy food.
- Avoid using technology, such as television, computers or smartphones, before bed.
- Establish a regular routine before bed and set up a calm sleeping environment. You may find soothing music helpful. Ensure the room is dark, quiet and a comfortable temperature.

Fatigue

Fatigue means feeling very tired and lacking energy to carry out day-to-day activities. For people with cancer, it is different from tiredness and does not always go away with rest or sleep. You may lose interest in things that you usually enjoy doing or feel unable to concentrate for very long. Fatigue can influence how you feel about yourself and others, which may affect your close relationships.

If fatigue is a problem, talk to your treatment team. Sometimes fatigue can be caused by a low red blood cell count or the side effects of drugs, and can be treated. While you cannot always get rid of fatigue, you can find ways to improve your energy levels.



Managing fatigue

- Set small, manageable goals for the day, and rest before you get too tired.
- Ask for and accept offers of help with tasks such as shopping, cleaning and gardening.
- Plan breaks throughout the day when you are completely still for a while. An eye pillow can help at these times.
- Say no to things you really don't feel like doing.
- Leave plenty of time to get to appointments.
- Sit down whenever you can.
- Ask your doctor about what sort of exercise would be suitable. Even a walk around the garden or block can boost your energy levels.
- Eat nutritious food to keep your energy levels up.
- Consider acupuncture – some find it helps with fatigue.

Lack of appetite and weight loss

Some people stop feeling interested in eating and lose weight even before mesothelioma is diagnosed. These symptoms may be caused by the disease itself, or by nausea, trouble swallowing, changes in taste or smell, breathlessness, abdominal pain, or feeling down.

Eating well will help you cope better with day-to-day living, treatment and side effects, and improve your quality of life. A palliative care specialist can help manage symptoms that impact on your appetite or ability to eat. You may also find it useful to talk to a dietitian who is experienced in treating people with cancer. They can provide helpful eating suggestions.



Eating when you have little appetite

- Eat small meals and snacks regularly. A large, full plate may put you off eating – try using a smaller plate with less daunting portions. Likewise, drink from a half-full glass.
- Eat more of your favourite foods – follow your cravings.
- Try eating salads or cold foods if hot food smells make you nauseous.
- Avoid fatty or sugary foods. These may make you feel sick.
- Use lemon juice and herbs to add flavour to bland food.
- Eat moist food such as scrambled eggs. Moist food tends to be easier to eat and will cause less irritation if you have a sore mouth.
- Add ice-cream or fruit to a drink to increase kilojoules and nutrients.
- If solid food doesn't appeal, ask a dietitian about protein drinks or other supplements.

Constipation

Constipation is when your bowel motions and wind are difficult to pass and infrequent. It may be caused by not moving around as much, eating less fibre, or not drinking enough fluids. Strong pain medicines, some anti-nausea medicines and some chemotherapy drugs also cause constipation.

Severe constipation accompanied by other symptoms such as abdominal pain and swelling, nausea and vomiting can indicate a blockage in the bowel (bowel obstruction). This occasionally happens with peritoneal mesothelioma, but rarely with pleural mesothelioma. It needs prompt medical attention.



Managing constipation

- Drink plenty of fluids.
- Eat fresh fruit and vegetables and fibre-rich foods (e.g. prunes) unless your doctor advises otherwise.
- Try to exercise every day. Talk to your doctor or physiotherapist to find the exercise that is right for you.
- Ask your doctor about medicines for constipation if it's caused by chemotherapy or other medicines.
- Try over-the-counter laxatives such as Coloxyl with senna, Duphalac or Movicol, but check the dose with the pharmacist and let your doctor know. Don't wait too long before starting laxatives.
- Call your treatment team or 000 if you have symptoms of a bowel obstruction (described above).
- Read Cancer Council's *Nutrition and Cancer* booklet.

Pain

People are naturally fearful of experiencing pain. It's vital to tell your treatment team if you are in pain. Pain can be a symptom of mesothelioma, but can also be a side effect of treatment.

The pain caused by the mesothelioma itself is usually dull and generalised – it can be difficult to say exactly where it is coming from. If the cancer spreads and presses on bones or other organs, it may feel sharp and stabbing. A sharp pain in the chest can also be caused by a blood clot in the lungs (pulmonary embolism), so seek urgent medical attention if the pain is new. Chemotherapy or surgery can injure nerves and cause pain or numbness.

Pain medicines – Pain medicines may be mild, like paracetamol; moderate, like codeine; or strong and opioid-based, like morphine. Pain-relieving drugs may be taken as tablets, oral liquids, patches, injections or intravenous infusions. Other drugs may also be prescribed, like non-steroidal anti-inflammatory drugs (NSAIDs) or drugs specifically for nerve pain.

To help find the right medicine for you, your doctor may prescribe different drugs, different doses or a combination of drugs.

““ The pain got so severe that I gave in and accepted some morphine. I wondered afterwards why I had resisted. I am pretty much pain-free most of the time and quite alert when I need to be. It has made such a difference to my quality of life. ”” Jack

Opioids, such as morphine or oxycodone, are the most common drugs used to control moderate to severe cancer pain. Morphine is available in quick-acting and long-acting forms.

Some people feel concerned that they might become addicted to morphine. However, pain specialists believe that this won't happen if you take it as prescribed by your doctor to relieve pain. Morphine can be taken for a long time and in increasing doses, if needed. It doesn't have to be kept for "when the pain gets really bad". There are now many strong pain medicines that are similar to morphine, so if one does not agree with you, ask your doctor about other options.

A small percentage of people have difficulty in controlling their pain, and may need to try many medical and non-medical methods of relieving it. A palliative care specialist or pain specialist can help find the right combination for you.

Procedures to manage fluid build-up – Fluid build-up around the lungs or abdomen can cause pain as well as breathlessness. There are various treatments that can help drain the fluid and try to prevent it building up again. These are described in *Breathlessness* on pages 29–33.

Radiotherapy – This may be used to shrink mesothelioma that is pressing on body parts such as nerves, bones or major blood vessels and causing pain. Sometimes the mesothelioma can grow through the scar from VATS surgery and produce a lump in the skin. Radiotherapy can reduce the size of the lump and ease any associated pain. See pages 48–50 for more information about radiotherapy.

Chemotherapy – This can reduce the size of the mesothelioma that is causing the pain. See pages 46–48 for more information.

Debulking surgery – If you are well enough and it is technically possible, surgery may be used to remove the part of the mesothelioma causing pain and other symptoms. This is known as debulking surgery.

To find out more about managing pain, call Cancer Council 13 11 20 and ask for a copy of *Overcoming Cancer Pain*, or download the booklet from your local Cancer Council website.



