



Mesothelioma

A guide for people with cancer,
their families and friends

Cancer
information

Cancer Council Helpline

13 11 20

www.cancervic.org.au



Introduction

Mesothelioma

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This booklet is dedicated to Julie Bastian (wife of Rod Smith) and Farid Moghaddas (husband of Lisa Moghaddas). Sadly they both passed away from mesothelioma before publication, but will always be remembered for their valuable insights and contributions to the production of this booklet.

Interpreting service: Deaf or hearing or speech impaired

If you use text-based communication, call the Cancer Council Helpline (13 11 20) through the National Relay Service (NRS) 13 3677. If you can hear and still use your voice, but have a speech impairment, call the Cancer Council Helpline through NRS 1300 555 727.

Generous Victorians who fundraise to fight cancer make many Cancer Council services, including the publication of this booklet, possible. For information on how you can help, visit www.cancervic.org.au or call 1300 65 65 85.

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This booklet is about mesothelioma. This is a rare type of cancer that develops in the lining of the lung (it is not the same as lung cancer) or abdomen (stomach area).

If you are looking for information about lung cancer, read the Cancer Council's booklet *Lung Cancer: For people with cancer, their families and friends* available at www.cancervic.org.au or from 13 11 20.

Many people feel understandably shocked and upset when they are told they have mesothelioma. This booklet aims to help you, your family, friends and carers understand how mesothelioma is diagnosed and treated. We also include information about support services you may use. By knowing about these things you and those close to you will be better able to comfort and support each other during a difficult time.

We cannot tell you what is the best treatment for your situation. You need to discuss this with your doctors. However, we hope we will answer some of your questions and help you think about the questions you want to ask your doctors.

You may like to pass this booklet on to your family and friends for their information.

This booklet does not need to be read from cover to cover, but can be read in sections according to your needs or interest. The words in **bold** are explained in the glossary at the back of this booklet.

Are you reading this for someone who does not understand English? Tell them about the Multilingual Cancer Information Line. See the back cover for details.



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What is cancer?

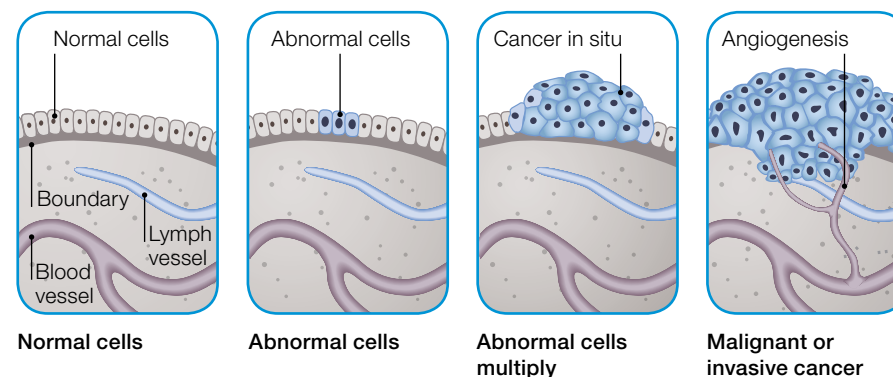
Cancer is a disease of the body's cells. Our bodies are always making new cells: so we can grow, to replace worn-out cells, or to heal damaged cells after an injury. This process is controlled by certain genes. All cancers are caused by changes to these genes. Changes usually happen during our lifetime, although a small number of people inherit such a change from a parent.

Normally, **cells** grow and multiply in an orderly way. However, changed **genes** can cause them to behave abnormally. They may grow into a lump. These lumps can be **benign** (not cancerous) or **malignant** (cancerous).

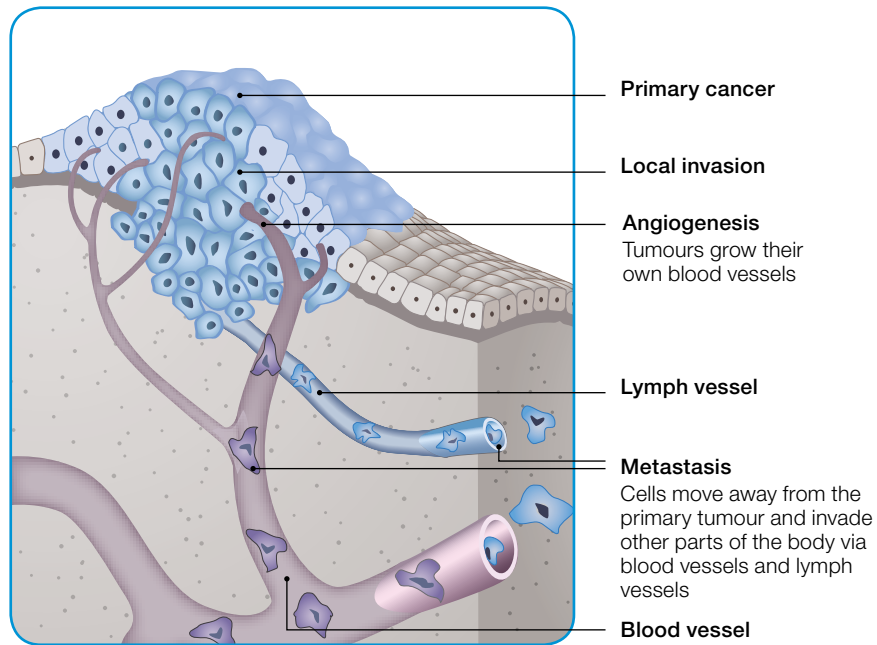
Benign lumps do not spread to other parts of the body.

A malignant lump (more commonly called a malignant **tumour**) is made up of cancer cells. When it first develops, this malignant tumour may be confined to its original site. If these cells are not treated they may spread through blood and other types of vessels into surrounding **tissue** and to other parts of the body.

The beginnings of cancer



How cancer spreads



When these cells reach a new site they may continue to grow and form another tumour at that site. This is called a secondary cancer or **metastasis**.

For a cancer to grow bigger than the head of a pin, it must grow its own blood vessels. This is called angiogenesis.



About mesothelioma

Mesothelioma is a type of cancer affecting the mesothelial cells. These cells cover most organs inside the body. They form a coating known as the mesothelium.

The mesothelium makes a lubricating fluid that helps protect the organs as well as allowing them to move around. For example, this fluid makes it easier for the lungs to move inside the chest when you breathe.

- The mesothelium is called the **pleura** in the chest area. Mesothelioma in the chest is called **pleural mesothelioma**. This is the most common type of mesothelioma.
- The mesothelium is called the **peritoneum** in the **abdomen**. This mesothelioma is called **peritoneal mesothelioma**. This is a less common type of mesothelioma.

Occasionally, mesothelioma starts in the membrane around the heart or the reproductive organs. It forms growths shaped like small pieces of cauliflower. They grow and spread gradually to surrounding areas. A person may develop mesothelioma in more than one place but this is rare.

Tumours developing in the mesothelium can be non-cancerous (**benign**) or cancerous (**malignant**). Benign tumours can usually be taken out with surgery and there are no further problems. This booklet only discusses malignant mesothelioma and mainly those in the chest and abdomen.

Mesothelioma can also be divided into another three types according to how the cells look under a microscope:

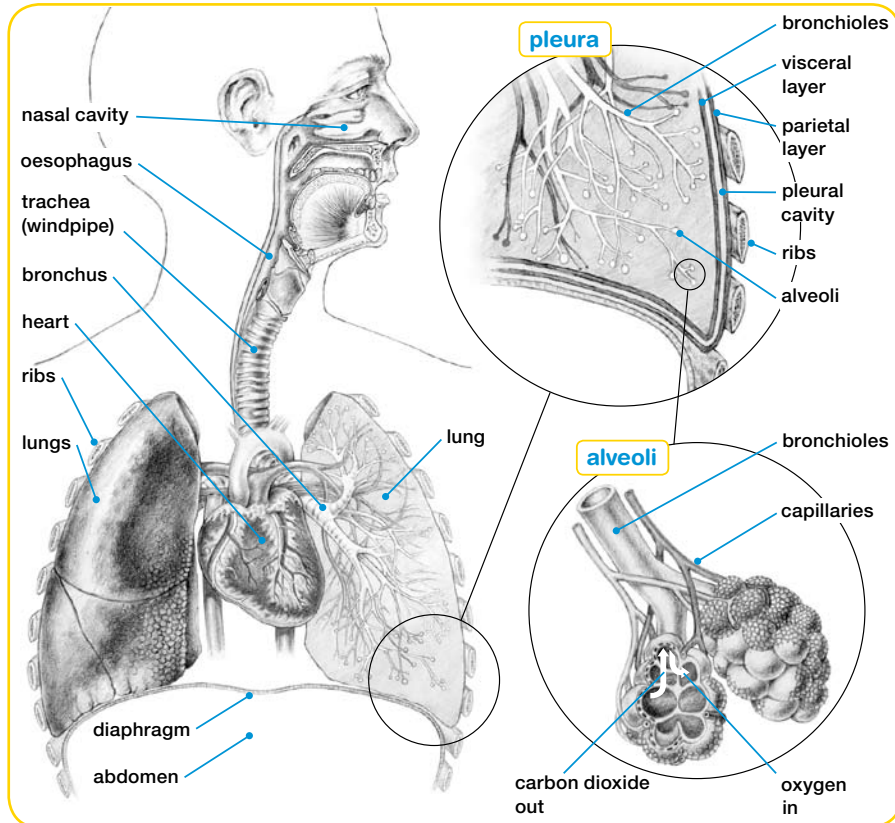
- epithelioid: around 60 out of every 100 cases of mesothelioma are this type; people with this type generally have a better **prognosis** (outcome) than those with other types
- sarcomatoid (fibrous): these make up about 15 out of every 100 cases

- mixed (biphasic): this means the mesothelioma is made up of both epithelioid and sarcomatoid cells. These make up about 25 out of every 100 cases.

Mesothelioma in the chest (pleural mesothelioma)

Pleural mesothelioma starts in the **pleura**. The pleura is the two layers of thin membrane that surround the **lungs** and line the chest wall. The inner layer is attached to the lungs and the outer layer lines the chest wall and diaphragm. Between the two layers is the pleural cavity. This cavity is almost empty. The two layers of pleura slide against each other. They're moist so that lungs can move smoothly against the chest wall as you breathe.

The lungs



Sometimes mesothelioma can spread into the area around the heart (pericardium).

Mesothelioma in the abdomen (peritoneal mesothelioma)

Peritoneal mesothelioma starts in the peritoneum. This is the sheet of **tissue** covering and lining the internal organs in the **abdomen**. This sheet helps to protect the organs and allows them to move around within the abdomen. The peritoneum makes a fluid that helps to keep the abdominal organs moving freely and smoothly as we move around.

Causes of mesothelioma

Asbestos exposure

Mesothelioma is very strongly linked with asbestos exposure. Almost everyone diagnosed with mesothelioma was exposed to asbestos.

Asbestos is a mineral rock made up of masses of tiny fibres. For many decades, asbestos was mined and widely used in building materials and for insulation, fireproofing and sound absorption. It was used to insulate buildings, ships, car parts, household appliances and power stations.

There are three types of asbestos – blue, brown and white. All are linked to mesothelioma although blue and brown are more commonly linked. The health hazards of asbestos have become clear in recent decades. Asbestos has been banned in Australia since 2004 and it is now illegal here to store, mine, import, sell, install or reuse any products containing asbestos. Any asbestos products already in place are allowed. However, great care needs to be taken if anything known to contain asbestos is to be disturbed or pulled down. There are strict regulations associated with removal and disposal of asbestos for areas greater than 10m². Refer to the 'Services and information' section on page 94.

Most people are at low risk of asbestos exposure and mesothelioma.

People who've been exposed to asbestos in their jobs are at greater risk. Such jobs include:

- mining or milling asbestos
- manufacture and repair of goods using raw asbestos fibres, such as brake linings
- use of products containing asbestos, like in building and construction, heating, shipyards, power stations, boiler making, gas fittings and plumbing
- alteration, repair or demolition of buildings or other structures containing asbestos.

It may take over 20 years after exposure for any disease caused by asbestos to become evident (it can take up to and over 50 years). However, most workers exposed to asbestos won't develop an asbestos-related disease.

Why is asbestos dangerous?

When asbestos is disturbed, it forms a dust made up of tiny fibres. This can easily be breathed in and cause serious health problems, notably:

- **pleural** plaque
- asbestosis
- diffuse pleural thickening
- **benign** pleural effusion
- lung cancer
- mesothelioma.

When asbestos is disturbed it sends out fibres into the air that can be inhaled by anyone nearby. Workers in mining and construction, plumbers, carpenters and auto mechanics have been at risk of exposure to asbestos. It can also affect family members of workers who brought home asbestos fibres on their clothing and shoes from their work site.

It is not clear how asbestos fibres get into the **peritoneal** cavity. It is unlikely that they come through the wall of the gut. However, they may come in through the diaphragm.

When asbestos fibres are taken into the body, **cells** react in an abnormal way. This may result in inflammation and scarring causing pleural plaque or diffuse pleural thickening. Or it may alter the DNA of the cells and result in the cells becoming **malignant**.

How common is mesothelioma?

Mesothelioma is a rare type of cancer but it is affecting more people. Australia has one of the highest rates of mesothelioma in the world. This is related to the high rate of asbestos use in mining, construction, manufacturing and home renovations over many years. In 2007 (the most recent data available), nearly 600 people were diagnosed with mesothelioma in Australia. Of these new cases, 81% were men.

In Victoria about 160 people are diagnosed each year.

These figures are likely to change. Experts believe the number of people diagnosed with asbestos-related diseases will not peak until 2020. Since 1980 there have been about 13,000 new cases of mesothelioma in Australia.

Symptoms

In its early stages mesothelioma (**pleural** and **peritoneal**) may not cause many symptoms. It is only later, when the cancer moves into the underlying **tissues** or causes fluid to leak into the cavity in the chest or **abdomen**, that symptoms appear.

