



Understanding Mesothelioma

A guide for people with cancer,
their families and friends

A blue circle containing the text "Cancer information". A thin orange line extends from the bottom of the circle, curving to the left and ending in a telephone handset icon.

Cancer
information

For information & support, call

13 11 20

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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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About this booklet

This booklet has been prepared to help you understand more about pleural mesothelioma and peritoneal mesothelioma. Many people feel shocked and upset when told they have mesothelioma. We hope this booklet will help you, your family and friends understand how mesothelioma is diagnosed and treated. We also include information about support services.

We cannot give advice about the best treatment for you. You need to discuss this with your doctors. However, this information may answer some of your questions and help you think about what to ask your treatment team (see page 74 for a question checklist).

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 (see page 75). You may also like to pass this booklet to 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 guidelines.¹

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. You can also visit your local Cancer Council website (see back cover).



**Cancer
Council**
13 11 20

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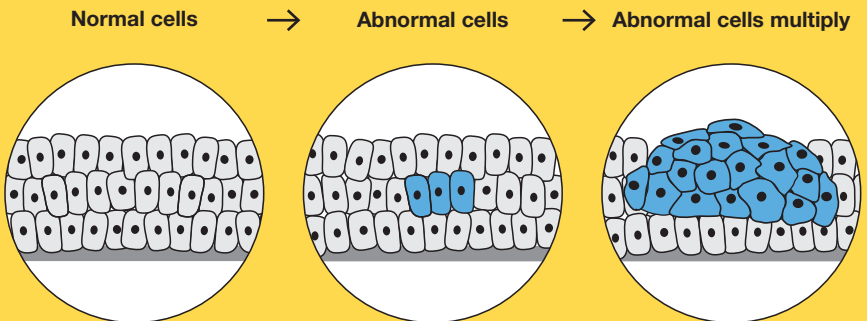
What is cancer?

Cancer is a disease of the cells. Cells are the body's basic building blocks – they make up tissues and organs. 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, so that each new cell replaces one lost. Sometimes, however, cells become abnormal and keep growing. In solid cancers, such as mesothelioma, the abnormal cells form a mass or lump called a tumour. In some cancers, such as leukaemia, the abnormal cells build up in the blood.

Not all tumours are cancer. Benign tumours tend to grow slowly and usually don't move into other parts of the body or turn into

How cancer starts

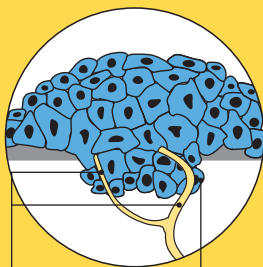


cancer. Cancerous tumours, also known as malignant tumours, have the potential to spread. They may invade nearby tissue, destroying normal cells. The cancer cells can break away and travel through the bloodstream or lymph vessels to other parts of the body.

The cancer that first develops is called the primary cancer. It is considered localised cancer if it has not spread to other parts of the body. If the primary cancer 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. For example, mesothelioma that has spread to the liver is called metastatic mesothelioma, even though the main symptoms may be coming from the liver.

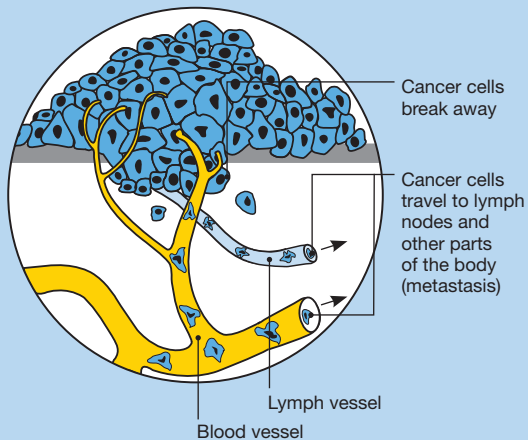
How cancer spreads

→ Malignant cancer



Grows own
blood vessels
(angiogenesis)

Invades
surrounding
tissue



Cancer cells
break away

Cancer cells
travel to lymph
nodes and
other parts of
the body
(metastasis)

Lymph vessel

Blood vessel



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, creating 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 each lung is called the pleura. Mesothelioma that develops in the pleura is known as malignant pleural mesothelioma or, simply, pleural mesothelioma. About 90% of all mesotheliomas are in the chest.

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 thin layers of tissue in the pleura. The inner layer (the visceral pleura) lines the lung surface, and the outer layer (the parietal pleura) lines the chest wall and diaphragm.

Between the two layers is the pleural cavity (also called the pleural space), which normally contains a thin film 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 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 known as 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. Less than 10% of all mesotheliomas are in the abdomen.

The peritoneum

There are two layers of thin tissue in the peritoneum. The inner layer (the visceral peritoneum) lines the surface of organs such as the bowel, liver and ovaries. The outer layer (the parietal peritoneum) lines the walls of the abdomen and pelvis.

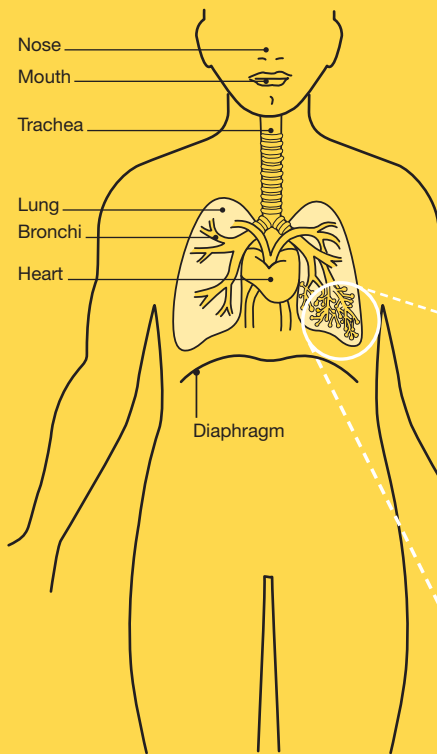
Between the two layers is the peritoneal cavity, which normally contains a thin film of fluid. This fluid allows the two layers to slide over each other as you move around. In people with peritoneal mesothelioma, excess fluid often collects between the two layers – this is known as ascites or peritoneal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



Rarely, mesothelioma occurs in the pericardium, the lining of 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.

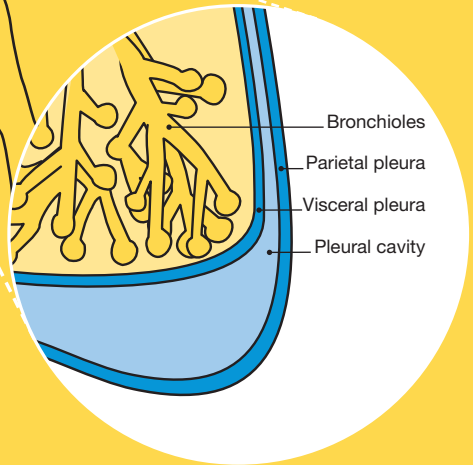
The pleura and the peritoneum

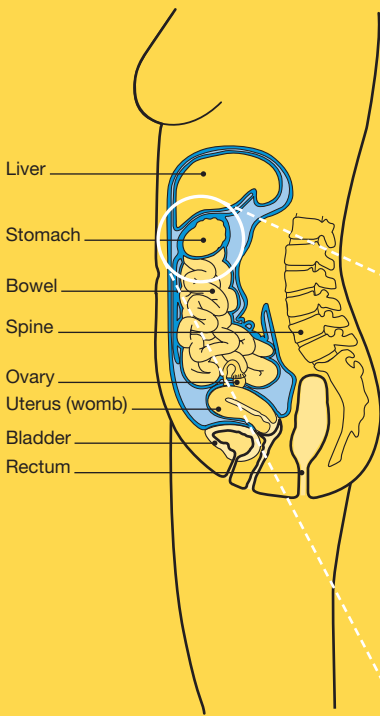
This booklet discusses pleural mesothelioma (lungs) and peritoneal mesothelioma (abdomen and pelvis). It is rare for mesothelioma to start in more than one area of the body.