Coping with pain

- Keep track of your pain in a symptom diary and try to describe it – what the pain feels like, how intense it is, exactly where it is, where it comes from and travels to, how long it lasts, and if it goes away with a specific pain medicine or with any other therapy, such as a heat pack.
- Allow a few days for your body to adjust to the dose of pain medicine/morphine and for the drowsiness to improve.
- Let your doctor know if you have vivid dreams, nausea or other side effects after taking a strong pain medicine such as morphine. Adjusting the dose may help, or you can try other methods of pain relief.
- Use a laxative regularly to prevent or relieve constipation from pain medicines.
- Take pain medicine regularly as prescribed, even when you're not in pain. It's better to stay on top of the pain.

“ My husband did not want to accept help from the palliative care people. He said that once they got involved he would not have much longer left to live. But his GP told him about what they do and how much they can help with symptoms and comfort. He agreed to try and now would not be without them. ” Grace

How palliative care can help

The options described in this chapter are generally considered palliative treatment because their main aim is to improve quality of life by reducing symptoms. Palliative treatment is one aspect of palliative care, in which a team of health professionals aim to meet your physical, practical, emotional, spiritual and social needs. The palliative care team also provides support to families and carers.

Contacting the palliative care team soon after diagnosis gives them the opportunity to get to know you, your family and your circumstances. Although other professionals will be responsible for your treatment in the earlier part of your diagnosis, the palliative care team can become involved when needed.

Ask the doctor in charge of your medical care about making an appointment with the palliative care team. To find out more about palliative care and advanced cancer, call Cancer Council 13 11 20. You can ask for free copies of the booklets *Understanding Palliative Care* and *Living with Advanced Cancer*, or download digital versions from your local Cancer Council website.



Key points

- For most people, treatment is given to control symptoms and improve quality of life.
- Breathlessness caused by fluid build-up is the most common symptom of pleural mesothelioma. It can usually be controlled with surgery – either a type of keyhole surgery called video-assisted thoracoscopic surgery (VATS) or a type of open surgery called thoracotomy.
- An indwelling pleural catheter allows fluid to be drained without surgery. The catheter is inserted through the chest wall into the pleural cavity, and can be collected into a bottle.
- Other ways to improve breathlessness include using a fan, leaning forward on a table over a pillow or sleeping in a recliner chair.
- Fluid in the abdomen (ascites) can be controlled with an indwelling peritoneal catheter or heated chemotherapy.
- Manage fatigue by exploring ways to improve sleep, setting small goals for the day, and resting before you get too tired.
- Try to drink plenty of fluids and eat fresh fruit and vegetables to ease constipation.
- While pain is common for people diagnosed with mesothelioma, it can be relieved. Strong pain is often treated with opioid-based drugs such as morphine.
- In some cases, radiotherapy, chemotherapy or surgery can be used to manage pain.
- Palliative treatment helps to improve a person's quality of life by managing symptoms. It's best to access it early. You can get in touch with the palliative care team soon after you have been diagnosed.



Active treatment

A range of active treatments are recommended for some people with mesothelioma. These aim to control or cure the cancer and can include chemotherapy, radiotherapy or surgery, which may be used alone or in combination. Trimodality therapy for pleural mesothelioma is a combination of all three (see pages 50–52).

Each person with mesothelioma is different and there is no standard treatment path. Your specialist will discuss your treatment options with you, and these will depend on a number of factors including:

- the location, stage and type of mesothelioma, which helps estimate the likelihood of response to treatment
- your age, health and fitness
- your family circumstances and support
- what is most important to you.

Deciding to pursue active treatment

The active cancer treatments discussed in this chapter help some people to achieve a longer period of control over the disease and improve their quality of life. It is important to realise that most are intensive treatments and they are not suitable for everyone.

Even if a particular treatment is recommended, it will be up to you whether or not to proceed (see *Making treatment decisions*, pages 27–28). Talk to your treatment team about what is involved and what recovery will be like. You can also call Cancer Council 13 11 20 or talk to one of the mesothelioma support services listed on page 72.

Recent advances in treating mesothelioma

Mesothelioma treatment has improved in recent years. There are more accurate ways to diagnose and stage the disease, better surgical techniques and post-surgery care, new evidence-based chemotherapy combinations and new radiotherapy methods.

Clinical trials (see page 28) are testing promising new drug treatments such as immunotherapy and targeted therapy. Immunotherapy

slows the growth of cancer or kills cancer cells by altering the body's immune system response. Targeted therapy attacks specific particles within cells that allow cancer to grow and spread.

These newer treatments are still experimental and can be very expensive unless you are part of a clinical trial. Your specialist may suggest that you join a clinical trial for your initial or later treatment.

Active treatment for pleural mesothelioma

Chemotherapy

Chemotherapy treats cancer using drugs known as cytotoxics. It aims to destroy cancer cells while causing the least possible damage to healthy cells. The main chemotherapy drugs for pleural mesothelioma are pemetrexed in combination with cisplatin or carboplatin. Research shows this combination can increase survival by a few months more than using a single drug. However, chemotherapy doesn't work for some people.

Chemotherapy is usually administered into a vein through a drip (intravenously). The drugs travel through the bloodstream and reach the entire body. This is known as systemic chemotherapy.

You will usually have chemotherapy during day visits to your hospital or treatment centre. Each session may last for several hours followed by a rest period of several weeks. Together, the session and rest period are called a cycle. You will probably have up to six cycles. However, the length and timing of the treatment and rest days of each cycle may vary.

Side effects of chemotherapy – People react to chemotherapy drugs differently. Some people will have few side effects, while others will have more.

The most common side effects of chemotherapy include:

- tiredness and feeling weak (fatigue)
- nausea and/or vomiting
- bowel problems (diarrhoea or constipation related to anti-nausea drugs)
- sore or dry mouth, or small ulcers in the mouth
- taste changes and/or loss of appetite
- increased risk of infection (low level of white blood cells) and anaemia (low level of red blood cells)
- reduced kidney function
- ringing in the ears (tinnitus)
- skin changes
- numb or tingling hands or feet
- red and itchy eyes (conjunctivitis).



Your risk of infection increases during chemotherapy treatment. If you have a temperature over 38°C, contact your doctor immediately or go to your nearest hospital emergency department.

While hair loss and scalp problems are rare with chemotherapy for mesothelioma, there may be hair thinning. Some people have trouble thinking clearly or experience short-term memory loss after chemotherapy, but this usually improves once treatment ends.

Side effects depend on the type and dose of chemotherapy drugs. Your specialist may prescribe vitamin B12 injections and low-dose folic acid, which have been shown to reduce the side effects of chemotherapy with pemetrexed and cisplatin. You will also be given medicines (such as anti-nausea medicine) to help control any side effects that are likely to occur. If side effects become too difficult to manage, your oncologist can adjust the dose or type of chemotherapy.

Call Cancer Council 13 11 20 for a free copy of *Understanding Chemotherapy*, or visit your local Cancer Council website.