Symptoms of pleural mesothelioma

The cancer causes **cells** in the **pleura** to produce fluid, called a pleural effusion. The fluid builds up between the two layers of pleura and presses on the **lungs**. This can cause:

- shortness of breath
- a persistent dry cough
- pain, which is often described as a heaviness or dull aching in the shoulder, arm, chest wall and upper abdomen. Some people describe it as like having pulled a muscle; others describe it as a sharp, stabbing or even 'burning' pain
- difficulty swallowing, a hoarse voice or coughing up sputum or blood – these are rare symptoms.

As the cancer progresses, it can grow into the lung, **lymph nodes**, chest wall, ribs, brain and liver, causing other symptoms.

Symptoms of peritoneal mesothelioma

Mesothelioma in the peritoneum ('peritoneal mesothelioma') causes:

- abdominal pain
- swollen **abdomen**
- poor appetite
- nausea and vomiting
- fever
- bowel or urinary problems.

Symptoms of advanced stage disease

Advanced stage cancer usually means cancer that has spread from where it began to other parts of the body. You may hear doctors call this 'metastatic', 'progressive' or 'secondary' cancer. Most people diagnosed with mesothelioma have **advanced cancer**, although at the time they are diagnosed they may not yet have symptoms of advanced cancer.

As well as the symptoms described above, other symptoms that may appear at this stage include:

- severe weight loss
- fatigue
- fever

- sweating
- confusion due to chemical imbalances in the body or spread of the cancer to the brain
- lumps under the skin.

All symptoms discussed in this section can be caused by other, less serious diseases. However, if you or someone close to you has any of them (especially if you know you have been exposed to asbestos) you should see your doctor. If necessary they can do further tests to find the cause of your problems.

If you have been exposed to asbestos in the past and develop shortness of breath, chest pain or other symptoms (pain, cough, weight loss), see your GP and ask for a referral for a chest x-ray or other tests they think may be necessary. Tell the doctor you have been exposed to asbestos. If any abnormalities show up on your x-ray or you remain unwell you should see a respiratory specialist.



Diagnosis

Facing a diagnosis of mesothelioma is difficult. At first most people feel lost and uncertain about their future. Although better treatments and continuing research has improved outcomes for many people, it remains a difficult cancer to treat.

To get the best outcomes it is important you:

- see the right specialist
- gain a definite diagnosis
- find out which treatment is best for your situation.

Can we screen for mesothelioma?

Screening means testing healthy people to detect a disease in its early stages. People being screened usually have no signs or symptoms of that disease.

For cancer screening to be effective there must be an accurate test that can pick up signs of early stage cancer, when treatment is more likely to cure the cancer. It is important the test doesn't give a positive result in people who do not have cancer ('false positive'). **At present there is no reliable screening test for mesothelioma.**

However, if you know you have been exposed to asbestos and may be at a higher risk of developing the disease, talk to your GP. They may suggest you have regular tests every few years to check for signs of the disease. If you are at a very high risk your GP may refer you to a chest specialist for regular check-ups.

People with mesothelioma sometimes have high levels of certain proteins in their blood but this is not a reliable method to diagnose mesothelioma. In the future we may be able to test for these substances to help with early

detection of the disease. However, for now they can only be used to help monitor the disease in someone who has already been diagnosed. See the 'Research into mesothelioma' section on page 39 for more about these tests.

Doctors and other health professionals you may see

If you have cancer, one or more specialists will advise you about treatment options. You should expect to be cared for by a team of health professionals from the relevant major fields (see following list). Ideally, all your tests and treatment will be available at your hospital. This may not be possible in some non-metropolitan areas. Your GP will be kept informed about all your test results and treatment. They will be able to answer questions you may have in between appointments with your specialist doctors.

Health professionals who care for people with mesothelioma include:

Respiratory physicians	investigate symptoms, make a diagnosis and stage the disease
Thoracic (chest) surgeons	are responsible for some biopsies and removing cancers that can be operated on
Abdominal surgeons	are responsible for operating on peritoneal mesothelioma
Medical oncologists	are responsible for chemotherapy
Radiation oncologists	are responsible for radiotherapy
Dietitians	will recommend the best diets to follow during and after treatment
Specialist nurses	lung cancer nurses, palliative care nurses, district nurses
Your GP	will help you through all stages of your cancer

Psychologists	help people with emotional and social concerns
Speech pathologists	help people with speech and swallowing problems
Social workers, physiotherapists and occupational therapists	will advise you on support services and help you to get back to normal activities
Palliative care team	will assist with symptom management and emotional support for you and your family

You may only see a few of these people. However, it is important to know you do have several health professionals supporting you through your treatment. Talking to them about your concerns can help you manage your disease and treatment in the best possible way.

How mesothelioma is diagnosed

Most people begin by seeing their GP. Your GP will examine you and ask you about your general health, family history and current symptoms. Your doctor may be able to feel lumps in the area where you are having pain or discomfort. If you are short of breath your doctor will listen to your chest for signs of fluid build-up. They may notice other symptoms you were not aware of.

If your GP suspects you may have mesothelioma they will ask you to have a series of tests or may refer you straight to a specialist. Depending on your symptoms this may be a lung specialist (for **pleural** mesothelioma) or a gastroenterologist (for **peritoneal** mesothelioma).

Mesothelioma can be difficult to diagnose. Even if you have symptoms and certain tests indicate mesothelioma, doctors may still not be sure. Because of this you may need to have quite a few tests so your doctor can be sure

of your **diagnosis**. This is important so they can recommend the right treatment.

Blood tests

You will have blood taken to check your overall general health. These tests will not show up mesothelioma but they can let your doctors know how your blood **cells**, liver, and certain chemicals are working. Cancer can affect how blood cells normally work so any changes to your blood can give your doctor important information.

X-ray

You will most likely have an x-ray of your chest or **abdomen**. The x-ray will look for any changes, like thickening of the **pleura** or fluid on the **lungs** or in the abdomen. These changes can be caused by other conditions. If they are present you will need to have further tests to find out what is causing the problems.

An x-ray is a simple test. You will be asked to stand in front of a machine with your chest or abdomen pressed to a plate and breathe in while pictures are taken. The radiation dose is low so it is not dangerous.

CT scan

A CT (computerised tomography) scan is a type of x-ray that takes pictures of the inside of the body. CT scans of the chest and the **abdomen** will show up swelling or fluid. The scan can detect the size and position of a mesothelioma. It can also help to show if the cancer has spread to the **lymph nodes** or to other organs.

This test takes about 30–40 minutes. To make the scan pictures clearer and easier to read you may have an injection of a dye into a vein in your arm. You may also be asked to drink a special liquid. It may make you feel hot all over for a few minutes.

You will be asked to lie on a table while the CT scanner, which is large and round like a doughnut, moves around you. Most people are able to go home as soon as their scan is over.

There is a small possibility of the injected dye causing an allergic reaction. Some people also have a strong metallic taste in their mouth. You should tell your doctor if you are allergic to iodine or contrast dyes, or if you are diabetic or have abnormal kidney function.

Pleural or peritoneal aspiration (fluid drainage/tap)

You may have a build-up of fluid either in your chest/lung area or **abdomen**. Fluid around the **lungs** is known as a pleural effusion. People with peritoneal mesothelioma may have fluid in the abdomen; this is called a peritoneal effusion or 'ascites'.

The build-up of fluid happens because the cancer **cells** irritate the area. This extra fluid around the lungs or abdominal cavity can feel uncomfortable. If it is in your **pleura** you may begin to have breathing problems. Peritoneal fluid can cause swelling, tightness and pain.

Your doctor can remove the fluid from your chest or abdomen by using a local **anaesthetic** on the skin and putting a needle through the skin into the fluid. They will draw a sample of the fluid into a syringe. This can be sent to the laboratory to test for mesothelioma cells.

Removing the fluid can improve your symptoms. Sometimes further aspirations or taps are needed for comfort. Medications can be provided if you are experiencing pain or discomfort.

Biopsy

This allows the doctor to take a sample from any thickened **tissue** around the **lungs** (pleural area) or **abdomen** (**peritoneal** area). It is usually done as an outpatient procedure. You will have a local **anaesthetic** to numb the area of skin where the biopsy needle will go in. Depending on where your

mesothelioma is, your doctor will gently guide the needle either through your chest wall or into your abdomen and into the **tumour**, guided by x-ray, CT or ultrasound pictures, and remove some tissue.

Your doctor may want to take a closer look to get the sample of tissue. If this is the case then you will probably need to have a general anaesthetic and a small operation. A small incision will be made into an area of skin and a thin flexible tube with a light and camera attached at the end will be inserted. The tube is called an endoscope. When it is passed through the skin of the chest it is called a thoracoscopy. Passed through the abdomen it is known as a laparoscopy.

Samples of tissue will be sent to the laboratory for testing. This may be the only sure way of diagnosing mesothelioma and ruling out other diseases.

Further tests

You may have some other types of scans.

A bone scan can show whether cancer has spread to the bones. In this test, a small amount of radioactive substance will be injected into a vein. It travels through the bloodstream and collects in areas of abnormal bone growth. A scanner measures the radioactivity levels in these areas and records them on x-ray film.

Positron emission tomography, also known as a PET scan, involves injecting radioactive glucose solution into the body. Because cancer **cells** use more glucose than most normal cells, the PET scanner may detect increased quantities of the radioactive glucose in those areas of the body where the cancer is. It scans the whole body, including the bones, but not the brain. It appears to be the most accurate method for detecting cancer spread to areas other than the brain.

Other tests that can show if the cancer has spread or if surgery is a treatment option for you include mediastinoscopy, pericardioscopy, endoscopic ultrasound scan and laparoscopy. Some may require you have a

general **anaesthetic** and stay overnight in hospital. If you need any of these tests your doctor will discuss them with you.

Waiting for test results

Waiting for test results is usually a worrying time. You and those close to you are likely to feel very anxious about what will happen if you do have mesothelioma. It is only natural to think the worst. However, try to take things day by day. Some results may come back quite quickly, within a day or two, but others can take up to a week or more. This can feel like a very long time.

Talk to your doctors and nurses about how you are feeling. Get as much information as you can from them about when and how you will get your results. Knowing how long they will take can make it less stressful than just continuing to believe they might be back tomorrow or the next day. Let those close to you know if you feel scared. They are probably feeling the same. Sharing your concerns can help a lot. You can try to support each other and reassure each other that feeling worried is normal during this time.

If you would like to talk to someone about how you are feeling call the Cancer Council Helpline on 13 11 20 and speak with one of the nurses.



Treatment

Many years of treating cancer patients and testing different treatments in clinical trials has helped doctors know what is likely to work for a particular type and stage of cancer. Your doctor will advise you of the best treatment for your cancer. This will depend on the type of cancer you have, where it is and how far it has spread, your general health, and what you want.

‘Staging’ the disease

The tests described on previous pages show whether you have cancer and some can also show whether it has spread. The cancer may have spread into surrounding **tissue** or to other parts of your body, including your **lymph nodes**. This is called **metastasis** or secondary cancer. Knowing if and how far the cancer has spread is called **staging** the disease. Staging helps your doctors to work out the best treatment plan for you.

‘Staging’ is a way of describing whether a cancer has spread, and if so, how far. Stage 1 means it has not spread; Stage 4 means it has spread to distant organs.

The staging system used for **pleural** mesothelioma is known as the 'TNM system' (T = **tumour**, N = lymph nodes, M = metastases).

TNM system

T	T followed by a number between 1 and 4 shows whether the cancer has spread in the area of the pleura and if so, how far. A higher number after the T (for example, T3 or T4) means it has spread beyond the pleura into tissue around the pleural cavity, or to nearby organs. People with T1 or T2 disease have cancer that is probably confined within the pleura (early stage mesothelioma).
N	N followed by 0 means that there is no spread to lymph nodes near the tumour. N followed by 1 means there is spread to nearby lymph nodes.
M	M followed by 0 means there is no distant metastasis; M1 means there is distant metastasis. Distant metastasis means that there is evidence the cancer has spread away from the area in and around the pleura, for example, to the bones or other organs.

Doctors combine this information to determine the stage of the cancer, from Stage 1 to Stage 4. For example, a pleural mesothelioma staged as T3, N1, M0 (tumour spread beyond the pleura into tissue around the pleural cavity, or to nearby organs, some lymph nodes affected, no metastasis) is a Stage 3 pleural mesothelioma.

There is no standard staging system for **peritoneal** mesothelioma. If your cancer is staged, doctors tend to use the TNM system described above.

Ask your doctor to explain the stage of your cancer in a way you can understand. This will help you to choose the best treatment for your situation.

It can sometimes be confusing to know which treatment is the best to have. Finding out as much as possible about the disease and its treatment helps

most people feel more in control of their situation. It allows people to make decisions about their treatment and care that are best for everyone. As with most types of cancer, the earlier someone is diagnosed, the better the outcome usually is.

Although there is no proven cure for mesothelioma, in the past few years there have been several major advances in treating the disease. These include:

- more accurate staging methods
- earlier **diagnosis**
- improvements in surgical techniques and post-surgery care
- using different **chemotherapy** combinations
- combining chemotherapy with newer treatments
- new **radiotherapy** techniques.

These advances have meant more people have received better symptom relief and possibly survived for longer. The aim of treatment is to make sure you have good quality of life for as long as possible.

All treatments have risks and you should talk these over with your doctor. Different specialists may have different opinions about the right treatment for you.

Treatment for both types of mesothelioma may include a combination of:

- surgery
- radiotherapy
- chemotherapy
- supportive care (**palliative care**).

People diagnosed in the earlier stages may be offered surgery followed by chemotherapy and/or radiotherapy. Surgery can also be used to reduce the size of a tumour, which may help relieve symptoms in people with advanced stage disease.

Chemotherapy and radiotherapy can shrink the mesothelioma and also relieve symptoms such as pain. Research has shown chemotherapy can help prolong life in some people by weeks or months.

Doctors can use **palliative** care treatments such as medications to help with pain relief and to relieve shortness of breath if you are too unwell for treatment

Surgery for pleural mesothelioma

There are two operations for **pleural** mesothelioma:

- pleurectomy
- extrapleural pneumonectomy.

