



# Understanding Pleural Mesothelioma

A guide for people with cancer,  
their families and friends

Cancer  
information

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*Understanding Pleural Mesothelioma* is reviewed approximately every two years. Check the publication date above to ensure this copy is up to date.

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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.

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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](http://cancer.org.au) or call your local Cancer Council.



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# Introduction

This booklet has been prepared to help you understand how pleural mesothelioma is diagnosed and treated. We also include information about support services.

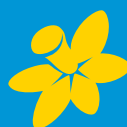
As the experience for every person with pleural mesothelioma is different, you need to discuss your treatment options with your doctor. However, we hope the information in this booklet will answer some of your questions and help you think about other questions to ask your treatment team.

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

## How this booklet was developed

This information was developed with help from a range of health professionals and people affected by pleural mesothelioma. It is based on an extensive review<sup>1</sup> of the medical literature and clinical practice guidelines developed with the support of the Asbestos Diseases Research Institute (ADRI) and approved by the National Health and Medical Research Council (NHMRC).

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



**Cancer  
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13 11 20**

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# What is cancer?

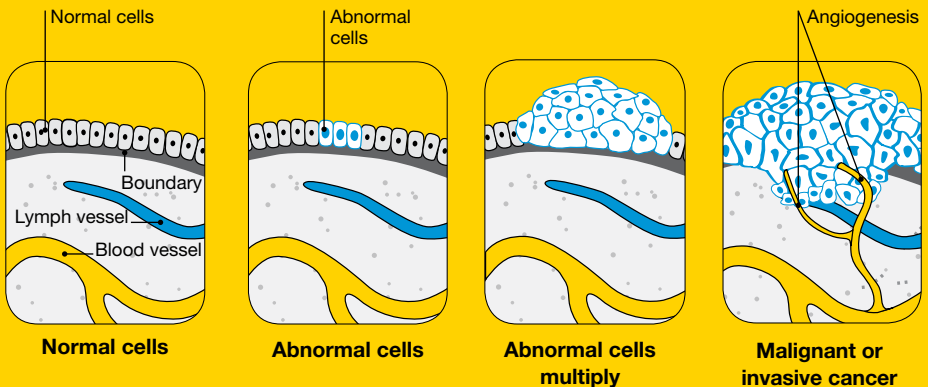
Cancer is a disease of the cells, which are the body's basic building blocks. The body constantly makes new cells to help us grow, replace worn-out tissue and heal injuries. Normally, cells multiply and die in an orderly way.

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

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

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

## How cancer starts



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

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

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

## How cancer spreads

Primary cancer

Local invasion

Angiogenesis –  
tumours grow their  
own blood vessels

Lymph vessel

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





# The lungs

The lungs are the main organs for breathing and are part of the respiratory system. The respiratory system also includes the nose, mouth, windpipe (trachea) and airways to each lung. These consist of large airways (bronchi) and smaller airways (bronchioles).

The lungs look like two large, spongy cones. Each lung is made up of sections called lobes – the left lung has two lobes and the right lung has three. The lungs rest on the diaphragm, which is a wide, thin muscle that helps with breathing.

## The role of pleura

The chest wall and lungs are covered by two layers of a thin sheet of tissue called the pleura.

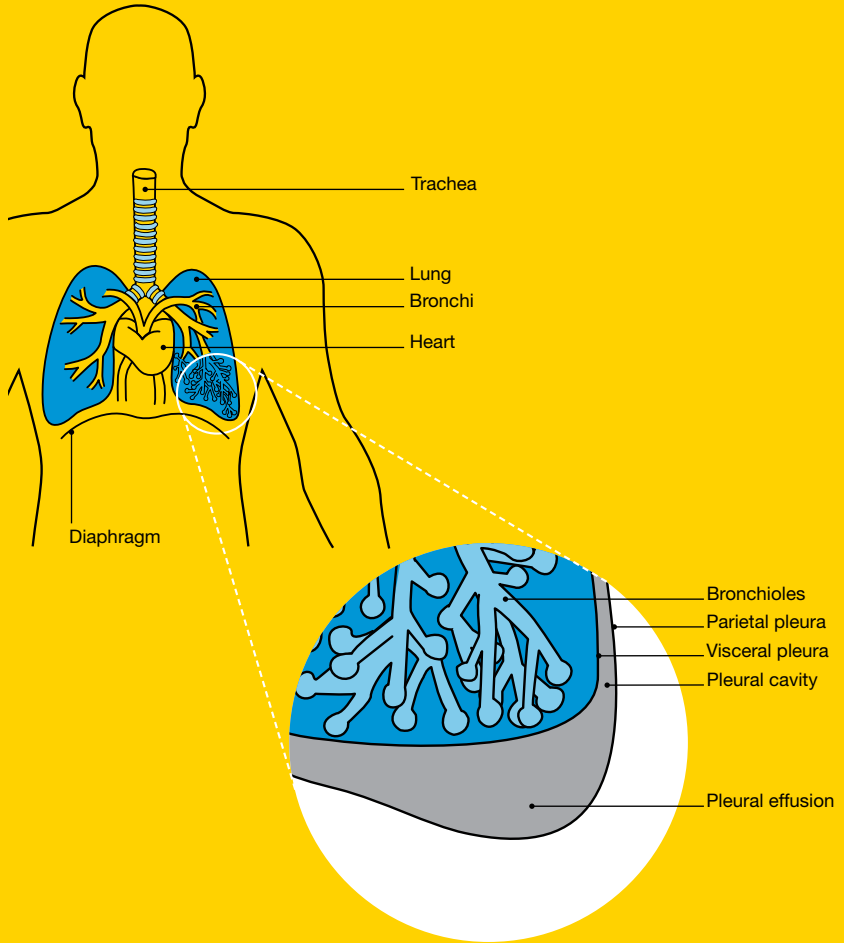
- **The inner layer (visceral pleura)** – lines the lungs.
- **The outer layer (parietal pleura)** – lines the chest wall and the diaphragm.

Between the two layers is the pleural cavity (also called the pleural space), which normally contains a small amount of fluid. This fluid allows the two layers of pleura to slide over each other so the lungs move smoothly against the chest wall when you breathe.

When mesothelioma develops in the pleura, the delicate layers of the pleura thicken and may press on the lung, preventing it from expanding when breathing in (inhalation). When excess fluid collects between the two layers, this is known as a pleural effusion.



## The respiratory system





## Key questions

### Q: What is mesothelioma?

**A:** Mesothelioma is a type of cancer that starts from mesothelial cells. These cells line the outer surface of most of the body's internal organs, forming a membrane called the mesothelium. The membrane that covers the lungs is the pleura.

### Q: What are the different types?

**A:** There are two main types of mesothelioma, which are classified according to the area affected.

- **Pleural** – this forms in the covering of the lungs. Pleural mesothelioma is the most common type, accounting for about 90% of all mesotheliomas. This type of mesothelioma is called malignant pleural mesothelioma (MPM). In this book we refer to it as pleural mesothelioma or, simply, mesothelioma.
- **Peritoneal** – this develops in the lining of the abdomen. It accounts for about 10% of cases and is called malignant peritoneal mesothelioma.

Rarely, mesothelioma occurs in the pericardium (the membrane around the heart) or the tunica vaginalis (the membrane around the testicles).

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

## Cell types of mesothelioma

Mesothelioma is also grouped according to how the cells look under a microscope. There are three main types:

- **Epithelioid** – cells look similar to normal mesothelial cells. This is the most common type, making up about 60% of cases.
- **Mixed or biphasic** – has epithelioid and sarcomatoid cells. These make up about 25% of all cases.
- **Sarcomatoid** – cells have changed and look like cells from fibrous tissue. Accounts for about 15% of cases.

Mesotheliomas can differ in the way they grow. Some form a mass; others grow along the pleura forming a thick covering on the lungs.

## Q: How common is pleural mesothelioma?

**A:** Australia has one of the highest rates of mesothelioma in the world. According to the Australian Mesothelioma Registry, each year close to 600 Australians are diagnosed with pleural mesothelioma. Men are over three times more likely than women to be diagnosed with pleural mesothelioma.<sup>2</sup> This is probably because many cases have been caused by exposure to asbestos at work (see next page). Western Australia has the most cases per population due to past asbestos mining.

Pleural mesothelioma is more common in people over the age of 70, but can sometimes occur in younger people.

## Q: What causes pleural mesothelioma?

**A:** Exposure to asbestos is generally the only known cause of mesothelioma. Sometimes mesothelioma is linked with previous radiotherapy to the chest.

Asbestos is the name of a group of naturally occurring minerals that are resistant to high temperatures and humidity. It was used in many building products in Australia from the 1940s until 1987.

People most likely to have been exposed to asbestos at work include asbestos miners and millers, transport workers (especially waterside workers), ladders and insulators, builders, plumbers and electricians, mechanics, and asbestos cement manufacturing workers.

People who haven't worked directly with asbestos but have been exposed to it can also develop mesothelioma. This can include people washing or cleaning work clothes with asbestos fibres on them or people renovating homes.

It can take many years after being exposed to asbestos for mesothelioma to develop. This is called the latency period or latent interval, and is usually between 20 and 60 years.

““ I remember buying sheets of asbestos and using it in bathrooms. You didn't think about it. My kids were little and we were all out there renovating.”” *Carol*



People who develop mesothelioma due to asbestos exposure may be able to claim compensation. It's important to get legal advice from an experienced lawyer as soon as possible after diagnosis. See pages 53–65.

## Q: What are the symptoms?

**A:** The earliest signs of pleural mesothelioma are often vague and similar to other conditions or diseases. If you are concerned, especially if you think you've been exposed to asbestos, see your general practitioner (GP).

**Shortness of breath (breathlessness)** – Most people with pleural mesothelioma experience breathlessness. You may feel like you can't catch your breath no matter what you do. It usually feels worse with activity or when you are lying down. In early mesothelioma, breathlessness is caused by a build-up of fluid in the chest (pleural effusion). See page 15 for information on how this can be treated.

