

Understanding Mesothelioma

A guide for people with cancer, their families and friends



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First published as *Understanding Pleural Mesothelioma* June 2015. This edition February 2023.

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Understanding Mesothelioma is reviewed approximately every 2 years. Check the publication date above to ensure this copy is up to date.

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Acknowledgements

This edition has been developed by Cancer Council NSW on behalf of all other state and territory Cancer Councils as part of a National Cancer Information Subcommittee initiative. We thank the reviewers of this booklet: Dr Anthony Linton, Medical Oncologist, Concord Cancer Centre and Concord Repatriation General Hospital, NSW; Dr Naveed Alam, Thoracic Surgeon, St Vincent's Hospital Melbourne and Monash Medical Centre, VIC; Donatella Arnoldo, Consumer; Polly Baldwin, 13 11 20 Consultant, Cancer Council SA; Dr Melvin (Wee Loong) Chin, Medical Oncologist, Sir Charles Gairdner Hospital and National Centre for Asbestos Related Diseases, WA; Prof Kwun Fong, Thoracic and Sleep Physician and Director, UQ Thoracic Research Centre, The Prince Charles Hospital, and Professor of Medicine, The University of Queensland, QLD; Vicki Hamilton OAM, Consumer and CEO, Asbestos Council of Victoria/GARDS Inc., VIC; Dr Susan Harden, Radiation Oncologist, Peter MacCallum Cancer Centre, VIC; Penny Jacomos, Social Worker, Asbestos Diseases Society of South Australia, SA; Prof Brian Le, Director, Parkville Integrated Palliative Care Service, The Royal Melbourne Hospital and Peter MacCallum Cancer Centre, VIC; Lung Cancer Support Nurses, Lung Foundation Australia; Jocelyn McLean, Mesothelioma Support Coordinator, Asbestos Diseases Research Institute, NSW; Prof David Morris, Peritonectomy Surgeon, St George Hospital and UNSW, NSW; Joanne Oates, Registered Occupational Therapist, Expert Witness in Dust Diseases, and Director, Evaluate, NSW; Chris Sheppard and Adam Barlow, RMB Lawyers. We also thank the health professionals, consumers and editorial teams who have worked on previous editions of this title. Previous editions of this title and related resources were funded in part by the Heads of Asbestos Coordination Authorities and a donation from Lyall Watts.

Note to reader

Always consult your doctor about matters that affect your health. This booklet is intended as a general introduction to the topic and should not be seen as a substitute for medical, legal or financial advice. You should obtain independent advice relevant to your specific situation from appropriate professionals, and you may wish to discuss issues raised in this book with them. All care is taken to ensure that the information in this booklet is accurate at the time of publication. Please note that information on cancer, including the diagnosis, treatment and prevention of cancer, is constantly being updated and revised by medical professionals and the research community. Cancer Council Australia and its members exclude all liability for any injury, loss or damage incurred by use of or reliance on the information provided in this booklet.

Cancer Council

Cancer Council is Australia's peak non-government cancer control organisation. Through the 8 state and territory Cancer Councils, we provide a broad range of programs and services to help improve the quality of life of people living with cancer, their families and friends. Cancer Councils also invest heavily in research and prevention. To make a donation and help us beat cancer, visit cancer.org.au or call your local Cancer Council.



Cancer Council acknowledges Traditional Custodians of Country throughout Australia and recognises the continuing connection to lands, waters and communities. We pay our respects to Aboriginal and Torres Strait Islander cultures and to Elders past, present and emerging.



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About this booklet

This booklet has been prepared to help you understand more about mesothelioma, which is also known as pleural mesothelioma and peritoneal mesothelioma.

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

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

This booklet does not need to be read from cover to cover – just read the parts that are useful to you. Some medical terms that may be unfamiliar are explained in the glossary (see page 75). You may also like to pass this booklet to family and friends for their information.

How this booklet was developed – This information was developed with help from a range of health professionals and people affected by mesothelioma. It is based on Australian and international clinical practice guidelines for mesothelioma.^{1, 4}



If you or your family have any questions or concerns, call **Cancer Council 13 11 20**. We can send you more information and connect you with support services in your area. You can also visit your local Cancer Council website (see back cover).



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Key to icons

Icons are used throughout this booklet to indicate:



More information



Alert



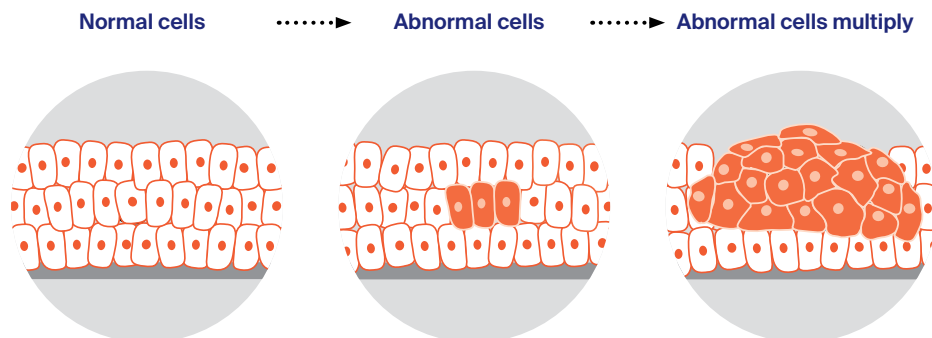
Tips

What is cancer?

Cancer is a disease of the cells. Cells are the body's basic building blocks - they make up tissues and organs. The body constantly makes new cells to help us grow, replace worn-out tissue and heal injuries. Normally, cells multiply and die in an orderly way, so that each new cell replaces one lost. Sometimes, however, cells become abnormal and keep growing. These abnormal cells may turn into cancer.

In solid cancers, such as mesothelioma, the abnormal cells form a mass or lump called a tumour. In some cancers, such as leukaemia, the abnormal cells build up in the blood.

How cancer starts

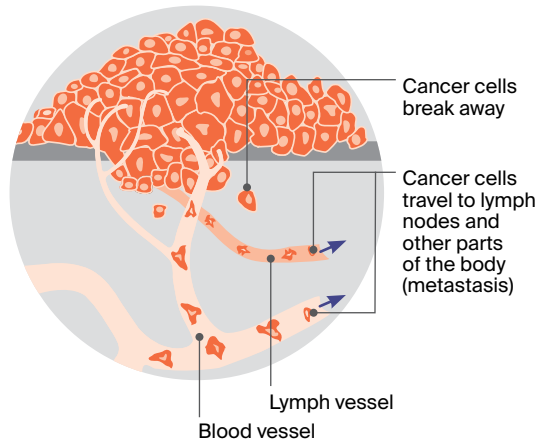
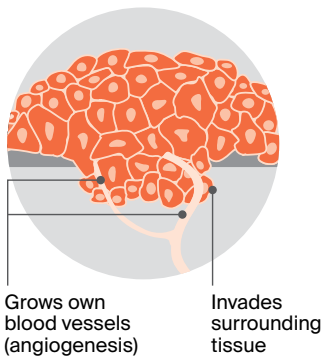


Not all tumours are cancer. Benign tumours tend to grow slowly and usually don't move into other parts of the body or turn into cancer. Cancerous tumours, also known as malignant tumours, have the potential to spread. They may invade nearby tissue, destroying normal cells. The cancer cells can break away and travel through the bloodstream or lymph vessels to other parts of the body.

The cancer that first develops in a tissue or organ is called the primary cancer. If the primary cancer cells grow and form another tumour at a new site, it is called a secondary cancer or metastasis. A metastasis keeps the name of the original cancer. For example, mesothelioma that has spread to the liver is called metastatic mesothelioma, even though the main symptoms may be coming from the liver.

How cancer spreads

.....▶ Malignant cancer





What is mesothelioma?

Mesothelioma is a type of cancer that starts from mesothelial cells. These cells line the surface of most of the internal organs and body cavities, creating a protective membrane called the mesothelium. Some mesotheliomas form a mass (tumour), while others grow along the mesothelium and form a thick covering. In later stages, mesothelioma may spread (metastasise) to other parts of the body.

Pleural mesothelioma

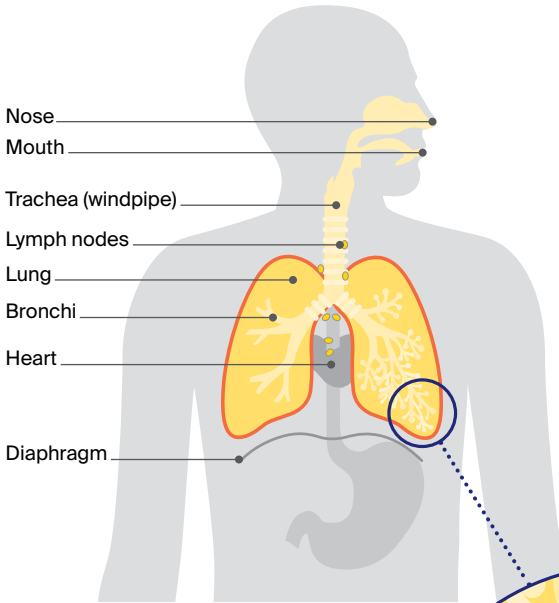
The mesothelium (protective membrane) that covers each lung is called the pleura. Mesothelioma that develops in the pleura is called pleural mesothelioma, and accounts for about 95% of mesothelioma cases. Pleural mesothelioma is not the same as lung cancer – it is diagnosed and treated differently.