Both operations are major surgery and not everyone is fit enough to go through with them. Neither has been shown to completely cure mesothelioma. However, some people who have had the operation have done well for several years. The question that still needs an answer is: Does surgery or other forms of treatment (chemotherapy, radiotherapy or other drugs) better control symptoms and help people live longer? Trials are underway throughout the world to help us get a clearer answer to this. Your specialist is the best person to ask about the likely outcome of the surgery.

See the 'Research into mesothelioma' section on page 39 for more about these trials.

Other types of surgery you may hear about are:

- decortications of the lung – removal of the outer layer of the lung
- wedge excision – removal of a section of the lobe of a lung
- pleurodesis – controlling fluid build-up – discussed on page 32.

Pleurectomy

Surgery can be used to completely remove mesothelioma that has not spread outside the **pleura**. This operation is known as **pleurectomy**. It involves removing part or all of the pleura and the lung **tissue** nearby. For many people with pleural mesothelioma this operation can help to control symptoms such as fluid build-up in the chest and relieve pain.

A pleurectomy is a major operation. However, some surgeons use keyhole surgery. If you have keyhole surgery you will have three small wounds, each about 2 cm long. You will need to stay in hospital for about seven days. Full recovery can take several weeks or more.

Extrapleural pneumonectomy

The surgeon may also suggest removing the **pleura**, diaphragm and the whole lung on the affected side, as well as the **tumour**. **Lymph nodes** may also be removed. This operation is known as **extrapleural pneumonectomy**. This type of surgery is usually done in combination with **chemotherapy** and **radiotherapy** to help improve outcomes.

The operation can be difficult to do and it will not help everyone. For a few people, however, it may be worthwhile. If the cancer is found when it's still small, and you're otherwise fit, surgery may help you gain more time and quality life.

The operation carries a risk of serious complications. Your doctor will talk to you in detail about these risks and together you can decide whether or not the risks outweigh the possible benefit for you.

If you decide to have this operation it is usually done by making a cut in the side of your chest (a thoracotomy). The wound will be quite long (about 22 cm). It is important to remember that you will be offered good pain relief methods during this time to cope with the effects of surgery.

You will need to stay in hospital for about two weeks. Full recovery from the operation can take some people several months.

Before and after your operation

Before you can have either of these operations you will need to have some tests to see if you are fit enough to cope with the surgery. Your doctor will explain in detail about each test. You may have already had some of the tests when you were being diagnosed. However, you may need to have them again. You may need:

- mediastinoscopy, which is a test to look into the centre of the chest where the heart is (**mediastinum**) – it can check to see if the mesothelioma has spread into this area. This test requires you to stay overnight in hospital because you need a general **anaesthetic**.
- pleuroscopy on the opposite lung to where the disease has been found, to see if it has spread to the other lung
- laparoscopy, to see if there is spread through the diaphragm to the **peritoneal** cavity
- pericardioscopy, which allows doctors to find out if the mesothelioma has spread into the layers covering the heart (pericardium). You will need a general anaesthetic for this test.
- PET or CT scans, to help find the size and extent of the mesothelioma
- lung function tests, to make sure your **lungs** are working well enough for you to have the operation
- echocardiogram, to find out how strong your heart is and how well it will cope if you have a lung taken out
- heart and lung exercise test, to find out how well these organs work during rest and exercise
- breathing and leg exercises
- blood tests such as full blood count, liver function and others.

You will need to sign a consent form for any operation you have. Your doctor will explain this.

Your medical team will talk to you about what will happen on the day of the operation as well as immediately after. This will include what tubes and drains you may have after the operation and how long you will be in hospital.

Surgery for peritoneal mesothelioma

Surgery is often not an option for people with mesothelioma in the **abdomen (peritoneal)**. However if it is an option, the operation is known as a peritonectomy. This means removing the lining of the abdomen (peritoneum). It's not often possible to remove all the cancer, but surgery may prolong life and can relieve symptoms such as bowel obstruction and pain.

There is a fairly new technique called cytoreductive or 'debulking' surgery. This is very intensive treatment and only possible in people who are fit and have early stage mesothelioma. It involves reducing the bulk of the cancer using surgery. During the surgery **chemotherapy** is given into the peritoneal cavity.

Although there has been some success with these treatments they are still considered experimental. For further information ask your doctor or call the Cancer Council Helpline on 13 11 20.

Going home after your operation

During your recovery at home it is important to gently exercise to help build up your strength. Your doctor or physiotherapist will advise you about the best type of exercise. Walking and swimming after the wounds have healed are usually good for most people after this type of operation.

It is likely you will have a community nurse visit you at home for a few weeks after you get home. You may have wounds to dress or need help with bathing. If you have any concerns after you get home, contact the hospital, lung cancer nurse if you have one, or your GP. Make sure you have these numbers before you leave the hospital and keep them handy at all times (by the phone or your bed).

Chemotherapy

This is the treatment of cancer by anti-cancer drugs. The aim is to destroy cancer **cells** while doing the least possible damage to normal cells. The drugs work by stopping cancer cells from growing and reproducing.

Your doctor may recommend **chemotherapy** if other treatments aren't suitable or the cancer has regrown following other treatment. In some cases it may reduce the size of the cancer, reduce its symptoms and improve quality of life. In addition, chemotherapy may help you to gain a few more months of life.

Chemotherapy for **pleural** mesothelioma is given as a drip into a vein in the arm or as an injection into a vein. You will have the drugs over a few days and then have a break for a few weeks (usually between two and four weeks). You will then begin your next cycle. The number of cycles you have will depend on the type of chemotherapy you have, the stage of your cancer and how well you cope with and respond to the drugs.

For people with **peritoneal** mesothelioma, chemotherapy is given directly into the **abdomen** area (peritoneal cavity). This is only suitable for people with early stage disease.

For information on particular chemotherapy drugs, call the Cancer Council Helpline on 13 11 20.

Side effects of chemotherapy

All drugs can have side effects. Side effects depend on which drugs you have. Not everyone having chemotherapy will get side effects and it is rare to have every side effect.

Chemotherapy used to treat mesothelioma may cause:

- tiredness and feeling weak (fatigue)
- changes to your blood levels: increasing the risk of infection, bleeding and anaemia

- nausea and vomiting
- bowel problems (diarrhoea or constipation)
- mouth problems (sore, dry or ulcerated mouth)
- dietary problems (loss of appetite, taste changes, weight loss)
- muscle and nerve problems
- skin changes (rash, swelling, itchiness)
- changes in your ability to have children (fertility)
- hair loss and scalp problems (rare with the drugs used to treat mesothelioma)
- changes in your memory and ability to concentrate. This usually improves once treatment is over.

Your doctors and nurses will talk to you about the side effects you may expect to have.

Cancer Council Victoria's booklet *Coping with Chemotherapy* discusses ways of managing side effects. Visit www.cancervic.org.au or phone 13 11 20 for a copy.

Some dietary supplements or herbal medicines can be harmful and change the effects of **chemotherapy** or make your side effects worse. It is very important to let your doctor know about any herbs, supplements or other products you have bought over the counter at health food stores, chemists, or from **complementary or alternative therapy** practitioners.

Radiotherapy

Radiotherapy treats cancer by using **radiation** to destroy cancer **cells**. Radiation can be targeted to cancer sites in your body. Treatment is carefully planned to do as little harm as possible to your normal body **tissues**.

Radiotherapy is not often used to treat **peritoneal** mesothelioma. For people with **pleural** mesothelioma, radiotherapy to small areas of the chest often helps control pain and lumps that grow up from the surgical scars.

If the cancer is in its early stages, radiotherapy may be given after surgery to help delay the cancer coming back. Radiotherapy given after surgery is called adjuvant radiotherapy. It has generally not been used to treat the whole **pleura** because it would do too much damage to the **lungs**, heart and liver. This damage can be reduced by delivering the radiotherapy after most of the mesothelioma has been removed by major surgery.

Radiotherapy is given in the hospital radiotherapy department. It is usually given Monday to Friday for several days or weeks depending on the reason for the treatment. Some hospitals now offer radiotherapy on Saturdays. Each treatment only lasts a few minutes. It does not hurt and you are not radioactive afterwards.

Side effects of radiotherapy

In radiotherapy, the x-rays are carefully targeted to do as little damage as possible to normal body **tissues**. It may cause some side effects during treatment or shortly after, but most side effects go away after treatment stops. Side effects will vary depending on which part of your body is treated. Side effects can include tiredness, reddened and peeling skin and loss of hair in the treatment area.

If you are having radiotherapy to the **abdomen** you may have nausea, vomiting and diarrhoea. Nausea and vomiting are usually controlled with anti-sickness drugs. Radiotherapy to the chest area can cause difficulty swallowing for a few days or weeks.

Radiotherapy may cause permanent changes ('fibrosis') in the lung tissue. This only occurs if high doses of radiotherapy are given to a large area.

Your doctors and nurses will tell you about what side effects to expect from your radiotherapy.

Cancer Council Victoria's booklet *Coping with Radiotherapy* discusses ways of managing side effects. Visit www.cancervic.org.au or phone 13 11 20 for a copy.

When cancer can't be cured

Palliative care is coordinated care provided by a team, which may include specialist doctors and nurses, your GP, volunteers, social workers, counsellors, psychologists, physiotherapists, occupational therapists and spiritual care workers and **complementary therapy** workers such as massage, music and art therapists. These people are known as the 'palliative care team'. They are all experts in helping care for people with **advanced cancer**. They will work together to make sure your quality of life is as good as it can be within the context of your illness.

Most people diagnosed with mesothelioma can benefit a lot from palliative treatment and care. Some people may have symptoms that make it too hard to cope with surgery, **radiotherapy** or **chemotherapy**. Your palliative care team can help you to cope with any concerns you may have if you are not having active treatment. Palliative treatment provides care to help relieve symptoms such as pain and breathing problems and also to help support you and your family emotionally. Palliative treatment can include:

- radiotherapy to help relieve pain
- chemotherapy
- surgical procedures, such as pleurodesis (see next page)
- other medications, such as pain-relieving drugs and steroids.

Being given a **diagnosis** of advanced cancer comes as a huge shock to most people. It is important you talk with your medical team often and let them know how you are feeling. The more they know about your symptoms and feelings the better they will be able to help you. There is more detailed information about living with advanced cancer on page 67.

For further information, contact the Cancer Council Helpline on 13 11 20 or Palliative Care Victoria on 9662 9644.

Cancer Council Victoria has a booklet on advanced cancer for people with cancer and a booklet for carers of people with advanced cancer. Visit www.cancervic.org.au or phone 13 11 20 for a copy.

Controlling the fluid build-up (pleurodesis)

Often the first concern with **pleural** mesothelioma is to prevent or control pleural effusion. This is the build-up of fluid around the **lungs**.

One treatment approach is to put an irritant like surgical talcum powder into the pleural sac. The pleura becomes inflamed and the two layers stick together. This leaves no space for fluid, so the **cells** stop producing fluid. This is called pleurodesis. It's often done during thoracoscopy, when the doctor is looking inside the chest with a flexible instrument like a small telescope or after drainage of fluid from your chest with a tube.

Pleurodesis doesn't work for everyone. Removing the pleura will also control fluid build-up, but it's a major operation. Other possibilities include drawing the fluid out gently through a needle.

Sometimes after a pleurodesis the lungs do not fully expand again. If this happens your doctor may put a small tube into the area to help drain the fluid out. This can stay in for a few weeks and will mean you don't have to keep coming to the hospital to have the fluid drained off.

Complementary and alternative medicines

It's common for people with cancer to seek out complementary and alternative treatments. Many people feel it gives them a greater sense of control over their illness, that it's 'natural' and low risk, or they just want to try everything that seems promising.

Complementary therapies include massage, meditation, acupuncture and other relaxation methods, which are used *along with* medical treatments. **Alternative therapies** are unproven remedies, including some herbal and dietary remedies, which are used *instead of* medical treatment. Some of these have been tested scientifically and found not to be effective or even to be harmful.

Some complementary therapies are useful in helping people to cope with the challenges of having cancer and cancer treatment. However, some alternative therapies are harmful, especially if:

- you use them instead of medical treatment
- you use herbs or other remedies that make your medical treatment less effective
- you spend a lot of time and money on alternative remedies that don't work.

Be aware that a lot of unproven remedies are advertised on the Internet and elsewhere without any control or regulation. Before choosing an alternative remedy, discuss it with your doctor or a cancer nurse via the Cancer Council Helpline.

For more information we recommend you read the following:

- *Complementary and alternative cancer therapies: for people with cancer, their family and friends* (booklet)
- *Complementary and alternative medicine: making informed decisions* (fact sheet for people with cancer and their families).

You can find out about what scientific research has been done into specific herbs, supplements and other products on the Memorial Sloan-Kettering website (<http://www.mskcc.org>). The US National Center for Complementary and Alternative Medicines (NCCAM) (<http://nccam.nih.gov>) and Quackwatch (www.quackwatch.com) are also reliable websites.

Prognosis

Prognosis means the outlook for your disease and your life expectancy.

Most people diagnosed with cancer want to know this information.

However, it can be difficult to predict. Statistics are often used to describe a person's prognosis. Statistics are averages based on large numbers of people.

They can be confusing! No statistics can tell you what will happen to you.

You and your cancer are unique. However, there are several factors that will affect your outlook such as:

- the type of mesothelioma you have
- the stage of your cancer (how far it has spread)
- the type of treatment you are able to have
- your fitness
- your age
- your overall health.

Some people believe that having a positive outlook will help your prognosis. While this can help many people cope better with their disease and treatment, there is no scientific evidence to prove it will help control or cure cancer or help you live longer. It is hard to find accurate statistics for the individual stages of either type of mesothelioma. This is because it is a rare disease. Also, accurate staging requires biopsies during surgery. Not everyone with mesothelioma will have surgery.

Your specialist is the best person to talk to about your prognosis. They will know your individual situation best and be able to discuss likely outcomes. Remember, doctors are often working from statistics that may be a few years old and there may have been improvements in treatments and survival since then.



Making decisions about treatment

Sometimes it is hard to decide which is the right treatment for you. You may feel that everything is happening so fast that you do not have time to think things through. Waiting for test results and for treatment to begin can be very difficult.

While some people feel they have too much information, others may feel that they do not have enough. Ask your doctor for clear recommendations for treatment. You need to make sure that you know enough about your illness, the possible treatment and side effects to make your own decisions.