**Pain** – This can be a sharp pain in the chest, which affects your breathing, or a dull pain in the shoulder and upper arm. The pain might not improve with pain relievers.

**Other general symptoms** – Less commonly, people notice loss of appetite with weight loss, a persistent cough, or a change in their coughing pattern. Some people also experience heavy sweating, especially at night.

## Q: What will it mean for me?

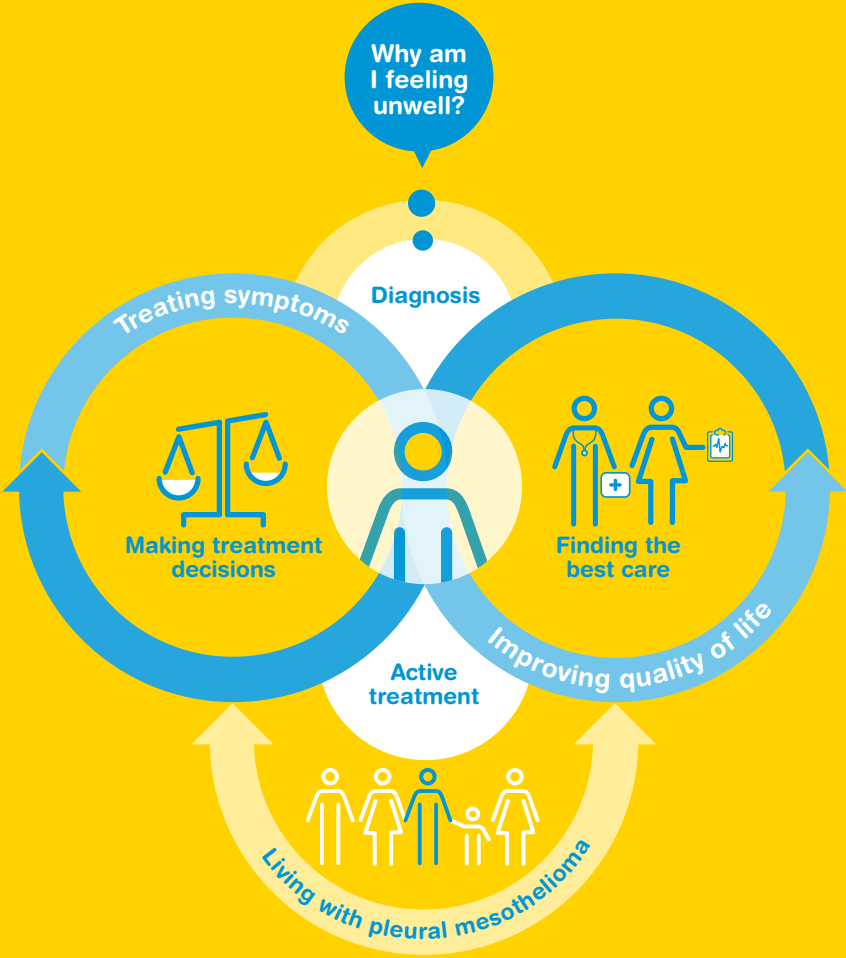
**A:** When your doctor first suggests that you may have pleural mesothelioma, you and your family will be understandably shocked. It's common to have many questions and concerns about what the diagnosis will mean for you.

To understand what is happening, it may help to break down the process into a series of steps. The diagram opposite is a guide to the main steps. Mesothelioma is different for everyone and you may not go through each step in the order shown. You can use the diagram to see what stage you are at and read the chapter relevant to you.

The diagnosis stage (pages 14–25) is represented as a central pathway leading to active treatment (pages 40–48). This will involve making treatment decisions about the best care for you (pages 27–28). During these periods, your health care team will also focus on treating symptoms and improving your quality of life (pages 29–38).

The blue arrows represent the quality of life experienced while living with pleural mesothelioma (pages 50–52). Depending on the impact of pleural mesothelioma on your health, you may experience periods of relatively good health when symptoms are under control or less active. These alternate with periods when symptoms are less controlled and the intensity of treatment needs to be increased to improve quality of life. For questions you may want to ask your doctor, see pages 72–73.

# Pathway through the mesothelioma experience





# Diagnosis

Usually you begin by seeing your GP or going to a hospital emergency room, perhaps for shortness of breath, chest pain or another symptom. The doctor will examine you, arrange for a number of tests and probably refer you to a specialist, usually a respiratory physician. Your doctor will also take a history of your general health and exposure to asbestos.

Pleural mesothelioma can be difficult to diagnose. The symptoms of pleural mesothelioma are often the same as those of other diseases, and mesothelioma cells can look similar to other types of cancer cells. This is why you are likely to have quite a few tests and there will be different health professionals involved in working out whether you have pleural mesothelioma (see pages 24–25 for a complete list of health professionals and a description of their roles). Each person's pathway to diagnosis will be unique.

## General tests

### Blood test

You will have blood taken to check your overall health. A blood test will not show up mesothelioma, but it can let your doctors know how your blood cells, liver and kidneys are working.

### Chest x-ray

You will have a chest x-ray to look for any abnormalities in the lungs, thickening of the pleura, and fluid in the space between the lungs and the chest wall. If abnormal growth or other changes are found, you will need more tests to find the cause as these changes can also be due to other conditions.



## Draining fluid from the pleura

In the early stages of pleural mesothelioma, the pleura leaks fluid into the pleural cavity. This is called pleural effusion, and it makes it hard to breathe. Most people with pleural mesothelioma will experience pleural effusion.

The feeling of breathlessness can be distressing, and your doctor may drain some fluid to relieve this symptom before suggesting further tests or treatment.

To drain the fluid, your doctor numbs the area with a local anaesthetic and inserts a needle through the chest wall into the pleural cavity. An ultrasound scan is used to help the doctor guide the needle to the place where the fluid is. A sample of the fluid is sent to a pathologist for testing to see whether cancer cells are present or whether the pleural effusion is caused by some other disease.

Draining the fluid from the pleura can be done during video-assisted thoracoscopic surgery or VATS (see page 17) along with a talc pleurodesis to prevent fluid building up again.

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

A respiratory physician may also perform a pleurodesis under local anaesthetic using a fine tube to introduce the sterile talcum powder (slurry). You will lie down for a few hours and be asked to change positions regularly to help distribute the talcum powder throughout the pleural cavity.

## CT scan

A CT (computerised tomography) scan uses x-ray beams to create a detailed, three-dimensional picture of the inside of the body.

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

A CT scan is painless and takes about 10 minutes. You will need to lie flat on a table that slides in and out of a large, round scanner. CT scans are usually done at a hospital or a radiology service. Before the scan, an iodine contrast dye is usually injected into a vein in your arm to make the scan pictures clearer. You will be asked if you have any allergies to iodine.

## Biopsy

A biopsy is the main procedure used to diagnose pleural mesothelioma. A doctor will remove a sample of pleural tissue for examination by a pathologist under a microscope to determine if the tumour is pleural mesothelioma and, if so, the type of mesothelioma cells present, i.e. epithelioid, sarcomatoid or biphasic.

Obtaining a biopsy for diagnosis can be challenging, so a respiratory physician, radiologist, thoracic surgeon and pathologist may all be involved. A biopsy can be taken in two ways. While either technique can diagnose pleural mesothelioma, both have pros and cons.

## Video-assisted thoracoscopic surgery (VATS)

VATS is a type of keyhole surgery. You will be given a general anaesthetic, then small cuts will be made between your ribs and a camera will be inserted into the pleural cavity. Samples of the pleura are taken and the tissue is sent to the pathologist for examination.

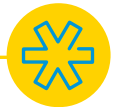
Aside from helping to diagnose pleural mesothelioma, VATS can be used to improve the feeling of breathlessness. See page 30 for more details.

After the VATS you may spend a few days in hospital. Soreness in the front and lower parts of the chest is common because the nerves between the ribs will have been irritated during surgery.

## CT-guided core biopsy

You will have a local anaesthetic and a needle (with a tip for cutting out tissue) will be passed between your ribs into the thickest part of the diseased pleura. A CT scan will be used to guide the needle into position. During the procedure, you will need to lie still on a table, either on your back or front, for about 30 minutes. Afterwards you will stay in the radiology suite for a couple of hours to watch for potential complications such as bleeding or a collapsed lung.

VATS is usually the preferred biopsy technique as several tissue samples can be taken. However, the choice will depend on your general health, fitness, and how suitable the tumour is for sampling using VATS.



## Other ways to diagnose mesothelioma

The current clinical practice guidelines for mesothelioma state that some techniques are not a reliable way to diagnose pleural mesothelioma. These include tissue obtained through a fine needle aspiration or a biopsy without CT image or ultrasound guidance.

In some cases, a fluid sample rather than a tissue sample may be used to make a diagnosis because it's easier to collect fluid removed while draining the pleural cavity. However, it is harder to see cells under the microscope with fluid samples, especially as abnormal mesothelioma cells can look similar to cells found in other conditions.

However, some specialist mesothelioma diagnostic centres have developed a high level of expertise in using fluid samples for diagnosis, provided a large volume of fluid is obtained.

Combining results from the fluid samples with information from an x-ray and CT scan (that show the tumour present in adjacent tissue) can provide an acceptable level of certainty of the diagnosis in experienced hands.

## Further tests

Sometimes diagnosing mesothelioma is challenging and the pathologist needs to do additional testing called special staining. This looks for specific molecules in the biopsy sample that may help to distinguish pleural mesothelioma from other cancers.

## 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 pleural mesothelioma. It may help to focus on recovering from the test procedures and any improvements in symptoms.

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

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

To learn more about what a mesothelioma diagnosis will mean for you, call Cancer Council **13 11 20**, Lung Foundation Australia on **1800 654 301** or Asbestos Diseases Research Institute (ADRI) on **1300 237 400**.