The respiratory system

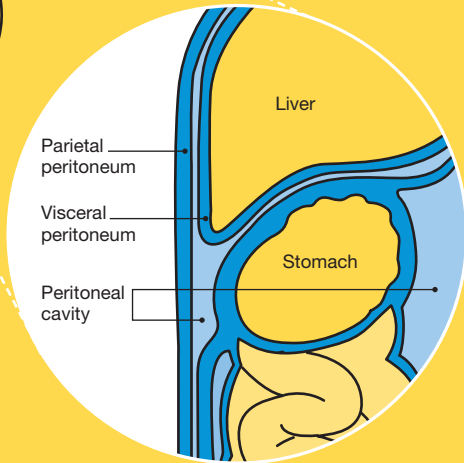
Pleural mesothelioma affects the pleura, the membrane that covers the lungs. The lungs are the main organs for breathing and are part of the respiratory system, along with the nose, mouth, windpipe (trachea), large airways (bronchi) and smaller airways (bronchioles). The lungs rest on the diaphragm,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





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 fibres or asbestos dust is the main cause of mesothelioma, but in some cases there is no clear link to asbestos.

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 banned asbestos being sold, reused and/or imported. Despite the ban, asbestos has been found in some products recently imported from overseas. It is still found in many older buildings, so special care needs to be taken when renovating.

People who may have been exposed to asbestos at work include: builders, plumbers and electricians; boilermakers and welders; asbestos miners; asbestos cement manufacturing workers; insulators; 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 because a case for compensation must be started within your lifetime. Mesothelioma or asbestos support groups may be able to help you. 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 757 Australians diagnosed in 2016.² Men are four times more likely than women to be diagnosed with mesothelioma, probably because many cases have been caused by exposure to asbestos at work.

Pleural mesothelioma makes up about 93% of all mesothelioma cases. Peritoneal mesothelioma is less common and makes up nearly 7% of cases. Mesothelioma is more common in people over the age of 65, but can occur in younger people.



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

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. Finding mesothelioma early will mean you have more treatment options.

Pleural mesothelioma may cause:

- shortness of breath (breathlessness), which usually feels worse with activity or when you are lying down
- pain in the chest around the ribs or in the shoulder, which may be sharp and stabbing, made worse by breathing in deeply, or dull and persistent
- extra sensitive skin or change in skin sensation
- general symptoms such as loss of appetite with weight loss; loss of muscle bulk; loss of energy; a persistent cough or a change in coughing pattern; and 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 (pages 16–26) – You will have various tests to confirm a diagnosis of mesothelioma and work out how far it has progressed. The results will help you and your health professionals make decisions about treatment.

Treatment (pages 29–39) – Depending on how advanced the mesothelioma is and other factors, treatment may achieve a longer period of disease control and improve quality of life.

Managing symptoms (pages 40–55) – For many people, the main goal of treatment will be to manage symptoms and improve quality of life. Depending on how mesothelioma affects your health, you may have periods of relatively good health when symptoms are under control or less active. You may also have periods when symptoms need to be relieved with more intensive treatment.

Q: Which health professionals will I see?

A: If mesothelioma is diagnosed, the specialist will consider treatment options. These are often discussed with other health professionals at what is known as a multidisciplinary team (MDT) meeting. Some people are diagnosed and treated in specialist centres in major cities around Australia. To find a specialist centre 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.

Health professionals you may see

GP	assists you with treatment decisions and works in partnership with your specialists in providing ongoing care
respiratory (thoracic) physician*	diagnoses diseases of the lungs, including pleural mesothelioma, and recommends ways to treat symptoms
gastroenterologist*	diagnoses and treats disorders of the digestive system, including peritoneal mesothelioma
radiologist*	analyses x-rays and scans; an interventional radiologist may also perform a biopsy under ultrasound or CT, and deliver some treatments
pathologist*	examines cells and tissue samples to work out the type and extent of mesothelioma
thoracic (respiratory) 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*	treats cancer with drug therapies such as chemotherapy, targeted therapy and immunotherapy (systemic treatment)
radiation oncologist*	treats cancer by prescribing and overseeing a course of radiation therapy

palliative care specialist*	treats pain and other symptoms to maximise wellbeing and improve quality of life
palliative care team	work closely with the GP and oncologist to help control symptoms such as pain, breathlessness, nausea and anxiety, and maintain quality of life
nurse	administers drugs and provides care, support and information throughout treatment
cancer care coordinator	coordinates your care, liaises with other members of the MDT and supports you and your family throughout treatment; care may also be coordinated by a clinical nurse consultant (CNC) or clinical nurse specialist (CNS)
community nurse	visits you at home to provide medical care and treatment, assesses your needs for supportive care, and liaises with your GP and MDT as required
dietitian	recommends an eating plan to follow while you are in treatment and recovery
physiotherapist, exercise physiologist, occupational therapist	assist with physical and practical problems, including restoring movement and mobility after treatment and recommending aids and equipment
social worker	links you to support services and helps you with emotional, practical and financial issues
psychologist	helps you manage your emotional response to diagnosis and treatment

**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 and even look like normal cells.

Diagnosing mesothelioma usually starts with a visit to 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 let your doctor know as many doctors won't automatically suspect mesothelioma. The doctor will send you for 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 several tests and see different health professionals (see pages 13–15) before a diagnosis of mesothelioma is made. The process may seem long and frustrating.

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 general health and let your doctors know how your blood cells, liver and kidneys are working. This helps them work out whether you're fit enough for treatment. Mesothelioma does not usually show up with a blood test, but results may show substances called markers that are produced by cancer cells.

X-ray

If your doctor thinks you have pleural mesothelioma, you will have a chest x-ray to look for any changes 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 changes in the abdomen, such as fluid and thickening in the peritoneum.

If fluid, thickening 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 on a CT scan (see next page).

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 tests and on any improvements in symptoms.

Some results are available within a few days, but others take several weeks. In some cases, you may need to have more tests before doctors are sure you

have mesothelioma. 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 also feeling anxious.

If you need support or want to learn more about what a mesothelioma diagnosis will mean for you, contact one of the support organisations listed on page 71 or call Cancer Council **13 11 20**.

CT scan

A CT (computerised tomography) scan uses x-rays and a computer to create a detailed picture of the inside of the body. Most people can go home as soon as the test is over.

Before the scan, you will be given a dye called contrast to make the pictures clearer. This is usually injected into a vein in your arm, but is sometimes given as a drink. The dye may make you feel hot all over and leave a strange taste in your mouth for a few minutes. You might also feel that you need to urinate, but this won't last long.

During the scan, you will need to lie still on a table that moves in and out of the CT scanner, which is large and round like a doughnut. The scan takes about 30 minutes. Although the test itself is painless, lying flat and still can be uncomfortable if you already have breathlessness or pain. Let your doctor know before the scan if you have claustrophobia, as the scanner is a confined space.

The CT scan shows 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 from the CT scan is used to work out the best way to get tissue for testing (see *Biopsy* opposite).



Before having scans, tell the doctor if you have any allergies or have had a reaction to dyes during previous scans. You should also let them know if you have diabetes or kidney disease or are pregnant.

Biopsy

A biopsy is the main test used to diagnose mesothelioma. It involves removing a sample of tissue, which is examined under a microscope by a specialist doctor called a pathologist. The pathologist looks for cell changes to work out if the tumour is mesothelioma and, if so, the type of mesothelioma cells present.