The pleura

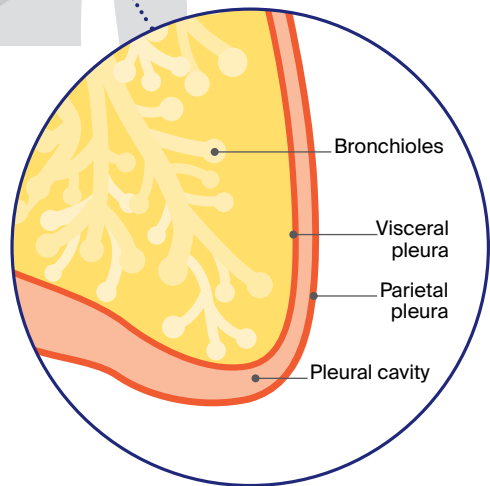
There are 2 layers of tissue in the pleura. The inner layer (the visceral pleura) covers the lung surface, and the outer layer (the parietal pleura) lines the chest wall and diaphragm. Mesothelioma causes these 2 layers of the pleura to thicken. They can then press on the lung, stopping it expanding when you breathe in (inhale).

Between the 2 layers of the pleura is the pleural cavity (also called the pleural space), which normally contains a thin film of fluid. This fluid allows the 2 layers of pleura to slide over each other – so the lungs move smoothly against the chest wall when you breathe. When too much fluid collects in the pleural cavity, it is called pleural effusion.

The respiratory system



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



Peritoneal mesothelioma

The mesothelium (protective membrane) that covers the organs and lines the walls of the abdomen and pelvis is called the peritoneum.

Mesothelioma that develops in the peritoneum is known as peritoneal mesothelioma. It is far less common than pleural mesothelioma (which is found around the lungs), and accounts for less than 5% of all mesotheliomas.

The peritoneum

There are 2 layers of thin tissue in the peritoneum. The inner layer (the visceral peritoneum) lines the surface of organs such as the bowel, liver and ovaries. The outer layer (the parietal peritoneum) lines the walls of the abdomen and pelvis.

Between the 2 layers of the peritoneum is the peritoneal cavity, which normally contains a very thin film of fluid. This fluid allows the 2 layers to slide over each other. In people with peritoneal mesothelioma, too much fluid often collects between the 2 layers in this cavity. This is called ascites or peritoneal effusion.

Mesothelioma in other parts of the body

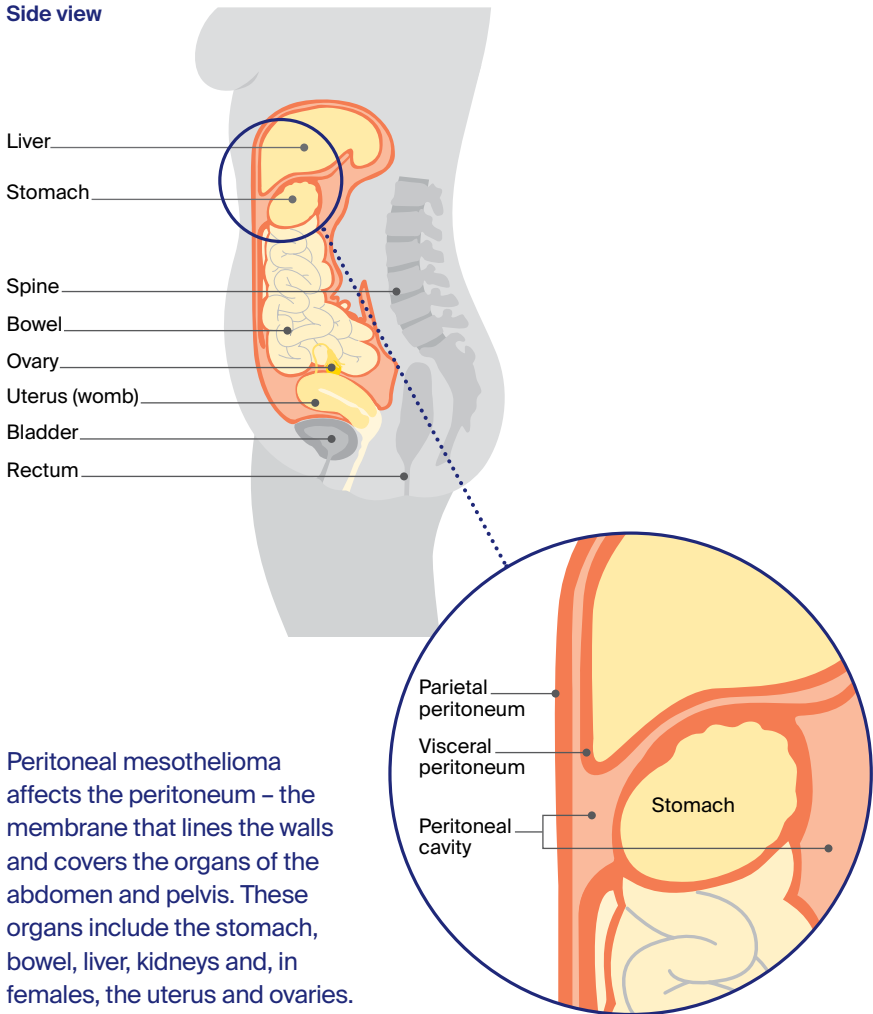
In rare cases, mesothelioma can develop in the pericardium, which is the lining of the heart. This is called pericardial mesothelioma.

Even more rarely, mesothelioma can occur in the membrane that surrounds the testicles, known as the tunica vaginalis. This is called testicular mesothelioma.

- ▶ See our *Understanding Rare and Less Common Cancers* booklet for more information.

The abdomen and pelvis

Side view



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

Key questions

Q: What causes mesothelioma?

A: Exposure to asbestos fibres or asbestos dust is the cause of most (9 out of 10) cases of mesothelioma. But in some cases there is no clear link to asbestos.

Asbestos is the name for a group of naturally occurring minerals that are resistant to high temperatures and humidity. Asbestos was used in many building products in Australia from the 1940s until 1987. Since 2004, Australia has banned asbestos being sold, reused and/or imported. Despite the ban, asbestos is still found in many older buildings, so special care needs to be taken when renovating. Asbestos has also been found in some products from overseas.

People who may have been exposed to asbestos at work include: builders, plumbers, gasfitters and electricians; metal-fitters, turners and toolmakers; boilermakers and welders; steelworkers; asbestos miners; asbestos cement manufacturing workers; insulators; automotive industry workers; mechanics; transport workers (especially waterside workers); telecommunications technicians; and textile workers.

People cleaning work clothes with asbestos fibres on them, or spending time in areas where asbestos has been disturbed during renovations or maintenance, can also develop mesothelioma.

It can take many years for mesothelioma to develop after a person is exposed to asbestos. It is often around 40 years after exposure, but may be 10–60 years. This is called the latency period or interval.

Q: How common is mesothelioma?

A: Australia has one of the highest rates of mesothelioma in the world, with an estimated 900 Australians diagnosed each year.² Men are 4 times more likely than women to be diagnosed with pleural mesothelioma. This is probably because asbestos exposure is more common in jobs that were traditionally done by men, such as building and plumbing.

Pleural mesothelioma makes up about 95% of mesothelioma cases. Peritoneal mesothelioma is less common and makes up less than 5% of cases. Mesothelioma is more common in people over the age of 65, but it can occur in younger people.

Q: What can I expect?

A: The plan for what happens if you have mesothelioma can vary from person to person, but is usually as follows:

- **Diagnosis and staging (pages 16–22)** – You will have various tests to confirm a diagnosis of mesothelioma and work out how far it has progressed. The results will help you and your health professionals make decisions about treatment.
- **Treatment (pages 28–38)** – Depending on how advanced the mesothelioma is and other factors, treatment may achieve a longer period of disease control and improve quality of life.
- **Managing symptoms (pages 39–56)** – For many people, the main goal of treatment will be to manage symptoms and improve quality of life. Depending on how mesothelioma affects your health, you may have periods of relatively good health when symptoms are under control or less active. You may also have periods when symptoms need to be relieved with more intensive treatment.

Q: What are the symptoms?

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

Pleural mesothelioma may cause:

- shortness of breath (breathlessness), which usually feels worse with activity or when you are lying down
- pain in the chest around the ribs or in the shoulder, which may be sharp and stabbing, worse with deep breaths, or dull and persistent
- extra-sensitive skin or change in skin sensation (less common)
- general symptoms such as loss of appetite with weight loss; loss of muscle bulk; fatigue or loss of energy; a persistent cough or a change in coughing pattern; and night sweats.

Peritoneal mesothelioma may cause:

- abdominal pain
- a swollen abdomen
- poor appetite, nausea and vomiting
- unexplained increase in fatigue and low energy
- night sweats or fever
- bowel or urinary problems.



For an overview of what to expect at every stage of your pleural mesothelioma cancer care, visit cancer.org.au/cancercareguides/pleural-mesothelioma. This is a short guide to what is recommended, from diagnosis to treatment and beyond.



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

Q: Can I seek compensation?

A: People who develop mesothelioma due to asbestos exposure may be able to make a claim for compensation. It's helpful to make notes and talk to family and friends about when and where you may have been exposed to asbestos.

It is important to get advice from an experienced lawyer as soon as possible after diagnosis, because a case for compensation must be started within your lifetime. Mesothelioma or asbestos support groups may be able to help you with more information about seeking compensation. See pages 63–68 to read more.

Q: Which health professionals will I see?