After pleural mesothelioma has been diagnosed, further tests are done to find out if the disease has spread to other parts of the body and, if so, by how much and how far. This process is called staging. Knowing the stage of the cancer helps doctors plan the best treatment for you (see page 21).

The following tests are commonly used in the staging process:

**CT scan** – This is the main test used to stage pleural mesothelioma. You may have had a CT scan earlier when mesothelioma was suspected, or during a CT-guided core biopsy. If this CT scan showed advanced disease, a further CT scan may not be necessary.

**Spiral CT scan** – This scan takes detailed pictures of the organs, chest lymph nodes and other locations where mesothelioma may be present.

**FDG-positron emission tomography (FDG-PET)** – This involves the injection of a specially modified sugar molecule (fluorodeoxyglucose or FDG) that is taken up by cells and helps distinguish between benign and malignant tumours. FDG-PET can find disease in lymph nodes and at other sites that may not have been seen on a CT scan.

**Mediastinoscopy** – This procedure is used to examine and sample the lymph nodes at the centre of the chest. A small cut is made in the lower neck, and an instrument is inserted through the opening and passed down into the chest. The surgeon will remove some tissue from the area between the lungs (mediastinum).

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

**Surgical staging** – Surgical staging is the most accurate way of staging cancer, but it is suitable for only a small number of people. It involves taking a biopsy of lymph nodes and other areas of the body that may be affected by mesothelioma. The aim is to find previously unknown disease and help doctors decide if radical surgery is a suitable treatment option (see page 46).

## Staging

Various systems have been used for staging pleural mesothelioma, but the one now recommended is the international tumour-node-metastasis or TNM staging system.

TNM staging	
<b>T (tumour)</b>	<p>Shows how far pleural mesothelioma has grown in and beyond the pleural cavity.</p> <ul style="list-style-type: none"><li>● <b>T1</b> – limited to the pleura on one side of the chest</li><li>● <b>T2</b> – grown into the lung and/or the diaphragm</li><li>● <b>T3</b> – invaded the inner layer of the chest wall and/or the pericardium</li><li>● <b>T4</b> – invaded nearby structures</li></ul>
<b>N (node)</b>	<p>Shows if pleural mesothelioma has spread to the lymph nodes.</p> <ul style="list-style-type: none"><li>● <b>N0</b> – no spread to lymph nodes</li><li>● <b>N1</b> – spread to lymph nodes where the airways enter the lung</li><li>● <b>N2 and N3</b> – spread to other lymph nodes in the chest</li></ul>
<b>M (metastasis)</b>	<p>Shows if pleural mesothelioma has spread to other parts of the body.</p> <ul style="list-style-type: none"><li>● <b>M0</b> – no spread to distant organs</li><li>● <b>M1</b> – has spread to distant organs, such as the bones or other organs</li></ul>

## 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 any doctor to predict the exact course of the illness.

Pleural mesothelioma behaves differently in different people. It can sometimes be present for many months and be 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.

While knowing the stage helps doctors plan the best treatment for you, it is not always useful for determining prognosis for people with pleural mesothelioma. This is partly because scans do not always pick up all the areas the disease has spread to.

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

- the cell type of mesothelioma you have – epithelioid types tend to have a better outcome than sarcomatoid or mixed types
- the stage
- the type of treatment you are able to have
- your symptoms, such as weight loss or chest pain
- white blood cell count – people with normal levels usually have a better prognosis
- your overall health – doctors refer to this as your performance status. Recovering quickly and returning to your usual levels of activity after pleural drainage and pleurodesis tend to suggest a better outcome.



In general, the earlier cancer is diagnosed, the better. However, pleural mesothelioma is usually not found until it is advanced as symptoms are often vague or go unnoticed. When cancer has advanced, it is more difficult to treat successfully, but relieving symptoms can keep the disease under control for months or years and improve your quality of life.

## Which health professionals will I see?

If you have pleural mesothelioma, you will be cared for by a range of health professionals who specialise in different aspects of your treatment. The health professionals involved in your treatment will take a team-based approach by referring you to a multidisciplinary team.

Some people are diagnosed and treated in specialist centres available in major cities around Australia. Specialists work together to develop the best plan for treatment and care. To find out if a specialist mesothelioma unit is located 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 a multidisciplinary team who have experience in treating pleural mesothelioma.

This multidisciplinary team will probably include some or all of the health professionals described in the table on the next two pages.

## Specialist health professionals you might see

<b>general practitioner (GP)</b>	responsible for general health and coordinates specialist treatment
<b>radiologist</b>	specialises in reading chest x-rays, CT scans and other scans
<b>respiratory physician</b>	investigates symptoms, begins the process of diagnosis, stages the cancer and determines initial treatment options
<b>interventional radiologist</b>	uses CT scan to guide needles and other instruments to the best position for draining fluid and removing tissue for diagnosis
<b>pathologist</b>	examines cells and tissue under the microscope to determine the type and extent of mesothelioma
<b>nurses and nurse care coordinator</b>	support you through all stages of your treatment and liaise with other health care staff to help organise care
<b>thoracic surgeon</b>	conducts some biopsy procedures and performs surgery to prevent and treat symptoms, including radical surgery
<b>medical oncologist</b>	prescribes and coordinates the course of chemotherapy

<b>radiation oncologist</b>	prescribes and coordinates the course of radiotherapy
<b>palliative care team (doctors, nurses and allied health professionals)</b>	assist with control of symptoms such as pain, nausea, depression and anxiety, as well as offering emotional and spiritual support
<b>dietitian</b>	recommends an eating plan to follow while you are in treatment and recovery
<b>psychologist</b>	provides emotional support and strategies to help deal with the impact of the disease
<b>community nurses</b>	visit you at home to give medical treatment, assess your needs for supportive care, and liaise with your GP and multidisciplinary team as required
<b>social worker</b>	provides counselling and support, links you to support services and helps with practical issues
<b>physiotherapist</b>	helps with maintaining and restoring strength and fitness during and after treatment
<b>occupational therapist</b>	assesses changes needed to your home and recommends equipment to assist with safety and mobility



## Key points

- Mesothelioma can be difficult to diagnose since many diseases of the lungs and respiratory system have similar symptoms.
- Many different types of tests are used to diagnose mesothelioma, but you probably won't need to have every test.
- Initial tests usually include a blood test, chest x-ray and CT scan.
- You will have a biopsy to collect pleural tissue samples. This may be done using video-assisted thoroscopic surgery (VATS) or a CT-guided core biopsy. Your doctor will determine the best technique for you.
- Scans and tests can help show if pleural mesothelioma has spread. These may include CT scan, spiral CT scan, FDG-PET, mediastinoscopy, endobronchial ultrasound (EBUS) and surgical staging. These tests and scans can also help your medical team decide on the best treatment plan for you.
- You may wish to talk to your doctor about your prognosis. Prognosis is the expected outcome of a disease.
- You will probably see many health professionals who specialise in different areas of care and work together as a multidisciplinary team to diagnose and treat you.
- Some major cities of Australia have specialist mesothelioma treatment units.
- If you live in a rural or regional area, or cannot travel far, you can be treated by your GP with advice from a lung cancer multidisciplinary team.



# Making treatment decisions

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

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

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

## Talking with doctors

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

If you are confused or want clarification, you can ask questions – see pages 72–73 for a list of suggested questions. If you have several questions, you may want to talk to a nurse or ask the office manager if it is possible to book a longer appointment.

## A second opinion

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

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

## Taking part in a clinical trial

Your doctor or nurse may suggest you take part in a clinical trial. Doctors run clinical trials to test new or modified treatments and ways of diagnosing disease to see if they are better than current methods.

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

It may be helpful to talk to your specialist or clinical trials nurse, or to get a second opinion. If you decide to take part in a trial, you can withdraw at any time. For more information, call Cancer Council 13 11 20 for a free copy of *Understanding Clinical Trials and Research*, or download it from your local Cancer Council website. You can also visit the Australian Cancer Trials website at [australiancancertrials.gov.au](http://australiancancertrials.gov.au) for more details.



# Treatment for symptoms

For many people, pleural mesothelioma is diagnosed at an advanced stage. The main goal of treatment is to manage your symptoms and keep them under control for as long as possible. Although there is no cure for pleural mesothelioma, treatment may make you feel better and help you live longer. This is called palliative treatment (see page 38).

This chapter describes different ways of managing symptoms. You may have a combination of these treatments. If the symptoms return after a period of wellness, you may be offered a different combination of treatments.

## Breathlessness

Breathlessness is the most common symptom of pleural mesothelioma. In the early stages of pleural mesothelioma, controlling the pleural fluid build-up around the lungs and using surgery will improve breathlessness (see next page). The level of improvement will depend on how healthy your lungs were before you developed pleural mesothelioma, and the level of lung function after surgery.

During the process of diagnosing pleural mesothelioma, fluid build-up will have been drained off, and further accumulation of fluid may be prevented by pleurodesis (see page 15).

Although living with breathlessness can be difficult and can cause distress, there are surgical and non-surgical ways to prevent or reduce its impact on your life.

## **Improving breathlessness with surgery**

### **Video-assisted thoracoscopic surgery (VATS) and talc pleurodesis**

– If you were diagnosed with pleural mesothelioma after a CT-guided core biopsy and the symptoms of breathlessness remain, your surgeon may suggest you have VATS.

During the VATS, some of the lining of the chest wall and lung will be removed (pulmonary decortication) and some sterile talcum powder will be injected into the pleural cavity (talc pleurodesis). This causes inflammation that closes the pleural cavity and prevents fluid from building up again. In most cases, this procedure improves your ability to breathe.

### **Open surgery (thoracotomy, pleurectomy and pulmonary decortication)**

– Following VATS and talc pleurodesis, the fluid build-up around the lungs may come back, making you feel breathless again. The surgeon may suggest more extensive surgery called thoracotomy with pleurectomy and pulmonary decortication (see page 46). In rare cases, if you are experiencing pain in the chest, the surgeon may suggest open surgery to relieve the pain.