Mesothelioma is usually classified according to how the cells look under a microscope (although in about 27% of cases, the classification is unknown). There are three main types of mesothelioma cells:

Epithelioid – cells look similar to normal mesothelial cells. This is the most common type, making up about 70% of cases.

Sarcomatoid – cells have changed and look like cells from fibrous tissue. This type makes up about 10–15% of cases.

Mixed or biphasic – has epithelioid and sarcomatoid cells. This type makes up about 10–15% of all cases.

Ways to take a biopsy for mesothelioma

A biopsy can be taken in different ways. The choice of biopsy will depend on your general health and fitness, and how suitable the tumour is for sampling using one of the methods described on the next page. Keyhole surgery (VATS or laparoscopy) is the most common biopsy technique as both tissue samples and fluid can be removed for testing. However, obtaining a sample can be challenging, so a respiratory physician or gastroenterologist, radiologist, surgeon and pathologist may all be involved.

Video-assisted thoracoscopic surgery (VATS) – This is used to obtain a tissue sample from the lining of the lungs (pleura). You will be given a general anaesthetic, then a thin tube with a light and camera will be inserted through a few small cuts in your chest. Tissue samples can be taken through the tube and sent to a laboratory for testing. If fluid has built up around the lungs and is causing breathlessness, it can be drained during the VATS (see box opposite) and you may have a pleurodesis to prevent the fluid building up again (see page 43). After the VATS you'll need painkillers.

Laparoscopy – This is used to get a tissue sample from the lining of the abdomen (peritoneum). You will be given a general anaesthetic, then a thin tube with a light and camera will be inserted through small cuts made in your abdomen. Tissue samples can be removed through the tube and sent to a laboratory for testing. If fluid has built up in the abdomen, it can be drained during the laparoscopy. Any infections that develop will be treated with antibiotics.

CT-guided core biopsy – A CT-guided core biopsy may be used instead of VATS or laparoscopy when there is a large mass but no fluid. You will have a local anaesthetic to numb the area, and a hollow needle will be inserted through the skin to remove a thin core of tissue from the lining of the lungs or abdomen. 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 possible complications (such as bleeding or a collapsed lung).

Draining fluid

When you first have symptoms of mesothelioma, you are likely to have 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 make it swollen and uncomfortable.

Before suggesting further tests or treatment, your doctor may

drain the built up fluid to ease symptoms. 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 find out more, see page 43.

Draining the fluid may be done at the same time as VATS or laparoscopy.

Less commonly used tests

PET scan – The specialised PET or positron emission tomography scan is being used more often. It is available at some major hospitals and may not be covered by Medicare for mesothelioma. For the PET scan, a small amount of radioactive glucose solution will be injected into a vein, usually in your arm. You will need to sit quietly for 30–90 minutes while the solution travels through your body. Your whole body will then be scanned for raised levels of radioactive glucose. Cancer cells show up brighter on the scan pictures because they are more active and take up more of the glucose solution than normal cells do.

Special stains – To confirm a diagnosis of mesothelioma, the pathologist sometimes needs to do further tests on the tissue sample using special stains. These look for specific molecules that may help to tell mesothelioma apart from other types of cancer.

Diagnosis from fluid samples

Sometimes 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 hard to diagnose mesothelioma from fluid samples because abnormal mesothelioma cells can look similar to other cells.

Some specialist centres are experienced in diagnosing mesothelioma using fluid samples. To be accurate, this technique needs to be done at a specialist centre, a large volume of fluid must be collected, and the results have to be combined with information from an x-ray and CT scan. Using fluid samples for diagnosing mesothelioma may be useful if you are not well enough for a biopsy.



Sometimes, even after several tests, the doctors may be unsure of the diagnosis and some of the tests may need to be repeated.

Staging mesothelioma

After mesothelioma has been diagnosed, you will have further tests to work out the extent of the disease in the chest or abdomen and whether the disease has spread to other parts of the body and, if so, by how much and how far. This process is called staging. 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 that CT scan showed advanced disease, a further CT scan may not be necessary.

Staging systems for mesothelioma

Staging is a way to describe 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, adjacent ribs, lining of the heart or beyond, it is T2, T3 or T4.
N (node) 0–2	Describes if the pleural mesothelioma has spread to the lymph nodes. No lymph nodes affected is N0; spread only to lymph nodes in the chest is N1; spread to lymph nodes in the neck is N2.
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). The area of the abdomen and pelvis is divided into 13 regions. A score out of 3 is given to any tumours found in these regions. The PCI is calculated by adding together the scores for all 13 regions, 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 suitable treatment option (see pages 34–37), you may have other scans and procedures to check whether mesothelioma has spread to other areas of the body.

These may include the following:

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 a powerful magnet and radio waves to create detailed, cross-sectional pictures of the soft tissues in your body. The noisy, narrow machine makes some people feel anxious or claustrophobic. If you think you may become distressed, mention it beforehand to your medical team. You may be given a mild sedative to help you relax.

Endobronchial ultrasound (EBUS) – 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 identify lymph nodes for biopsy.

Surgical staging – Before radical surgery for pleural mesothelioma (see pages 34–36), if it's unclear from the PET scan whether mesothelioma has spread, the surgeon may remove a sample of lymph nodes and tissue from other areas of the body. Surgical staging is not recommended before a peritonectomy for peritoneal mesothelioma.

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 or longer.

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

- the type of mesothelioma cell (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 blood count – people with normal levels of blood cells 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 the outcome. 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 about diagnosing mesothelioma

Overview

Mesothelioma can be very difficult to diagnose since many other diseases have similar symptoms. You are likely to need several tests before a diagnosis can be confirmed. The most reliable tests are CT scan and a biopsy.

Main tests

- The preferred biopsy method to collect tissue samples from the lung is VATS.
- The preferred biopsy method to collect tissue samples from the abdomen is laparoscopy.
- Another method for both the lung and abdomen is CT-guided core biopsy.
- Sometimes it is difficult to diagnose mesothelioma even after a biopsy.

Other tests

- Fluid that has built up in the lungs or abdomen can be drained, either during a biopsy or as a separate procedure. A sample of this fluid can be tested for mesothelioma, but the results may not be reliable.
- 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 how far the cancer has spread (the stage).

Staging and prognosis

- The stage shows how far the mesothelioma has spread through the body.
- In general, earlier stages have a better prognosis (expected outcome). You may also wish to discuss the prognosis with your doctor.



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, or you might be anxious to get started. Check with your specialist how soon treatment should begin – often it won't affect the success of the treatment to wait a while. Ask them to explain the options, and take as much time as you can before making a decision.

Know your options – Understanding the disease, the available treatments, possible side effects and any extra costs can help you weigh up the options and make a well-informed decision. Check if the specialist is part of a multidisciplinary team (see pages 13–15) and if the treatment centre is the most appropriate one for you – you may be able to have treatment closer to home, or it might be worth travelling to a centre that specialises in a particular treatment.

Record the details – When your doctor first tells you that you have mesothelioma, you may not remember everything you are told. Taking notes or recording the discussion can help. It is a good idea to have a family member or friend go with you to appointments to join in the discussion, write notes or simply listen.

Ask questions – If you are confused or want to check anything, it is important to ask your specialist questions. Try to prepare a list before appointments (see page 74 for suggestions). If you have a lot of questions, you could talk to a cancer care coordinator or nurse.

Consider a second opinion – You may want to get a second opinion from another specialist to confirm or clarify your specialist's recommendations or reassure you that you have explored all of

your options. Specialists are used to people doing this. Your GP or specialist 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 your first doctor. You might decide you would prefer to be treated by the second specialist.