A: Your GP will arrange the first tests to assess your symptoms. If these tests do not rule out mesothelioma, you will usually be referred to a specialist, such as a respiratory physician or gastroenterologist. The specialist will arrange further tests.

If mesothelioma is diagnosed, the specialist will consider the treatment options. Often these will be discussed with other health professionals at what is known as a multidisciplinary team (MDT) meeting. During and after treatment, you will see a range of health professionals who specialise in different aspects of your care (see next page).

Health professionals you may see

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

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



Diagnosis

Mesothelioma can be difficult to diagnose because the symptoms are similar to other health problems. Mesothelioma cells can look similar to other types of cancer cells or even like normal cells.

The process for diagnosing mesothelioma often starts after seeing your GP or going to a hospital emergency department with shortness of breath, pain or another symptom. The doctor will examine you and take a history of your general health.

If you think that you may have been exposed to asbestos – even if it was a long time ago – it’s important to let your doctor know. They will send you for initial tests and then refer you to a specialist – usually a respiratory physician (for chest symptoms) or a gastroenterologist (for abdominal symptoms).

You are likely to have several tests and see a range of different health professionals (see pages 14–15) before a diagnosis of mesothelioma is made. This process can feel long and frustrating.

Initial tests

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

Blood test

You will have blood taken to check your general health and let your doctors know how your blood cells, liver and kidneys are working. This helps them work out your fitness for any treatment.

Mesothelioma does not usually show up on a blood test, but results may show substances (called markers) that are produced by cancer cells.

X-ray

If you have chest symptoms, you may first have a chest x-ray to look for any changes in the lungs, thickening of the pleura, and fluid in the space between the lungs and the chest wall. If you have abdominal symptoms, an x-ray may look for changes in the abdomen, such as fluid and thickening in the peritoneum.

If fluid, thickening or other changes are found, you will need more tests to check whether mesothelioma or another condition is the cause.

Mesothelioma does not always show up on an x-ray and can be hidden by other organs within the chest cavity. So let your doctor know if you think you may have been exposed to asbestos so that they can investigate further.

CT scan

If mesothelioma is suspected, you will usually have a CT scan. A CT (computerised tomography) scan uses x-ray beams and a computer to take detailed cross-sectional pictures of the inside of your body. Most CT scans are done at a hospital or radiology clinic and you can usually go home as soon as the test is over. You may be asked not to eat or drink (fast) for several hours leading up to having the scan.



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

Immediately before the scan, you will be given an injection of a liquid dye into a vein. This dye is known as contrast, and it makes the pictures clearer. The contrast may make you feel flushed or hot all over and leave a bitter taste in your mouth, and you may feel sick or feel a sudden urge to pee. These feelings should pass quickly, but tell someone if you feel unwell.

The CT scanner is a large, doughnut-shaped machine. You will need to lie still on a table while the scanner moves around you. Getting ready for the scan can take 10–30 minutes, but the scan itself takes only a few minutes and is painless. Lying flat and still can be uncomfortable, so speak to your doctor or radiologist about any discomfort.

The CT scan shows the location and thickness of the tumour/s in the chest or abdomen. It may also show if the mesothelioma has spread to other organs. The information from the CT scan is used to work out the best way to get tissue for testing (called a biopsy).

Biopsy

A biopsy is the main test used to diagnose mesothelioma. It involves removing a sample of tissue, which is examined under a microscope by a specialist doctor called a pathologist.

The pathologist looks for cell changes to work out if the tumour is mesothelioma and, if so, the type of mesothelioma cells present.

There are 3 main types of mesothelioma cells :

Epithelioid – cells look similar to normal mesothelial cells. This is the most common type, making up about 75% of cases.

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

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

Ways to take a biopsy for mesothelioma

A biopsy can be taken in different ways. The choice of biopsy will depend on your general health and fitness, and how suitable the tumour is for sampling using one of the methods described below and on the next 2 pages. Keyhole surgery (VATS or laparoscopy) is the most common biopsy technique, as both tissue samples and fluid can be removed for testing. Obtaining a sample can be challenging, so a respiratory physician or gastroenterologist, radiologist, surgeon and pathologist may all be involved.

Video-assisted thoracoscopic surgery (VATS) – Sometimes called a thoracoscopy, VATS is used to obtain a tissue sample from the lining of the lungs (pleura). You will be given a general anaesthetic, then a thin tube with a light and camera (thoracoscope) will be inserted through a few small cuts in your chest. Tissue samples can be taken through the tube and sent to a laboratory for testing. If fluid has built up around the lungs and is causing breathlessness, it can be drained during the VATS (see page 21) and you may have a pleurodesis to prevent the fluid building up again (see pages 42 and 44). You will usually be given medicine for any pain you feel after VATS.

Laparoscopy – This is used to get a tissue sample from the lining of the abdomen (peritoneum). You will be given a general anaesthetic, then a thin tube with a light and camera will be inserted through small cuts made in your abdomen. Tissue samples can be removed through

the tube and sent to a laboratory for testing. If fluid has built up in the abdomen, it can be drained during the laparoscopy. Any infections that develop will be treated with antibiotics.

CT-guided core biopsy – A CT-guided core biopsy may be used instead of VATS or laparoscopy when there is a large mass but no fluid. You will be given a local anaesthetic. Using a CT scan for guidance, the doctor inserts a needle through the skin to remove a small piece of tumour from the lining of the lungs or abdomen.

During a CT-guided core biopsy, you will need to lie still on a table for about 30 minutes. You will be monitored for a few hours afterwards. There is a small risk of damaging the lung, but this can be treated if it does occur.

Other tests

PET-CT scan – A PET (positron emission tomography) combined with a CT scan may be used to see how far mesothelioma has spread. It is usually available at major hospitals. A small amount of radioactive glucose solution is injected into a vein, usually in your arm. You will sit quietly for 30–90 minutes as the glucose solution travels around your body. You then lie on a table that moves through the scanning machine very slowly. Cancer cells take up more of the glucose solution than normal cells, so they show up brighter on the scan. This test is painless.

Molecular tests and special stains – To confirm a diagnosis of mesothelioma, the pathologist sometimes needs to do further tests on the tissue sample. These are known as molecular tests and special stains. They look for specific molecules that help to tell mesothelioma apart from other types of cancer.

Draining build-up of fluid

When you first have symptoms of mesothelioma, you are likely to have a build-up of fluid in the space around your lungs or in your abdomen. Fluid around the lungs is called pleural effusion and can make it hard to breathe. Fluid in the abdomen is called ascites and may make it swollen and uncomfortable.

Before further tests or treatment, your doctor may drain the collection

of fluid to help ease symptoms. When fluid is drained from the pleura, it is called a pleural tap, pleurocentesis or thoracentesis; when fluid is drained from the peritoneum, it is called a peritoneal tap or paracentesis (see pages 42–45).

Draining the fluid may be done at the same time as VATS or laparoscopy and the fluid may be tested to look for mesothelioma (see below).

Diagnosis from fluid samples

Sometimes a fluid sample may be used to help make a diagnosis of mesothelioma – particularly if you are not well enough to have a biopsy. In this case, fluid is collected at the same time as draining the pleural or peritoneal cavity.

It can be hard to diagnose mesothelioma from these fluid samples, because abnormal mesothelioma cells often look similar to other cells. To be as accurate as possible, this technique should be done at a specialist centre. This is because a large volume of fluid must be collected, and the results have to be combined with information from an x-ray and CT scan.



Sometimes, even after several tests, doctors may be unsure of the diagnosis and some tests may need to be repeated. This is common when trying to diagnose mesothelioma.

Staging mesothelioma

If mesothelioma is diagnosed, you will have tests to work out the extent of the disease and if it has spread to other parts of the body. This is called staging, and helps your health care team recommend the best treatment for you. The main tests used are a CT or a PET-CT scan. If you already had a CT or PET-CT scan during diagnosis, which showed advanced disease, a further scan may not be necessary.

Staging systems for mesothelioma

Staging can be difficult for mesothelioma. Doctors use the systems described below to stage the different types of mesothelioma.

TNM staging system for pleural mesothelioma

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

T
(tumour)
1–4

Describes if the pleural mesothelioma has grown in and beyond the pleural cavity. The higher the number, the further it has grown. If limited to the pleura on one side of the chest, it is T1. If it has grown into the lung, nearby ribs, lining of the heart or beyond, it is T2, T3 or T4.

N
(node)
0–2

Shows if pleural mesothelioma has spread to lymph nodes. No lymph nodes affected is N0; spread only to lymph nodes in the chest is N1; spread to lymph nodes in the neck is N2.

M
(metastasis)
0–1

Shows if pleural mesothelioma has spread to other parts of the body. M0 means no spread to distant organs; M1 means it has spread to the bones, liver or other distant organs.

PCI system for peritoneal mesothelioma

Peritoneal mesothelioma is usually staged using the peritoneal cancer index (PCI). The area of the abdomen and pelvis is divided into 13 regions. A score out of 3 is given to any tumours found in these regions. The PCI is calculated by adding together the scores for all 13 regions, with a maximum score of 39. The higher the PCI, the further the cancer has spread.

Tests before surgery

If radical surgery is being considered as a suitable treatment option (part of trimodal therapy, see pages 34–36), you may have other scans and procedures to check whether mesothelioma has spread to other areas of the body. These tests may include:

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

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

Endobronchial ultrasound (EBUS) – This is a type of bronchoscopy that allows the doctor to see the trachea and deep into the lung. It can also take samples of cells from a tumour or lymph nodes in the middle of your chest (mediastinum) or next to the airways, or from the outer parts of the lung. Samples of lymph nodes can help to confirm whether or not they are also affected by cancer. This can help the treatment team to work out the stage of the cancer.