Under a general anaesthetic, the surgeon will open the chest by making a cut from the back to the side of the chest, and between the ribs. The pleural fluid is drained and the part of the pleura most affected with cancer is removed. After this procedure, the lung is inflated by the anaesthetists and the chest is closed. Chest tubes are left in place for at least 48 hours to drain blood and any air that is leaking from the peeled lung surface. This type of surgery controls recurring pleural effusion in most cases.




Pain after open surgery can last longer than after VATS, but the improvement in symptoms and lung function may make this worthwhile if VATS has been unsuccessful.

**Indwelling pleural drain** – An indwelling pleural drain may be offered to people who are too unwell for VATS or open surgery. It can also be used if the pleural fluid builds up again after pleurodesis.

The surgeon or interventional radiologist inserts a thin tube (catheter) through the chest wall into the pleural cavity. The pleural drain is connected to a bottle to drain off fluid and help your breathing. You may have to drain the fluid 1–2 times a week depending on how quickly it builds up again. You can manage the drain at home with the help of a community nurse. Your family or a friend can also be taught how to do this.

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

For more information about managing breathlessness, call Cancer Council 13 11 20.



If your breathlessness is caused by the lungs not supplying enough oxygen to your blood, your doctors can arrange for you to receive an oxygen concentrator. This device delivers oxygen to your lungs and can be used at home. You can use a portable oxygen cylinder for social outings and medical appointments.



## Improving breathlessness without surgery

- Let your doctor know if you feel breathless. Other conditions, such as anaemia, a lung infection or a heart-related issue, may make you feel short of breath, and these may be able to be treated.
- Use a fan or medical gas to direct a cool stream of air across your face if you feel breathless when you are not exerting yourself.
- Talk to your doctor about medicines, such as a low dose of morphine, to manage feelings of distress.
- Listen to a relaxation CD or learn other ways to relax. This can help you control anxiety and breathe more easily.
- Lean forward on a table with an arm crossed over a pillow to allow your breathing muscles to relax.
- Use a recliner chair to help you sleep in a more upright position.
- Ask your health care team for assistance obtaining any equipment that may help.

## Difficulty sleeping

Getting a good night's sleep is important for maintaining your energy levels and reducing your fatigue. Difficulty sleeping may be due to pain, breathlessness, anxiety or depression.

Talk to your doctor about what might be helpful for you, and whether medication may be an option. You may want to limit use of technology, such as television or computers, before bed and set up a calm sleeping environment with soothing music.

## Fatigue

Fatigue means feeling very tired and lacking energy to carry out day-to-day activities. Fatigue for people with cancer is different from tiredness. It does not always go away with rest or sleep.

If fatigue continues for long periods of time, you may lose interest in things that you usually enjoy doing or feel unable to concentrate on one thing for very long. Fatigue can influence how you feel about yourself and others, which may affect your close relationships.

If fatigue is a problem, talk to your treatment team. Sometimes fatigue can be caused by a low red blood cell count or the side effects of drugs, and can be treated.

While you cannot always get rid of fatigue, you can find ways of managing it and boosting your energy levels.

## Loss of appetite and weight loss

For many people, losing weight and interest in eating are common even before pleural mesothelioma is diagnosed. Weight loss may be caused by nausea, difficulty swallowing, breathlessness, changes in taste or smell, or feeling down.

Maintaining good nutrition will help you cope better with day-to-day living, treatment and side effects, and improve your quality of life. You may find it useful to talk to a dietitian who is experienced in treating people with cancer. They can provide helpful eating suggestions.

## Constipation

Constipation is when your bowel motions are difficult to pass and infrequent. It may be caused by reduced physical mobility, low fibre intake, and not drinking enough fluids. Some medications, particularly strong pain medicines and anti-nausea medicines, may cause constipation.

## Pain

People are naturally fearful of experiencing pain, and it's vital to let your health care team know if you are in pain. If it is caused by the pleural mesothelioma itself, it is usually a dull, generalised pain, but if the cancer spreads or presses on the ribs, it may be sharp and affect your breathing. Pain can also be a side effect of treatment. Chemotherapy and surgery can injure nerves and cause pain or numbness in certain parts of your body.

## Managing pain with medicines, radiotherapy and chemotherapy

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

To help find the right medicine for you, your doctor may prescribe different drugs, different doses or a combination of drugs. Pain can usually be relieved with the right medicine.

“ I didn’t want to resort to morphine. I felt it meant I was giving up, and I was so scared I would become addicted to it or it would make me sleep all the time. The pain got so severe that I gave in and accepted some morphine. I wondered afterwards why I had resisted. I am pretty much pain-free most of the time and quite alert when I need to be. It has made such a difference to my quality of life. ” Jack

**Opioids** – Opioids, such as morphine, are the most common drugs used to control moderate to severe cancer pain. Morphine is available in quick-acting and long-acting forms. Some people feel concerned about taking morphine, thinking they will become addicted. However, pain specialists believe that a person does not become addicted to morphine if they are taking it as prescribed by their 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’.

**Radiotherapy** – This is used when pleural mesothelioma spreads, or presses on specific body parts like nerves, bones or major blood vessels, causing pain.

**Chemotherapy** – This is used to reduce the size of the pleural mesothelioma tumours that are causing the pain.

For more information on radiotherapy and chemotherapy, see pages 41–44. For further details on managing pain, call Cancer Council 13 11 20 and ask for a copy of *Overcoming Cancer Pain*.

## Coping with symptoms

### 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 ahead. For example, set your clothes out before you shower or bathe to avoid walking back and forth to your wardrobe.
- Leave plenty of time to get to appointments.
- Sit down whenever you can.
- Say no to things you really don't feel like doing.
- Seek your doctor's approval to exercise. Even a walk around the garden or block can boost your energy levels.
- Eat nutritious food to keep your energy levels up.

### Loss of appetite

- Eat small meals and snacks regularly.
- Use a small plate or bowl so the plate looks fuller.
- Eat moist food, e.g. scrambled eggs are usually easier to eat and cause less irritation to a sore mouth.
- Add ice-cream or fruit to a drink to increase calories and nutrients.
- Drink from a 'half-full' glass. It is more satisfying to empty a half-full glass than only half finish a full one.
- If solid food doesn't appeal to you, ask your dietitian about commercially prepared supplements, such as protein drinks.
- Use lemon juice and herbs to add flavour to bland food.
- Try eating salads or cold foods if hot food smells make you feel nauseous.
- Avoid fatty foods or heavy, sugary foods if they make you feel sick.
- Eat more of your favourite foods – follow your impulse.



## Constipation

- Drink plenty of fluids – aim for 8 glasses a day.
- Eat fresh fruit and vegetables, and fibre-rich foods (e.g. dessert prunes).
- Exercise as much as you can every day. Talk to your doctor or physiotherapist about the amount and type of exercise that is right for you.
- Talk to your doctor for advice about medicines to treat constipation if it's caused by chemotherapy or other medicines.
- Try over-the-counter laxatives such as Coloxyl® with senna, Duphalac® or Movicol®. Don't wait too long before you start taking a laxative, and adjust the dose once you are having regular bowel movements.
- Read Cancer Council's booklet *Nutrition and Cancer* for more suggestions. Call **13 11 20** for a free copy.

## Pain

- Keep track of your pain in a symptom diary and try to describe it as best you can. Write down what the pain feels like, how intense it is, exactly where it is, where it goes and comes from, how long it lasts, and if it goes away with a specific pain medicine or with any therapy like a heat pack.
- Allow a few days for your body to adjust to the dose of pain medicine/morphine and for the drowsiness to improve. This will help you continue with your usual activities.
- Let your doctor know if you have vivid dreams after taking morphine. Adjusting the dose may help, or you can ask to try other methods of pain relief.
- Use a laxative regularly to help relieve or prevent constipation caused by pain medicines.
- Take morphine regularly, even if you're not in pain. It's better to stay on top of the pain rather than treat it when it returns.

## Palliative treatment

Palliative treatment helps to improve a person's quality of life by reducing pain and managing other physical and emotional symptoms. Treatment may include radiotherapy, chemotherapy or other medicines.

It is often assumed that palliative treatment is for people at the end of life; however, it is beneficial for people at any stage of a mesothelioma diagnosis. Contacting the palliative care team soon after diagnosis gives them the opportunity to get to know you, your family and your circumstances. Although other professionals will be responsible for your treatment in the earlier part of your diagnosis, the palliative care team can become involved when needed and manage your care when active medical management becomes less effective.

Ask the doctor in charge of your medical care about making an appointment with the palliative care team. To find out more about palliative care and advanced cancer, call Cancer Council 13 11 20 or visit your local Cancer Council website.

“ 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

- For most people, treatment is given to control symptoms and improve quality of life.
- Breathlessness is the most common symptom of pleural mesothelioma. It can be controlled with two types of surgery: video-assisted thoracoscopic (VATS) and open surgery.
- If a pleural effusion recurs after VATS and you are experiencing pain, it may be suggested that the fluid be controlled with open surgery.
- An indwelling pleural drain allows fluid to be drained without surgery. A catheter is inserted through the chest wall into the pleural cavity, and drains into a bottle.
- Other ways to improve breathlessness include using a fan, leaning forward on a table over a pillow or sleeping in a recliner chair.
- Manage fatigue by setting small goals for the day and resting before you get too tired.
- Try to drink at least 8 glasses of fluid a day, and eat fresh fruit and vegetables to ease constipation.
- While pain is common for people diagnosed with pleural mesothelioma, it can be relieved. Pain medicines may be mild, like aspirin or paracetamol, or moderate, like codeine. Strong pain is often treated with opioid-based drugs such as morphine.
- In some cases, radiotherapy and/or chemotherapy can be used to manage pain.
- Palliative treatment helps to improve a person's quality of life by managing physical and emotional symptoms. It's best to access it early. You can contact the palliative care team soon after your diagnosis.