Radiotherapy

Also known as radiation therapy, radiotherapy uses radiation, such as x-rays, to kill or damage cancer cells. Radiotherapy may be used at different stages of pleural mesothelioma treatment and in different ways. It can relieve pain or other symptoms caused by tumours (palliative radiotherapy).

Radiotherapy is also given after chemotherapy and surgery (adjuvant radiotherapy) to help kill remaining cancer cells.

Treatment is carefully planned to destroy as many cancer cells as possible while causing the least harm to your normal tissue. The initial appointment to map out the treatment (simulation) may take a few hours. You will have CT scans of the affected area, and your skin may be marked with a special ink. This makes sure that the radiation is directed at the same place on your body every time you receive radiotherapy. Although the ink is permanent, the mark is the size of a freckle.

Radiotherapy is usually given every day Monday to Friday as an outpatient treatment. A session usually lasts about 20 minutes because the radiation therapists have to set up the equipment and position you, but the treatment itself takes only a few minutes. The length of the treatment course will vary depending on why you're having radiotherapy – it might involve 1–10 sessions for up to two weeks for palliative treatment, or longer if radiotherapy is combined with other treatments with the aim of long-term control. Radiotherapy doesn't hurt and you aren't radioactive afterwards.

Side effects of radiotherapy – Radiotherapy may cause various side effects during treatment or shortly afterwards, but most side effects go away after the treatment stops.

Your doctors and nurses will tell you what side effects to expect and how to manage them. The most common side effects are listed on the next page.

The side effects of radiotherapy vary depending on the area of the body being treated, but can include:

- fatigue
- peeling, cracked skin that looks red or sunburnt and may be painful
- painful swallowing
- loss of hair in the treatment area.

Radiotherapy to the chest area can cause difficulty swallowing and symptoms of reflux for a few days or weeks, sometimes leading to weight loss. If high doses of radiotherapy are given to the chest area, it may cause permanent changes (fibrosis) in the lung tissue.

Call Cancer Council 13 11 20 for a free copy of *Understanding Radiotherapy*, or visit your local Cancer Council website.

Trimodality therapy

Trimodality therapy includes a combination of induction chemotherapy, radical surgery (also called cytoreductive surgery) and radical radiotherapy. The aim of the three phases is to remove as much pleural mesothelioma as possible, stop any remaining mesothelioma cells from growing or spreading, and prolong disease-free living.

The benefits of trimodality therapy for pleural mesothelioma are not yet clear. Not all mesothelioma specialists recommend trimodality therapy, and it's available only in a few specialist centres. There has not yet been an evidence-based trial comparing the results of trimodality treatment to less intensive treatment.

The three phases of trimodality therapy

1 Induction chemotherapy phase

Three cycles of chemotherapy are given to shrink the tumour. A scan then checks the size of the tumour. If it has been reduced, you will have a rest for 4–6 weeks before having surgery. If there is little or no response, you will not have radical surgery.

2 Radical surgery phase

The surgery is usually an extrapleural pneumonectomy (EPP). It removes the affected lung as well as parts of the lining of the heart (pericardium), lining of the chest (parietal pleura) and diaphragm. Lymph nodes in the centre of the chest that drain the lung are also removed. Mesh is used to repair the pericardium and diaphragm. You'll stay in hospital for 10–14 days, or longer if complications occur. Once at home, recovery can take 6–8 weeks and then you'll be able to start radiotherapy.

3 Radical radiotherapy phase

This phase aims to treat the tumour cells that may still be present. Radiotherapy is delivered using intensity-modulated radiation therapy (IMRT). This type of radiotherapy can be accurately shaped around the chest cavity to allow higher doses to be delivered directly to the tumour cells while minimising the damage to other organs in the chest and abdomen. You will have treatment every day, Monday to Friday, for up to six weeks. The side effects of radiotherapy (see opposite) usually become more intense as treatment progresses. Most people start to feel better 2–3 weeks after treatment ends.

Who can have trimodality therapy – Only a small number of people with pleural mesothelioma have trimodality therapy each year as it is only suitable for people:

- with a small amount of pleural mesothelioma at an early stage (T1–T3)
- with an epithelioid type of pleural mesothelioma
- whose scans show a good response to chemotherapy before surgery and no signs of pleural mesothelioma progression
- with no signs of spread into the lymph nodes or any other disease on CT and/or FDG-PET scans
- who are able to live independently with one lung
- who are physically fit enough for surgery.

The best person to determine if you will be a suitable candidate for this treatment is the surgeon who would perform the surgery.

It is important to ask your surgeon, oncologist and nurse to explain the likely outcome of the surgery for you. An EPP is a major operation, and not everyone wants to go ahead after the risks, benefits and implications of the therapy are explained by their treatment team.

Sometimes, despite a person appearing suitable at first, the doctor may decide it is best for them not to continue with trimodality therapy. This might be because:

- the mesothelioma does not respond well to the chemotherapy
- tests of specimens taken at surgery show that the cancer is growing quickly or has spread
- the person has become too tired or unwell.

Active treatment for peritoneal mesothelioma

Peritonectomy

It is possible for some people to have an operation called a peritonectomy (or cytoreductive surgery). During this procedure, a surgeon removes the parts of the peritoneum where the mesothelioma is growing.

The aim of peritonectomy is to achieve the complete removal of the cancer to reduce symptoms, improve quality of life and increase life expectancy.

Peritonectomy surgery is complex and recovery can take a long time. Whether this surgery is an option for you will depend on a number of factors, including your overall health and fitness, and whether the small bowel is cancer-free.

Only a small number of surgeons in Australia perform peritonectomy. It is recommended you seek an opinion from one of these surgeons if considering this surgery. To find one of these surgeons, talk to your treatment team or contact a mesothelioma support organisation (see page 72).

Radiotherapy is rarely used for peritoneal mesothelioma as the doses required would cause too much damage to the liver, kidneys and other organs in the abdomen.



Chemotherapy

Chemotherapy is sometimes used to treat peritoneal mesothelioma. It may be given as a systemic treatment (into the bloodstream) on its own or before or after surgery. Systemic chemotherapy for peritoneal mesothelioma is similar to that given for pleural mesothelioma (see pages 46–48 for more information).

If you have a peritonectomy, you will have chemotherapy directly into the abdomen. This is known as intraperitoneal chemotherapy and may be given in three ways:

- **HIPEC** – Heated intraoperative intraperitoneal chemotherapy (HIPEC) may be given as part of peritonectomy. For this “hot chemotherapy”, the drugs are heated to 42.5°C and inserted into the abdomen for 60–90 minutes during the operation.
- **EPIC** – After surgery, chemotherapy may be delivered into the abdomen through a thin tube. When given soon after surgery as a single course, it is called early postoperative intraperitoneal chemotherapy (EPIC).
- **NIPEC** – There is evidence that receiving a long-term course of normothermic (normal temperature) intraperitoneal chemotherapy (NIPEC) may offer some benefit.