Surgical staging – If it is unclear from the PET–CT scan whether pleural mesothelioma has spread, the surgeon may remove a sample of lymph nodes and tissue from other areas of the body to check. This is known as surgical staging. It is not recommended before a peritonectomy for peritoneal mesothelioma.

Prognosis

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

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

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

- the type of mesothelioma cell (see pages 18–19)
- the stage (see page 22)
- the type of treatment you are able to have
- your symptoms, such as weight loss or pain
- your blood count – people with normal levels of blood cells usually have a better prognosis
- your overall health – recovering quickly after procedures tends to suggest a better outcome.

While knowing the stage helps doctors plan treatment, it can't always indicate a prognosis for people with mesothelioma. This is partly because it is hard to predict how quickly mesothelioma will grow. Usually the earlier the stage, the better the prognosis. If the mesothelioma has advanced to a point where it is unlikely to respond to treatment, the priority will be to relieve symptoms and improve your quality of life (see *Palliative treatment*, page 53).

Key points about diagnosing mesothelioma

Overview

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

Main tests

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

Other tests

- Fluid that has built up in the lungs or abdomen can be drained, either during a biopsy or as a separate procedure. A sample of this fluid can be tested for mesothelioma, but the results may not be reliable.
 - The main tests to see if mesothelioma has spread are a CT or PET-CT scan. If radical surgery is being considered, you may have other types of scans and surgical procedures to work out how far the cancer has spread (the stage).
-

Staging and prognosis

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



Making treatment decisions

Sometimes it is difficult to decide on the type of treatment to have. You may feel that everything is happening too fast, or you might be anxious to get started.

Check with your specialist how soon treatment should begin, as it may not affect the success of the treatment to wait a short time. Ask them to explain the options, and take what time you can before making a decision.

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

Record the details – When your doctor first says you have cancer, you may not remember everything you are told. Taking notes can help. If you would like to record the discussion, ask your doctor first. It is a good idea to have a family member or friend go with you to appointments to join in the discussion, write notes or simply listen.

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

Consider a second opinion – You may want to get a second opinion from another specialist to confirm or clarify your specialist's recommendations or reassure you that you have explored all of your options. Specialists are used to people doing this. Your GP or specialist can refer you to another specialist and send your initial results to that person. You can get a second opinion even if you have started treatment or still want to be treated by your first doctor. You might decide you would prefer to be treated by the second specialist.

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

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

Should I join a clinical trial?

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

led to better outcomes for people diagnosed with mesothelioma.

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

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

Treatment

Treatment for people with mesothelioma may be aimed at improving symptoms or trying to control the disease. Various treatments may be offered alone or in combination, including chemotherapy, immunotherapy, radiation therapy and surgery.

The main types of mesothelioma are treated in different ways:

- pleural mesothelioma, see pages 29–35
- peritoneal mesothelioma, see pages 36–37.

The treatment options suggested by your health care team will vary depending on:

- the location, stage and type of mesothelioma, which helps doctors predict how the cancer will respond to treatment
- your age, health and fitness and home support available
- what is most important to you.

Deciding to have treatment

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

Some treatments are not suitable for everyone. Even if a particular treatment is recommended, it is up to you whether or not you want to have it (see *Making treatment decisions*, pages 26–27). You can also call Cancer Council 13 11 20 or talk to one of the mesothelioma support services listed on page 72.

Treatment for pleural mesothelioma

Chemotherapy

Chemotherapy uses drugs to kill or slow the growth of cancer cells while causing the least possible damage to healthy cells.

The main chemotherapy drugs for pleural mesothelioma are pemetrexed in combination with cisplatin or carboplatin. Research shows that using some drugs together can give improved results compared with using just a single drug. Vinorelbine or gemcitabine may be used if mesothelioma comes back.

The goal of chemotherapy is usually to shrink the cancer, reduce symptoms and improve quality of life. For some people with mesothelioma, chemotherapy doesn't always work.

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

You will usually have chemotherapy during day visits to your hospital or treatment centre. Each session may last for several hours and be followed by a rest period of several weeks. Together, the session and rest period are called a cycle. You will probably have up to 6 cycles. However, the length and timing of the treatments and rest days of each cycle may vary from person to person.

Chemotherapy weakens the immune system by lowering the level of white blood cells, making it harder for your body to fight infections. If you have a temperature over 38°C, contact your doctor immediately or go to your nearest hospital emergency department.

Side effects of chemotherapy – Most chemotherapy drugs cause side effects. Side effects depend on the type and dose of chemotherapy drugs. Your specialist may prescribe vitamin B12 injections and low-dose folic acid, which have been shown to reduce the side effects of pemetrexed and cisplatin chemotherapy.

Common side effects of chemotherapy include:

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

You will also be given medicines (such as anti-nausea drugs) to help control any side effects that are likely to occur. If side effects become too difficult to manage, your oncologist can adjust the dose or type of chemotherapy.

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

- ▶ See our *Understanding Chemotherapy* booklet and *Understanding Peripheral Neuropathy* fact sheet.

Immunotherapy

This is a type of drug treatment that uses the body's own immune system to fight cancer. Immunotherapy drugs known as checkpoint inhibitors block proteins that stop immune cells from recognising and destroying the cancer cells. Once the proteins are blocked, the immune cells can potentially recognise and attack the cancer.

Immunotherapy is a relatively new treatment for mesothelioma. However, it is now commonly used for most people who are fit enough to have any type of treatment. It may not be used upfront if you are having trimodality treatment (see pages 34–35). Your medical oncologist will discuss whether immunotherapy is suitable for you.

In NSW, some people may be able to get help paying for immunotherapy through icare (Dust Diseases Care, see page 65).

Having immunotherapy – The drugs used are ipilimumab and nivolumab in combination. Immunotherapy drugs are usually given through a vein (intravenously) in hospital and can take between 30 and 90 minutes. You will usually wait a short time to be monitored for any reaction before going home. Immunotherapy may be used alone or with chemotherapy.

Side effects of immunotherapy – The side effects of immunotherapy drugs are different to those from chemotherapy. Immunotherapy can cause inflammation throughout the body, which may lead to different side effects depending on which part of the body is inflamed.

The combination of immunotherapy drugs may increase the risk of side effects, which include fatigue, rash, painful joints and diarrhoea. Most people have mild side effects that are easily treated and usually

improve. More serious side effects may include heart and thyroid problems, but your doctor should discuss any concerns with you. It's important to let someone on your medical team know if you have any new or worsening symptoms, rather than just put up with them – even if they happen weeks or months after you had immunotherapy treatment. This is because if left untreated, some side effects can become serious and may even be life-threatening. For a detailed list of side effects, visit eviq.org.au.

► See our *Understanding Immunotherapy* fact sheet.

Radiation therapy

Radiation therapy (also sometimes called radiotherapy) is the use of targeted radiation to kill or damage cancer cells so that they cannot grow, multiply or spread. Many other types of cancer may respond well to radiation therapy. It can be more difficult to target radiation therapy for mesothelioma because the cancer is often spread over a large area. However, radiation therapy may still be used at different stages of treatment for pleural mesothelioma and in different ways:

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

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

Radiation therapy is usually every day, Monday to Friday, as an outpatient (you don't stay in hospital). A session usually lasts about 20 minutes – the radiation therapists have to set up the equipment and position you, but the treatment itself takes only a few minutes. Radiation therapy doesn't hurt and you aren't radioactive afterwards.

The length of the treatment course will vary depending on the purpose of radiation therapy. It might involve 1-10 sessions for up to 2 weeks for palliative treatment, or longer if radiation therapy is combined with other treatments with the aim of long-term control.

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

Depending on the area of the body being treated, side effects can include: fatigue; peeling, cracked skin that looks red or sunburnt and may be uncomfortable; painful swallowing; or loss of hair in the treatment area.

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

► See our *Understanding Radiation Therapy* booklet.

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

Trimodality therapy

Having a combination of chemotherapy, radical surgery and radical radiation therapy to treat mesothelioma is known as trimodality therapy. The aim of having the 3 types of treatment is to remove as much pleural mesothelioma as possible, and stop any remaining mesothelioma cells from growing or spreading. The most effective combination will depend on how you respond to treatment.

Trimodality therapy is an intensive treatment available only in a few centres. Despite reduced lung capacity afterwards, some people continue to live independently. Studies are promising, but there are no results comparing trimodality therapy with less intensive treatment.

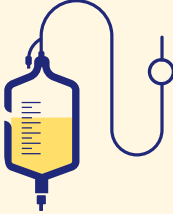
Trimodality therapy may be suitable for people:

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

Your surgeon is the best person to work out if trimodality therapy may be suitable for you. Ask your surgeon or oncologist to explain the likely outcome for you. An EPP or PD (see opposite page) is a major operation, and not everyone wants to go ahead after the risks and benefits are explained. Sometimes, even if someone seems suitable for intensive treatment, the doctor may adjust treatment if the mesothelioma doesn't respond well to chemotherapy, is growing quickly or has spread, or if the person has become too tired or unwell.