If you are offered a choice of treatments, you will need to weigh up the pros and cons for each treatment. If only one type of treatment is recommended, ask your doctor to explain why other treatment choices have not been advised.

Some people with **advanced cancer** will always choose treatment, even if it only offers a small chance of response. Others want to make sure that the benefits of treatment outweigh any side effects. Still others will choose the treatment they think offers them the best quality of life. Some may choose not to have treatment except to have any symptoms managed to maintain the best possible quality of life.

“ It is important to discuss all your treatment options with your specialist. Ask what the pros and cons of each treatment are and about any long-term side effects. You want to be sure you can achieve optimal outcomes in a difficult situation. Involve your close family, friends and GP in your decision process.”
(Jed, 55)

Talking with doctors

You may want to see your specialist cancer doctor a few times before making a final decision about your treatment and care. You may also find it helpful to talk with your GP. Many GPs are an excellent source of information about **palliative care**. It is often hard to take everything in, and you may need to ask the same questions more than once. You always have the right to find out what a suggested treatment means for you, and the right to accept or refuse it and to seek a second opinion.

Before you see the specialist, it may help to write down your questions. There is a list of questions to ask your doctor at the end of this booklet, which may help you. Taking notes during the session can also help. Many people like to have a family member or friend go with them, to take part in the discussion, take notes, or simply listen. Some people find it is helpful to tape record the discussion, but check with your doctor first.

Talking with others

Once you have talked about treatment options with your doctor, you may want to talk them over with family or friends, with nursing staff or your GP, the hospital social worker or chaplain, or your own religious or spiritual adviser. Talking it over can help to sort out which course of action is right for you.

You may be interested in looking for information about mesothelioma on the Internet. While there are some very good websites, you need to be aware that some sites provide wrong or biased information. We recommend that you begin with the Cancer Council website (www.cancervic.org.au) and use our links to find other good cancer sites.

Getting a second opinion

Seeing another specialist and asking for their view on your cancer and its treatment options is known as 'getting a second opinion'. Some people feel uncomfortable about asking for a second opinion but this is common practice. Most cancer doctors understand why patients may want to do this. People say gaining the opinion of another specialist helps them feel more in control of their cancer and its treatment.

Your specialist or local doctor can refer you to another specialist. You can ask for a copy of your results to be sent to the second-opinion doctor. You can still ask for a second opinion even if you have started treatment or still want to be treated by your first doctor.

“ I think you need to trust your specialist. If you don't, then get another one. But if you trust them, and work with them, you'll come out as best as you possibly can. You don't have to be friends: they may be quite abrupt, and may not want to sit at the end of your bed and have a chat. But it's the trust that's important.”

Taking part in a clinical trial

Cancer Council Victoria supports participation in **clinical trials**. They are the most accurate way to determine the effectiveness of promising new treatments or new ways of combining cancer treatments. Always discuss treatment options with your doctor.

If your doctor suggests taking part in a clinical trial, make sure that you fully understand the reasons for the trial and what it means for you. Before deciding whether or not to join the trial, you may wish to ask your doctor:

- What is the standard (best available) treatment for my cancer if I don't go in the trial?
- Which treatments are being tested and why?

- Which tests are involved?
- What are the possible risks or side effects?
- How long will the trial last?
- Will I need to go into hospital for treatment?
- What will I do if any problems occur while I am in the trial?

If you decide to join a randomised clinical trial, you will be given either the best existing treatment or a promising new treatment. You will be allocated at random to receive one treatment or the other. In clinical trials, people's health and progress are carefully monitored.

If you do join a clinical trial, you have the right to withdraw at any time. Doing so will not affect your treatment for cancer.

It is always your decision to take part in a clinical trial. If you do not want to take part, your doctor will discuss the best current treatment choices with you.

Most trials on offer for people with mesothelioma patients will be phase I or II. For more information on phases of a clinical trial, visit www.cancervic.org.au/trials.

The Victorian Cooperative Oncology Group and Clinical Trials Office have developed a clinical trials database to make it easier for people affected by cancer and health professionals to find suitable clinical trials. This database was funded by the Victorian Cancer Agency.

Visit www.cancervic.org.au/trials for more information about clinical trials for cancer.

Follow-up care

After the completion of your treatment, you may need to have regular check-ups. Your doctor will decide how often you will need check-ups – everyone is different. Your check-ups will gradually become less frequent if you have no further problems. However, because mesothelioma is often diagnosed in the advanced stages it is likely that you will continue to have regular check-ups or as you need them. If the cancer comes back, you may need further treatment and it may be different from the first treatment.

It is important that you tell your doctor about any new symptoms.

Research into mesothelioma

Scientists and doctors are looking for new ways to prevent, diagnose and treat mesothelioma, and are seeking to discover whether other factors, apart from the known causes, may cause the disease.

Research into causes and prevention

Almost all mesothelioma cases are linked to asbestos exposure. Other causes have been considered, such as a mineral called zeolite. However, as yet there are no other scientifically proven causes. More research is needed.

A lot of research is looking into exactly how the asbestos changes the mesothelial cells in the body to cause the cancer. Gaining a better understanding of how the asbestos fibres cause cancer may help us develop ways to prevent this change from happening in the body.

Research into diagnosis

With some cancers, doctors are able to use a test called a 'tumour marker' to help diagnose the cancer. This is done by measuring the level of a protein in the blood given off by the cancer cells. An example is the prostate specific antigen (PSA) test for men to help diagnose prostate cancer.

Tumour markers cannot make a definite diagnosis. However, they can help doctors making an earlier **diagnosis** and monitor how well treatment is working. If doctors could develop a tumour marker for mesothelioma it could help in the same ways. Scientists are studying two markers, called serum mesothelin-related protein (SMRP) and osteopontin. Both these markers seem to be raised in people with mesothelioma. More research is needed before we will know how helpful they really are.

New drug treatments

Doctors have been trying to work out which are the best **chemotherapy** drugs to help treat mesothelioma. While the standard drugs such as cisplatin, pemetrexed and carboplatin have shown to help, their effectiveness is still fairly limited. Doctors are looking at how they can improve this by:

- using new chemotherapy drugs
- using known chemotherapy drugs in different combinations
- combining chemotherapy with other treatments.

Chemotherapy drugs being tested for mesothelioma in **clinical trials** around the world include: gemcitabine, usually in combination with cisplatin; mitomycin; irinotecan; topotecan; vinorelbine; and vinflunine.

Trials are also looking into injecting chemotherapy that has been heated up directly into the **abdomen** following surgery to help treat **peritoneal** mesothelioma.

Another new chemotherapy drug called ranpirnase is being trialled in Germany and the US. It is not available in Australia. It can be very frustrating to read about new treatments that you do not have access to. You may worry you are not getting the best treatment. However, if a drug becomes a safe and effective standard treatment for a cancer then it will become available in Australia.

New ways to use radiotherapy

Radiotherapy is not generally useful in treating mesothelioma. This is because the cancer can grow in different directions and it is not well defined. This means it is difficult to target with radiotherapy and avoid surrounding healthy **tissue**.

Doctors are looking at new ways of delivering radiotherapy. Eventually, if it is possible, it will be used to help to treat mesothelioma.

For information, call the Cancer Council Helpline on 13 11 20.

New approaches to surgery

Many people with mesothelioma are not able to have surgery. Doctors are looking at using **chemotherapy** and **radiotherapy** along with surgery to get better results.

There are also trials currently looking at how to help control the fluid build-up in the **pleura** that can happen in the **advanced** stages of the disease. Currently doctors drain the fluid and stick the pleura together (pleurodesis). Some research suggests that removing the pleura (a **pleurectomy**) may be more effective.

Research into photodynamic therapy (PDT)

PDT involves injecting a drug that makes **cells** sensitive to light. The drug spreads through the body and is mainly attracted to cancer cells. The drug is usually injected just before surgery. During surgery or a few days after the surgery, a small tube with a red laser light at the end of it is placed into the **chest cavity**. This laser light kills the cancer cells.

This treatment is still very experimental. At the moment there is no evidence that PDT helps cure mesothelioma.

Other research

Several other therapies are being tested as treatments for mesothelioma. They include:

- cancer vaccines
- growth factors for blood cells
- monoclonal antibodies
- drugs that stop the growth of cancer blood vessels
- gene therapy.

All these therapies work in different ways. Testing is in the early stages. If you are interested in finding out more, ask your doctor if they have up-to-date information on **clinical trials** into these treatments.



Living with mesothelioma

Cancer is a life-altering event. It often affects the way people see themselves, their bodies, and those around them. Priorities may change and people may seem to treat you differently. Many people say having cancer takes them on a journey involving a lot of loss and change in their life: loss and change that is often very difficult to cope with and causes grief.

You are likely to be in shock when you first hear the words ‘cancer’ or ‘mesothelioma’. You may not be able to believe it at first. (‘It’s not me: they’ve got the wrong person’). You may find it very hard to take in the information you are being given. This is normal. There is a lot to understand and many things will be so new to you that you cannot take everything on board at once.

Along with trying to deal with feelings of anxiety, fear and anger about having cancer and its treatment, you may also have to cope with practical issues such as:

- making a compensation claim for the disease
- other money matters
- going back or not returning to work
- looking after your home, children or grandchildren.

Coping with all these issues can be overwhelming. How can you possibly find the strength and time to manage? Most people need help in this situation. However, many people don’t ask for it. They may feel it is a weakness to admit they need help or they don’t want to bother people with their problems. Research has shown this is especially true of people with mesothelioma. They are often very stoic and find it difficult to discuss their needs, especially their psychological needs. Men generally find it more difficult to seek help during illness than women do.

This section talks about some common problems and suggests where you may be able to seek help.

Insurance, superannuation and loans

Many people with cancer feel they want to get their 'money matters' in order. This could mean talking with a superannuation fund, wanting to get life insurance or managing your income to provide for yourself or your family.

Getting new insurance (life, income cover or travel) may be more difficult because you have cancer. You will need to provide your medical history for many insurance policies. Generally a mortgage is associated with some kind of insurance so you're likely to have to let the financial institution know that you have cancer.

Many people don't know that they can claim disability benefits from their superannuation or insurance. If your working life is cut short, you probably won't have enough superannuation. Extra disability benefits will help you. This is because your superannuation is designed to last for an 'average' period of retirement, not longer.

The Superannuation and Insurance Advice Service is a free service. It has been set up to provide legal advice to people with disabilities. The advice is given by volunteer lawyers. The service is based in Melbourne. Appointments can be made by calling the Chronic Illness Alliance on 1800 180 182.

You may wish to ask lawyers who have expertise in superannuation and insurance for advice or see a financial counsellor. To find a lawyer who specialises in this area, call the Law Institute of Victoria Referral Service on 9607 9550.

Returning to work after treatment

You may have stopped work before or during your treatment. Having an **advanced** stage cancer is likely to make it difficult to return to work. This can be very hard to accept.

Some people may be able to return to work. This is a big commitment and may take a lot of courage and patience. Whether or not you return to work will depend on several factors such as:

- the stage of your disease (how far advanced your cancer is)
- which treatments you had and how effective it was
- how well you feel
- whether or not you have to return to work because of personal choice, income and family needs
- whether your previous employer treated you unfairly.

If you are able to return to your job, or start a new one, and people are aware that you have had cancer treatment, you may face some challenges. Often, the more relaxed and open you are about your cancer and its treatment, the more likely it will be that your co-workers respond to you in a way that feels right for you. If you are having a lot of trouble settling back into your work life it may help to talk with a counsellor. Some workplaces will have someone on site who you can talk to. If not, call the Cancer Council Helpline on 13 11 20.

Unfair treatment at work

Some people are forced to leave their jobs because of a cancer **diagnosis** or treatment. If you believe you have been unlawfully discriminated against because of a diagnosis of cancer you should seek legal advice immediately.

You can obtain free initial advice from the Disability Discrimination Legal Service. This is a service that specialises in disability discrimination law. Contact the Chronic Illness Alliance (www.chronicillness.org.au) for further information.

You can also contact the Equal Opportunity Commission of Victoria or the Human Rights and Equal Opportunity Commission (Commonwealth). See the 'Services and information' section on page 94.

What if I can no longer work?

If you can no longer work, this can be very stressful. You will probably still need a regular income to pay for bills, the mortgage or rent, and other living expenses.

It's important that you get the support and advice that you need. If you are waiting on a compensation claim this may not come through for a while. You will still need an income to live on. The Department of Human Services can help with financial and practical matters (1300 650 172). For information on Commonwealth Government disability, sickness and carers payments, call Centrelink on 13 27 17.

If you were working at the time you were diagnosed with mesothelioma your past loss of wages and future loss of earning capacity will form part of your legal claim. Starting the compensation process will allow some relief from these concerns.

Claiming compensation and sorting out other benefits and money matters can be quite complicated for someone diagnosed with mesothelioma. We discuss compensation claims on page 48. To be sure you get the best deal for your situation you may find it useful to see a financial adviser to discuss your financial concerns. (You may also hear them called a financial planner or consultant or sometimes a financial counsellor.) Your bank may have a financial adviser you can talk to. Or look for an independent financial adviser in the telephone book or on the Internet.

For financial counselling you may also like to visit the websites of the Commonwealth Financial Directory or the Wesley Mission financial counselling service.

Support for carers

The person caring for you may be able to get financial assistance such as a non-means-tested carer allowance or concession cards from Centrelink. Many people caring for someone with cancer don't seek assistance, thinking they would not be eligible for help or they may be put off by the paperwork! Don't avoid finding out because you feel embarrassed about getting financial assistance. This is money that you may be entitled to and has been specifically allocated by the government to help sick people and their carers. You are saving the government money by caring for someone at home.

Carers can contact the following organisations for more information:

- Commonwealth Carer Resource Centre: 1800 242 636
- Centrelink: 13 27 17 (the Centrelink Multilingual Service is on 13 12 02)
- Cancer Council Helpline: 13 11 20 for financial assistance information.

For further information about caring for someone with mesothelioma see page 90.

Support with childcare and home duties

You may be eligible for help with childcare costs: call the Family Assistance Office on 13 61 50.