Key points

- The type of treatment you have will depend on the location, stage and type of mesothelioma, as well as your age, health and fitness.
- Active cancer treatment for pleural mesothelioma may include chemotherapy and radiotherapy.
- Chemotherapy for pleural mesothelioma often uses pemetrexed in combination with cisplatin or carboplatin.
- Radiotherapy may be used at different stages of pleural mesothelioma and in different ways. It may be used to relieve pain or shrink tumours, or given after chemotherapy and surgery to kill remaining cancer cells.
- Some people with pleural mesothelioma may be offered trimodality therapy, with chemotherapy first, followed by major surgery, and then radiotherapy. The surgery removes the affected lung and parts of the pericardium, parietal pleura and diaphragm. This is known as an extrapleural pneumonectomy (EPP).
- Active cancer treatment for peritoneal mesothelioma may include surgery and chemotherapy.
- Some people with peritoneal mesothelioma can have a peritonectomy. This major surgery aims to remove all of the cancer by removing parts of the peritoneum.
- Chemotherapy for peritoneal mesothelioma may be systemic (given into the bloodstream) or intraperitoneal (given directly into the abdomen).
- New trials are testing targeted therapy and immunotherapy drugs.



Living with mesothelioma

Life with a mesothelioma diagnosis can present many challenges. Take some time to adjust to the physical and emotional changes, and establish a daily routine that suits you and the symptoms you're coping with.

You are likely to feel a range of emotions about having mesothelioma. Cancer Council's *Emotions and Cancer* booklet offers strategies for coping with anxiety, fear, anger and other feelings. You may also have practical concerns, such as how to make a compensation claim for asbestos exposure (see pages 62–67) and what to do about work (see Cancer Council's *Cancer, Work and You* booklet).

Dealing with feelings of sadness

If you have continued feelings of sadness, have trouble getting up in the morning, or have lost motivation to do things that previously gave you pleasure, you may be experiencing depression. This is quite common among people who have been diagnosed with mesothelioma.

Talk to your GP, as counselling or medication – even for a short time – may help. Some people are able to get a

Medicare rebate for sessions with a psychologist. Ask your doctor if you are eligible. Your local Cancer Council may also run a counselling program.

The organisation [beyondblue](http://beyondblue.org.au) has information about coping with depression and anxiety. To order a fact sheet, call **1300 22 4636** or go to beyondblue.org.au. You can also connect with a counsellor over the phone, online or by email.

Finding support

The organisations listed on page 72 can offer support or connect you with other people who have mesothelioma. You can also call Cancer Council 13 11 20 or visit your local Cancer Council website (see back cover) for information about many aspects of living with cancer.

Looking after yourself

A mesothelioma diagnosis will cause physical and emotional strain. It's important to try to look after your wellbeing as much as possible.

Nutrition – Healthy food can help you cope with treatment and side effects. A dietitian can help you manage special dietary needs or eating problems, and choose the best foods for your situation.

Call Cancer Council 13 11 20 for a free copy of the *Nutrition and Cancer* booklet, or download a copy from your local Cancer Council website.

Staying active – Physical activity often helps to reduce tiredness, improve circulation and elevate mood. The amount and type of exercise you do depends on what you are used to, how you feel, and your doctor's advice.

Cancer Council's *Exercise for People Living with Cancer* booklet provides more information about the benefits of exercise, and outlines simple exercises that you may want to try.

Complementary therapies – These therapies are used with conventional medical treatments. You may have therapies such as massage, relaxation and acupuncture to increase your sense of control, decrease stress and anxiety, and improve your mood. Alternative therapies are used instead of conventional medical treatments. These therapies, such as coffee enemas and magnet therapy, can be harmful.

Let your doctor know about any therapies you are using or thinking about trying, as some may not be safe or evidence-based. For more information, call 13 11 20 for a free copy of the *Understanding Complementary Therapies* booklet, or download it from your local Cancer Council website.

Relationships with others

Having cancer can affect your relationships with family and friends. This may be because cancer is stressful and tiring, or as a result of changes to your values, priorities or outlook on life.

Give yourself time to adjust to what's happening, and do the same for others. People may deal with the cancer in different ways – for example, they may be overly positive, play down fears, or keep their distance. It may be helpful to discuss your feelings with each other.



Call **13 11 20** for free copies of *Sexuality, Intimacy and Cancer* and *Fertility and Cancer*, or download the booklets from the website.

Sexuality, intimacy and fertility

Cancer can affect your sexuality in physical and emotional ways. The impact of these changes depends on many factors, such as treatment and side effects, your self-confidence, and if you have a partner. Although sexual intercourse may not always be possible, closeness and sharing can still be part of your relationship.

If you are able to have sex, you may be advised to use contraception to protect your partner or avoid pregnancy for a certain period of time. Your doctor will talk to you about the precautions to take. They will also tell you if treatment will affect your fertility permanently or temporarily. If having children is important to you, talk to your doctor before starting treatment.

Ongoing management

As symptom management and treatment for mesothelioma are likely to be ongoing, you will have regular check-ups to monitor your health. Everyone is different, so your doctor will decide how often you need check-ups, but it's usually every 6–8 weeks.

During check-up appointments, your doctor will do a physical examination and may also arrange a CT scan to see how active the mesothelioma is. What other tests you have, and who you see and where, will depend on your health and the type of treatment you've had. If you live a long way from the hospital or treatment centre, you may be able to arrange for some of the tests to be done by your GP or the specialist who referred you for major treatment.

If you notice any change in your symptoms between appointments or you experience side effects from treatment, you should contact your doctor as soon as possible. You don't have to wait until the next scheduled appointment.

What happens when mesothelioma becomes active again?

For nearly every person with mesothelioma, the disease will become active again even if it has responded well to treatment. This is known as disease progression or recurrence.

When mesothelioma becomes active again, you and your doctor will need to consider what treatment is needed to try to regain control of the disease and provide relief from symptoms.

Treatment options will depend on the symptoms you are experiencing and may include:

- radiotherapy to reduce the size of the regrowth and pain
- further chemotherapy or second line chemotherapy
- further surgery
- participating in a clinical trial to access new drugs being developed and tested.

Palliative treatment for mesothelioma can be offered alone or in combination with surgery, chemotherapy and radiotherapy. See page 43 for details. You may find it helpful to read the Cancer Council booklets *Understanding Palliative Care* and *Living with Advanced Cancer*.

At some point, you may decide to stop active treatment and focus on managing symptoms and maximising quality of life. The booklet *Facing End of Life* discusses the physical, emotional, spiritual and practical aspects of living with end-stage cancer. Call 13 11 20 for a copy, or visit your local Cancer Council website.

The role of hope

A diagnosis of advanced cancer does not mean giving up hope. People with mesothelioma often have many good months or years ahead of them and can continue to enjoy many aspects of life, including spending time with their families and other people who are important to them.