The 3 parts of trimodality therapy

1. Chemotherapy



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

2. Radical surgery



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

3. Radical radiation therapy



- Radiation therapy aims to kill any remaining mesothelioma and is delivered using intensity-modulated radiation therapy (IMRT). This type of radiation therapy can be accurately shaped around the chest cavity, so higher doses can be delivered directly to the tumour cells while minimising the damage to other organs in the chest and abdomen.
- IMRT is often given after surgery, but may be given before surgery. How long you need radiation therapy will depend on your circumstances.
- Radiation therapy may cause side effects (see page 33), but most improve after treatment.

Treatment for peritoneal mesothelioma

Surgery

It is possible for some people with peritoneal mesothelioma that has not spread to have an operation called a peritonectomy. Surgery is usually followed by chemotherapy (see below).

Having surgery – In this procedure, the surgeon removes the parts of the peritoneum where the mesothelioma is growing. The amount of surgery needed will vary from person to person. Removing as much of the cancer as possible will help reduce symptoms such as abdominal pain and poor appetite. It will also improve quality of life and increase life expectancy.

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

Only a small number of surgeons in Australia perform peritonectomy. You will usually need to get the medical opinion from one of these specialist surgeons if you are thinking about having a peritonectomy. To find their contact details, talk to your treatment team or contact a mesothelioma support organisation (see page 72).

Chemotherapy

Chemotherapy is sometimes used to treat peritoneal mesothelioma. It may be given as a systemic treatment (into the bloodstream) on its own, or before or after surgery. Systemic chemotherapy for peritoneal mesothelioma is similar to that given for pleural mesothelioma (see pages 29–30 for more information).

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

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

Immunotherapy

This is a type of drug treatment that uses the body’s own immune system to fight cancer. Immunotherapy drugs known as checkpoint inhibitors block proteins that stop immune cells from recognising and destroying the cancer cells. Once the proteins are blocked, the immune cells can potentially recognise and attack the cancer.

Having immunotherapy – The drugs used are ipilimumab and nivolumab in combination. Immunotherapy for peritoneal mesothelioma is similar to that given for pleural mesothelioma (see pages 31–32), however evidence of how well it works is limited at this time.



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

Key points about treating mesothelioma

Overview

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

Pleural mesothelioma

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

Peritoneal mesothelioma

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

Managing symptoms

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

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

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

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

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

Fatigue

It is common to feel tired during and after treatment, and to lack energy for day-to-day activities. Fatigue for people with cancer is different from tiredness, as it may not go away with rest or sleep. You may lose interest in things that you usually enjoy doing or feel unable to concentrate for very long.

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



Managing fatigue

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

Difficulty sleeping

Getting a good night's sleep is important for maintaining your energy levels, reducing fatigue, and improving mood. Difficulty sleeping may be caused by pain, breathlessness, anxiety or depression. Some medicines can also disrupt sleep.

If you had sleep problems before the mesothelioma diagnosis, these could become worse. Talk to your doctor about what might be helpful for you. Medicines you are taking may need adjusting or you may need other drugs to help you sleep. Strategies that may be helpful in improving your sleep quality are listed below.



Getting a better night's sleep

- Try to do some gentle exercise daily. This will help you sleep better. Talk to a physiotherapist or exercise physiologist, who can tailor an exercise program, and an occupational therapist, who can suggest equipment to help you move safely. See our *Exercise for People Living with Cancer* booklet.
- Limit or cut out the use of alcohol, caffeine, nicotine and spicy food.
- Avoid television or using computers or smartphones before bed, as the blue light may tell your body it's time to wake up.
- Follow a regular routine before bed and set up a calm sleeping environment. Make sure that the room is dark, quiet and a cool temperature.
- Try soothing music, a recording of rain sounds, or a relaxation recording. Listen to our "Sleep and Cancer" podcast episode and our *Finding Calm During Cancer* podcast series for more tips.

Breathlessness

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

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

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

Other problems such as infection or a low level of red blood cells (anaemia) can also cause breathlessness. Living with breathlessness can be difficult, but there are ways to reduce its impact on your life and manage it at home (see pages 46–47).

Draining fluid around the lungs

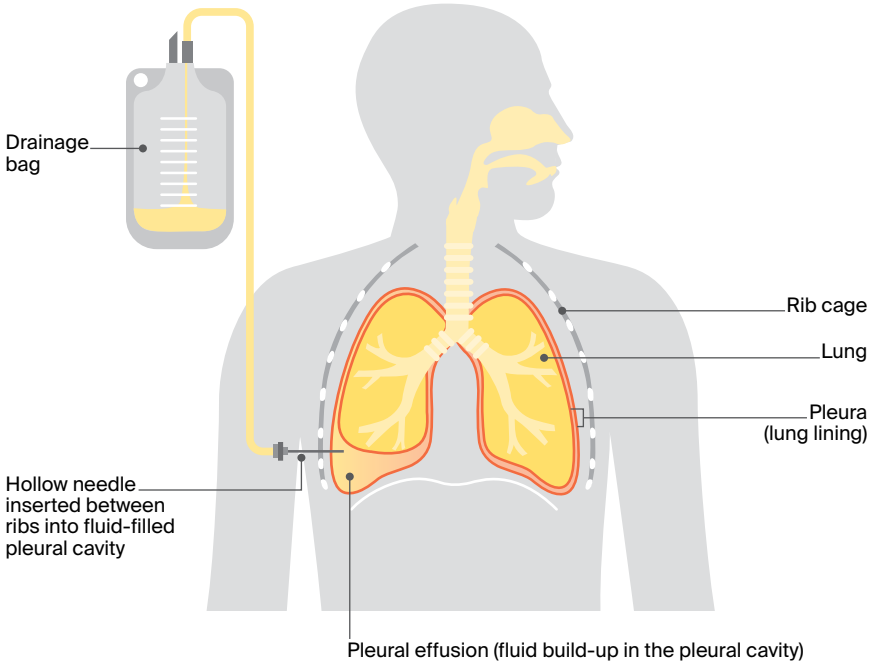
Fluid build-up around the lungs may be drained before mesothelioma is diagnosed or at the same time as a biopsy (see opposite page).

Ways to control fluid around the lungs

Talc pleurodesis – To prevent fluid building up again in the lining of the lungs, you may have a talc pleurodesis. Pleurodesis means closing the pleural cavity. Sterile talcum powder (talc slurry) is injected into the pleural cavity, and the talc slurry causes an inflammation that helps fuse the 2 layers of the pleura together and closes the space.

Having a pleural tap

In pleural mesothelioma, a pleural tap (also known as pleurocentesis or thoracentesis) drains fluid from around the lungs.



- Your doctor will numb the area with a local anaesthetic and insert a needle between your ribs into the fluid-filled pleural cavity.
- An ultrasound scan may guide the needle to the fluid. The needle is connected to a bag for the fluid to drain into.
- The process of draining the fluid usually takes anywhere between 30 and 60 minutes.
- You usually don't have to stay overnight in hospital after having a pleural tap.

A talc pleurodesis is best done during VATS (see page 19) by a thoracic surgeon, but is sometimes done by a respiratory physician. After a talc pleurodesis, some people experience a burning pain in the chest for 24–48 hours. This pain can be eased with medicine and you will be able to have physiotherapy to improve lung expansion.

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

Thoracotomy with pleurectomy decortication – Even after VATS and talc pleurodesis, the fluid may build up around the lungs again, causing breathlessness. The surgeon may suggest a more extensive surgery called thoracotomy (open surgery) with pleurectomy decortication (PD). This surgery may also be recommended as a first option if the cancer has grown in a way that makes it difficult to perform VATS successfully. A thoracotomy helps to prevent fluid building up again in most cases. It also makes it easier for the lungs to expand and to transfer oxygen to the blood. Pain after having a thoracotomy can last longer than pain after having VATS, but the improvement in symptoms may make open surgery a worthwhile option if VATS has not been successful or if it isn't possible.

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

Under local anaesthetic, the specialist inserts a thin tube (the catheter) through the chest wall into the pleural cavity. You can manage the drain at home with the help of a community nurse, family member or friend. When the fluid builds up and needs to be drained (usually once or twice a week), the end of the catheter is connected to a bottle.

With an indwelling pleural catheter, the fluid may stop building up, and the cavity may close. In these cases the drain can be removed.

Ways to drain or control fluid in the abdomen

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

Indwelling peritoneal catheter – If fluid keeps building up around the abdomen, a small tube can be inserted to allow fluid to flow into a bottle. This is known as an indwelling peritoneal catheter or drain. Under local anaesthetic, the specialist inserts a thin tube (catheter) into the abdomen. You can manage the drain at home with the help of a community nurse, family member or friend. When the fluid builds up and needs to be drained (usually once or twice a week), the end of the catheter is connected to a bottle.

Heated chemotherapy – To help prevent fluid building up again, you may have a single dose of heated chemotherapy directly into the abdomen (HIPEC, see page 37) during a laparoscopy.

Improving breathlessness at home

It can be distressing to feel short of breath, but several simple strategies can help provide some relief from breathlessness at home.

Treat other conditions



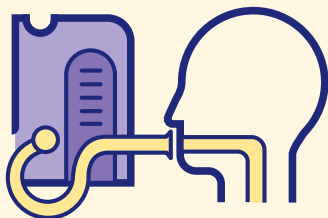
Let your doctor know if you feel breathless. Conditions such as anaemia, a lung infection or chronic obstructive pulmonary disease may also make you feel short of breath and these can often be treated.

Sleep more upright



Use a recliner chair or prop yourself up in bed to help you sleep in a more upright position. An occupational therapist may be able to recommend a special pillow for sleeping.

Check if equipment could help



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

Relax on a pillow



Rest your head and upper chest on a table with a pillow. Bend from your hips and keep your back straight. This helps to relax your breathing muscles.