It's your decision – Adults have the right to accept or refuse any treatment that they are offered. For example, some people with advanced cancer choose treatment that has significant side effects even if it gives only a small benefit for a short period of time. Others decide to focus their treatment on quality of life. You may want to discuss your decision with the treatment team, GP, family and friends.

▶ See our *Cancer Care and Your Rights* booklet.

Should I join 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.

You may find it helpful to talk to your specialist, clinical trials nurse or GP, or to get a second opinion. If you decide to take part in a clinical trial, you can withdraw at any time. For more information, visit australiancancertrials.gov.au.

▶ See our *Understanding Clinical Trials and Research* booklet.

Treatment

A range of treatments are recommended for some people with mesothelioma. These aim to control the cancer and can include chemotherapy, radiation therapy or surgery, which may be used alone or in combination. The different types of mesothelioma are treated in different ways:

- pleural mesothelioma, see pages 30–36
- peritoneal mesothelioma, see pages 37–38.

Your specialist will discuss your treatment options with you, and these will depend on several 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 have treatment

The cancer treatments discussed in this chapter help control the disease for a longer period of time and improve quality of life for some people. It is important to talk to your treatment team about what each treatment involves, what side effects to expect and what recovery will be like.

While some treatments 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). You can also call Cancer Council 13 11 20 or talk to one of the mesothelioma support services listed on page 71.

Treatment for pleural mesothelioma

Chemotherapy

Chemotherapy uses drugs to kill or slow the growth of 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 improve quality of life and increase survival by a few months more than using a single drug.

The goals of chemotherapy are not only to increase length of life but also to shrink the cancer, reduce symptoms and improve quality of life. However, chemotherapy doesn't work for some people.

Having chemotherapy – 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 – Most chemotherapy drugs cause side effects. 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 pemetrexed and cisplatin chemotherapy. 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.

Common side effects of chemotherapy include:

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

Chemotherapy weakens the immune system by lowering the level of white blood cells, making it harder for your body to fight infections. 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, hair may thin. Some people have trouble thinking clearly or experience short-term memory loss after chemotherapy, but this usually improves once treatment ends.

- ▶ See our *Understanding Chemotherapy* booklet, *Understanding Changes in Thinking and Memory* fact sheet and brain fog podcast.

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 radiation therapy methods.

Clinical trials (see page 28) are testing promising new drugs called immunotherapy for treating mesothelioma. Immunotherapy slows the growth of cancer or kills cancer cells by altering the body's immune system response.

Immunotherapy does not work for most people with mesothelioma, but some people may have good results from this treatment.

Immunotherapy for mesothelioma is still experimental and available only through a clinical trial. In NSW, some people who have responded to chemotherapy may be able to get help paying for immunotherapy through icare Dust Diseases Care (see page 73). Talk to your specialist about whether immunotherapy is an option for you.

Radiation therapy

Also known as radiotherapy, radiation therapy is the use of targeted radiation to kill or damage cancer cells so they cannot grow, multiply or spread.

Radiation therapy may be used at different stages of pleural mesothelioma treatment and in different ways:

- as palliative treatment to relieve pain or other symptoms caused by tumours and improve quality of life
- after chemotherapy and surgery (adjuvant radiation therapy) to help kill any remaining cancer cells.

Having radiation therapy – 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 radiation therapy. Although the ink is permanent, the mark is only the size of a freckle.

Radiation therapy 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 radiation therapy – it might involve 1–10 sessions for up to two weeks for palliative treatment, or longer if radiation therapy is combined with other treatments with the aim of long-term control. Radiation therapy doesn't hurt and you aren't radioactive afterwards.

Side effects of radiation therapy – Radiation therapy 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 side effects of radiation therapy vary depending on the area of the body treated, but can include fatigue; peeling, cracked skin that looks red or sunburnt and may be uncomfortable; painful swallowing; or loss of hair in the treatment area.

Radiation therapy 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 radiation therapy are given to the chest area, it may cause permanent changes (fibrosis) in the lung tissue.

➤ See our *Understanding Radiation Therapy* booklet.

Trimodality therapy

Having a combination of chemotherapy, radical surgery and radical radiation therapy to treat mesothelioma is known as trimodality therapy. The aim of having the three types of treatment is to remove as much pleural mesothelioma as possible, and stop any remaining mesothelioma cells from growing or spreading. The most effective combination will depend on your situation.

Trimodality therapy is an intensive treatment. Despite reduced lung capacity afterwards, some people continue to live independently.

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

“ After I was diagnosed, I had chemotherapy for 10 months. Then I had my right lung removed. This surgery was followed by 30 treatments of radiation therapy. ” *Serafina*

The three parts of trimodality therapy

1. Chemotherapy

- Several cycles of chemotherapy are given to shrink the tumour.
- A scan then checks the size of the tumour. If it has been reduced, you'll have surgery in 4–6 weeks. If there is little or no response, you will not have radical surgery. Chemotherapy is usually given before surgery, but some people have chemotherapy after surgery.

2. Radical surgery

- This is either an extrapleural pneumonectomy (EPP) or pleurectomy decortication (PD). An EPP removes the whole lung, a PD keeps the lung but removes the outer lining of the pleura (parietal pleura) and any visible tumours. Sometimes a smaller operation removes only part of the parietal pleura. Lymph nodes in the centre of the chest that drain the lung are also removed.
- You'll stay in hospital for 10–14 days, or longer if complications occur. After 6–8 weeks you'll be able to start radiation therapy.

3. Radical radiation therapy

- This aims to treat any tumour cells that may still be present.
- Radiation therapy is delivered using intensity-modulated radiation therapy (IMRT). Because this type of radiation therapy can be accurately shaped around the chest cavity, higher doses can be delivered directly to the tumour cells while minimising the damage to other organs in the chest and abdomen.
- While IMRT is often given after surgery for up to six weeks, in some cases it is given before surgery for only one week. This shorter treatment is experimental, and your radiologist will decide how long you need radiation therapy depending on your circumstances.
- Radiation therapy may cause various side effects (see pages 33–34), but most get better after treatment ends.

Who can have trimodality therapy – Only a small number of people with pleural mesothelioma have trimodality therapy. It is suitable only 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 work out if trimodality therapy may be suitable for you 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 or PD is a major operation, and not everyone wants to go ahead after the risks and benefits of the therapy are explained by their treatment team.

When trimodality therapy is not suitable – Sometimes, despite a person appearing suitable for intensive treatment at first, the doctor may need to adjust the treatment plan or they may decide it is best 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.

Treatment for peritoneal mesothelioma

Surgery

It is possible for some people with peritoneal mesothelioma that has not spread to have an operation called a peritonectomy. The surgeon removes the parts of the peritoneum where the mesothelioma is growing. The amount of surgery needed will vary between people. Surgery is usually followed by chemotherapy (see next page).

Removing as much of the cancer as possible will help reduce symptoms such as abdominal pain and poor appetite. It will also 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 several factors, including your overall health and fitness, and whether the small bowel is cancer-free.

Only a small number of surgeons in Australia perform this surgery. It is recommended you seek an opinion from one of these surgeons if considering a peritonectomy. To find contact details, talk to your treatment team or contact a mesothelioma support organisation (see page 71).

Radiation therapy is rarely used for peritoneal mesothelioma as the doses required to the whole abdomen would cause too much damage to surrounding organs. However, it can be used for localised symptoms.



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 30–31 for more information).

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

- **HIPEC** – Heated intraoperative intraperitoneal chemotherapy (HIPEC) is known as “heated chemotherapy”. It involves heating the drugs to 42.5°C and inserting the solution 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 about treatment

Overview

The type of treatment you have will depend on the location, stage and type of mesothelioma, as well as your age, health and fitness. It may include chemotherapy, radiation therapy or surgery. Clinical trials are testing immunotherapy drugs.