As the disease progresses, the things that are hoped for tend to change. For example, a person may now focus on living comfortably for as long as possible or being able to celebrate a particular event. You can have these hopes while still acknowledging the reality of the situation.

“As hard as it was for us, my wife decided it was time to ‘rest’ and not struggle with needles, tests and hospital appointments. She said she would now prefer to spend time with those she loved, watch her garden grow and watch her grandchildren play.”  *Bill*



Making a claim

Some people who develop mesothelioma due to asbestos exposure may be able to claim compensation. Your legal entitlements will depend on the state or territory in which you were exposed to asbestos. In some cases, the exposure may have occurred overseas.

Mesothelioma takes a long time to develop, so your exposure to asbestos may have occurred some 40 years ago. You might think it was a trivial exposure, or you may not remember any exposure. Talking to your friends and family can help to bring back memories of places where you may have been exposed to asbestos.

An expert lawyer will also talk you through your life history and help you find out where the exposure took place. They will explain what compensation you may be able to claim and help make the process easy for you to understand.

Generally, a person diagnosed with mesothelioma has two different types of legal entitlements:

- a claim through the court, known as a “common law claim”
- a claim under a government compensation scheme, known as a “statutory claim”.

“When my husband was diagnosed with terminal mesothelioma, we were advised to apply for compensation. He reluctantly contacted lawyers, and they assured us we had a very strong case. My husband didn’t survive to ‘win’ his case but I did, with a lot of help, caring, understanding and good advice from our lawyers. ” Sharon

Common law claim

A common law claim is a claim process through a court. The claim is brought against the party or parties who caused a person to be exposed to asbestos. These parties are known as the “defendants”. A common law claim begins by filing a formal court document known as an “originating process”. The originating process must be lodged within your lifetime to protect your entitlement to compensation. As long as you start a common law claim during your lifetime, your estate will still be able to continue with your claim if you die before the claim is finalised.

You need to speak with a lawyer experienced in asbestos-related compensation claims as soon as possible after your diagnosis. If you’re too unwell to visit the lawyer in their office, they can visit you at home or in hospital to discuss the process and how it can be simplified for you and your family.

It may still be possible to bring a common law claim even if:

- you were exposed to asbestos many years ago
- you no longer work for the employer where you were exposed
- you have worked for many employers
- you were self-employed or a contractor
- your employer is no longer in business
- you are, or were, a smoker
- you were exposed to asbestos in another state or overseas
- you were not exposed in the workplace
- you were only briefly exposed to asbestos
- you were exposed to asbestos on more than one occasion
- you don’t know how you may have been exposed to asbestos.

Finding a lawyer

Making a mesothelioma claim is a specialised area. It is important to talk to a lawyer or law firm experienced in this area of work, as they often have a wealth of knowledge about how and where asbestos was used.

You can find a leading lawyer in asbestos by checking the Doyles Guide Directory – visit doylesguide.com/australia and type “asbestos” in the search bar. The mesothelioma

support organisations listed on page 72 can also assist you in contacting an expert asbestos lawyer.

Talking to an expert in this field can help reduce the time taken to investigate a claim. Experienced lawyers also understand mesothelioma and what you are coping with. Your lawyer will work around medical appointments or treatments to try to make things less stressful for you.

How long will a common law case take?

The majority of common law claims for mesothelioma are settled out of court within 3–6 months of the claim being lodged. If your prognosis is poor, or you suddenly become very unwell, the process can be sped up to try to ensure that your common law claim is resolved in your lifetime. Only a few cases actually proceed to a court trial.

What if I die before my claim is settled?

Many people diagnosed with mesothelioma worry that their claim won't be finalised before they die. The largest component of compensation is usually the general damages. So long as you

start a common law claim in your lifetime, then your entitlement to general damages is protected, and your estate would be able to continue with your claim if you die before your claim is finalised.

In some circumstances, your family may also be entitled to dependency entitlements if you die because of the mesothelioma. Your lawyer will let you know if this applies to you and your family.

How much does legal action cost?

Legal costs are generally dependent on the amount of legal work required to resolve your case. Most lawyers who specialise in asbestos-related compensation claims offer a “no win, no fee” agreement. This means that the lawyers will only charge for legal services if they are successful in resolving your case. You are also entitled to claim a large portion of your legal costs from the defendants as part of your common law claim. The amount of costs awarded will depend on whether your case was resolved at mediation or at trial.

Ask your lawyer for a costs agreement and get them to talk it through with you so you know what is involved. Be aware that even under a “no win, no fee” agreement, if you:

- start a claim but decide to cease the action, you will usually need to pay any legal costs up to that point
- proceed but lose the court case, you will not need to pay your lawyer, but you may still need to pay court costs for yourself and possibly for the defendant
- are successful, a significant portion of your compensation might be absorbed by any costs that the defendant doesn't have to pay.

Statutory claims

Some states and territories have special government compensation schemes for people who develop mesothelioma and other asbestos-related diseases. These schemes usually apply only if you have been exposed to asbestos during your employment.

The authorities for Australia's asbestos compensation schemes are:

- **ACT** – WorkSafe ACT, call 02 6207 3000 or visit worksafe.act.gov.au
- **NSW** – Dust Diseases Authority, also known as icare dust diseases care, call 02 8223 6600 or visit icare.nsw.gov.au
- **NT** – NT WorkSafe, call 1800 019 115 or visit worksafe.nt.gov.au
- **QLD** – WorkCover Queensland, call 1300 362 128 or visit worksafe.qld.gov.au
- **SA** – ReturnToWorkSA, call 13 18 55 or visit rtwsa.com
- **TAS** – WorkSafe Tasmania, call 1300 366 322 or visit worksafe.tas.gov.au
- **VIC** – WorkSafe Victoria, call 1800 136 089 or visit worksafe.vic.gov.au
- **WA** – Your employer's insurer or if unknown, Insurance Commission of Western Australia, call 08 9264 3333 or visit icwa.wa.gov.au
- **Commonwealth** – Comcare, call 1300 366 979 or visit comcare.gov.au.

Do I need a lawyer?

It is possible for you and sometimes your dependants to lodge a statutory claim directly with the authority in your state or

territory. However, most people with mesothelioma prefer to use a lawyer to arrange all their claims.

The laws around Australia vary and can be complex. Some people may be entitled to bring a common law claim instead of, or in addition to, a statutory claim. It is vital to consult an expert asbestos lawyer before applying for statutory benefits to ensure you aren't excluded from also claiming common law compensation.

Using an expert asbestos lawyer will allow you to access all your entitlements while concentrating on your health and spending time on the things that are important to you.

Advance care planning

It is also worth seeking the advice of a lawyer to ensure your will is up to date and that your intentions for your estate are clear.

You may wish to arrange legal documents appointing a substitute decision-maker. Depending on where you live, the documents for appointing this person may be known as an enduring power of attorney, enduring power of

guardianship, or appointment of an enduring guardian. You can also outline your wishes for your future medical care in an advance care directive. These documents are part of advance care planning.