Local councils provide a range of community and in-home services, including meals on wheels, house-keepers and respite care. Telephone your council (listed by council name in the White Pages).

For more information about practical and financial support, contact your local hospital, community health centre or the Cancer Council Helpline on 13 11 20.

Claiming compensation

This section tells you about your potential legal rights. It is not legal advice. Please contact a lawyer for legal advice about your own situation.

Almost every case of mesothelioma is caused by previous exposure to asbestos in the workplace or at home. Everyone who is diagnosed with mesothelioma in Australia is entitled to investigate bringing a compensation claim either at common law or under a statutory compensation scheme.

The process for bringing legal claims for compensation for mesothelioma is straightforward. Depending on the treatment you are receiving and how you are feeling, it is advisable to see a lawyer as soon as you are up to it to discuss your potential claim.

You should be aware that you **must** lodge your claim in court within your lifetime to protect your rights to common law compensation. In many states this is the largest component of damages available to you. A lawyer can lodge this document on your behalf to ensure that your common law entitlements are protected.

During this very difficult time your lawyer can advise you about the process and how this can be made easier for you and your family.

Common law compensation

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

- your employer and/or the manufacturer of the asbestos products to which you were exposed owed you a duty of care
- they were negligent in exposing you to asbestos dust and fibre

- because of that negligence you have been injured
- because of that injury you have suffered damage.

The claim begins with a formal court document called a Statement of Claim.

Most Australian states and the ACT are able to speed up the hearing of asbestos claims. New South Wales has a dedicated tribunal called the Dust Diseases Tribunal to deal with these types of claims. Your lawyer will present a medical report from your treating doctor to confirm your condition to speed up your claim.

Most asbestos claims are settled at a pre-trial conference or mediation. If it cannot be resolved, it will proceed to a hearing or trial. At the hearing or trial, your lawyer will need to prove duty of care, negligence, injury and damage as described above.

Statutory benefits

Some states have statutory compensation schemes for people with mesothelioma. Ask your lawyer whether you qualify for any of these schemes.

New South Wales

In New South Wales, the relevant Act is the *Workers Compensation (Dust Diseases) Act 1942* (NSW).

You can make a claim to the Dust Diseases Board if you can show that:

- at all relevant times you were a worker and employed in New South Wales within the meaning of the Act
- you have been exposed to offending dust such as asbestos dust
- you have contracted a disease named in the Act.

If you meet these criteria you are entitled to weekly compensation payments or a pension. You are also entitled to relevant hospital, medicines and related expenses.

This entitlement continues through your lifetime. If you die from the asbestos-related disease, your dependants at the time you made the claim become eligible to claim for lump sum and weekly compensation.

You are not required to prove fault.

Your lawyer will submit the application. The Dust Diseases Board will then contact you. See www.ddb.nsw.gov.au or talk with your lawyer.

Victoria

In Victoria, the relevant Act is the *Accident Compensation Act 1985* (Vic).

You have entitlements if you were exposed to asbestos in the course of your employment after 31 August 1985.

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

Queensland

In Queensland, the relevant Act is the *Workers' Compensation and Rehabilitation Act 2003* (Qld).

Your entitlement to claim damages begins on the date you are diagnosed with an asbestos-related illness.

Your entitlement depends on where your asbestos exposure occurred. Generally, people who were exposed in the workplace are entitled to workers' compensation benefits.

Any claim for these benefits must be made within six months of being diagnosed with an asbestos-related illness.

You do not have to prove fault by your employer to qualify. However, you must prove you were exposed to asbestos in the workplace for which the workers' compensation insurer is liable.

It doesn't matter if you are retired or still working. Your lawyer will advise you whether you qualify for these benefits and how much you can expect to receive.

Generally, workers' compensation benefits for serious asbestos-related illnesses are paid in a series of lump sums.

Western Australia

In Western Australia, you may have entitlements under the *Workers Compensation & Injury Management Act 1981* (WA).

Please discuss this with your lawyer.

Tasmania

At the time of writing, the Asbestos Related Diseases (Occupational Exposure) Compensation Bill 2011 is to be passed and come into operation on 1 October 2011. The Act will seek to provide statutory benefits in a short timeframe to sufferers of mesothelioma.

Your lawyer will be able to discuss this with you.

Commonwealth statutory entitlements

Some current and former Commonwealth Government employees may also be able to apply for statutory benefits. They need to have been exposed to asbestos during the course of this employment.

Please discuss with your lawyer.

Does it matter where in Australia I was exposed to asbestos?

Usually the law of the state where you were exposed to asbestos will govern your claim. Different Australian states have different compensation schemes and entitlements. Depending on where you were exposed, you may have entitlements to common law damages, pensions and/or statutory benefits.

It may be that you have entitlements in competing jurisdictions. If you were exposed to asbestos in two or more states in Australia your lawyer will advise you as to where you should bring your claim to maximise your compensation entitlements.

What if I was exposed to asbestos in the UK?

If your only exposure to asbestos happened in the UK, you may be able to bring a common law claim in England or Scotland. Unlike in Australia, you do not need to issue this common law claim in your lifetime to protect your rights. Discuss your claim with a lawyer as soon as you are able to, as time limits apply.

If your asbestos exposure was as a result of work for an employer on or after 5 July 1948 you can also apply for a pension from the Industrial Injuries and Disablement Benefit Scheme. See www.dwp.gov.uk for a claim form. You will need your national insurance number and your inland revenue history. Your lawyer can help with this.

You may also be able to apply for a one-off payment under the UK *Pneumoconiosis Etc (Workers' Compensation) Act (1979)* and the Diffuse Mesothelioma Scheme 2008. See www.nidirect.gov.uk for a claim form.

If you were exposed to asbestos in both Australia and the UK you may still be able to apply for a pension or one-off payment under these schemes.

In the UK there are differences between English and Scottish laws. If you have questions, seek advice from a lawyer who practises in this area.

Who can I sue for compensation?

To ensure your rights are protected, contact a lawyer who will take a life and employment history of all of your potential lifetime exposures to asbestos.

From this history your lawyer will be able to tell you which entities to sue, known as defendants. Common defendants to asbestos claims include:

- former employers
- manufacturers of products containing asbestos such as James Hardie or Wunderlich
- occupiers of sites where asbestos was present.

Very often if you worked with asbestos your previous employer may have gone out of business. This may not stop you from starting a claim for your compensable injury of mesothelioma. If it can be shown that your former employer had workers' compensation insurance at the time of your employment, an application can be made to the Court to reinstate the company for the purpose of litigating your claim.

Depending on your own personal history, your lawyer will issue your claim against your former employers and/or the manufacturers of the asbestos products you used and/or the occupiers of the sites you worked at.

If you have any documents related to your previous employers, please bring this to your first meeting with your lawyer.

What if I was self-employed?

If you were self-employed and remember using asbestos products, it is likely you will be entitled to claim compensation from the:

- manufacturers of the products you used and/or
- occupiers of the sites at which you worked.

Lawyers who practise in this area will be able to advise you more about this.

What if I smoked?

Mesothelioma is not caused by tobacco. Therefore you can still bring a compensation claim for mesothelioma if you smoked.

What sort of compensation will I receive?

Your common law claim may include damages for:

- pain and suffering
- loss of expectation of life
- past and future medical expenses
- past and future care and assistance
- past loss of wages and loss of future earning capacity if you were working at the time of **diagnosis**
- past and future domestic care expenses for a dependent (e.g. a child) (these damages are only available in New South Wales and South Australia).

Statutory benefits will be calculated in line with the relevant scheme.

What will be required of me during the claim process?

First, you will meet with a lawyer at your home or in the hospital. Your lawyer will take a detailed life and work history from you and discuss any exposures to asbestos you may have had. To prepare for this meeting, you may wish to make notes about your work history and the names of any former workmates.

If you can't remember any asbestos exposure, don't worry. Many people can't remember straight away how they were exposed to asbestos. This is normal: 20 to 50 years may pass between inhaling asbestos fibres and developing mesothelioma. It may take time to talk through your history and work out how you were exposed to asbestos.

Your lawyer will issue proceedings based on this advice and any investigations that were required to identify the defendants.

You may be asked to visit doctors, for your lawyers and the defendants. If you are not well enough, you will not have to do this. Your lawyer will work around your medical appointments or treatments to make things less stressful for you.

During your claim your lawyer will contact you often to discuss progress. Make sure that you or a family member contacts your lawyer if there is a change in your health. You should feel able to speak to your lawyer at any time about any aspect of your claim.

“ My father was initially reluctant to contact a lawyer, but once he did he felt very comfortable with the lawyers he used who were very experienced in this area of law. They were professional, forthright, upfront and honest, yet compassionate. Dad was encouraged by the fact that his lawyers sought the best possible outcome for him, and that this was achieved in a short timeframe and within his lifetime, with the least amount of intrusion into his remaining time.” (Ellie, 46)

Before a trial, there is a 'pre-trial conference' or 'mediation' stage. Your lawyer will ask you for instruction in relation to any offers made to resolve your claim. This can be done over the phone.

If your case is to be heard before a court, you may be required to give evidence in court. If you are not well enough, you can give evidence at home.

How long will a claim take?

Generally the whole process should be complete within three to six months. Claims can be done in a shorter timeframe if you become very unwell. To allow this to happen your medical team would need to provide evidence in support of your situation.

What if I die before my claim resolves?

Many people suffering from mesothelioma have concerns about what will happen to their claim if they die before it is resolved. Provided the claim is lodged or issued in Court within your lifetime, your entitlement to general damages, often the largest component of a common law claim, is protected for your estate and your family.

Your family may also have dependency entitlements if you die because of your mesothelioma. Your lawyer will be able to advise you as to whether this applies to you and your family.

“When my husband was diagnosed with terminal Mesothelioma our lives were shattered. We were advised to apply for compensation. He reluctantly contacted lawyers, as he was unsure of his chances of “winning” his case and didn’t want to leave me in financial strife if he lost. Lawyers assured us we had a very strong case. My husband didn’t survive to “win” his case but I did, with a lot of help, caring, understanding and good advice from our lawyers. This has enabled me to have the financially secure future that Gordon had hoped for me.” (Sharon, 68)

Will I need to pay money back?

When your claim is resolved, you will need to reimburse the following for treatment and other costs related to your illness:

- Medicare Australia
- your private health insurer (if you have one)
- Centrelink, if you are receiving a disability pension or
- the Department of Veterans’ Affairs.

After your matter has settled there may be a period you will no longer receive a pension on account of your settlement. Your lawyer will discuss this with you during settlement negotiations.

Your lawyer may be able to negotiate a cap on future payments to your private health insurer. This will give you and your family some certainty about the costs of your future care.

How to choose a lawyer

Because making a mesothelioma claim is a specialised area it is important you deal with a lawyer and law firm experienced in this area of work. Lawyers who practise exclusively in this area often have a wealth of knowledge about asbestos and how and where it was used. This will often cut down the time taken to investigate a claim.

They will have a good understanding not only of how to make the claim but also about your disease and what you are coping with.

Questions you may like to ask the law firm:

- How much experience of mesothelioma compensation claims does the lawyer have?
- How successful has the lawyer been in past mesothelioma compensation claims?
- How long does a mesothelioma compensation claim dealt with by this lawyer normally take to go to court or be settled? As a guide, claims for living mesothelioma sufferers should be finished within three to six months or sooner if possible.
- What charges does the lawyer make for dealing with a mesothelioma compensation claim? Does the lawyer work on a no win–no charge basis or what are the full details of charges? What are the conditions attached to no win-no charge?
- How much compensation am I likely to receive?

How will I afford a lawyer?

All lawyers who practise solely in asbestos litigation will offer you a no win–no charge agreement. This means that you do not have to come up with any out-of-pocket expenses until the claim is resolved. Conditions will apply to this and you will need to discuss this with your lawyer. You should feel free to ask your lawyer about legal costs when you first meet them and throughout the conduct of your claim.

Is it worth it?

In most common law claims for mesothelioma, people receive most of the settlement monies in an out-of-court or court settlement. This applies to statutory benefits as well.

If your case is successful, you will need to pay legal fees.

“ I strongly recommend recently diagnosed persons try to seek legal advice on asbestos litigation. I now know how respectful and sensitive they are in processing what is often an exhausting claim on your behalf. They do all the hard work and research and were always very understanding of the awful range of emotions during this very confusing time in your life - don't wait.” (Jane, 52)

To find a lawyer

For a referral to a lawyer who only deals with common law claims for mesothelioma and other asbestos-related diseases such as lung cancer or asbestosis, contact the law society in your state or territory:

Victoria: (03) 9607 9311

New South Wales: (02) 9926 0333

Queensland: (07) 3842 5842

Northern Territory: (08) 8981 5104

Western Australia: (08) 9322 7877

South Australia: (08) 8229 0222

Tasmania: (03) 6234 4133

Your feelings

Finding out you have cancer is usually devastating. Fear of the future, anger, denial and an uncertainty about everything in your life right now are a few of the common feelings for someone diagnosed with cancer. One of the first things most people think about is death: Will I die? If so how long do I have left? You may begin to dread the thought of what lies ahead for you and those close to you.

“ Well in less than a minute my life stopped. All I could say to the doctor was ‘Am I going to die?’ I have three young children – I want to see them grow up.”
(Ben, 55)

You may find you cry a lot in the first few weeks after your **diagnosis**. You may feel very low in mood. Some people say they feel resentful when they see others going about their normal life when their life has been turned upside down. You may also feel:

- guilt
- denial
- uncertainty
- sadness
- depression
- grief.

It is not uncommon to feel angry about the cancer not being found earlier and what this means for you and those close to you. You may feel angry about having had to work in a job where you were exposed to asbestos.

Others say they feel anger towards their employers. Sometimes employers have been suspected of having chosen to ignore warnings of the dangers of asbestos. This can be very upsetting, especially when you were a loyal and hard-working employee for many years.

Others direct anger towards people they do not know.

“ I had randomised anger – towards everybody who looked fit and healthy – to anybody and everybody just walking down the street. Totally without reason!”
(Sam, 68)

It is very natural to feel sad when you have cancer but many say the feelings can improve with time. For some people the feelings linger and may turn into depression. See page 81 for more about coping with depression.