Pleural mesothelioma

- The chemotherapy drugs used include pemetrexed together with cisplatin or carboplatin.
- Radiation therapy may be used at different stages of pleural mesothelioma and in different ways. It may be used to relieve pain, or given after chemotherapy and surgery to kill any remaining cancer cells.
- Some people with pleural mesothelioma may be offered trimodality therapy, which is a combination of chemotherapy, major surgery and radiation therapy. Surgery may include an extrapleural pneumonectomy (EPP) or a pleurectomy decortication (PD).

Peritoneal mesothelioma

- Some people with peritoneal mesothelioma have surgery to remove as much cancer as possible. This is known as a peritonectomy.
- Chemotherapy for peritoneal mesothelioma may be systemic (given into the bloodstream) or intraperitoneal (given directly into the abdomen). Intraperitoneal chemotherapy can be given in several ways, but often involves the chemotherapy being heated (HIPEC).



Managing symptoms

For many people, mesothelioma is diagnosed at an advanced stage, and the main aim of treatment is to manage symptoms and keep them under control for as long as possible. Treating symptoms will help improve your quality of life. Treatment may slow tumour growth and make you feel better and help you live longer. This is called palliative treatment.

Palliative treatment aims to manage the symptoms without trying to cure the disease. It can be used at any stage of advanced cancer to improve quality of life. It does not mean giving up hope – rather it is about living as fully and comfortably as possible. Early palliative care is sometimes also called supportive care. A palliative care specialist can help manage symptoms that affect your quality of life.

This chapter describes treatments and strategies for managing some common symptoms of mesothelioma such as fatigue, breathlessness, pain, difficulty sleeping, weight loss and constipation. As you may be experiencing several symptoms, you may have a combination of treatments. Keep in mind, however, that you won't necessarily experience all the symptoms listed here.

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

“ There's treatments, but there's no cure. It just gives people a bit more time. At the moment I feel fine. I have my ups and downs and get tired. ” *Serafina*

Fatigue

It is common to feel tired during and after treatment, and to lack energy for day-to-day activities. Fatigue for people with cancer is different from tiredness, as it may not 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.

If fatigue is a problem, talk to your treatment team. Sometimes fatigue can be caused by a low red blood cell count (anaemia) 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 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.
- See our *Fatigue and Cancer* fact sheet and listen to the “Managing Cancer Fatigue” episode of our podcast.

Breathlessness

Shortness of breath, also called breathlessness or dyspnoea, is the most common symptom of pleural mesothelioma. This is often caused by a build-up of fluid in the pleural cavity known as a pleural effusion. The fluid can put pressure on the lung, making it harder to breathe.

In the earlier stages of pleural mesothelioma, controlling this fluid build-up will improve breathlessness. The level of improvement will depend on the health of your lungs before diagnosis, and how well they function after surgery. You may also feel breathless because of the cancer itself not allowing the lung to work properly (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.

Other problems such as infection or a low level of red blood cells (anaemia) can also cause breathlessness.

Although living with breathlessness can be difficult, there are ways to reduce its impact on your life and manage the condition at home (see pages 46–47).



For an overview of what to expect during your care for mesothelioma, visit cancerpathways.org.au. You will find short guides to what is recommended for both pleural and peritoneal mesothelioma, from diagnosis to treatment and beyond.

Ways to drain fluid around the lungs or abdomen

Fluid build-up around the lungs or abdomen may be drained before mesothelioma is diagnosed or at the same time as the biopsy.

Pleural tap – In pleural mesothelioma, a pleural tap (also known as pleurocentesis or thoracentesis) drains fluid from around the lungs. Your doctor will numb the area with a local anaesthetic and insert a needle between your ribs into the pleural cavity. An ultrasound scan may guide the needle to the fluid. The needle is connected to a bag for the fluid to drain into. This may take about 30–60 minutes. You usually don't have to stay overnight after a pleural tap.

Peritoneal tap – In peritoneal mesothelioma, a peritoneal tap (also known as paracentesis) drains fluid from the abdomen. Your doctor will numb the area with a local anaesthetic into the abdomen and insert a needle through the skin into the peritoneal cavity. An ultrasound may guide the needle to the fluid. The needle is connected to a bag for the fluid to drain into. It takes a few hours for all the fluid to collect into a drainage bag. A peritoneal tap may be done while you are still having tests. You usually don't have to stay overnight after a peritoneal tap.

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. Pleurodesis means closing the pleural cavity.

Sterile talcum powder (talc slurry) is inserted into the pleural cavity, and the talc slurry causes an inflammation that helps fuse the two

layers of the pleura together and closes the space. A talc pleurodesis is best done during VATS (see page 20) by a cardiothoracic surgeon, but is sometimes done by a respiratory physician.

After a talc pleurodesis, some people experience a burning pain in the chest for 24–48 hours. This pain can be eased with medicine and you will be able to have physiotherapy to improve lung expansion.

VATS with pleurectomy decortication – When fluid is drained and talc pleurodesis is done during VATS, part or all of the outer layer of the pleura (parietal pleura) is removed. This is known as pleurectomy decortication or PD. This may be done when the parietal pleura, which lines the chest wall, has become thick and inelastic.

Open surgery (thoracotomy) with pleurectomy decortication – Even after VATS and talc pleurodesis, the fluid may build-up around the lungs again, causing breathlessness. The surgeon may suggest more extensive surgery called thoracotomy with pleurectomy decortication (PD). 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.

A thoracotomy 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. Instead, you may be offered an indwelling pleural catheter (also known as a drain) to remove the fluid and improve your breathing. This can also be used if the pleural fluid builds up again after pleurodesis.

Under local anaesthetic, the specialist inserts 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 the fluid builds up and needs to be drained (usually once or twice a week), the end of the catheter is 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 into a bottle. This is known as an indwelling peritoneal catheter or drain and is managed similarly to an indwelling pleural catheter (see above).

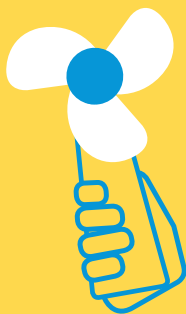
Heated chemotherapy – To control ascites, your doctor may suggest a single dose of heated chemotherapy directly into the abdomen (HIPEC, see page 38). This can be given during laparoscopy (see page 20), and there is some evidence that it can help prevent fluid building up again.

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.

Create a breeze

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



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.



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 you can listen to the recordings online.

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.



Sleep in a chair

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





Relax on a pillow

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



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.

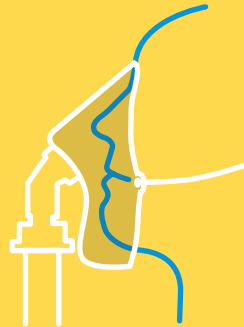
Modify your movement

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.



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.



Pain

Many people are naturally worried about being in pain. It's important to tell your treatment team if you are in pain. Pain may 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.

There are several different ways to control pain:

Pain medicines – Different types and strengths of pain medicines may be used:

- mild, like paracetamol
- moderate, like codeine
- 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. Many people need a combination of medicines to achieve good pain control.

Opioids, such as morphine or oxycodone, are the most common drugs used to control moderate to severe mesothelioma 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 trying other options.



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 and for any 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 or oxycodone.
- Adjusting the dose may help, or you can try other methods of pain relief.
- Ask your doctor if you need a laxative or stool softener prescribed to prevent or relieve constipation caused by 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.
 - Ask your doctors to regularly review your pain management plan.
 - See our *Overcoming Cancer Pain* booklet and listen to our podcast episodes on pain.