# Active treatment

A range of active cancer treatments are recommended for some people with pleural mesothelioma. These can include chemotherapy, radiotherapy or surgery, or a combination of these treatments called trimodality therapy (see page 45).

Your specialist will discuss suitable treatment options with you. These suggestions will be based their on a number of factors, including the location, stage and type of mesothelioma. Each person with pleural mesothelioma is different, and your age, health and fitness, family circumstances and support will be considered to determine the best treatment options for you.

Although there is no cure for pleural mesothelioma, the active cancer treatments discussed in this chapter help some people to achieve a longer period of control over the disease and improve prognosis. These treatments differ from palliative treatment, which primarily aims to improve quality of life without extending survival.

## Recent advances in treating mesothelioma

In recent years, treatment options for pleural mesothelioma have improved. This includes more accurate diagnostic and staging methods, better surgical techniques and post-surgery care, evidence-based chemotherapy combinations, new radiotherapy techniques and clinical trials. These advances offer hope for improved living. While there is still no standard treatment path for people with pleural mesothelioma, chemotherapy is frequently an important part of treatment.

## Chemotherapy

Chemotherapy treats cancer using anti-cancer (cytotoxic) drugs. It aims to destroy cancer cells while causing the least possible damage to healthy cells.

The most commonly used chemotherapy drugs to treat a person with pleural mesothelioma include pemetrexed (Alimta®) with cisplatin or carboplatin. Research shows that this combination can increase survival by a few months and improve quality of life<sup>3</sup>, and is better than receiving a single chemotherapy drug.<sup>4</sup> However, chemotherapy doesn't work for some people.

Most doctors will recommend that you start chemotherapy when the CT scans show signs of active disease and/or you have developed symptoms. Sometimes your doctor will recommend that you start chemotherapy before symptoms develop further. Talk to your specialist about the best time for you to begin.

Chemotherapy is generally administered into a vein through a drip (intravenously). Each session may last for several hours followed by a rest period of several weeks. This is known as a cycle. You will probably have up to six cycles. However, the length and timing of the treatment and rest days of the cycle may vary.

During the chemotherapy, you will have CT scans to check if the pleural mesothelioma is shrinking. Other scans, such as FDG-PET or FDG-PET-CT, may be used to assess whether the treatment is working and show how active the disease is. Certain blood tests may also show whether the disease is responding to chemotherapy.

For some people, quality of life improves for a while after chemotherapy. If the disease becomes active again, you may be offered additional courses of the same type of chemotherapy. If this is unsuccessful, you may be offered a different chemotherapy drug as ‘second line’ chemotherapy, or an experimental drug. Your medical oncologist will use new information from clinical trials to decide on the best treatment options for you. See page 28 for more information about taking part in a clinical trial.

## Side effects of chemotherapy

People react to chemotherapy differently – some people will have few side effects, while others have more. The side effects depend on the type and dose of drugs you’ve been prescribed. Your doctor may change the dose or type of chemotherapy if necessary.

The most common side effects you may experience include:

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

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

You will be given medicines to control any side effects related to the chemotherapy treatment. To find out more, call Cancer Council 13 11 20 to ask for a free copy of *Understanding Chemotherapy*, or visit your local Cancer Council website.



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

## Radiotherapy

Radiotherapy is the use of high-energy x-rays to kill or damage cancer cells. Radiotherapy may be used at different stages of pleural mesothelioma treatment and in different ways. It can relieve pain or other symptoms caused by tumours. Radiotherapy is also given after chemotherapy and surgery (adjuvant radiotherapy) to help kill remaining cancer cells.

Treatment is carefully planned to destroy as many cancer cells as possible while causing the least harm to your normal tissue. To plan your treatment, you will have CT scans of the affected area.

The radiation oncologist may mark your skin with a special ink to make sure the radiation is directed at the same place on your body every time you receive radiotherapy. Although the ink is permanent, the mark is the size of a freckle.

The initial appointment to see the radiation oncologist and set up the machine may take a few hours, but the treatment itself takes only a few minutes. It is usually given Monday to Friday as an outpatient treatment. The length of the treatment course will vary depending on why you're having radiotherapy – often 2–4 weeks for managing palliative symptoms or 6 weeks for radical radiotherapy.

Radiotherapy does not hurt and you are not radioactive afterwards.

### **Side effects of radiotherapy**

Radiotherapy may cause some side effects during treatment or shortly afterwards, but most side effects go away after the treatment stops. Side effects vary depending on the area of the body being treated, but include tiredness, reddened and peeling skin, painful swallowing and loss of hair in the treatment area.

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

Your doctors and nurses will tell you about what side effects to expect from radiotherapy. For more information, call Cancer Council 13 11 20 for a free copy of *Understanding Radiotherapy*.

## Trimodality therapy

Trimodality therapy includes a combination of induction chemotherapy, radical surgery and radical radiotherapy. The aim of the three phases is to control the disease for as long as possible.

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

### Who can have trimodality therapy

Only a small number of people have trimodality therapy each year as it is only suitable for people:

- with a small amount of pleural mesothelioma at an early stage (T1–T3)
- with an epithelioid type of pleural mesothelioma
- whose scans show a good response to chemotherapy before surgery and no signs of pleural mesothelioma progression
- with no signs of spread into the lymph nodes, or any other disease on CT and/or FDG-PET scans
- who are able to live independently with one lung
- who are physically fit for surgery
- who want to proceed after the risks, benefits and implications of the therapy are explained by their surgeon, oncologist and thoracic nurse.

## Induction chemotherapy phase

Trimodality therapy starts with chemotherapy to shrink the tumour. After three cycles, you will have a scan to check the size of the tumour. If it has been reduced, you will have a rest for 4–6 weeks before having surgery. If there is little or no response, you will continue treatment under supervision of the medical oncologist and you will not have radical surgery.

## Radical surgery phase

This can be done in two ways:

**Extrapleural pneumonectomy (EPP)** – This is a common radical surgical procedure for pleural mesothelioma. It involves removing the tumour along with the pleura, the covering of the heart (pericardium), diaphragm and the whole lung on the affected side. Lymph nodes in the centre of the chest that drain the lung are also removed. Mesh is used to repair the pericardium and diaphragm.

You will need to stay in hospital for 10–14 days to be monitored for any complications and to have physiotherapy. If complications occur, your hospital stay may be extended. Once at home, recovery can take 6–8 weeks and then you'll be able to start radiotherapy.

**Pleurectomy with pulmonary decortication (P/D)** – This operation is a more extensive version of the talc pleurodesis procedure used to drain fluid and re-inflate trapped lungs (see page 30). The aim is to remove all visible pleural mesothelioma from the pleural cavity. This may involve removing all the pleura, depending on the circumstances and what the surgeon decides.





Both types of radical surgery are major operations, and not everyone is fit enough to go through with them. There is no clear evidence for which treatment works best. Ask your treatment team to explain each option and the likely outcome of the surgery.

## Radical radiotherapy phase

The aim of the radical radiotherapy phase is to treat the tumour cells in and around the pleural cavity that may still be present after chemotherapy and surgery.

Radiotherapy is delivered using intensity-modulated radiation therapy (IMRT). This type of external beam radiotherapy can be accurately shaped around the chest cavity to allow higher doses to be delivered directly to the tumour cells while reducing the damage to other organs in the chest and abdomen.

If the tissue removed during surgery shows that pleural mesothelioma cells are still present in some areas of the chest, these areas may receive higher x-ray doses than other areas.

Special scans are taken and computers are used to develop an individualised plan of treatment. Radiotherapy usually begins 6–8 weeks after radical surgery. You will have treatment every day on Monday to Friday for six weeks.

Each week the radiation oncologist will examine you, review your blood test results and ask about any side effects. The side effects of radiotherapy usually become more intense as treatment progresses.

Common side effects include nausea, reflux, skin irritation, lethargy, soreness when swallowing, tiredness and exhaustion. Anti-nausea medicines are usually provided from the beginning, but many people find it difficult to eat larger quantities of food, even when they aren't feeling nauseous.

You will have regular blood tests during radiotherapy to monitor blood counts and liver function. You may need a few days break from the treatment or, rarely, the treatment may be stopped early if your blood count becomes too low. Radiotherapy may temporarily damage liver function, but you will not feel any symptoms. Liver function should return to normal within a few months. Most people start to feel better 2–3 weeks after treatment ends.



Sometimes, despite a person appearing suitable at first, the doctor may decide it is best for them not to continue with trimodality therapy. This might be because the pleural mesothelioma does not respond well to three cycles of chemotherapy, and pathology examination of specimens taken at surgery shows unfavourable grade or that the cancer has spread.



## Key points

- Active cancer treatment for pleural mesothelioma includes chemotherapy and radiotherapy.
- The type of treatment you have will depend on the location, stage and type of pleural mesothelioma. Your age, health and fitness will also be considered.
- The most commonly used chemotherapy drugs are pemetrexed (Alimta®) with cisplatin or carboplatin.
- Studies have shown that treatment with these chemotherapy drugs can increase survival and improve quality of life.
- Radiotherapy may be used at different stages of pleural mesothelioma and in different ways. It's often used to relieve pain, and it can be used after chemotherapy and surgery to help kill remaining cancer cells.
- Some people have a combination of chemotherapy, surgery and radiotherapy. This is called trimodality therapy, and is given in three phases.
- The first phase consists of three cycles of chemotherapy.
- The second phase is surgery. You may have an operation called an extrapleural pneumonectomy, which removes the affected lung, along with the diaphragm and a portion of the lining of the heart (pericardium).
- The other surgical option is pleurectomy/decortication, which removes the pleura and as much disease as possible.
- The third phase is radiotherapy. This includes intensity-modulated radiation therapy (IMRT), which precisely targets the tumour while sparing other parts of the body from radiation.