Cancer Council offers a Legal Referral Service that can help with wills and advance care planning, and assistance is free for eligible clients. Call **13 11 20** to find out more.



Caring for someone with mesothelioma

You may be reading this booklet because you are caring for someone with mesothelioma. Being a carer can be stressful and cause you much anxiety. Try to look after yourself – give yourself some time out and share your worries and concerns with somebody neutral, such as a counsellor or your doctor.

Many cancer support groups and cancer education programs are open to carers, as well as people with cancer. Support groups and programs can offer valuable opportunities to share experiences and ways of coping.

Support services such as Meals on Wheels, home help or visiting nurses can help you in your caring role. You can find local support services, as well as practical information and resources, through the Carer Gateway. Call 1800 422 737 or visit carergateway.gov.au.

There are also many groups and organisations that can provide you with information and support, such as Carers Australia, the national body representing carers in Australia. Carers Australia works with the Carers Associations in each of the states and territories. Phone 1800 242 636 or visit carersaustralia.com.au for more information and resources.

Mesothelioma support organisations often place particular emphasis on the wellbeing of the carer. You can find a list of these organisations on page 72. You can also call Cancer Council 13 11 20 or visit your local Cancer Council website to find out more about carers' services and to get a copy of the *Caring for Someone with Cancer* booklet.



Question checklist

You may find this checklist helpful when thinking about the questions you want to ask your doctor about mesothelioma and its treatment. If your doctor gives you answers that you don't understand, ask for clarification.

- What type of mesothelioma do I have? How far has it spread?
- What treatment do you recommend and why?
- What is the aim of the treatment?
- Will my treatment be given by a mesothelioma specialist?
- How do I get a second opinion?
- Are there other treatment choices for me? If not, why not?
- Are there any clinical trials of new treatments that I could join?
- What are the risks and possible side effects of the treatment?
- How long will the treatment take? Will I have to stay in hospital?
- How much will treatment cost? How can the cost be reduced if I can't afford it?
- How will I know if the treatment is working?
- What if I decide not to have any treatment?
- Who can I see if I'm worried between my appointments?
- Will I have pain from the mesothelioma? What will be done about this?
- I'm worried about what will happen to me: who can I talk to about my feelings?
- Will others in my family also be at risk of mesothelioma?
- Might I be able to claim compensation for the illness? Who do I contact about this?



Further information and support

Cancer can affect every area of your life. Support is available to help you with practical and financial issues, as well as the emotional aspects of the experience.

Practical and financial help

There are many services that can help deal with practical or financial problems caused by mesothelioma.

Benefits, pensions and programs can help pay for prescription medicines, transport costs or utility bills. Home care services, aids and appliances can also be arranged to help make life easier. Ask the hospital social worker which services are available in your local area and if you are eligible to receive them.

If you need legal or financial advice, it is important to talk to a qualified professional about your situation. Cancer Council offers free legal and financial services in some states and territories for people who can't afford to pay – call 13 11 20 to ask if you are eligible. You can also ask for a copy of *Cancer and Your Finances* for information on managing finances, superannuation and work issues.

For information and advice on applying for compensation, it is best to contact a specialist lawyer who has extensive experience with asbestos claims. See page 64 for suggestions on finding a specialist asbestos litigation lawyer. You may also want to read the rest of the *Making a claim* chapter (pages 62–67) for an introduction to the compensation process.

Talk to someone who's been there

You and your carers may find it helpful to make contact with other people who have had similar experiences. You may feel supported and relieved to know that others understand what you are going through and that you are not alone.

People with mesothelioma may be able to join a telephone support group facilitated by a trained counsellor or be put in touch with someone else who has mesothelioma. There are also support groups specifically for carers. Talk to your nurse, social worker or Cancer Council 13 11 20 about what is available in your area, or contact one of the mesothelioma support organisations listed on the next page.

Another option available at any time is to visit an online forum such as the Cancer Council Online Community (see below).

Cancer Council services

Cancer Council Information and Support

including links to transport, accommodation, home help, legal and financial referral service, telephone support groups, peer support programs, and counselling

13 11 20

Cancer Council Australia

cancer.org.au

Cancer Council state and territory websites

See back cover

Cancer Council Online Community

cancercouncil.com.au/OC

Mesothelioma support in Australia

Bernie Banton Foundation	1800 031 731 berniebanton.com.au
New South Wales	
Asbestos Diseases Foundation of Australia (ADFA)	1800 006 196 adfa.org.au
Asbestos Diseases Research Institute (ADRI)	02 9767 9800 adri.org.au
Queensland	
Asbestosis and Mesothelioma Association of Australia (AMAA)	1800 017 758 asbestosassociation.com.au
Asbestos Disease Support Society (ADSS)	1800 776 412 adss.org.au
South Australia	
Asbestos Diseases Society of South Australia (ADSSA)	1800 157 540 adssa-inc.com.au
Asbestos Victims Association of South Australia (AVA)	08 8212 6008, 1800 665 395 avasa.asn.au
Tasmania	
Asbestos Free Tasmania Foundation	asbestosfreetasmania.org.au
Victoria	
Asbestos Council of Victoria/ Gippsland Asbestos Related Diseases Support (ACV/GARDS)	03 5127 7744 gards.org
Asbestoswise	03 9654 9555 asbestoswise.com.au
Western Australia	
Asbestos Diseases Society of Australia (ADSA)	08 9344 4077, 1800 646 690 asbestosdiseases.org.au
Reflections through Reality	reflections.org.au

Other useful information and support

Australian

Cancer Australia	canceraustralia.gov.au
Carers Australia	1800 242 636 carersaustralia.com.au
Department of Health	health.gov.au
Healthdirect Australia	1800 022 222 healthdirect.gov.au
My Aged Care (including how to find help in your home and ACAT assessments)	1800 200 422 myagedcare.gov.au
Palliative Care Australia	palliativecare.org.au
Asbestos Safety and Eradication Agency	1300 326 148 asbestossafety.gov.au
Australian Asbestos Network	australianasbestosnetwork.org.au
Australian Mesothelioma Registry	1800 378 861 mesothelioma-australia.com
Lung Foundation Australia	1800 654 301 lungfoundation.com.au

International

American Cancer Society	cancer.org
Cancer Research UK	cancerresearchuk.org
Macmillan Cancer Support (UK)	macmillan.org.uk
National Cancer Institute (US)	cancer.gov
Mesothelioma Applied Research Foundation (US)	curemeso.org
Mesothelioma UK	mesothelioma.uk.com



Glossary

abdomen

The part of the body between the chest and hips, which contains the stomach, liver, bowel, kidneys and ovaries.

adjuvant treatment

A treatment given with or shortly after another treatment to enhance its effectiveness.

advanced cancer

Cancer that is unlikely to be cured. It may be limited to its original site (primary cancer) or may have spread to other parts of the body (secondary or metastatic cancer).