A small number of people have difficulty controlling their pain and a pain management specialist may need to consider several different medicines to find a suitable combination.

Procedures to manage fluid build-up – Aside from breathlessness, fluid build-up around the lungs or abdomen can cause pain. Various treatments can help drain the fluid and try to prevent it building up again. These are described on pages 42–45.

Radiation therapy – This may be used to shrink mesothelioma that is pressing on 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. Radiation therapy can reduce the size of the lump and ease any associated pain. See pages 32–34 for more information about radiation therapy.

Chemotherapy – This can reduce the size of the mesothelioma that is causing the pain. See pages 30–31 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. Talk to your doctor for more information.

“ I could not believe how much better I felt after taking some pain relief. Everything seemed less stressful and I did not feel so angry and upset all the time. ” *Bill*

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 you may need medicines to help you sleep. Other strategies that may be helpful are listed 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 or exercise physiologist, who can tailor an exercise program, and an occupational therapist, who can suggest equipment to help you move safely. See our *Exercise for People Living with Cancer* booklet.
- Limit or cut out the use of alcohol, caffeine, nicotine and spicy food.
- Avoid using technology, such as television, computers or smartphones, before bed, as the light tells your body it's time to wake up.
- Follow a regular routine before bed and set up a calm sleeping environment. Ensure the room is dark, quiet and a cool temperature.
- Try listening to soothing music, a recording of rain sounds, or a relaxation recording. Listen to our "Sleep and Cancer" podcast episode for more tips.

Lack of appetite and weight loss

Some people have little interest 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 (see page 56).

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 affect 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

- Have small meals and snacks regularly. A large, full plate may put you off eating – try using a smaller plate with smaller portions. Likewise, drink from a half-full glass.
- 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.
- Avoid fatty or sugary foods if these make you feel sick.
- Use lemon juice and herbs to add flavour to bland food.
- Eat more of your favourite foods – follow your cravings.
- If solid food doesn't appeal, ask a dietitian about protein drinks or other supplements.
- See our *Nutrition and Cancer* booklet and listen to our "Appetite Loss and Nausea" podcast episode.

Constipation

Having infrequent or difficult-to-pass bowel motions is known as constipation. Common causes include lack of exercise, eating less fibre, or not drinking enough fluids. Opioid medicines, some anti-nausea medicines and some chemotherapy drugs also cause constipation.

Severe constipation plus abdominal pain, bloating, nausea and vomiting may be signs of a blockage in the bowel (bowel obstruction). This occasionally happens with peritoneal mesothelioma, but rarely with pleural mesothelioma. To relieve the symptoms, you may have a small tube (stent) put in to help keep the bowel open. If the bowel is completely blocked, it needs to be cleared with emergency surgery.



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 be physically active every day. Talk to your doctor or physiotherapist to find the exercise that is right for you.
- Ask your doctor how to manage constipation. You may be prescribed medicines to help control symptoms.
- 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.
- Talk to your treatment team about how to manage bowel obstruction (described above). If your stomach is swollen and you are in pain, call **000** as it may be an emergency.

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 your health providers aim to meet your physical, emotional, cultural, social and spiritual needs. Palliative care also provides support to families and carers.

Contacting a specialist palliative care service 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 service can become involved at any time.

Ask the doctor in charge of your medical care about a referral to a specialist palliative care service.

- ▶ See our *Understanding Palliative Care* and *Living with Advanced Cancer* booklets.

“ 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



Key points about symptom management

Overview

Most people have treatment to control the symptoms of mesothelioma and improve their quality of life.

Main symptom

- Breathlessness caused by fluid build-up around the lungs 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.
- Breathlessness caused by fluid build-up in the abdomen (ascites) is a common symptom of peritoneal mesothelioma. It can be controlled with an indwelling peritoneal catheter or heated chemotherapy.
- Other ways to improve breathlessness include using a fan, leaning forward on a table over a pillow or sleeping in a recliner chair.

Other symptoms

- Manage fatigue by setting small goals for the day, and resting before you get too tired.
- Strong pain is often treated with opioid-based drugs such as morphine. In some cases, radiation therapy, chemotherapy or surgery can be used to manage pain.
- Try to drink plenty of fluids and eat fresh fruit and vegetables to ease constipation.
- Palliative treatment helps to improve a person's quality of life by managing symptoms. It's best to start it early.



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, including fear, sadness, anxiety, anger, frustration, and loss and grief.

Because mesothelioma is often diagnosed at an advanced stage, treatment may be ongoing and it may be hard to accept that life won't return to normal. Cancer Council 13 11 20 can help you connect with other people with a similar diagnosis, and provide you with information about managing the emotional and practical impacts.

- ▶ See our *Emotions and Cancer* booklet, and information about compensation claims for asbestos exposure, pages 62–67.

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 had cancer.

Talk to your GP, as counselling or medicine – even for a short time – may help. Some people

can get a Medicare rebate for sessions with a psychologist. Ask your doctor if you are eligible. Cancer Council may also run a counselling program in your area.

For information about coping with depression and anxiety, call Beyond Blue on **1300 22 4636** or visit beyondblue.org.au. For 24-hour crisis support, call Lifeline **13 11 14** or visit lifeline.org.au.

Looking after yourself

Dealing with cancer can cause physical and emotional strain, so it's important to look after your wellbeing. Cancer Council has free booklets and programs to help you during and after treatment. To find out more, call 13 11 20, or visit your local Cancer Council website.

Eating well – Healthy food can help you cope with treatment and side effects. A dietitian can explain how to manage any special dietary needs or eating problems and choose the best foods for your situation.


➤ See our *Nutrition and Cancer* booklet.

Staying active – Physical activity can reduce tiredness, improve circulation and lift mood. The right exercise for you depends on what you are used to, how you feel, and your doctor's advice.

➤ See our *Exercise for People Living with Cancer* booklet.

Complementary therapies – Complementary therapies are designed to be used alongside conventional medical treatments. Therapies such as massage, relaxation and acupuncture can increase your sense of control, decrease stress and anxiety, and improve your mood. Let your doctor know about any therapies you are using or thinking about trying, as some may not be safe or evidence-based.

➤ See our *Understanding Complementary Therapies* booklet.



Alternative therapies are therapies used instead of conventional medical treatments. These are unlikely to be scientifically tested and may prevent successful treatment of the cancer. Cancer Council does not recommend the use of alternative therapies as a cancer treatment.

Work and money – Cancer can change your financial situation, especially if you have extra medical expenses or need to stop working. Getting professional financial advice and talking to your employer can give you peace of mind. You can also check with a social worker or Cancer Council whether any financial assistance is available to you.

➤ See our *Cancer and Your Finances* and *Cancer, Work & You* booklets.

Relationships – Having cancer can affect your relationships with family, friends and colleagues in different ways. Cancer is stressful, tiring and upsetting, and this may strain relationships. It may also result in positive changes to your values, priorities or outlook on life. Give yourself time to adjust to what's happening, and do the same for those around you. It may help to discuss your feelings with each other.

➤ See our *Emotions and Cancer* booklet.

Sexuality – 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.

➤ See our *Sexuality, Intimacy and Cancer* booklet.

Contraception and fertility – If you can have sex, you may need to use certain types of contraception to protect your partner or avoid pregnancy for a time. Your doctor will explain what 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.

➤ See our *Fertility and Cancer* booklet.

Ongoing management

As management of symptoms 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. At your check-ups, you will also be able to discuss how you're feeling and mention any concerns you may have.

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.

Between appointments, if you notice any change in your symptoms 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 comes back?