# Living with pleural mesothelioma

Life between treatments for pleural mesothelioma can present its own 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.

Several organisations can offer support at this time. Call Cancer Council 13 11 20, Lung Foundation Australia on 1800 654 301 or Asbestos Diseases Research Institute (ADRI) on 1300 237 400 for information about the emotional and practical aspects of living with cancer. They can also connect you with other people who have had pleural mesothelioma.

## Dealing with feelings of sadness

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

Talk to your GP, as counselling or medication – even for a short time – may help. Some people are able to get a Medicare rebate for sessions with a psychologist. Ask your doctor if you are eligible. Your local Cancer Council may also run a counselling program.

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


## Ongoing management

As managing symptoms and treatment for pleural 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 follow-up appointments, you will have a physical examination and may also have a CT scan to check how active the pleural mesothelioma is. What other tests you have, and who you see and where will depend on your health and the type of treatment you've had.

If you live a long way from the hospital or centre where you had treatment, you may be able to arrange for some of the follow-up tests to be done by your GP or the specialist who referred you for major treatment.

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



Palliative and supportive care for pleural mesothelioma can be offered alone or in combination with surgery, chemotherapy and radiotherapy. See page 38 for more details. You can also call Cancer Council **13 11 20** and ask for copies of *Understanding Palliative Care* and *Living with Advanced Cancer*.

## What if pleural mesothelioma becomes active again?

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

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

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

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

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



# Making a claim

Some people who develop mesothelioma due to asbestos exposure may be able to claim compensation. Your legal entitlements may vary depending on the state or territory in which you were exposed to asbestos.

Generally, a person diagnosed with mesothelioma may have 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’.

## Common law claim

A common law claim is a claim process through a court. The claim is brought against the party, or parties, who caused a person to be exposed to asbestos. These parties are known as the ‘defendants’. A common law claim begins by filing a formal court document known as an ‘originating process’. The originating process must be lodged within your lifetime to protect your entitlement to compensation.

As long as you start a common law claim during your lifetime, your estate will still be able to continue with your claim if you die before the claim is finalised.

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

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

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

### What you must prove?

In a common law compensation claim, you need to prove that:

- you were exposed to asbestos in your past
- the defendant owed you a legal duty of care
- your exposure to asbestos has caused you to develop mesothelioma
- you have suffered pain, suffering, loss and damage because of the mesothelioma
- the defendant was negligent in causing, or allowing, you to be exposed to asbestos (for example, your employer failed to prevent you from being exposed to asbestos in your workplace, or a manufacturer failed to warn you that asbestos could be dangerous to your health).



## **Q: What happens during the claim process?**

**A:** First, you will meet with a lawyer in their office, at your home or in the hospital. Your lawyer will take a detailed life and work history from you and discuss any exposures to asbestos you may have had. If you can't remember any asbestos exposure, don't worry. Many people can't remember straightaway how they were exposed to asbestos, as it was probably a long time ago. It may take time to talk through your history and work out how you were exposed to asbestos.

Your lawyer may organise for you to see a doctor who is an expert in the field of asbestos-related diseases. If you are not well enough to leave your home, then your lawyer can organise for the doctor to visit you at your home or in hospital. Your lawyer will work around your medical appointments or treatments to try to make things less stressful for you.

During the course of your common law claim, your lawyer will contact you regularly to discuss the progress of your claim. If there is a change in your health, you or a family member should let your lawyer know. You should feel able to speak to your lawyer at any time about any aspect of your claim.

Before a common law claim can proceed to a court trial, the claim will usually go to a 'settlement conference' or 'mediation'. A settlement conference or mediation is a chance for the parties in the claim to meet and attempt to settle the claim. Most common law claims for asbestos-related diseases settle at this stage, and do not proceed to a court trial.

If your common law claim does not resolve at the settlement conference or mediation, your claim will go to trial before a court. During the trial, you may be required to give evidence in court. If you are not well enough to attend court, a judge or court-appointed representative will visit you at home or in hospital to take your evidence.

### **Q: What sort of compensation will I receive?**

**A:** There are different categories of compensation (known as heads of damages) that you may be eligible for. These are used by the court to determine how much compensation you are entitled to. They include compensation for:

- the pain and suffering you have endured as a result of the mesothelioma diagnosis (known as general damages)
- loss of life expectancy
- past and future loss of income caused by the mesothelioma diagnosis (including your entitlements, such as superannuation)
- compensation for any out-of-pocket expenses you have incurred as a result of the diagnosis, such as medical or pharmaceutical expenses
- compensation for the gratuitous care provided to you by your friends and family, as a result of mesothelioma
- compensation for your legal costs in bringing a common law claim for compensation.

In some circumstances compensation may be claimed for your loss of ability to provide care and domestic assistance to a dependant, such as a spouse, child and/or grandchild.

### **Q: How long will a common law case take?**

**A:** Most common law claims for mesothelioma are settled out of court. Only a few cases actually proceed to a court trial. Most claims settle within 3–6 months of a 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.

### **Q: What if I die before my claim is settled?**

**A:** Many people diagnosed with pleural 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 dependancy entitlements if you die because of the mesothelioma. Your lawyer will let you know if this applies to you and your family.

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

### **Q: How much does legal action cost?**

**A:** Legal costs are generally dependent on the amount of legal work required to resolve your case. Most lawyers who specialise in asbestos-related compensation claims offer a ‘no win, no fee’ agreement. This means that the lawyers will only charge for legal services if they are successful in resolving your case. Additionally, 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 will depend on whether your case was resolved at mediation or at trial. Talk to your lawyer for more details.

### **Q: Will I need to pay money back?**

**A:** If your claim is successful, your lawyer will let you know if you need to make any repayments to the following:

- Medicare for any medical treatments received relating to your diagnosis of mesothelioma
- your private health insurer for any medical treatments that were covered by the insurer, and that related to your diagnosis of mesothelioma
- Centrelink, if you are receiving a disability pension
- Department of Veterans’ Affairs, if you have received certain veterans’ entitlements
- any public hospital where you have received certain inpatient or outpatient services.

Usually, your lawyer will include any amounts you are required to repay in your common law claim. This means that you will still receive your compensation, and you will not be left ‘out of pocket’ for any repayments you may be liable to make.

## Finding a lawyer

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

Talking to an expert in this field can help reduce the time taken to investigate a claim. Experienced lawyers also have a good understanding of pleural mesothelioma and what you are coping with.

To find a lawyer who specialises in common law claims for mesothelioma and other asbestos-related diseases such as lung cancer or asbestosis, contact the law society in your state or territory:

**New South Wales** 02 9926 0333

**Victoria** 03 9607 9311

**Queensland** 1300 367 757

**South Australia** 08 8229 0200

**Western Australia** 08 9324 8600

**Tasmania** 03 6234 4133

**Northern Territory** 08 8981 5104

**ACT** 02 6274 0300

## Statutory benefits

Some states and territories have special government compensation schemes for people who develop mesothelioma and other asbestos-related diseases.

These compensation schemes usually apply only if you have been exposed to asbestos during the course of your employment. Some people may be entitled to bring a common law claim instead of, or in addition to, a statutory claim. It is important that you talk to a lawyer before applying for statutory benefits to ensure you are not excluded from also claiming common law compensation. See the tables on the following pages for details.



## New South Wales

<b>Name of the Act</b>	<i>Workers' Compensation (Dust Diseases) Act 1942</i>
<b>Who can make a claim</b>	<ul style="list-style-type: none"><li>• Only people who were employed in NSW</li><li>• People exposed to offending dust such as asbestos dust while employed in NSW</li><li>• People who contracted a disease named in the Act, i.e. pleural mesothelioma</li></ul>
<b>What are my entitlements?</b>	Weekly compensation payments or a pension. The Dust Diseases Board pays for your hospital, medical and pharmaceutical expenses, nursing care, nursing aids and equipment, and other related expenses such as assistance with housework and garden maintenance.
<b>Do I have to prove fault?</b>	No
<b>Can I apply for other benefits?</b>	Yes, benefits are in addition to your right to claim at common law.
<b>Can my family apply?</b>	If you were working at the time of your diagnosis and you die because of your asbestos-related disease, your dependants may also receive entitlements. Your lawyer will discuss this with you and your family.
<b>How to make a claim</b>	You or your lawyer can submit an application to the Dust Diseases Board. Visit <a href="http://ddb.nsw.gov.au">ddb.nsw.gov.au</a> .



## Victoria



## Queensland

*Workplace Injury Rehabilitation and Compensation Act 2013*

*Workers' Compensation and Rehabilitation Act 2003*

People exposed to asbestos in the course of their employment after 31 August 1985

People exposed to asbestos while working in Queensland

Payment for pain and suffering, past and future medical expenses, past and future loss of income, cost of assistance around the home, and travel to medical appointments.

Lump sum compensation. It doesn't matter if you are retired or still working.

No

No

You may be entitled to workers' compensation benefits and superannuation and total permanent disability claims.

You may be entitled to workers' compensation benefits, and superannuation and total permanent disability claims.

If you were working at the time of your diagnosis and you die because of your asbestos-related disease, your dependants may also receive entitlements. Your lawyer will discuss this with you and your family.

If you were working at the time of your diagnosis and you die because of your asbestos-related disease, your dependants may also receive entitlements. Your lawyer will discuss this with you and your family.