alternative therapies

Therapies that have not been scientifically tested but are used in place of conventional treatment, often in the hope that they will provide a cure.

anaesthetic

A drug that stops a person feeling pain during a medical procedure. Local and regional anaesthetics numb part of the body; a general anaesthetic causes temporary loss of consciousness.

asbestos

A naturally occurring silicate mineral that forms long, crystallised fibres.

asbestosis

A slowly progressing lung disease caused by asbestos in which the lungs are gradually replaced by scar tissue.

asbestos-related diseases

Disorders of the lung and pleura caused by the inhalation of asbestos fibres. They include lung cancer and mesothelioma as well as

non-cancerous disorders such as asbestosis, diffuse pleural thickening, pleural plaques, pleural fluid build-up and rounded atelectasis.

ascites

Collection of fluid in the abdomen, making it swollen and bloated. Also known as peritoneal effusion.

benign

Not cancerous or malignant.

biopsy

The removal of a sample of tissue or cells from the body for examination under a microscope to help diagnose a disease.

biphasic

See mixed mesothelioma.

breathlessness

Shortness of breath or difficulty breathing. Also called dyspnoea.

cancer

Uncontrolled growth of cells that may result in abnormal blood cells or grow into a lump called a tumour. These cells may spread throughout the lymphatic system or bloodstream to form secondary or metastatic tumours.

cells

The basic building blocks of the body. A human is made of billions of cells that are adapted for different functions.

chemotherapy

A cancer treatment that uses drugs known as cytotoxics to kill cancer cells or slow their growth. May be given alone or in combination with other treatments.

chest cavity

The area enclosed by the ribs that includes the lungs (covered by the pleura) and the heart. Also known as the thoracic cavity.

clinical trial

A research study that tests new and better treatments to improve people's health.

complementary therapies

Supportive treatments that are used in conjunction with conventional treatment. They may improve general health, wellbeing and quality of life, and help people cope with side effects of cancer.

CT-guided core biopsy

A procedure that uses CT to guide the biopsy needle to an area to remove a sample.

CT scan

A computerised tomography scan. This scan uses x-rays to create a detailed, cross-sectional picture of the inside of the body.

cytoreductive surgery

Surgical removal of part of a malignant tumour that cannot be completely removed, so as to enhance the effectiveness of radiotherapy or chemotherapy.

debulking

Surgery to remove as much of a tumour as possible. This makes it easier to treat the cancer that is left and helps to increase the effectiveness of other treatments, such as chemotherapy.

diagnosis

The identification and naming of a person's disease.

diaphragm

A dome-like sheet of muscle that divides the chest cavity from the abdomen and is used in breathing.

EPIC

Early postoperative intraperitoneal chemotherapy – chemotherapy given soon after surgery as a single course and delivered directly into the abdomen through a thin tube. May be used after a peritonectomy.

epithelioid

A type of mesothelioma. The cells resemble normal mesothelial cells.

extrapleural pneumonectomy (EPP)

Surgery used for some people with pleural mesothelioma. It removes the affected lung, plus parts of the lining of the heart (pericardium), lining of the chest (parietal pleura) and diaphragm.

FDG-PET

A fluorodeoxyglucose-positron emission tomography scan. For this scan, a low-level radioactive drug called fluorodeoxyglucose (FDG) is injected into the body to show up areas of abnormal tissues.

genes

The microscopic units that determine how the body's cells grow and behave. Genes are found in every cell of the body and are inherited from both parents.

HIPEC

Heated intraoperative intraperitoneal chemotherapy – chemotherapy in which the drugs are heated and inserted directly into the abdomen for 60–90 minutes during a peritonectomy. Sometimes called “hot chemotherapy”.

induction chemotherapy

Chemotherapy given as the first treatment with the aim of making the next treatments (such as surgery or radiotherapy) more effective.

indwelling catheter

A thin tube inserted into either the pleural or peritoneal cavity to help drain a build-up of fluid. Sometimes called an indwelling drain.

intensity-modulated radiation therapy (IMRT)

A type of radiotherapy that can be accurately shaped around the chest cavity. This allows higher doses to be delivered to the tumour cells while reducing the damage to other organs.

laparoscopy

Surgery done through small cuts in the abdomen using a tiny telescope called a laparoscope for viewing.

latency period/interval

The interval between exposure to a cancer-causing material and the clinical appearance of disease.

lungs

The two spongy organs in the chest cavity, made up of large numbers of tiny air sacs. The lungs are used for breathing (respiration).

lymphatic system

A network of tissues, vessels, ducts and nodes that removes excess fluid from tissues, absorbs fatty acids and transports fat, and produces immune cells. Includes the bone marrow, spleen, thymus and lymph nodes.

lymph nodes

Small, bean-shaped glands that form part of the lymphatic system. Also called lymph glands.

malignant

Cancerous. Malignant cells can spread (metastasis) and eventually cause death if they cannot be treated.

mediastinoscopy

A surgical procedure that allows a surgeon to examine the lymph nodes at the centre of the chest and remove a sample, if necessary.

mediastinum

The area in the chest between the lungs. It contains the heart and large blood vessels, the oesophagus, the trachea and many lymph nodes.

medical oncologist

A doctor who specialises in treating cancer with drugs such as chemotherapy, immunotherapy and targeted therapy (systemic treatments).

mesothelial cells

The cells of the mesothelium.

mesothelioma

Cancer that starts in the mesothelial cells, which line parts of the body, such as the chest cavity or abdominal cavity. Sometimes called malignant mesothelioma.

mesothelium

A membrane that lines the chest cavity (pleura) and abdominal cavity (peritoneum) and surrounds the heart (pericardium).

metastasis

Cancer that has spread from a primary cancer in another part of the body. Also called secondary cancer.

mixed mesothelioma

A type of mesothelioma made up of both epithelioid and sarcomatoid cells. Sometimes known as biphasic mesothelioma.

multidisciplinary team (MDT)

A team of health professionals who collaborate to discuss a patient's physical and emotional needs and decide on treatment.

NIPEC

Normothermic intraperitoneal chemotherapy – chemotherapy given as a long-term course directly into the abdomen after a peritonectomy.

palliative care

The holistic care of people who have a life-limiting illness, their families and carers. It aims to maintain quality of life by addressing physical, practical, emotional, spiritual and social needs.

palliative treatment

Medical treatment for people with advanced cancer to help them manage pain and other symptoms.

parietal peritoneum

The peritoneum's outer layer that lines the walls of the abdomen and pelvis.

parietal pleura

The outer layer of the pleura that lines the chest wall and diaphragm.