For nearly every person with mesothelioma, the disease will come back even if it has initially responded well to treatment. This is known as disease progression or recurrence. How long this takes is different for each person.

When mesothelioma comes back, you and your doctor will need to consider what treatment to have and how to control symptoms. Treatment options will depend on the symptoms you are experiencing. Palliative care can help reduce symptoms either alone or in combination with any of the following:

- radiation therapy to reduce the size of the regrowth and pain
- further chemotherapy or immunotherapy
- further surgery
- participating in a clinical trial that is testing new drugs.

Palliative treatment for mesothelioma can be offered alone or in combination with surgery, chemotherapy and radiation therapy.

- See page 54 and our *Understanding Palliative Care* and *Living with Advanced Cancer* booklets.

At some point, you may decide to stop treatment and focus on managing symptoms and maximising quality of life.

- See our *Facing End of Life* booklet for information about the physical, emotional, spiritual and practical aspects of living with end-stage cancer.

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 various 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 feel it is more important to 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.

“ I think more than anything else, I have learnt how important it is to have hope. Without hope there really is nothing. ” *Serafina*



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 you may have been exposed to asbestos some 40 years ago. You might think it was a minor exposure, or you may not remember any exposure. Talking to your friends and family can help to recall 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 get 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.

If you'd like to make a claim, it's important 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 information about how and where asbestos was used.

Talking to an experienced lawyer 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.

The support organisations listed on page 71 can also help you find a lawyer experienced in dealing with asbestos cases. The Law Societies in each state and territory have “find a lawyer” search on their websites. Search the internet for the Law Society in your state or territory.

How long will a common law case take?

The majority of common law claims for mesothelioma are settled out of court through a process called mediation. This often happens 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 generally depend 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 not continue with 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 during their employment. Contact the relevant organisations below for more information.

State and territory compensation schemes	
Australian Capital Territory	Default Insurance Fund 02 6207 0723 apps.treasury.act.gov.au/insurance-and-risk-management/default-insurance-fund
New South Wales	Dust Diseases Care 1800 550 027 icare.nsw.gov.au
Northern Territory	NT WorkSafe 1800 250 713 worksafe.nt.gov.au
Queensland	WorkCover Queensland 1300 362 128 worksafe.qld.gov.au
South Australia	ReturnToWorkSA 13 18 55 rtwsa.com
Tasmania	WorkSafe Tasmania 1300 366 322 worksafe.tas.gov.au
Victoria	WorkSafe Victoria 1800 136 089 worksafe.vic.gov.au
Western Australia	WorkCover WA 1300 794 744 workcover.wa.gov.au
Commonwealth	Comcare 1300 366 979 comcare.gov.au

Do I need a lawyer?

You, and sometimes your dependants, can 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.

Advance care planning

It is 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 can legally appoint someone to make decisions for you if you lose the capacity to make your own decisions. 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 a medical treatment decision

maker. You can also outline your treatment goals and preferences for future medical care in an advance care directive. These documents are part of advance care planning.

Cancer Council's Pro Bono Program may be able to refer you to a lawyer for help with wills and advance care planning. Call **13 11 20** to find out what services are available in your area and whether you are eligible for this assistance.



Caring for someone with mesothelioma

You may be reading this booklet because you are caring for someone with mesothelioma. What this means for you will vary depending on the situation. Being a carer can bring a sense of satisfaction, but it can also be challenging and stressful.

It is important to look after your own physical and emotional wellbeing. Give yourself some time out and share your concerns with somebody neutral such as a counsellor or your doctor, or try calling Cancer Council 13 11 20. There is a wide range of support available to help you with both the practical and emotional aspects of your caring role.

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

Support groups and programs – Many cancer support groups and cancer education programs are open to carers as well as to people with cancer. Support groups and programs offer the chance to share experiences and ways of coping. You can find a list of mesothelioma support organisations on page 71.

Carers Associations – Carers Australia works with the Carers Associations in each state and territory to provide information and services to carers. Call 1800 242 636 or visit carersaustralia.com.au.

Cancer Council – You can call Cancer Council 13 11 20 or visit your local Cancer Council website to find out more about carers' services.

➤ See our *Caring for Someone with Cancer* booklet.



Support and information

Mesothelioma can affect every aspect of your life, and create practical and financial issues. There are many sources of support and information to help you, your family and carers navigate all stages of the cancer experience, including:

- information about mesothelioma and its treatment
- access to benefits and programs to ease the financial impact of cancer treatment
- home care services, such as Meals on Wheels, visiting nurses and home help
- aids and appliances
- mesothelioma support organisations and programs (see page 71)
- counselling services.

The availability of services may vary depending on where you live, and some services will be free but others might have a cost.

To find good sources of support and information, you can talk to the social worker or nurse at your hospital or treatment centre, or get in touch with Cancer Council 13 11 20.

“ My family members don't really understand what it's like to have cancer thrown at you, but in my support group, I don't feel like I have to explain. ” Sam

Support from Cancer Council

Cancer Council offers a range of services to support people affected by cancer, their families and friends. Services may vary depending on where you live.

Cancer Council 13 11 20

Trained professionals will answer any questions you have about your situation and link you to services in your area (see inside back cover).



Information resources

Cancer Council produces booklets and fact sheets on over 25 types of cancer, as well as treatments, emotional and practical issues, and recovery. Call **13 11 20** or visit your local Cancer Council website (see back cover).

Practical help

Your local Cancer Council can help you find services or offer guidance to manage the practical impact of a cancer diagnosis. This may include access to transport and accommodation services.



Legal and financial support

If you need advice on legal or financial issues, we can refer you to qualified professionals. These services are free for people who can't afford to pay. Financial assistance may also be available. Call Cancer Council **13 11 20** to ask if you are eligible.

Peer support services

You might find it helpful to share your thoughts and experiences with other people affected by cancer. Cancer Council can link you with individuals or support groups by phone, in person, or online. Call **13 11 20** or visit cancercouncil.com.au/OC.



Mesothelioma support in Australia

Bernie Banton Foundation	berniebantton.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 or 08 8241 7297 adssa-inc.com.au
Asbestos Victims Association of South Australia (AVA)	08 8212 6008 or 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	asbestoswise.com.au
Western Australia	
Asbestos Diseases Society of Australia (ADSA)	1800 646 690 asbestosdiseases.org.au
Reflections Through Reality	reflections.org.au

Other useful websites

You can find many useful resources online, but not all websites are reliable. These websites are good sources of support and information.

Australian

Cancer information	
Cancer Council Australia	cancer.org.au
Cancer Council Online Community	cancercouncil.com.au/OC
<i>The Thing About Cancer</i> podcast	cancercouncil.com.au/podcasts
Optimal Care Pathways	cancerpathways.org.au
Cancer Australia	canceraustralia.gov.au
eviQ	eviq.org.au
Carer services	
Carers Australia	carersaustralia.com.au
Carer Gateway	carergateway.gov.au
Young Carers Network	youngcarers.net.au
Clinical trials	
Australian Cancer Trials	australiancancertrials.gov.au
Counselling	
Beyond Blue	beyondblue.com.au
Financial assistance	
Department of Human Services	humanservices.gov.au

Patient travel assistance schemes	wiki.cancer.org.au/policy/Patient_travel_assistance_schemes
General	
Department of Health	health.gov.au
Healthdirect Australia	healthdirect.gov.au
My Aged Care	myagedcare.gov.au
Mesothelioma-related	
Asbestos Safety and Eradication Agency	asbestossafety.gov.au
Australian Asbestos Network	australianasbestosnetwork.org.au
Australian Mesothelioma Registry	mesothelioma-australia.com
Palliative care	
CareSearch	www.caresearch.com.au
Palliative Care Australia	palliativecare.org.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



Question checklist

Asking your doctor questions will help you make an informed choice. You may want to include some of the questions below in your own list.