Contact WorkSafe Victoria:  
**[worksafe.vic.gov.au](http://worksafe.vic.gov.au)**

Contact WorkCover Queensland:  
**[worksafe.qld.gov.au](http://worksafe.qld.gov.au)**

*As state and territory statutory compensation schemes are subject to change from time to time, the information in this table may not reflect any recent amendments. You need to obtain up-to-date advice from an experienced lawyer.*



## South Australia

<b>Name of the Act</b>	<i>Return to Work Act 2014</i>
<b>Who can make a claim</b>	People exposed to asbestos while employed in South Australia
<b>What are my entitlements?</b>	Weekly payments of 100% from 0–52 weeks, 80% from 53 weeks until retirement age. Medical, health and support services will be provided for the life of the worker.
<b>Do I have to prove fault?</b>	No
<b>Can I apply for other benefits?</b>	Yes, benefits are in addition to your right to claim at common law.
<b>Can my family apply?</b>	If you were working at the time of your diagnosis and you die because of your asbestos-related disease, your dependants may also receive entitlements. Your lawyer will discuss this with you and your family.
<b>How to make a claim</b>	Contact ReturnToWorkSA: <b>rtwsa.com.</b>





## Western Australia



## Tasmania

*Workers' Compensation and Injury Management Act 1981*

People who have at least 15% impairment as determined by a Medical Assessment Panel

Lump sum compensation is available if you were exposed to asbestos as an employee in Western Australia, although the compensation awarded is much less than at common law.

No

Yes, benefits are in addition to your right to claim at common law.

If you were working at the time of your diagnosis and you die because of your asbestos-related disease, your dependants may also receive entitlements. Your lawyer will discuss this with you and your family.

File a claim with your employer's insurer. If unknown, file with Insurance Commission of Western Australia: [icwa.wa.gov.au](http://icwa.wa.gov.au).

*Asbestos-Related Diseases (Occupational Exposure) Compensation Act 2011*

People exposed to asbestos while working as an employee in Tasmania

Lump sum payment with an additional payment for those under 80 years of age, with the amount dependent on your age at diagnosis, plus medical and funeral expenses.

No

Yes, but you must apply for compensation under the *Asbestos-Related Diseases (Occupational Exposure) Compensation Act 2011* before you can begin action for common law damages.

Yes, if you were eligible for compensation but die before you can make a claim, your family has 12 months to apply.

Complete the claim form available from [worksafe.tas.gov.au/compensation/asbestos\\_compensation](http://worksafe.tas.gov.au/compensation/asbestos_compensation).

*As state and territory statutory compensation schemes are subject to change from time to time, the information in this table may not reflect any recent amendments. You need to obtain up-to-date advice from an experienced lawyer.*



## Northern Territory

<b>Name of the Act</b>	<i>Return to Work Act</i>
<b>Who can make a claim?</b>	People exposed to asbestos while employed in the Northern Territory
<b>What are my entitlements?</b>	Weekly payments plus medical, surgical and rehabilitation treatment costs.
<b>Do I have to prove fault?</b>	No
<b>Can I apply for other benefits?</b>	May be entitled to compensation under other laws, in which case won't be entitled to compensation under this Act.
<b>Can my family apply?</b>	If you were working at the time of your diagnosis and you die because of your asbestos-related disease, your dependants may also receive entitlements. Your lawyer will discuss this with you and your family.
<b>How to make a claim</b>	Contact NT WorkSafe: <b><a href="http://worksafe.nt.gov.au">worksafe.nt.gov.au</a></b> .



## ACT



## Commonwealth

### *Workers Compensation Act 1951*

People who have at least 15% impairment as determined by a Medical Assessment Panel

Lump sum compensation is available if you were exposed to asbestos as an employee in the ACT, although the compensation awarded is much less than at common law.

No

Yes, benefits are in addition to your right to claim at common law.

Discuss your dependants' entitlements with your lawyer.

Contact WorkSafe ACT:  
**worksafe.act.gov.au.**

### *Safety, Rehabilitation and Compensation Act 1988*

Current and former Commonwealth Government employees, including former members of the armed forces, if they were exposed to asbestos during the course of their employment

Lump sum plus medical expenses. The amount of the lump sum is determined by the level of disability at the time of the application, with further applications required as your condition deteriorates.

No

If you make a claim through Comcare, you cannot also make a claim at common law. However, your dependants may bring a 'dependency claim' later on. This claim will not affect the common law claim made in the lifetime of the person with pleural mesothelioma.

Contact Comcare:  
**comcare.gov.au.**

*As state and territory statutory compensation schemes are subject to change from time to time, the information in this table may not reflect any recent amendments. You need to obtain up-to-date advice from an experienced lawyer.*



# Looking after yourself

Cancer can cause physical and emotional strain. It's important to try to look after your wellbeing as much as possible.

**Nutrition** – Eating healthy food can help you cope with treatment and side effects. A dietitian can help you manage special dietary needs or eating problems, and choose the best foods for your situation. Call Cancer Council 13 11 20 for a free copy of the *Nutrition and Cancer* booklet.

**Staying active** – Physical activity often helps to reduce tiredness, improve circulation and elevate mood. The amount and type of exercise you do depends on what you are used to, how you feel, and your doctor's advice. Cancer Council's *Exercise for People Living with Cancer* booklet provides more information about the benefits of exercise, and outlines simple exercises that you may want to try.

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

Alternative therapies are used instead of conventional medical treatments. These therapies, such as coffee enemas and magnet therapy, can be harmful. For more information, call 13 11 20 for a free copy of the *Understanding Complementary Therapies* booklet or download it from your local Cancer Council website.

## Relationships with others

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

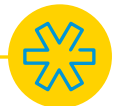
Give yourself time to adjust to what's happening, and do the same for others. People may deal with the cancer in different ways – for example, by being overly positive, playing down fears, or keeping a distance. It may be helpful to discuss your feelings with each other.

## Sexuality, intimacy and fertility

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

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

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





# Seeking support

Cancer may cause you to experience a range of emotions, such as fear, sadness, anxiety, anger or frustration. It can also cause practical and financial problems.

## Practical and financial help

There are many services that can help deal with practical or financial problems caused by the cancer. Benefits, pensions and programs can help pay for prescription medicines, transport costs or utility bills. Home care services, aids and appliances can also be arranged to help make life easier.

Ask the hospital social worker which services are available in your local area and if you are eligible to receive them.

If you need legal or financial advice, you should talk to a qualified professional about your situation.

Cancer Council offers free legal and financial services in some states and territories for people who can't afford to pay – call 13 11 20 to ask if you are eligible. You can also ask for a copy of *When cancer changes your financial plans* for information on managing finances, superannuation and work issues.

For information and advice on applying for compensation, it is best to contact a lawyer who has experience with asbestos claims. See page 59 for suggestions on finding a lawyer. You may also want to read the *Making a claim* chapter (pages 53–65) for an introduction to the compensation process.

## Talk to someone who's been there

Coming into contact with other people who have had similar experiences to you can be beneficial. You may feel supported and relieved to know that others understand what you are going through and that you are not alone.

In a support group, people often feel they can speak openly and share tips with others who have gone through a similar experience. You may find that you are comfortable talking about your diagnosis and treatment, relationships with friends and family, and hopes and fears for the future. Some people say they can be even more open and honest in these support settings because they aren't trying to protect their loved ones.

### Types of support

There are many ways to connect with others for mutual support and to share information. These include:

- **face-to-face support groups** – often held in community centres or hospitals
- **telephone support groups** – facilitated by trained counsellors
- **online forums** – such as [cancerconnections.com.au](http://cancerconnections.com.au).

Talk to your nurse, social worker or Cancer Council 13 11 20 about what is available in your area.

“ 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. ” *John*

## Asbestos diseases support groups

### New South Wales

<b>Asbestos Diseases Foundation of Australia (ADFA)</b>	<b>1800 006 196</b> adfa.org.au
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### Victoria

<b>Asbestoswise</b>	<b>03 9654 9555</b> asbestoswise.com.au
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<b>Gippsland Asbestos Related Diseases Support Inc (GARDS)</b>	<b>03 5127 7744</b> gards.org
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### Queensland

<b>Asbestos Related Disease Support Society Qld Inc</b>	<b>1800 776 412</b> asbestos-disease.com.au
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<b>Asbestosis and Mesothelioma Association of Australia (AMAA)</b>	<b>1800 017 758</b> asbestosassociation.com.au
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### South Australia

<b>Asbestos Diseases Society of South Australia Inc (ADSSA)</b>	<b>1800 157 540</b> adssa-inc.com.au
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<b>Asbestos Victims Association SA Inc</b>	<b>08 8212 6008, 1800 665 395</b> avasa.asn.au
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### Western Australia

<b>Asbestos Diseases Society of Australia Inc (ADSA)</b>	<b>1800 646 690</b> asbestosdiseases.org.au
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### Tasmania

<b>Asbestos Free Tasmania Foundation</b>	asbestosfreetasmania.org.au
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## Caring for someone with pleural mesothelioma

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

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

Support services such as Home Help, Meals on Wheels or visiting nurses can help you in your caring role. There are also many groups and organisations that can provide you with information and support, such as Carers Australia, the national body representing carers in Australia. Carers Australia works with the Carers Associations in each of the states and territories. Phone 1800 242 636 or visit [carersaustralia.com.au](http://carersaustralia.com.au) for more information and resources.

You can also call Cancer Council 13 11 20 to find out more about carers' services and to get a copy of the *Caring for Someone with Cancer* booklet.



# Question checklist

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

- What stage of pleural mesothelioma do I have?
- How far has the mesothelioma spread? How fast is it growing?
- What treatment do you recommend and why?
- Will my treatment be performed by a doctor who specialises in mesothelioma?
- How do I get a second opinion?
- Are there other treatment choices for me? If not, why not?
- Will I have surgery, chemotherapy or radiotherapy?
- What are the risks and possible side effects of each treatment?
- Will the treatment affect me sexually or physically? Will I be able to do the things I normally do?
- Is there anything that can be done to help control the side effects?
- How will I know if the treatment is working?
- What are my chances of cure?
- What if I decide not to have any treatment?
- Will I have to stay in hospital, or will I be treated as an outpatient?