Ask about medicines



Talk to your doctor about medicines, such as a low dose of morphine, to ease breathlessness. It is important to keep any chest pain well controlled because pain may prevent you from breathing deeply.

Modify your movement



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

Create a breeze



Use a handheld fan to direct a cool stream of air across your face if you feel short of breath when not exerting yourself. You may also find it helpful to sit by an open window.

Find ways to relax



Listen to a relaxation recording or learn other ways to relax. This can help you to control anxiety and breathe more easily. Some people find breathing exercises, acupuncture and meditation helpful.

- ▶ See our *Understanding Complementary Therapies* booklet and listen to the relaxation and meditation recordings in our *Finding Calm During Cancer* podcast series.

Pain

Many people are naturally worried about being in pain. It's important to tell your treatment team if you are in pain. Pain may be a symptom of mesothelioma, but can also be a side effect of treatment.

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

There are several different ways to control pain.

Pain medicines – Different types and strengths may be used:

- mild, like paracetamol
- moderate, like codeine
- strong and opioid-based, like morphine.

Pain medicines may come as tablets, oral liquids, patches, injections or intravenous infusions. Non-steroidal anti-inflammatory drugs (NSAIDs) or drugs for nerve pain may also be prescribed. Many people need a combination of medicines for good pain control.

Opioids, such as morphine or oxycodone, are the most common drugs used to control moderate-to-severe mesothelioma pain. Morphine is available in quick-acting and long-acting forms. Some people worry they might get addicted to morphine. Pain specialists believe this is unlikely if you take it as prescribed to relieve acute pain or for palliative care. Morphine can be taken for a long time and in increasing doses, if needed. It doesn't have to be saved for when pain is very bad.

There are many strong pain medicines similar to morphine, so if one doesn't work, ask your doctor for other options. A small number of people have difficulty controlling their pain, and a pain management specialist may help find a solution.

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

Radiation therapy – This may be used to shrink mesothelioma that is pressing on nerves, bones or major blood vessels and causing pain. Sometimes the mesothelioma can grow through the scar from VATS surgery and produce a lump in the skin. Radiation therapy can reduce the size of the lump and ease any associated pain. See pages 32-33 for more information about radiation therapy.

Chemotherapy – This can reduce the size of the mesothelioma that is causing the pain. See pages 29 and 36 for more information.

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

- ▶ See our *Understanding Cancer Pain* booklet and listen to our podcast episodes on pain.

“I couldn't believe how much better I felt after some pain relief. Everything seemed less stressful and I didn't feel so angry and upset all the time.” BILL

Ways to cope with pain at home



Keep notes on your pain

Describe and track pain in a symptom diary – what it feels like, how intense it is, exactly where it is, where it comes from and goes to, how long it lasts, and if it goes away with a medicine or a heat pack, etc.



Take it slow

Allow a few days for your body to adjust to the dose of pain medicine and for any drowsiness to improve.



Report side effects

Let your doctor know if you have vivid dreams, nausea or other side effects after taking a strong pain medicine such as morphine or oxycodone.



Watch for constipation

Ask your doctor if you need a laxative or stool softener prescribed to prevent or relieve constipation (difficulty passing bowel movements) caused by pain medicines.



Keep up your medicine

Take pain medicine regularly as prescribed, even when you're not in pain. It's better to stay on top of the pain.



Check your pain plan

Ask your doctor to review your pain management plan regularly. If you have problems, adjusting the dose may help, or you can try other methods of pain relief.

Constipation

Having infrequent or difficult-to-pass bowel movements (also called faeces, stools or poo) is known as constipation. Common causes include not getting enough exercise, eating too little fibre, or not drinking enough fluids. Opioid pain medicines, some anti-nausea drugs and some chemotherapy drugs may also cause constipation.

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



Managing constipation

- Drink plenty of fluids.
- Eat fresh fruit and vegetables and fibre-rich foods (e.g. prunes, apples with skin on), unless your doctor advises otherwise.
- Try to be physically active every day. Talk to your doctor or physiotherapist to find the exercise that is right for you.
- Ask your doctor how to manage constipation. You may be prescribed medicines to help stimulate bowel movements.
- Try over-the-counter laxatives such as Coloxyl with senna, Duphalac or Movicol. Check the dose with the pharmacist and let your doctor know. Don't wait too long before starting laxatives.
- Talk to your treatment team about how to manage bowel obstruction (described above). If your stomach is swollen and you are in pain, call Triple Zero (000) as it may be an emergency.

Poor appetite and weight loss

Some people have little interest in eating and lose weight even before mesothelioma is diagnosed. These symptoms may be caused by the disease itself, or by nausea, trouble swallowing, changes in taste or smell, breathlessness, abdominal pain, or feeling down (see page 57).

Eating well will help you cope better with day-to-day living, treatment and side effects, and improve your quality of life.

A palliative care specialist can help manage symptoms that affect your appetite or ability to eat. You may also find it useful to talk to a dietitian who is experienced in treating people with cancer. They can provide helpful eating suggestions.



Eating when you have little appetite

- Have small meals and snacks regularly. A large, full plate may put you off eating – try using a smaller plate with smaller portions. Likewise, drink from a half-full glass.
 - Eat moist food such as scrambled eggs. Moist food tends to be easier to eat and will cause less irritation if you have a sore mouth.
 - Avoid fatty or sugary foods if these make you feel sick.
 - Use lemon juice and herbs to add flavour to bland foods.
 - Eat more of your favourite foods – follow your cravings.
 - Carry snacks so you can eat any time you feel like it. Try muesli bars, dried fruit and nuts, crackers or fruit buns.
 - If solid food doesn't appeal, ask a dietitian about protein drinks or other supplements.
- ▶ See our *Nutrition for People Living with Cancer* booklet and listen to our podcast episode called “Appetite Loss and Nausea”.

Palliative treatment

The options described here are usually considered palliative treatment because their main aim is to manage symptoms rather than cure the disease. Your doctor may suggest palliative treatment for any symptoms caused by mesothelioma or refer you to a palliative care specialist.

Chemotherapy, immunotherapy, radiation therapy and surgery may be used to slow the spread of mesothelioma and control symptoms such as pain or breathlessness. If you have a build-up of fluid around the lungs or abdomen, various procedures can drain the fluid and help prevent it building up again. See pages 42–45 for more details.

Palliative treatment can be used at any stage of mesothelioma to improve quality of life. In fact, palliative treatment can help some people with mesothelioma to live fulfilling lives with minimal symptoms for longer.

Palliative treatment is one aspect of palliative care. Read about the various ways palliative care can help on the next 2 pages.

- ▶ See our *Understanding Palliative Care* and *Living with Advanced Cancer* booklets and listen to *The Thing About Advanced Cancer* podcast series.

“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

Understanding palliative care

Many people fear hearing the words palliative care because they think it is just for people who are dying, but it's not. Palliative care is useful at all stages

What is palliative care?



Palliative care is person-centred care that helps people with a progressive life-limiting illness to live as fully and as comfortably as possible. Palliative care can link you with support. For example, you may need help to move around your home more safely. The main goal is to help you maintain your quality of life by identifying and meeting your physical, emotional, cultural, social and spiritual needs. It also provides support to families and carers.

Who is in a palliative care team?



Palliative care may be led by your GP or community nurse, or by the specialist palliative care team in your area. The team may include doctors, nurses, social workers, physiotherapists, occupational therapists, and spiritual care practitioners. They may also link you to a counsellor, psychologist or other health professionals.

Where is palliative care usually given?



The palliative care team will help you to work out the best place for your care. This may be in your own home supported by community palliative care services, in hospital, at a residential aged care facility or in a palliative care unit (sometimes called a hospice). Many health care services are now available to you at home.

of advanced cancer and involves a range of services that can help with many things like pain management or getting around more easily.

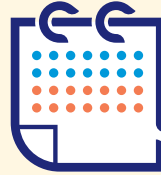
How can palliative care help?



Palliative care involves a range of services that will be tailored to your individual needs. There are various ways it can help, including:

- relief of pain, breathlessness, nausea and other symptoms
- help organising equipment for home (e.g. wheelchairs, special beds)
- links to other services such as home help and financial support
- referrals to respite care services
- volunteer services trained in palliative care
- counselling, grief and bereavement support.

When can I start care?



Depending on your needs, you may use palliative care services occasionally or continuously, for a few weeks or months.

The number of people receiving palliative care for several years is increasing. Contacting the palliative care team early means that you can find out what the different team members do and see which services might be useful now or in the future. This will vary according to how you feel, what problems you have, and how your carers are managing.

Where to find out more



For more information about what palliative care is and how it helps, visit the Palliative Care Australia website, palliativecare.org.au. Use the directory on this website to find a palliative care service in your local area, or speak to your doctor or nurse.

Key points about managing symptoms

Overview

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

Main symptom

- Breathlessness caused by fluid build-up around the lungs is the most common symptom of pleural mesothelioma. It can usually be controlled with surgery – either a type of keyhole surgery called video-assisted thoracoscopic surgery (VATS) or a type of open surgery called thoracotomy.
 - Breathlessness caused by fluid build-up in the abdomen is a common symptom of peritoneal mesothelioma. It can be controlled with an indwelling peritoneal catheter or heated chemotherapy (HIPEC).
 - Simple ways to improve breathlessness at home include using a fan, leaning forward on a table over a pillow or sleeping in a recliner chair.
-

Other symptoms

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

Living with mesothelioma

Life with a mesothelioma diagnosis can present many challenges. Take some time to adjust to the physical and emotional changes, and establish a daily routine that suits you and the symptoms you're experiencing. You are likely to feel a range of emotions about having mesothelioma, including fear, sadness, anxiety, anger, frustration, and loss and grief.