PCI system

Peritoneal cancer index, a type of staging system indicating the extent of cancer in the peritoneal cavity.

pericardium

A thin, double-layered sac that surrounds the heart.

peritoneal cavity

The space between the two layers of peritoneum, which normally contains a small amount of fluid.

peritoneal effusion

See ascites.

peritoneal tap

A procedure using a needle to drain fluid from the abdomen. Also known as paracentesis.

peritonectomy

An operation to remove the parts of the peritoneum where the mesothelioma is growing. The aim is to completely remove the cancer.

peritoneum

The mesothelium (thin membrane) that lines the walls and organs of the abdomen and pelvis. It has two layers: parietal and visceral.

pleura

The mesothelium (thin membrane) that lines the chest wall and covers the lungs. It has two layers: parietal and visceral.

pleural cavity

The space between the two layers of pleura, which normally contains a small amount of fluid.

pleural effusion

A collection of excess fluid between the two layers of the pleura that cover the lungs.

pleural fluid

The fluid in the pleural cavity that allows the two layers of the pleura to slide over each other as you breathe. Mesothelioma can cause excess fluid to build up, see pleural effusion.

pleural plaque

An area of fibrous thickening on the pleura. It can be seen on x-rays of some people exposed to asbestos.

pleural tap

A procedure using a needle to drain fluid from around the lungs. Also known as pleurocentesis or thoracentesis.

pleural thickening

Extensive scarring that thickens the pleura. As the scar tissue grows, it can encase the lung and close off the pleural cavity. Also known as diffuse pleural thickening (DPT).

pleurectomy

Surgical procedure to remove part of the pleura.

pleurodesis

An injection of sterile talcum powder into the pleural cavity. This causes inflammation that closes the space and prevents fluid building up again.

precancerous

A term used to describe a condition that may or is likely to become cancer.

prognosis

The expected outcome of a person's disease.

pulmonary decortication

Surgical procedure to remove some of the lining of the chest wall and lung to allow the lung to re-expand.

radiation oncologist

A doctor who specialises in treating cancer with radiotherapy.

radical radiotherapy

High-dose radiotherapy aimed at destroying cancer cells that are likely to remain after surgery.

radical surgery

A type of extensive surgery that aims to remove the diseased organ or tumour as well as the blood supply, lymph nodes and, sometimes, attached structures.

radiotherapy

The use of radiation, such as x-rays, gamma rays, electron beams or protons, to kill cancer cells or injure them so they cannot grow and multiply. Also called radiation therapy.

sarcomatoid

A type of mesothelioma. The cells have a growth pattern resembling a malignant tumour arising from fibrous tissue.

second line chemotherapy

Chemotherapy that is given if standard chemotherapy doesn't work or the disease comes back.

staging

Performing tests to determine how far a cancer has spread.

systemic treatment

Treatment that affects the whole body.

thoracic

Relating to the chest (thorax).

thoracotomy

Surgery in which a long cut is made in the chest to examine, sample and/or remove a tumour.

tissue

A collection of cells of similar type that make up an organ or structure in the body.

TNM system

A type of staging system detailing the extent of the cancer. T stands for tumour, N stands for lymph node and M stands for metastasis.

trimodality therapy

The use of three different types of treatment: chemotherapy, surgery and radiotherapy.

tumour

A new or abnormal growth of tissue on or in the body. A tumour may be benign or malignant.

video-assisted thoracoscopic surgery (VATS)

A surgical procedure where a cut is made in the chest and a small video camera with a telescope called a thoracoscope is inserted. Sometimes called keyhole surgery.

visceral peritoneum

The inner layer of peritoneum that lines the surface of the organs in the abdomen and pelvis.

visceral pleura

The inner layer of pleura that lines the surface of the lungs.

Can't find a word here?

For more cancer-related words, visit:

- cancercouncil.com.au/words
- cancervic.org.au/glossary
- cancersa.org.au/glossary

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How you can help

At Cancer Council, we're dedicated to improving cancer control. As well as funding millions of dollars in cancer research every year, we advocate for the highest quality care for cancer patients and their families. We create cancer-smart communities by educating people about cancer, its prevention and early detection. We offer a range of practical and support services for people and families affected by cancer. All these programs would not be possible without community support, great and small.

Join a Cancer Council event: Join one of our community fundraising events such as Daffodil Day, Australia's Biggest Morning Tea, Relay For Life, Girls' Night In and Pink Ribbon Day, or hold your own fundraiser or become a volunteer.

Make a donation: Any gift, large or small, makes a meaningful contribution to our work in supporting people with cancer and their families now and in the future.

Buy Cancer Council sun protection products: Every purchase helps you prevent cancer and contribute financially to our goals.

Help us speak out for a cancer-smart community: We are a leading advocate for cancer prevention and improved patient services. You can help us speak out on important cancer issues and help us improve cancer awareness by living and promoting a cancer-smart lifestyle.

Join a research study: Cancer Council funds and carries out research investigating the causes, management, outcomes and impacts of different cancers. You may be able to join a study.

To find out more about how you, your family and friends can help, please call your local Cancer Council.



Cancer Council 13 11 20

Being diagnosed with cancer can be overwhelming. At Cancer Council, we understand it isn't just about the treatment or prognosis. Having cancer affects the way you live, work and think. It can also affect our most important relationships.

When disruption and change happen in our lives, talking to someone who understands can make a big difference. Cancer Council has been providing information and support to people affected by cancer for over 50 years.

Calling 13 11 20 gives you access to trustworthy information that is relevant to you. Our cancer nurses are available to answer your questions and link you to services in your area, such as transport, accommodation and home help. We can also help with other matters, such as legal and financial advice.

If you are finding it hard to navigate through the health care system, or just need someone to listen to your immediate concerns, call 13 11 20 and find out how we can support you, your family and friends.

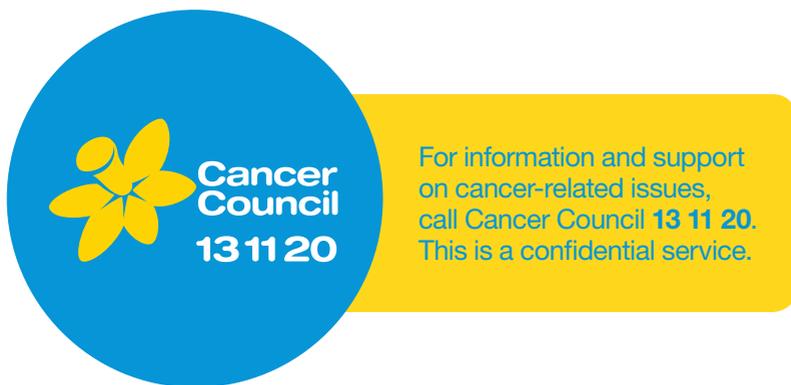
Cancer Council services and programs vary in each area.

13 11 20 is charged at a local call rate throughout Australia (except from mobiles).



If you need information in a language other than English, an interpreting service is available. Call 13 14 50.

If you are deaf, or have a hearing or speech impairment, you can contact us through the National Relay Service. www.relayservice.gov.au



Visit your local Cancer Council website

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