- How long will the treatment take? How much will it affect my everyday activities?
- Will I have follow-up appointments after my treatment is over?
- Who will I see if I am worried in between my appointments?
- Are there any clinical trials of new treatments that I could join?
- Will I have pain from the mesothelioma? What will be done about this?
- I'm worried about what will happen to me: who can I talk to about my feelings?
- Will others in my family also be at risk of developing pleural mesothelioma?
- Is it harmful to take supplements or vitamins while I am having treatment?
- Who do I contact about claiming compensation for my illness?
- What practical help is available for me?
- Is there anyone else with mesothelioma I can speak to?
- How much will treatment cost? How can the cost be reduced?
- What do I do if I become unwell and cannot see my GP?



# Useful websites

## Australian

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Cancer Council Australia.....	<b>cancer.org.au</b>
Cancer Australia.....	<b>canceraustralia.gov.au</b>
Carers Australia.....	<b>carersaustralia.com.au</b>
Department of Health.....	<b>health.gov.au</b>
healthdirect Australia.....	<b>healthdirect.gov.au</b>
Palliative Care Australia.....	<b>palliativecare.org.au</b>

## Asbestos and mesothelioma specific

Asbestos Diseases Research Institute.....	<b>adri.org.au</b>
Asbestos Diseases Foundation of Australia.....	<b>adfa.org.au</b>
Australian Asbestos Network.....	<b>australianasbestosnetwork.org.au</b>
Australian Mesothelioma Registry.....	<b>mesothelioma-australia.com</b>
Bernie Banton Foundation.....	<b>berniebantton.com.au</b>
Workers Compensation Dust Disease Board.....	<b>ddb.nsw.gov.au</b>
Lung Foundation Australia.....	<b>lungfoundation.com.au</b>

## International

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American Cancer Society.....	<b>cancer.org</b>
Cancer Research UK.....	<b>cancerresearch.org.uk</b>
Macmillan Cancer Support.....	<b>macmillan.org.uk</b>
US National Cancer Institute.....	<b>cancer.gov</b>

## Asbestos and mesothelioma specific

Asbestos (The Mesothelioma Center).....	<b>asbestos.com</b>
International Mesothelioma Interest Group.....	<b>imig.org</b>
Mesothelioma UK.....	<b>mesothelioma.uk.com</b>
Pleural Mesothelioma Center.....	<b>pleuralmesothelioma.com</b>



# Glossary

## **abdomen**

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

## **adjuvant therapy**

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

## **advanced cancer**

Cancer that has spread and is less likely to be cured.

## **alternative therapies**

Therapies that are used in place of conventional treatment, but not based on scientific evidence. They can be expensive, unproven and sometimes harmful.

## **anaesthetic**

A drug that stops a person feeling pain during a medical procedure. A local anaesthetic numbs part of the body; a general anaesthetic causes temporary loss of consciousness.

## **anti-cancer treatments**

A medicine or procedure used to reduce or destroy cancer and cancer cells. Includes surgery, chemotherapy and radiotherapy.

## **asbestos**

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

## **asbestosis**

A slowly progressing lung disease caused by asbestos.

## **asbestos-related diseases**

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

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

## **benign**

Not cancerous or malignant.

## **biopsy**

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

## **biphasic**

Mesothelioma that is made up of both epithelioid and sarcomatoid cells.

These make up about 25% of all cases of mesothelioma. Also called mixed.

## **breathlessness**

The sensation of shortness of breath or difficulty breathing.

## **cancer**

A disease of the body's cells that starts in the genes. Damaged genes cause cells to behave abnormally, and they may grow into a lump called a tumour.

## **cells**

These are the basic building blocks of the body. A human is made of billions of cells, which are adapted for different functions.

## **chemotherapy**

The use of cytotoxic drugs to treat cancer by killing cancer cells or slowing their growth. Chemotherapy can also harm normal cells, but they are usually able to repair themselves.

## **chest cavity**

The area enclosed by the ribs that includes the lungs, pleura, heart and cardiovascular vessels.

**clinical trial**

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

**complementary therapies**

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

**CT-guided core biopsy**

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

**CT scan**

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

**decortication**

Surgical removal of a layer of connective tissue covering the lung, chest wall and diaphragm to allow the lung to re-expand.

**diagnosis**

The identification and naming of a person's disease.

**diaphragm**

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

**epithelioid**

A cell that resembles normal mesothelial cells. The cells that line the surface of body organs and cavities. A type of pleural mesothelioma.

**extrapleural pneumonectomy (EPP)**

Surgery to remove the affected

lung, plus the lining of the heart (pericardium), the diaphragm and the lining of the chest (parietal pleura) on the affected side.

**FDG-PET**

A fluorodeoxyglucose-positron emission tomography scan. This scan produces a 3D image of the body using biologically active molecules, such as fluorodeoxyglucose (FDG), that is injected into the body to show up cancer cells. When combined with a CT (computed tomography) scan it is called an FDG-PET-CT.

**fine-needle biopsy (FNA)**

The removal of tissue with a fine needle for examination under a microscope.

**genes**

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

**induction chemotherapy**

The first chemotherapy treatment used to make further treatments (surgery or radiotherapy) more effective.

**indwelling pleural drain**

A soft tube inserted into the pleural cavity to help drain a build-up of pleural fluid.

**intensity-modulated radiation therapy (IMRT)**

The use of multiple beams of radiation to target a tumour. The radiation beams are shaped to closely fit the area of cancer.

**latency period/interval**

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

**lungs**

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

**lymphatic system**

A network of tissues, capillaries, vessels, ducts and nodes that remove excess fluid from tissues, absorb fatty acids and transport fat, and produce immune cells.

**lymph nodes**

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

**malignant**

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

**malignant mesothelioma**

Cancer that starts in the mesothelial cells that line parts of the body, such as the chest cavity or abdominal cavity.

**mediastinoscopy**

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

**mediastinum**

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

**medical oncologist**

A doctor who specialises in treating

cancer with chemotherapy, hormonal therapy, biological therapy and targeted therapies.

**mesothelium**

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

**metastasis**

A cancer that has spread from another part of the body. Also known as secondary cancer.

**multidisciplinary team (MDT)**

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

**palliative care**

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

**palliative treatment**

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

**parietal pleura**

The outer layer of the pleura, lining the walls of the chest cavity.

**pemetrexed (Alimta®)**

A chemotherapy drug used to treat malignant mesothelioma.

**pericardium**

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

**peritoneum**

The lining of the abdomen.

**pleura**

A thin sheet of tissue that lines the chest wall and cover the lungs. It has two layers: parietal and visceral.

**pleural cavity**

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

**pleural effusion**

A collection of fluid between the two sheets of tissue that cover the lungs.

**pleural fluid**

Fluid that builds up between the two layers of the pleura.

**pleural plaque**

A localised area of fibrous thickening sometimes containing calcium material on the pleura, which can be seen on x-rays of people exposed to asbestos. Strongly linked to inhaling asbestos.

**pleural thickening**

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

**pleurectomy**

Surgical procedure to remove part of the pleura.

**pleuritic pain**

Pain caused by inflammation of the pleura. It can be sudden and sharp, stabbing, burning or dull, and occur during breathing, especially when inhaling and exhaling.

**pleurodesis**

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

**precancerous**

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

**prognosis**

The predicted outcome of a person's disease.

**pulmonary decortication**

Surgical procedure to remove some of the linings of the chest wall and lung.

**radiation oncologist**

A doctor who specialises in treating cancer with radiotherapy.

**radical radiotherapy**

High-dose radiotherapy aimed at treating all areas where cancer cells are likely to remain after surgery.

**radical surgery**

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

**radiotherapy**

The use of radiation, usually x-rays or gamma rays, to kill cancer cells or injure them so they cannot grow or multiply.

**sarcomatoid**

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

**second line chemotherapy**

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

**serous membrane**

A smooth membrane consisting of a



thin layer of cells that secrete fluid, and an underlying thin epithelial layer.

#### **spiral CT scan**

A computerised tomography scan that scans the body in a spiral path (helical pattern) to create clearer pictures.

#### **staging**

Performing tests to determine how far a cancer has spread.

#### **symptom**

Change in normal function or feeling that is noticed by the patient and indicates there is something wrong.

#### **systemic treatment**

Treatment that affects the whole body.

#### **thoracotomy**

A type of surgery. A cut is made into the pleural cavity of the chest.

#### **tinnitus**

Continuous ringing in the ears.

#### **tissue**

A collection of cells that make up a part of the body.

#### **TNM**

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

#### **trimodality therapy**

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

#### **tumour**

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

#### **tunica vaginalis**

A pouch of serous membrane covering the testicles.

#### **video-assisted thoracoscopic surgery (VATS)**

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

#### **visceral pleura**

The inner layer of pleura that is attached to the external lung tissue.

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## How you can help

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

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

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

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

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

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

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



# Cancer Council 13 11 20

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

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

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

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

Cancer Council services and programs vary in each area.

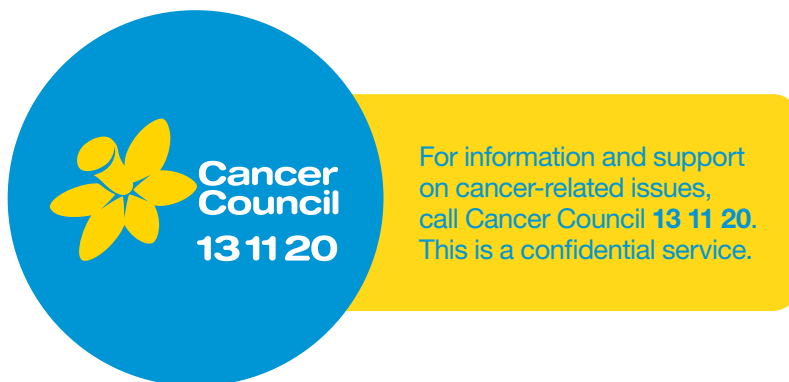
13 11 20 is charged at a local call rate throughout Australia (except from mobiles).



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



**If you are deaf, or have a hearing or speech impairment, contact us through the National Relay Service.**  
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