You may be wishing your life could return to how it was before you were diagnosed with cancer. You may focus on what you have lost. Losses may include:

- the loss of some of the most enjoyable parts of your relationship with your partner, children and other close family and friends
- loss of work, friendships, regular exercise or an active and fun social life
- loss of sexuality
- loss of future goals
- changes in your financial situation.

Maybe you know others who have been diagnosed with mesothelioma. You may live in a community where others have developed the disease. You may be afraid that other family members may develop the disease because of your exposure. For example, partners who washed the clothes of men working with asbestos may have been exposed to the asbestos fibres.

You will cope with your cancer and your feelings about it in your own way. There is no right or wrong way of coping. Two people with the same type of cancer and treatment may respond differently to their losses. Acknowledging feelings and knowing where to get help will allow most people to cope better. Many people say that time and support from others are very important.

Be kind and patient with yourself. Try to talk about how you are feeling with those you trust. Ask for support when you can. Those close to you will want to help and support you but they may need some guidance from you. Don't be afraid to tell them.

Many people find it helps to talk to family and friends. Others prefer to speak with their hospital social worker who can put you in touch with a counsellor. Your GP is also a good source of help. They may be able to refer you to a professional counsellor for a number of free counselling sessions under the national health system. Ask your GP about this.

The cancer nurses on the Cancer Council Helpline 13 11 20 are trained to listen and provide you with further information and support.

Your relationships

Facing cancer with people close to you can create more meaningful and lasting relationships. However, sometimes cancer can put a huge strain on a relationship.

If you feel a relationship is coming under pressure, consider talking with a counsellor, social worker or therapist. Your medical team, close friends and family or a support group may be helpful, even in dealing with intimate problems. Your children and friends may also benefit from coming to a support group with you.

“ It felt like we found home. Here was a group of people who were expressing thoughts, fears and symptoms

so similar to ours. We were able to share treatment news and more and be fully understood.”
(Fred, 58, partner to Linda, 54)

Children

It is common for everyone to want to spare children pain. You may think it is better to delay telling them what is going on, or even to let them expect that things could return to normal. But it is best to be honest with young children, even when you find this difficult. Children always know that something is wrong. So they will need explanations they can understand. They will want to be reassured that there will be someone to care for them. Teenagers may also feel abandoned and need a lot of reassurance about what is happening. Older adult children will probably want to support you the best they can. To find out more about how to help your children (young, teenage and adult children) contact the Cancer Council Helpline on 13 11 20.

Partners

We use the word ‘partner’ to mean husband, wife, girlfriend or boyfriend.

Most people find their relationship changes during cancer and its treatment. The way you deal with it as a couple will most likely reflect your relationship before the cancer. If you were having difficulties it may become worse now. If your relationship was stable then it is likely to continue in this way. Sometimes relationships that were troubled actually improve and become stronger as people pull together in tough times.

“ Every so often, usually when lying awake at night and in particular while alone in the hospital when I was having my chemotherapy, I would get these pangs of fear about what my last moments of life would be like. These anxiety attacks made me realise how lucky I was to have my husband there. He would come to the

hospital in the middle of the night to reassure me. Just his embrace was comforting. My partner was also the informer to family and friends of my treatment dates, etc. He was really there for me and I felt the experience made us even closer.” (Ali, 45)

Sometimes there can be trouble when two people feel differently about one situation. One of you may feel quite negative and the other hopeful. The hopeful partner can help to give the other a lift!

Other problems that can sometimes occur include:

- difficulties about making treatment decisions
- your partner wanting to protect you all the time
- a partner who has difficulty facing up to what is happening.

Sexuality

Whether you are in an intimate relationship or not, your sexuality may play an important part in how you feel about yourself. Having cancer and its treatment can affect how you feel emotionally and sexually. It can change your self-image. It is often difficult to feel good about yourself when you feel unwell.

Symptoms of mesothelioma and its treatment, such as breathlessness, cough, weight loss, pain, tiredness and nausea will all affect how you feel about sex. Extensive surgery, **chemotherapy** or **radiotherapy** may have changed the way your body looks, functions and feels. Many people say they lose their libido during cancer treatment and for some time afterwards.

Dealing with sexual issues can be distressing and upsetting. It can have a significant effect on your daily life. If you have a partner you may find it difficult to talk about what is happening and how you are both feeling. However, if you can manage to talk, most people say it helps.

You may be avoiding intimacy with your partner for fear of it having to end in sex. Your partner may be interpreting this as rejection. Let them know you still love them and want to be close, but sex is not possible right now and may not be possible in the future. Most loving partners will understand. They may find it helpful to read the section on the next page about 'what partners can do'.

You can find other ways to enjoy being intimate, such as holding hands, cuddling or simply chatting over a meal. These things can become very important, especially if the cancer is advanced. The important thing is to try to stay close even if it does not involve sex. Knowing you have the support from your partner, no matter what, will be one of the best 'treatments' you can get during your illness. Sex is usually much less important than this.

“ Sex was very painful for my wife after photodynamic therapy, so that was another thing that we lost immediately after the operation. To accept this was nothing in comparison to what my wife was going through.” (Leslie, 65)

If you are not in a relationship sexual issues can be just as difficult. You may have fears about still being attractive to others or enjoying sexual activity again. This can cause a lot of anxiety. You may not know who to share your feelings with. You can call the Cancer Council Helpline on 13 11 20 to ask for contact details for sexuality counsellors who work with people with cancer.

For Cancer Council information on sexuality and cancer, visit www.cancervic.org.au or phone 13 11 20.

What partners can do

Watching someone you love go through all the discomforts of cancer and its treatment is often heartbreaking. You may feel helpless and not know how to give them the love and support they need. But now more than ever your partner needs your acceptance, support and love. Many partners find this hard because of the pressure of the whole situation. For some people physical changes caused by the cancer and its treatment can make it difficult to show your partner your love in ways you were used to.

Your partner may not be ready or able to have much physical contact. Or they may be ready but withdraw because of fear, anxiety, loss of self-esteem or imaginary thoughts about how you are feeling. You may shy away, not wanting to pressure them or appear insensitive. However, you may find holding each other, sitting close and cuddling can also show your love without it leading to sex. As awkward as it may feel, touching your partner and showing them you still find them attractive and desirable, despite any changes in how their body looks, feels or works, will go a long way in helping them recover their confidence and self-esteem.

The key to supporting each other is to talk openly and often. Holding everything in can be damaging and lead to misunderstandings and resentment. You may need to gently persist with physical contact and talking to your partner. Even when they shy away, try to keep reaching out to them. Your reassurance will show them you are in this for the long haul: you love them, no matter what.

You may find it helps to see a professional counsellor. Call the Cancer Council Helpline on 13 11 20 for contact details.

Exercise

Most people with cancer find it helpful to stay active and exercise regularly. However, if your cancer is advanced you may not feel much like exercising. You may feel too tired and unmotivated.

Exercise can help with fatigue. The amount and type of exercise you do will depend upon what you are used to and how well you feel. You may only manage a short walk around the house each day. Gentle yoga exercises can also help. Talk with your doctor about what will be best for you. Remember to stop if you feel too tired or have pain.

For a copy of Cancer Council Victoria's booklet *Nutrition and Exercise*, visit www.cancervic.org.au or phone 13 11 20.

Relaxing

Some people find relaxing or meditating helps them to feel better. The hospital social worker or nurse will know whether your hospital runs any programs, or may be able to advise you about programs in your area. Your local community health centre may also be able to help.

You can also choose to do things that you know have helped you relax in the past. This might be listening to music, reading or spending time with people close to you.

For Cancer Council information on relaxing and coping with anxiety, visit www.cancervic.org.au or phone 13 11 20.



Advanced cancer

Knowing you have advanced cancer and reading about it can stir up difficult feelings. You and those close to you may not be ready to read any or all of this part of the booklet. That is a normal response. Don't force yourself to read it because you think you should or someone else is encouraging you to. Make your own decisions, as you know best how you are feeling.

Perhaps you could just glance through the headings over the next few pages and read the sections only if you feel ready.

If you want to read the whole section we suggest you have someone you trust nearby. They can help support you if you encounter any upsetting ideas, emotions and words.

Most of the quotes in this section come from people with **advanced cancer** and their carers, close friends and family. They describe how they cope with having advanced cancer and what has helped them. Above all, their words and ideas offer hope to others.

If you or someone close to you would like more information or support, call the Cancer Council Helpline on 13 11 20.

What is advanced cancer?

Advanced cancer is a cancer that has spread from where it began. The cancer is usually still confined to the place where it began. But it has grown and spread into nearby **tissue**. It may also spread to other parts of the body. Symptoms tend to develop first at the place where the cancer began.

When mesothelioma is advanced it is not curable. However, your doctor may still recommend treatment. This may help relieve any symptoms, can make you feel better and may allow you to live longer. You may hear this called **palliative care** (see page 69).

Cancer Council Victoria has a booklet on advanced cancer for people with cancer and a booklet for carers of people with advanced cancer. Visit www.cancervic.org.au or phone 13 11 20.

What if my cancer is advanced?

The news touches every aspect of your life. At first, it may be hard to believe things will improve – but many people with **advanced cancer** say they can. In time, you're likely to feel more in control again. So try not to rush into decisions at this stage.

You will need to discuss your cancer and your outlook (**prognosis**) with your doctor. Remember that for some people, treatment can keep the disease in check for months or years. Treatment can also manage symptoms. So even though the cancer cannot be stopped, treatment will continue. Treatment decisions are very important at all stages of your illness.

Most people find they want information and support. You might find encouragement through talking with other patients or by joining a support group for people with cancer. See the 'Services and information' section on page 94.

“ I initially resisted joining our support group. I had enough to cope with and didn't want to surround myself with sick people. I felt it would bring my mood down and reinforce that 'I am sick'. I wanted to ignore my disease for as long as possible and refuse it the

power to change my life – a form of denial I guess. Once I attended a couple of times I experienced the very uplifting feeling of talking with people who understood my disease: people who had been through similar treatments and had similar feelings to me. I learnt also that I could contribute to the group by sharing my experiences and give people hope.”
(Jill, 68)

Treatment

Although there is no cure, many people with advanced mesothelioma will have treatment to help control the cancer, as well as relieve symptoms (supportive care). This usually involves one or a combination of surgery, **chemotherapy** and **radiotherapy**. We discuss these in the 'treatment' section on page 21.

Palliative care

The goal of **palliative care** is to provide care and support so that people who are ill can live as fully and comfortably as possible. Palliative care involves looking after your physical, emotional and spiritual needs as well as supporting your family and other carers. Palliative care:

- combines medical, nursing, psychological, social and spiritual care so that people with life-threatening illnesses may come to terms with what's happening to them
- provides relief from pain and other distressing symptoms
- doesn't prolong treatment when it's no longer beneficial
- doesn't include deliberate ending of life
- offers a support system to help families and friends cope during a person's illness and in bereavement
- aims to help the person and their family be in control of their treatment and their quality of life
- can be provided in the home, a hospital or a hospice setting.

Many people believe palliative care is only for people who are going to die. However, palliative care can be given at any stage of **advanced cancer**. Some people live for months or years having palliative care.

“ My husband did not want to accept help from the palliative care people. He said that once they get 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, 62)

If you're not linked in with a palliative care service and would like to be, speak to your GP, specialist doctor or nurses at the hospital. You can also contact the service directly. In Victoria, each palliative care organisation covers a particular geographic area, so you'll be visited by the organisation that serves your area. If you are in another state or territory call the Cancer Council Helpline on 13 11 20 and ask for contact numbers to the palliative care services in your area.

“ It was such a relief to have the palliative care nurse visit me every day. I could not believe how much they helped me feel better, and me and my family better cope with our situation.” (Bill, 59)

Palliative care services work with your local doctor and the treatment team from the hospital or clinic – they don't take over all the care and treatment decisions. Palliative care services often can include visits from a trained volunteer support worker.

You can ensure that everyone involved in your care will communicate well by providing names, addresses and telephone numbers of all the health care professionals involved. The list could be quite long; it may include an

oncologist, radiation specialist, surgeon, local doctor and key nurses from an outpatient clinic. It is better to have a long list than miss someone.

A hospice is a place that provides residential palliative care services. It has hospital facilities but a homelike atmosphere, where trained staff care for people with life-threatening illnesses. A person may go into a hospice to have pain or other worrying symptoms brought under control, to give the person caring for them a break, or to be cared for in their last days or weeks.

Many people go into a hospice for a short time and then return to their home.

In general, palliative care services are free. There may be a charge for hire of some equipment for home care.

Visit Palliative Care Victoria www.pallcarevic.asn.au or call the Cancer Council Helpline on 13 11 20 for a list of palliative, hospice and respite care providers in your state.

The palliative care team will have a 24-hour phone number you can call if you have concerns.

When treatment seems too much

Sometimes you will ask yourself if the treatment is worth it.

“ As hard as it was for us, my wife decided it was time to 'rest' and not struggle with needles, tests and hospital appointments. She said she would now prefer to spend time with those she loved, watch her garden grow and watch her grandchildren play.” (Bill, 65)

What does quality of life mean to you? Perhaps you would choose **chemotherapy** if it meant you could have two good weeks in each month. Or you might value keeping mobile, being able to spend as much time as possible with family and friends, without the disruption of treatment.

Before you make decisions about your treatment, give yourself time to think about it. It is important you feel you can decide to stop treatment if you feel this is right for you. Even if those close to you find this difficult to accept, you need to make the choices you want. In time it is likely they will understand and accept your choices.

It may help to ask:

- Are you feeling bad from the side effects of the treatment, from advancing disease or from emotional overload? Some or all of these can be treated.
- Are you continuing with treatment because you want to or because you are being encouraged to by those close to you?

Talk to your health team about the pros and cons of continuing with active treatment. Discuss this with those close to you. If you feel uncertain, you can speak to someone less closely involved – a counsellor, social worker or a nurse on the Cancer Council Helpline (13 11 20) – who can help you to weigh up what is best for you.