Diagnosis

- What type of mesothelioma do I have?
- Has the mesothelioma spread? How fast is it growing?
- Are the latest tests and treatments for mesothelioma available in this hospital? Will a multidisciplinary team be involved in my care?
- Are there clinical guidelines for this type of cancer?

Treatment

- What treatment do you recommend? What is the aim of the treatment?
- Are there other treatment choices for me? If not, why not?
- If I don't have the treatment, what should I expect?
- How long do I have to make a decision?
- I'm thinking of getting a second opinion. Can you recommend anyone?
- How long will treatment take? Will I have to stay in hospital?
- Are there any out-of-pocket expenses not covered by Medicare or my private health cover? Can the cost be reduced if I can't afford it?
- How will we know if the treatment is working?
- Are there any clinical trials or research studies I could join?

Side effects

- What are the risks and possible side effects of each treatment?
- Will I have a lot of pain? What will be done about this?
- Can I work, drive and do my normal activities while having treatment?
- Will the treatment affect my sex life and fertility?
- Are there any complementary therapies that might help me?

Support

- Who can I call if I'm worried between my appointments?
- Will others in my family also be at risk of mesothelioma?
- Can I claim compensation for the illness? Who do I contact about this?



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 the main treatment to enhance the main treatment's 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).

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 a 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

Diseases caused by inhaling asbestos fibres. Includes lung cancer and mesothelioma as well as non-cancerous disorders such as asbestosis, pleural thickening, pleural plaques, pleural effusion and rounded atelectasis.

ascites

Collection of fluid between the two layers of tissue that line the abdomen and pelvis, making the abdomen swollen and bloated. Also known as peritoneal effusion.

benign

Not cancerous or malignant.

biopsy

The removal of a sample of tissue 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.

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 to kill cancer cells or slow their growth.

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 approaches to prevention, screening, diagnosis or treatment, to see if they are better than current approaches.

CT-guided core biopsy

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

CT scan

Computerised tomography scan. This scan uses x-rays to create a detailed cross-sectional picture of the body.

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 radiation therapy or chemotherapy.

decortication

Surgical removal of any tumours from the surface of the lung, chest wall and diaphragm to allow the lung to re-expand.

diaphragm

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

early postoperative intraperitoneal chemotherapy (EPIC)

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)

This surgery removes the affected lung, plus parts of the lining of the heart (pericardium), lining of the chest (parietal pleura) and diaphragm.

FDG-PET

Fluorodeoxyglucose-positron emission tomography scan. A person is injected with a low level radioactive drug (fluorodeoxyglucose or FDG) that helps show up cancer cells. When combined with a PET scan, it is called an FDG-PET.

genes

The microscopic units that determine how the body's cells grow and behave.

heated intraoperative intraperitoneal chemotherapy (HIPEC)

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

immunotherapy

Treatment that uses the body's own immune system to fight cancer.

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 radiation therapy that can be accurately shaped around the chest cavity. This allows higher doses to be delivered directly to the tumour cells while reducing the damage to other organs.

laparoscopy

Surgery done through small cuts in the abdomen using a thin viewing instrument called a laparoscope.

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. The lungs are made up of many tiny air sacs and are used for breathing. They are part of the respiratory system.

lymphatic system

A network of tissues, capillaries, vessels, ducts and nodes that removes excess

fluid from tissues, absorbs fatty acids, transports fat, and produces immune cells. Includes the bone marrow, spleen, thymus and lymph nodes.

lymph nodes

Small, bean-shaped structures that collect and destroy bacteria and viruses. Also called lymph glands.

malignant

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

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.

mesothelial cells

The cells of the mesothelium.

mesothelioma

See pleural mesothelioma and peritoneal mesothelioma.

mesothelium

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

metastasis (plural: metastases)

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

mixed mesothelioma

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

normothermic intraperitoneal chemotherapy (NIPEC)

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, emotional, cultural, spiritual and social needs. Also known as supportive care.

palliative treatment

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

parietal peritoneum

The outer layer of the peritoneum 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. Assesses the extent of cancer in the peritoneal cavity.

pericardium

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

peritoneal cavity

The space between the layers of the peritoneum; normally contains a small amount of fluid.

peritoneal effusion

See ascites.

peritoneal mesothelioma

Cancer that affects the layers of tissue that line the walls and organs of the abdomen and pelvis (the peritoneum).

peritoneal tap

A procedure that uses 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 sheet of tissue) that lines the walls and organs of the abdomen and pelvis. It has two layers: parietal and visceral.

PET scan

Positron emission tomography scan. A scan in which the person is injected with a small amount of radioactive glucose solution to find cancerous areas.

pleura

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

pleural cavity (pleural space)

The space between the layers of the pleura; normally contains a thin film of fluid.

pleural effusion

A collection of excess fluid between the two layers of tissue 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 mesothelioma

Cancer that affects the layers of tissue that cover the lungs (the pleura).

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 in which a hollow needle is inserted between the ribs to drain excess fluid. Also called thoracentesis.

pleural thickening

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

This surgery removes part of the pleura. When combined with decortication it is known as pleurectomy decortication (PD).

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.

radiation therapy

The use of targeted radiation to kill or damage cancer cells so they cannot grow, multiply or spread. The radiation is usually in the form of x-ray beams. Also called radiotherapy.

radical radiation therapy

High-dose radiation therapy 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.

sarcomatoid

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

staging

Performing tests to work out how far a cancer has spread.

systemic treatment

Cancer drugs that spread throughout the whole body. Includes chemotherapy, targeted therapy and immunotherapy.

targeted therapy

Drugs that attack specific particles (molecules) within cells that allow cancer to grow and spread.

thoracic

Relating to the chest (thorax).

thoracotomy

Surgery in which a long cut is made in the chest to examine, biopsy 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 that describes how far the cancer has spread. 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 radiation therapy.

tumour

A new or abnormal growth of tissue on or in the body. A tumour may be benign (not cancer) or malignant (cancer).

video-assisted thoracoscopic surgery (VATS)

Keyhole surgery performed through small cuts in the chest using a small video camera with a viewing instrument (thoracoscope) for guidance.

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 lung surface.

Can't find a word here?

For more cancer-related words, visit:

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

References

1. Organising Committee, *Guidelines for the Diagnosis and Treatment of Malignant Pleural Mesothelioma*, Asbestos Diseases Research Institute, Sydney, 2013.
2. Australian Institute of Health and Welfare, *Mesothelioma in Australia 2017*, AIHW, Canberra, 2018.



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 other Pink events, 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.

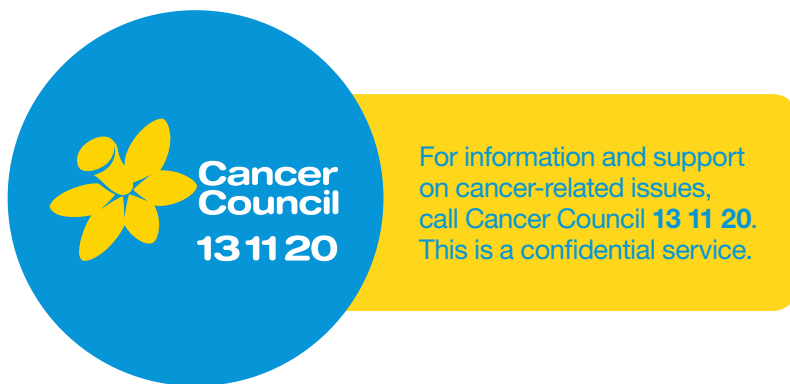
Cancer Council services and programs vary in each area.

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



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