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

- ▶ See our *Emotions and Cancer* booklet. You can also read about compensation claims for asbestos exposure on pages 63–68.

Dealing with feelings of sadness

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

Talk to your GP, because counselling or medication – even for a short time – may help. Some people can

get a Medicare rebate for sessions with a psychologist. Cancer Council may also run a counselling program in your area.

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

Looking after yourself

Cancer can cause physical and emotional strain, so it's important to look after your wellbeing. Cancer Council has free booklets and programs to help you during and after treatment. Call 13 11 20 to find out more, or visit your local Cancer Council website (see back cover).

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

▶ See our *Nutrition for People Living with Cancer* booklet.

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

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

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

▶ See our *Understanding Complementary Therapies* booklet.



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

Work and money – Cancer can change your financial situation, especially if you have extra medical expenses or need to stop working. Getting professional financial advice and talking to your employer can give you peace of mind. You can also check whether any financial assistance is available to you by asking a social worker at your hospital or treatment centre or calling Cancer Council 13 11 20.

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

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

▶ See our *Emotions and Cancer* booklet.

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

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

Contraception and fertility – If you can have sex, you may need to use certain types of contraception to protect your partner or avoid pregnancy for a time. Your doctor will explain what precautions to take. They will also tell you if treatment will affect your fertility permanently or temporarily. If having children is important to you, discuss the options with your doctor before starting treatment.

▶ See our *Fertility and Cancer* booklet.

Ongoing care

As treatment and symptom management for mesothelioma are likely to be ongoing, you will have regular check-ups to monitor your health. Timing differs from person to person and depending on treatments. Some people may see a doctor every 3 weeks, others every 6–8 weeks.

During check-up appointments, your doctor will do a physical examination and may also arrange a CT scan to see how active the mesothelioma is. What other tests you have, and who you see and where, will depend on your health and the type of treatment you have had. At your check-ups, you will also be able to discuss how you are feeling and mention any concerns you may have.

If you live a long way from the hospital or treatment centre, you may be able to have some tests done by your GP or another specialist.

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

What if mesothelioma comes back?

For people with mesothelioma, the disease will come back even if it responds well to initial treatment. This is called recurrence, relapse or disease progression. How long this takes is different for everyone.

When mesothelioma comes back, you and your doctor will need to consider what treatment to use and how to control symptoms. Treatment options available to you will depend on symptoms you are experiencing, as well as your general health, and may include:

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

You may have these cancer treatments as part of palliative care (see pages 53–55). At some point, you may decide to stop treating the cancer and focus on managing symptoms and maximising quality of life. Your cancer care and palliative care teams can help you understand your treatment options so you can make well-informed decisions.

- ▶ See our *Understanding Palliative Care, Living with Advanced Cancer* and *Facing End of Life* booklets and listen to *The Thing About Advanced Cancer* podcast series.

The role of hope

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

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

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

Advance care planning

Making plans for the future may help put your mind at ease and let you focus on treatment or living. Advance care planning lets you look at your future health and legal options and know that what you want is recorded in case it's needed.

You can legally appoint someone to make decisions for you if you lose the ability (called capacity) to make your own decisions – for example, if you become too sick. Depending on where you live, the documents for appointing this person may have different names, including an Enduring Power of Attorney, Enduring Power of Guardianship, or appointment of an Enduring Guardian.

You can also outline your treatment goals and what you want for your future medical care in an official document called an Advance Care Directive. These documents are all part of advance care planning.

It may be worth getting legal advice to be sure that your will is up to date and that what you want to happen to your estate (house, car, investments, etc.) is clear.

Cancer Council can refer you to a lawyer for help with wills and advance care planning. These services are usually free for people who can't afford to pay. Call 13 11 20 to find out what services are available in your area and whether you are eligible for free legal assistance.

- ▶ Also see our *Living with Advanced Cancer* and *Cancer Care and Your Rights* booklets.

Making a claim

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

Mesothelioma usually takes a long time to develop, so you may have been exposed to asbestos up to 40 years ago or even longer. You might think it was a small exposure, or you may not remember coming into contact with asbestos. Talking to your friends and family can help you remember places where you may have been exposed to asbestos.

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

Generally, a person diagnosed with mesothelioma has 2 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”.



If you have developed mesothelioma as part of your job, you may be entitled to make a claim under a government-run workers compensation scheme in your state or territory. As well as financial compensation, these schemes may sometimes cover certain medical tests or treatment. See page 65 for contact details of the scheme relevant to you.

Common law claim

A common law claim is brought against the party or parties (the people or organisations) who caused you to be exposed to asbestos. These are called 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. This means that your estate will still be able to continue with your claim if you die before it is finalised.

If you'd like to make a claim, it's important to speak with a lawyer experienced in asbestos-related compensation claims as soon as possible after your diagnosis.

If you're too unwell to see a lawyer in their office, they may be able to 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
- no longer work for the employer where you were exposed
- have worked for many employers
- were self-employed or a contractor at the time of exposure
- worked for an employer who is no longer in business
- are, or were, a smoker
- were exposed to asbestos in another state or overseas
- were not exposed in the workplace
- were only briefly exposed to asbestos
- were exposed to asbestos on more than one occasion
- don't know how you may have been exposed to asbestos.

Statutory claims

Some states and territories have special government compensation schemes for people who develop mesothelioma and other asbestos-related diseases while at work. Contact the relevant organisations below for more information.

State and territory compensation schemes

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

Common questions about making a claim

Do I need legal help?

You, and sometimes your dependants, can lodge a statutory claim directly with the authority in your state or territory. But most people with mesothelioma find it can be easier to use a lawyer to arrange all their claims. The laws around Australia vary and can be complex. Some people may be entitled to bring a common law claim instead of, or as well as, a statutory claim. It is vital to consult an expert asbestos lawyer before applying for statutory benefits to make sure that you aren't excluded from also claiming common law compensation.

How can I find a lawyer?

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

Talking to an experienced lawyer may help to reduce the time it takes to investigate a claim. Experienced lawyers will also understand mesothelioma and what you are coping with.

Your lawyer will work around medical appointments or treatments to try to make things less stressful for you.

The support organisations listed on page 72 can also help you find a lawyer experienced in dealing with asbestos cases.

The law societies in each state and territory have a “find a lawyer” search on their websites. Search the internet for the law society in your state or territory.

If you need help to find a lawyer, or want more information about how Cancer Council can help link you to relevant legal services, call 13 11 20.

How long will a common law case take?

Most common law claims for mesothelioma are settled out of court through a process called mediation. This can happen within a few months to a year of the claim being lodged. If your prognosis is poor, or you suddenly become very unwell, the process may be sped up to try to ensure that your common law claim is resolved in your lifetime. Very few cases actually proceed to a court trial.

What if I die before my claim is settled?

Many people diagnosed with mesothelioma worry that their claim won't be finalised before they die. The largest component of compensation is usually the general damages. So long as you start a common law claim in your lifetime, then your entitlement to general damages is protected, and your estate would be able to continue with your claim if you die before your claim is finalised.

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

How much does legal action cost?

Legal costs generally depend on the amount of legal work required to resolve your case. Most lawyers who specialise in asbestos-related compensation claims offer a “no win, no fee” agreement. This means that the lawyers will only charge for legal services if they are successful in resolving your case.

You are also entitled to claim a large portion of your legal costs from the defendants as part of your common law claim. The amount of costs awarded will depend on whether your case was resolved at mediation or at trial.

Ask your lawyer for a costs agreement, and ask them to explain what is involved. Be aware that even under a “no win, no fee” agreement, if you:

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

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

Caring for someone with mesothelioma

You may be reading this booklet because you are caring for someone with mesothelioma. What this means for you will vary depending on the situation. Being a carer can bring a sense of satisfaction, but it can also be challenging and stressful. It is important to look after your own physical and emotional wellbeing. Give yourself some time out and share your concerns with somebody neutral such as a counsellor or your doctor, or try calling Cancer Council 13 11 20. There is a wide range of support available to help you with the practical and emotional aspects of your caring role.

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

Support groups and programs – Many cancer support groups and cancer education programs are open to carers as well as to people with cancer. Support groups and programs offer the chance to share experiences and ways of coping. You can find a list of mesothelioma support organisations on page 72.

Carers Australia – Carers Australia provides information and advocacy for carers. Visit carersaustralia.com.au.

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

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

Seeking support

A cancer diagnosis can affect every aspect of your life. You will probably experience a range of emotions – fear, sadness, anxiety, anger and frustration are all common reactions. Cancer also often creates practical and financial issues.

There are many sources of support and information to help you, your family and carers navigate all stages of the cancer experience, including:

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

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

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

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

Support from Cancer Council

Cancer Council offers a range of services to support people affected by cancer, their families and friends. Services may vary by location.

Cancer Council 13 11 20



Our experienced health professionals will answer any questions you have about your situation and link you to local services (see inside back cover).

Information resources



Cancer Council produces booklets and fact sheets on more than 25 types of cancer, as well as treatments, emotional and practical issues, and recovery. Call 13 11 20 or visit your local Cancer Council website.

Legal and financial support



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

Practical help



Cancer Council can help you find services or offer guidance to manage the practical impacts of cancer. This may include helping you access accommodation and transport services.