“ When someone is diagnosed with a terminal illness like mesothelioma, there is a feeling that there is very little time, and decisions can be made in a hurry. Maybe not the best decisions! There is a lot of time spent visiting doctors and specialists, while precious time is passing away. If the prognosis is that the mesothelioma is in its advanced stage, from my experience I would strongly recommend that the decision to fight the disease

at any cost is questioned, and that a quality of life approach may be better for all. More help is needed to assist in making the best decisions.” (Lesley, 62)

Coping with symptoms and side effects

When you are in the advanced stages of mesothelioma you may have symptoms and side effects. Many of these can be well controlled with medications such as pain-relieving drugs and steroids. The most common symptoms are discussed below.

No matter how small or big your symptoms are, discuss them with your medical team. They will want to help you in any way they can. There is always something that can be done to help someone with **advanced cancer**.

If you would like to know about other symptoms and side effects, speak with your medical team or contact the Cancer Council Helpline on 13 11 20.

Fatigue

Fatigue means feeling very tired and lacking energy to do day-to-day things. Fatigue for people with cancer can be very different from normal tiredness. It doesn't always go away with rest or sleep.

Fatigue is the most common symptom associated with **advanced cancer**. Many people with cancer say that fatigue is very disruptive. Day-to-day tasks such as bathing, cleaning, shopping, eating and cooking may leave you feeling completely exhausted. Even talking to those close to you can sometimes feel too tiring.

People with cancer have described their fatigue as:

- overwhelming, unbelievable, debilitating and frustrating
- unrelated to how much you do

- affecting your whole body: every part of you feels tired and worn out; your muscles may even ache
- difficult to describe and hard for others to understand
- not helped by rest or sleep
- mentally, physically, emotionally and spiritually exhausting
- a heaviness, especially in the arms and legs.

Many people with cancer say that they worry their fatigue is a sign their cancer is getting worse and treatment is not being as effective as hoped. This can be difficult to cope with. It is not uncommon for people with mesothelioma to feel very tired a lot of the time.

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

A lot of people with cancer don't report fatigue to their doctor because they think that nothing can be done about it. However, bring it up with your doctor, as there are things that can be done to help. Keeping active can help increase energy levels in people with cancer – ask your doctor about how much exercise you can do.

If fatigue is a problem, talk to your treatment team (doctors and nurses). They may be able to suggest things that can help you.

Letting those close to you know will help them to understand why you might be feeling so down or lacking motivation.

Coping with fatigue

You can't always stop your fatigue but you can find ways of managing it. If your fatigue is caused by low red blood **cells** or the side effects of drugs that you are taking, your doctor may be able to treat that cause. Medications such as steroids may help to boost your energy. Otherwise you may have to

learn to take shortcuts and get help from others to make sure your fatigue doesn't take over your life.

You may be surprised how small changes can help to save your energy.

Tips

- Plan your day. Set small, manageable goals.
- Don't be afraid to ask for help: ask a friend to do the shopping or come to clean the house once a week.
- Plan ahead. For example, get all your clothes ready before you shower or bathe, this way you only have to walk to your wardrobe once!
- Rest before you get too tired. Learn to recognise when this will be.
- Try not to rush: leave plenty of time to get to appointments.
- Sit down when doing things like cutting up vegetables or talking on the phone. Leave chairs around the house so that you can sit down whenever you feel tired.
- Say no to things you really don't feel like doing. Try not to feel you must please others all the time.
- If you are fit enough and your doctor has said it is okay, get some exercise. This may be the last thing you feel like doing. But research shows that exercise can boost energy levels and make you feel better – even if you just walk around the garden or block a few times a week. It all helps.
- Smoking reduces your energy. If you smoke, talk to your doctor or the Quitline on 13 7848 about stopping.
- Don't do the shopping during busy times. Write a list of what you want to save time thinking on your feet!

- If you have young children or grandchildren, try to play with them sitting or lying down: board games, puzzles and drawing are good ideas.
- Eat nutritious meals and snacks throughout the day to keep your energy levels up.
- Try to take some time out to do things that you enjoy. For example, having a relaxing bath, listening to some music or just being with your dog may help you relax, and for a short time, take your mind off how tired you feel.
- Join a Cancer Support Group. Talking about your feelings can ease the burden of fatigue, and you can hear how other people in similar situations have managed.

Breathlessness

People with mesothelioma can suffer from breathlessness. This will be worse in the advanced stages of the disease. It is likely to be frightening if you find yourself feeling breathless a lot of the time. Your breathing rate might speed up or you may feel you can't catch your breath. If you are in hospital when this happens, let your doctor or nurses know. If you are at home and you are unable to relieve it, contact your GP or hospital for advice.

People with pleural mesothelioma can be short of breath if there is fluid around their **lungs**. This may need to be drained (discussed on page 32) or you may have antibiotics if there is an infection present. Breathlessness can also be caused by the cancer, scarring from **radiotherapy**, anaemia (low red blood **cells**) or pressure from a swollen **abdomen** with **peritoneal** mesothelioma. Treatment can help.

Tips

Whatever the cause, feeling anxious can make your breathing worse. While you are waiting for treatment to work, these ideas may help you breathe better:

- First, try to relax. If you panic when you become breathless, try to concentrate on slowing down your breath. It may help to learn a relaxation technique. Many people say it helps to listen to a relaxation CD or read about these techniques.
- Have a fan in the room or open a window and get a draught of air moving near your face.
- Sit up to ease your breathing or lean forward, resting on a table.
- If you don't own a reclining chair, borrow one so you can sleep in a more upright position.
- You may want to practise breathing techniques, alone or with someone else.

Try breathing with someone else, especially slowing your breathing. This can be done during a breathless episode and at other times, to practise.

Your doctor will be able to prescribe oxygen for you in hospital and at home if it helps. A wheelchair may allow you to move around more freely. It is very common for doctors to prescribe a low dose of morphine to assist with breathing problems. As well as helping with pain, morphine is very effective in relieving breathlessness and coughing.

Discuss any fears you have about your breathing with your doctor or another member of your treatment team. Knowing how breathless you are and how much it is affecting your day-to-day life can help your medical team plan the best form of treatment and care for you.

The Cancer Council has information about coping with breathlessness. Visit www.cancervic.org.au or phone 13 11 20.

Pain

Most people with **advanced cancer** will have some kind of pain. People with mesothelioma may find their pain is complicated by issues such as anger relating to the cause of the disease, and compensation claims they have to go through.

It can be very frightening to be in a lot of pain. You may fear having a lot of pain due to your cancer. **But it is always possible to reduce pain or relieve it completely.** It may take a little time to find the correct pain-control measure but it can be done. It is important you know who to ask for the help you need.

You may have pain before, during or after your treatment for mesothelioma. Pain can be a side effect from treatment. For example, **chemotherapy** and surgery can injure nerves and cause pain and numbness in certain areas of your body. Your skin may be very sensitive in the area you received **radiotherapy**; this can last for a few months. Scars can also be painful for a long time following surgery. A **tumour** growing and pressing on nerves or other organs in the body may cause pain.

There are different types of pain, such as nerve pain, muscle pain or bone pain. Each of these can feel different and will be relieved by different types of treatments.

Pain can come and go. It may not necessarily get worse as your cancer progresses.

Whatever the cause or type of pain you have, the most important thing is you get relief. Be honest with yourself and your doctors. Once your doctors

know how much pain you are in, how often you are having it and the type of pain, they will plan treatment they know is likely to help.

Try not to put up with the pain and think that you should be able to handle it. Asking for help isn't a weakness.

There is usually something that can be done to help most types of cancer pain.

There are many ways to manage pain, including:

- medications such as morphine, codeine and paracetamol
- treating the cause of the pain with chemotherapy, surgery and radiotherapy, alone or together
- rarely, a 'nerve block' procedure is used when targeted medication is not effective.

A combination of these methods may achieve the best results. How and where the pain is felt, and how it affects one's life, can change. Regular reviews by pain-management experts will ensure the best results are achieved.

The main methods of pain management are described below.

Pain-relieving drugs

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

The doctor will aim to find the right drug, dose, frequency for taking the drug and delivery means (for example, tablet or injection), and aim to control any side effects. This may involve trying one drug at different doses and then trying another drug at different doses.

Morphine

Morphine is one of the most common drugs used to control moderate to severe cancer pain. It comes in quick-acting and long-acting forms. Morphine has been used for centuries as a pain reliever. Unfortunately, morphine has an undeserved reputation, because some people associate it with drug addiction and people often think that morphine is only used for people who are dying.

A person does not become addicted to morphine if they are taking it to relieve pain.

Morphine is a very effective pain-reliever. It can be taken for a long time, in increasing doses if needed. It doesn't have to be kept for 'when the pain gets really bad'. The 'drowsiness' effect of morphine decreases after a couple of days and people can continue their normal activities and be pain free.

It is not uncommon for people taking morphine to have vivid dreams. If the dreams become frightening or difficult to deal with, tell your doctor. They will be able to prescribe other methods of pain control.

Morphine causes constipation. Regular laxatives can relieve or prevent this. Morphine is most effective when taken regularly, even if the pain is not present. It is better to stay pain free rather than wait to treat the pain when it returns.

Some people cannot tolerate morphine because of side effects such as nausea. Other drugs can be as effective.

“ I did not want to resort to morphine. I felt it meant I was giving up and I was so scared I would become addicted to it or it would make me sleep all the time. The pain got so severe that I gave in and accepted some morphine. I wondered afterwards why I had resisted. I am pretty much pain-free most of the time

and quite alert when I need to be. It has made such a difference to my quality of life.” (Jack, 59)

Chemotherapy, radiotherapy and surgery

Chemotherapy, radiotherapy and surgery are used to cure **primary cancers**. They are also used in **advanced cancer** to reduce symptoms such as pain. Chemotherapy can sometimes shrink cancer that is causing pain because of the cancer's size and location. Radiotherapy can relieve some symptoms, such as bone pain. When used for symptom control, courses of radiotherapy are usually much simpler and shorter than when treating early cancer.

Surgical procedures may be done to improve certain symptoms such as fluid build-up causing breathlessness for people with mesothelioma (see page 32). Surgery may also be used to treat a serious condition, such as a bowel obstruction, that can happen in people with **peritoneal mesothelioma**.

Depression

It isn't uncommon for someone with **advanced cancer** to feel very low in mood or depressed. Some people feel sad or depressed because of the changes that their cancer has caused. Others become very down because they are frightened about the future: How will the family cope if they are ill or die? Whatever it is that might be making you feel down, you need to get support.

There is a difference between feeling down and sad for a while and feeling very depressed for long periods. Depression is much harder to shake and can go on for a long time if you don't get the right sort of help. If you have one or more of these signs for a few weeks or more you should see your GP:

- depressed mood that is difficult to change
- loss of pleasure or interest in things
- a sense of worthlessness or low self-esteem
- feeling frightened

- social isolation or withdrawal
- brooding or self-pity
- persistent feelings of hopelessness and helplessness
- guilt, self-blame and regret (which may be expressed in the use of words like 'ought' or 'should')
- thoughts of suicide
- poor concentration
- difficulties sleeping (insomnia)
- difficulties making decisions or problem solving.

These are not the only signs of depression. Some can be caused by other medical conditions.

If you have some of these signs or think that you may be depressed, it is important that you get some help. Let your GP know. Be honest about how bad you feel. This will help your doctor and you make the right decisions about the type of support and care you need.

It isn't a weakness to feel depressed and ask for help. It takes a lot of courage to ask for help and it is important to feel good about yourself and life again. There are lots of things that can be done to help with depression, including professional counselling or psychotherapy. Antidepressant drugs can make a dramatic difference for some people. Whatever works for you is all that matters. Your doctor will be able to explain the difference between counselling and psychotherapy, and between a counsellor, psychologist and psychiatrist. This will help you to choose the support you need.

Feeling low

If you are feeling low, here are a few suggestions that may help you cope with this better.

- **Complementary therapies** such as massage, yoga, hypnosis, acupuncture and reflexology may help improve your mood.
- Make sure you take care of yourself. Eat a well-balanced diet with lots of fresh fruit and vegetables and drink plenty of water.
- Get regular exercise. Many people say that being active helps lift their mood.
- Share your feelings with someone close to you: just having them know exactly how you feel can help you feel less alone.
- Even if you don't feel like it, try to push yourself to go out and do something you enjoy. A change of scenery may make you feel better.
- Some people find it helps a lot to write down how they are feeling. Others might find it easier to express themselves in painting, drawing, music or singing.

If you have signs of depression, see your doctor. Some of the approaches described above may also help, but depression really needs the care of a doctor as well.

Nutritional and dietary problems

Nutritional problems can happen to people who with mesothelioma. Some problems may be worse for those with **peritoneal** mesothelioma. Problems may include:

- loss of appetite
- weight loss
- nausea and vomiting
- difficulty swallowing

- loss of taste
- sore mouth.

These problems can result from the illness, treatment, tiredness, an altered sense of taste, pain, lack of activity, depression, nausea and vomiting.

You may go through phases of not wanting to eat. These phases may last a few days or weeks or it could become the 'norm' for you: you may just be unable to eat the way you used to. You and those close to you may find this difficult to accept. Family members may try to encourage you to eat when you don't want to. They may even want you to try foods and supplements that you are not used to or don't like. This can become difficult for everyone. The important thing is that you eat when you can.

There is no special diet we recommend to people with cancer. There are no foods or supplements known to help treat, control or cure cancer. So all we can recommend is you eat a healthy, well-balanced diet when able: fresh fruit and vegetables and plenty of water. This doesn't mean cutting out treats! If you feel like eating some ice-cream or chocolate or having a beer or a glass of wine – go for it! In moderation these things will not do you any harm and they may even help give you a bit more energy or put on some weight.

Tips

Here are some other ideas that may be useful to help with dietary problems.

- Eat small meals and snacks frequently.
- Use a small plate so a small amount doesn't look lost. Dessert in a wineglass is another idea.
- Eat moist food, for example scrambled eggs, which is usually easier to eat and is less irritating to a sore mouth.
- Add ice-cream or fruit to a drink to increase calories and nutrients.
- Drink from a 'half-full' glass. It is more satisfying to empty a half-full glass than only half finish a full one.
- If solid food does not always appeal to you, ask your dietitian if it is okay to have commercially prepared supplements, such as protein drinks.
- Lemon juice and salt may give flavour to food when it tastes bland.
- Salads or cold food will help with the nausea that some hot food smells can bring on.
- You may prefer to sip clear liquids and then follow these with biscuits or something light.
- Avoid fatty foods or heavy, sugary food if they make you feel sick.
- Try to eat a little bit regularly so that your stomach is never quite empty.
- If you have a sore mouth, cold foods are easier to tolerate than hot.
- Eat more of your favourite foods – follow your impulse.