Peer support services



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

Mesothelioma support in Australia

New South Wales

Asbestos Diseases Foundation of Australia (ADFA) 1800 006 196
adfa.org.au

Asbestos Diseases Research Institute (ADRI) 02 9767 9800
adri.org.au

Queensland

Asbestosis and Mesothelioma Association of Australia (AMAA) 1800 017 758
asbestosassociation.com.au

Asbestos Disease Support Society (ADSS) 1800 776 412
adss.org.au

South Australia

Asbestos Diseases Society of South Australia (ADSSA) 1800 157 540 or 08 8241 7297
adssa-inc.com.au

Asbestos Victims Association of South Australia (AVA) 08 8212 6008
avasa.asn.au

Tasmania

Asbestos Free Tasmania Foundation asbestosfreetasmania.org.au

Victoria

Asbestos Council of Victoria (ACV)
Gippsland Asbestos Related Diseases Support (GARDS) 03 5127 7744
gards.org

Western Australia

Asbestos Diseases Society of Australia (ADSA) 1800 646 690
asbestosdiseases.org.au

Reflections 1800 031 731
reflections.org.au

Other useful websites

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

Australian

Cancer Council Australia	cancer.org.au
Cancer Council Online Community	cancercouncil.com.au/OC
Cancer Council podcasts	cancercouncil.com.au/podcasts
Guides to Best Cancer Care	cancer.org.au/cancercareguides
Advance Care Planning Australia	advancecareplanning.org.au
Asbestos Safety and Eradication Agency	asbestossafety.gov.au
Australian Mesothelioma Registry	mesothelioma-australia.com
Cancer Australia	canceraustralia.gov.au
Carer Gateway	carergateway.gov.au
Healthdirect Australia	healthdirect.gov.au
My Aged Care	myagedcare.gov.au
Palliative Care Australia	palliativecare.org.au
Patient travel assistance schemes	healthdirect.gov.au/travelling-to-your-healthcare-appointment
Services Australia	servicesaustralia.gov.au
The Australian Asbestos Network	australianasbestosnetwork.org.au
Young Carers Network	youngcarers.net.au

International

American Cancer Society	cancer.org
Cancer Research UK	cancerresearchuk.org
Macmillan Cancer Support (UK)	macmillan.org.uk
Mesothelioma UK	mesothelioma.uk.com

Question checklist

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

Diagnosis

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

Treatment

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

Side effects

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

Support

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

Glossary

abdomen

The part of the body between the chest and hips, which contains the stomach, spleen, pancreas, liver, gall bladder, bowel, kidneys and uterus. Also known as the belly.

adjuvant therapy

A treatment given after the main treatment to lower the risk that the cancer will come back.

advanced cancer

Cancer that is unlikely to be cured. In most cases, the cancer has spread to other parts of the body (secondary or metastatic cancer). Treatment can often still control the cancer and manage symptoms.

anaesthetic

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

asbestos

A group of naturally occurring silicate minerals that form long, crystallised fibres. Formerly used in manufacturing and building, asbestos use is now banned in Australia because the fibres can cause serious illness.

asbestosis

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

asbestos-related diseases

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

ascites

Collection of fluid between the 2 layers of tissue that line the abdomen and pelvis,

making the abdomen swollen and bloated. Also known as peritoneal effusion.

benign

Not cancerous or malignant.

biopsy

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

biphasic

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

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

breathlessness

The sensation of shortness of breath or difficulty breathing. Also called dyspnoea.

cells

The basic building blocks of the body.

A human is made of billions of cells that are adapted for different functions.

chemotherapy

A cancer treatment that uses drugs to kill cancer cells or to slow their growth. Chemotherapy can also be used as a palliative treatment to reduce the size of the cancer and to help to lessen pain.

chest cavity

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

clinical trial

A research study that tests new approaches to prevention, screening, diagnosis or treatment, to see if they are better than current approaches.

CT-guided core biopsy

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

CT scan

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

debulking

Surgery to remove as much of a tumour as possible. This makes it easier to treat the cancer that is left and helps to increase the effectiveness of radiation therapy or chemotherapy.

decortication

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

diaphragm

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

early postoperative intraperitoneal chemotherapy (EPIC)

Chemotherapy given soon after surgery as a single course and delivered directly into the abdomen through a thin tube. May be used after a peritonectomy.

epithelioid

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

external beam radiation therapy

Radiation therapy delivered to the cancer from outside the body.

extrapleural pneumonectomy (EPP)

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

FDG-PET

Fluorodeoxyglucose-positron emission tomography scan. A test in which a person is injected with a low-level radioactive solution (fluorodeoxyglucose or FDG) that helps to show up cancer cells on a PET-CT scan.

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.

heated intraoperative intraperitoneal chemotherapy (HIPEC)

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

immunotherapy

Drugs that use the body's own immune system to fight cancer.

indwelling pleural catheter

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

intensity-modulated radiation therapy (IMRT)

A highly accurate type of external beam radiation therapy that shapes and divides multiple radiation beams into many beamlets that vary in strength.

laparoscopy

Surgery done through small cuts in the abdomen using a viewing instrument called a laparoscope. Also called keyhole surgery or minimally invasive surgery.

latency period/interval

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

lungs

The 2 spongy organs in the chest. The lungs are made up of many tiny air sacs and are used for breathing. They are part of the respiratory system.

lymphatic system

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

lymph nodes

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

malignant

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

mediastinum

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

mesothelial cells

The cells of the mesothelium.

mesothelioma

See pleural mesothelioma and peritoneal mesothelioma.

mesothelium

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

metastasis (plural: metastases)

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

mixed mesothelioma

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

normothermic intraperitoneal chemotherapy (NIPEC)

Chemotherapy given at a normal temperature as a long-term course directly into the abdomen after a peritonectomy.

palliative care

The holistic care of people who have a life-limiting illness, their families and carers. It aims to maintain a person's quality of life by addressing their physical, emotional, cultural, spiritual and social needs. Also known as supportive care. It is not just for people who are about to die, although it does include end-of-life care.

palliative treatment

Medical treatment for people with advanced cancer to help them manage pain and other physical and emotional symptoms. Treatment may include radiation therapy, chemotherapy, immunotherapy or other therapies. It is an important part of palliative care.

parietal peritoneum

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

parietal pleura

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

PCI system

Peritoneal cancer index. Assesses the extent of cancer in the peritoneal cavity.

pericardium

A thin, double-layered sac around the heart.

peritoneal cavity

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

peritoneal effusion

See ascites.

peritoneal mesothelioma

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

peritoneal tap

A procedure that uses a needle to drain excess fluid from the abdomen.

Also known as paracentesis.

peritonectomy

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

peritoneum

The mesothelium (thin sheet of tissue) that lines the walls and organs of the abdomen and pelvis. It has 2 layers: parietal and visceral.

PET-CT scan

Positron emission tomography scan combined with CT scan. In a PET scan, a person is injected with a small amount of radioactive solution. This makes cancerous areas show up brighter on the scan.

pleura

The mesothelium (thin sheet of tissue) that lines the chest wall and covers the lungs. It has 2 layers: parietal and visceral.

pleural cavity (pleural space)

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

pleural effusion

A build-up of excess fluid between the 2 layers of tissue that cover the lungs.

pleural fluid

The fluid in the pleural cavity that allows the 2 layers of the pleura to slide over each other as you breathe. Mesothelioma can cause excess fluid to build up, see pleural effusion.

pleural mesothelioma

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

pleural plaque

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

pleural tap

A procedure that uses a hollow needle inserted between the ribs to drain excess fluid. Also called pleurocentesis or thoracentesis.

pleural thickening

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

pleurectomy

Surgery to remove part of the pleura. When combined with decortication it is known as pleurectomy decortication (PD).

pleurodesis

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

precancerous

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

prognosis

The expected outcome of a person's disease.

radiation therapy

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

Also called radiotherapy.

radical radiation therapy

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

radical surgery

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

sarcomatoid

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

silicosis

A lung disease caused by inhalation of silica dust, often found among coal miners and stonemasons.

staging

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

systemic treatment

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

targeted therapy

Drugs that target specific features of cancer cells to stop the cancer growing and spreading.

thoracic

Relating to the chest (thorax).

thoracotomy

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

tissue

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

TNM system

A type of staging system that describes how far the cancer has spread. T stands for tumour, N stands for lymph node and M stands for metastasis.

trimodality therapy

Combination of 3 different types of treatment: chemotherapy, surgery and radiation therapy.

tumour

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

VATS (video-assisted thoracoscopic surgery)

Keyhole surgery performed through small cuts in the chest using a thoracoscope.

visceral peritoneum

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

visceral pleura

The inner layer of pleura lining the lung surface.

Can't find a word here?

For more cancer-related words, visit:

- cancercouncil.com.au/words
 - cancervic.org.au/glossary
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How you can help

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

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

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

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

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

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

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



Cancer Council

13 11 20

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

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

Calling 13 11 20 gives you access to trustworthy information that is relevant to you. Our experienced health professionals 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.



If you need information in a language other than English, an interpreting service is available. Call 131 450.



If you are deaf, or have a hearing or speech impairment, you can contact us through the National Relay Service. communications.gov.au/accesshub/nrs

*Cancer Council services and programs vary in each area.
13 11 20 is charged at a local call rate throughout Australia (except from mobiles).*

For information & support
on cancer-related issues,
call **Cancer Council 13 11 20**

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*This booklet is funded through the generosity of the people of Australia.
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