If you are not eating properly because you have a sore mouth, tell your doctor or nurse. The soreness may be able to be treated.

If you are very breathless, make sure you are as relaxed as you can be when you eat. Chew your food well, take small mouthfuls and take sips of water in between to help with getting the food down more freely and to prevent coughing.

Speak to a dietitian with a special interest in cancer – ask your doctor, your hospital or the Cancer Council Helpline.

Coping with everyday life

Living each day knowing your cancer is in its advanced stages is not easy. We all want control, predictability, connection and meaning in our lives. You may feel that cancer has taken these away, leaving you unsure about what will happen, how you will cope and who to ask for help.

How you feel from day to day will vary depending on:

- what treatment you are having at the time
- how well your symptoms are kept under control
- the amount of support you have.

Some days will be easier than others. There will be days when you may feel very tired and unsure. Other days you will have more energy and feel more positive. This will allow you to enjoy life on a less stressful level. The important thing is to feel well when you can.

The **palliative care** team is a large team of people. Each team member will be able to help you in a different way. Your doctors and nurses will be the best people to talk to about your symptoms and side effects. You may also find it helpful to talk to the hospital social worker, a counsellor or pastoral care worker about any strong emotions you may have or your spiritual needs. The dietitian can help with any dietary problems. The physiotherapist can advise you on some ways to help control your breathing problems. Use everyone you need to, as often as you need to. They will all want to make this time as comfortable as possible for you and those close to you.

If you have close family and friends, lean on them. They know you best. They will be able to love and support you in many ways. Try not to expect them to guess what you need, or withdraw in fear of upsetting them. It is better to communicate your needs. This doesn't come naturally to everyone but try – it is likely to ease your burden quite a lot.

You can call the Cancer Council Helpline on 13 11 20 for advice about who you may turn to for support.

Many people say they gain a lot of help and support by talking to others in similar situations. Contact the Cancer Council Helpline about mesothelioma support groups in your area, as well as general support.

What to expect as the disease progresses

Most people diagnosed with cancer are faced with thinking about what will happen if their disease progresses. Even if it is not going to happen in the near future, you and those close to you may wonder about the end stages of life – death and dying. You may question how much more time you have to live and begin going over your life and what it has meant for you. These thoughts are very normal.

Being told time is short will bring up different emotions and reactions for everyone. There is no right or wrong way to cope with such news. Everyone will deal with it in their own way. At first you may be silent and not know what to say or not want to say anything. Others may cry a lot or even want to shout and scream.

You may feel anger, sadness or guilt about various parts of your life. For some there may be a huge sense of relief – this difficult time will be over soon. Others may find their feelings and actions become focused and you begin making decisions about things that are important to you.

Many people say they feel frightened and anxious. It is very natural to look around and think things like:

- Why me? Or, Why my partner?
- Why is everyone else still living life to the full?
- It's not fair.
- How long do I have left?
- I am not ready to die. I have so many things I want to still do and achieve.
- How can I stop this happening?
- I don't want to live any more: what's the point, I want it to be over now.

You may have many questions. There may not be answers to some of your questions. However, talk to your medical team, family, friends, spiritual carers and anyone else you trust. Different people may be able to help you work through answers to some of your questions.

The Cancer Council's booklet on advanced cancer discusses coping with death and dying. Visit www.cancervic.org.au or phone 13 11 20 for a copy.

The importance of hope

Feeling hopeful is important for people living with cancer. It helps them cope during times of suffering and uncertainty. Knowing how to boost your hope and at the same time maintain a sense of reality about what to be hopeful for will help many people feel better able to deal with their situation.

Remember that many people with mesothelioma have many good months or years ahead of them following treatment.

Often the most difficult issue for people living with mesothelioma is realising that, at present, there is no known cure for mesothelioma.

Research continues in this area with the hope of finding new and better treatments.

Hope is part of the way people deal with cancer. It is best if you ask your doctor about your own **prognosis** so that your hopes can be positive and realistic. Allow yourself time to talk, listen and discuss your feelings and wishes.

Your hopes may change over time. At one time you may hope for a cure, at another you may hope to be around for a special event such as the birth of a grandchild. You may hope that symptoms will be well controlled.

In an ancient myth, hope follows on the heels of evil and sadness, bringing healing and pointing the way to a happier future. Most people have precious hopes of simply spending time with the people they love – perhaps this is the most important hope of all.



Caring for someone with mesothelioma

A carer is anyone, whether family or friend, who is helping to look after someone with cancer. Although caring for someone with cancer is often rewarding, it can also be stressful, particularly when it is someone you care about very much. The person with cancer may have distressing emotions about their cancer diagnosis, side effects from treatment and mood changes from the effects of drugs. Dealing with all of this takes time, energy and patience.

You are also likely to go through many emotions, such as sadness, anxiety and fear, along with possible anger, guilt and frustration. All of these are normal. You may be tempted to ignore your own emotions and needs during your caring role. However, it is important you look after yourself during this time. Give yourself some time out, enjoy a cup of coffee with a friend, and share your worries and concerns with someone not involved. Make a list of 10 things you like to do and make sure that you do one enjoyable thing each day.

You may have to make many decisions. You will probably have to attend many appointments with doctors, support services and hospitals. Many people have found it helpful to take with them another member of the family or a close friend. It also helps to write down questions before you go, and to take notes during the appointment.

Cancer Support Groups are usually open to patients and carers. A support group can offer the chance to share experiences and ways of coping. There is a range of support services such as home help, meals on wheels and visiting nurses that can help you cope with treatment at home. These are provided by local councils, the Royal District Nursing Service and the **palliative care** services.

Call the Cancer Council Helpline on 13 11 20 to:

- be linked with another carer by telephone
- speak with a cancer nurse for further support and information
- be sent a carer's kit so that you can find out about financial assistance and other resources.

Cancer Council Victoria has a booklet about caring for someone with cancer. You may also find it helpful to read the booklet *When Cancer Won't Go Away: For carers of people whose cancer has advanced*. Visit www.cancervic.org.au or call 13 11 20.



Questions you may like to ask your doctor

You may find the following list helpful when thinking about the questions you want to ask your doctor about treatment and living with mesothelioma:

1. What stage of the disease do I have?
2. Has my mesothelioma spread? If so, how far?
3. Is my cancer in the advanced stages? If so, what can be done to help me?
4. How is mesothelioma treated?
5. What treatment do you advise for my cancer and why?
6. Will my treatment be performed by a doctor who specialises in mesothelioma?
7. How do I go about getting a second opinion?
8. Are there other treatment choices for me? If not, why not?
9. Will I have surgery, chemotherapy or radiotherapy?
10. What are the side effects from treatment?
11. Will the treatment affect me sexually or physically? Will I be able to do normal things?
12. Is there anything that can be done to help control the side effects?
13. How will I know if the treatment is working?
14. What are my chances of cure?
15. What if I decide not to have any treatment?
16. Will I have to stay in hospital, or will I be treated as an outpatient?
17. How long will the treatment take? How much will it affect what I can do?
18. Will I have follow-up appointments after my treatment is over?
19. Who will I see if I am worried in between my appointments?

20. Are there any clinical trials of new treatments that I should know about?
21. Will I have pain from the cancer? What will be done about this?
22. I am feeling frightened about what will happen to me: who can I talk to about my feelings?
23. Will others in my family also be at risk of developing mesothelioma if I have it?
24. Is it harmful to take supplements or vitamins while I am having treatment?
25. Who do I contact about claiming compensation for my illness?
26. What practical help is available for me?
27. Is there anyone else with mesothelioma I can speak to?

If there are answers you don't understand, feel comfortable to say 'Can you explain that again?' or 'I am not sure what you mean by ...'.



Services and information

We have listed resources throughout the booklet. Here are some other resources that you may find useful.

Living with Cancer Education Program

This Cancer Council program provides information on cancer and ways of coping with it. The program runs over one day or a few hours over several weeks. Groups are small, with plenty of time for talking. Courses are held at hospitals and community organisations throughout Victoria and other states and territories in Australia. Contact your hospital social worker or the Cancer Council Helpline. The program is also conducted in languages other than English.

Talk to someone who has been there

In these support settings, most people feel they can speak openly, share tips with others, and just be themselves. You will probably find that you feel comfortable talking about your diagnosis and treatment, your relationships with friends and family, and your hopes and fears about the future.

Support services available for patients, carers and family members with mesothelioma include:

- face-to-face support groups, which are often held in community centres or hospitals
- telephone support groups for certain situations or types of cancer, which are facilitated by trained counsellors
- online discussion forums where people can connect with each other any time – see www.cancerconnections.com.au

Support groups

Victoria	<p>Asbestoswise www.asbestoswise.com.au Phone 9654 9555</p> <p>Gippsland Asbestos Related Diseases Support (GARDS) www.gards.org Phone 5127 7744 / 0407 274 173</p>
New South Wales	<p>Bernie Banton Foundation www.berniebantton.com.au Phone (02) 8850 1223 / 0412 830 485</p> <p>Asbestos Diseases Support Group, Wagga Wagga and District Phone (02) 6922 3826 / (02) 6922 5414</p> <p>Asbestos Diseases Foundation of Australia www.adfa.org.au / Phone (02) 9637 8759</p>
Queensland	<p>Queensland Asbestos Related Disease Support Society Inc. (QARDSS) www.asbestos-disease.com.au Phone 1800 776 412</p> <p>Asbestosis and Mesothelioma Support Group (AMSG) www.amsg.com.au / Phone (07) 5599 7876</p>

South Australia	Asbestos Diseases Society of SA Inc. (ADSSA) www.adssa-inc.com.au Phone (08) 8359 2423 / 1800 157 540 Asbestos Victims Association (SA) Inc. www.avasa.asn.au Phone (08) 8212 6008
Tasmania	Asbestos Free Tasmania Foundation Inc. (AFTF) www.asbestosfreetasmania.org.au Phone (03) 6233 7950
Western Australia	Asbestos Diseases Society of Australia Inc. (ADSA) www.asbestosdiseases.org.au Phone (08) 9344 4077 / 1800 646 690
Visit www.cancervic.org.au to search for cancer support groups in your area.	

Consumer advocacy groups

Joining a consumer advocacy group can be rewarding for people who would like to use their experience to make a difference for others. Visit www.cancervoicesvic.org.au for more information.

Helplines and other resources

Cancer Council Helpline

The Cancer Council Helpline is a confidential service where you can talk about your concerns and needs with cancer nurses for the cost of a local call. They can send you information and can put you in touch with support services in your area. Phone 13 11 20.

Multilingual Cancer Information Line

The Multilingual Cancer Information Line is a confidential Cancer Council service. You can call and speak to a trained nurse, with the help of an interpreter, for the cost of a local call. It is for people with cancer, and people who are close to them. People who speak any language can use the service. See the back cover for details.

Support for carers

Advice Line

The Carers Advice Line provides information and support for people caring for people with illness and disability. Phone 1800 242 636.

Care Ring

Care Ring can provide information, counselling and referral for people with health- and family-related problems. Phone 13 61 69, 24 hours, Monday to Friday.

Bereavement support

Grief Line

Grief Line offers support to people who are experiencing grief as a consequence of a significant loss in their lives. Phone 9596 7799.

Home visitors

DoCare (see the White Pages for the service in your region) and the Australian Red Cross (8327 7700) can organise home visitors. Other charitable organisations may be able to help, as may a Cancer Support Group. For information, phone 13 11 20.

Lifeline

Lifeline provides information, counselling and referral for people with personal problems. Phone 13 11 14, 24 hours, seven days.

Social and pastoral care workers

For information, support and advice, contact your hospital and ask for the social worker or patient services unit. Your local community health centre may also have a social worker on staff, or be able to refer you to a social work service. Pastoral care workers are able to discuss practical and spiritual concerns (from all religious and atheistic viewpoints). Contact your hospital, hospice or palliative care service.

Financial, legal and practical services

Cancer Council

Cancer Council Victoria's Financial Assistance Program can provide financial assistance for people with cancer. Phone 13 11 20.

Australian Funeral Directors Association

The Australian Funeral Directors Association can provide a listing of funeral directors and estimates of funeral costs. Phone 9859 9571.

Australian Human Rights Commission

Leading the promotion and protection of human rights in Australia. Phone (02) 9284 9600.

Centrelink

Can provide information on Commonwealth Government disability, sickness and carers payments. Phone 13 27 17.

Legal advice and information

If you have one, see your lawyer. If you do not, contact the Law Institute of Victoria's Legal Referral Service on 9607 9550. You can also contact Victoria Legal Aid on 9269 0234 or 1800 677 402 (country callers) or visit www.legalaid.vic.gov.au

Local councils

Local councils provide a range of community and in-home services, including foster care for children, meals on wheels, housekeepers and respite care. Phone your council (see the White Pages).

Office of the Public Advocate

The Office of the Public Advocate can help with information about enduring power of attorney. Phone 1800 136 829 or visit www.publicadvocate.vic.gov.au

Palliative, hospice, nursing and respite care

Palliative Care Victoria provides information about palliative care and hospice facilities and services. Phone 9662 9644.

Your local council can tell you about respite services available in your area. Phone your council (listed by council name in the White Pages). Your local palliative care group or hospital social worker will be able to advise you.

The Royal District Nursing Service provides care to people with terminal illness in their own home and advice and support for family and carers. Phone 9536 5222.

Removal of asbestos

Home environment (Victorian Government Information)

Website: www.health.vic.gov.au/environment / Phone 1300 761 874.

Local council (Environmental Health Officer)

Contact your local council for enquiries or complaints regarding the incorrect removal or disposal of asbestos in your neighbourhood, and for enquiries regarding the potential health effects of exposure to asbestos in the home environment.

Workplace

For a list of licensed asbestos removalists in your area, complaints regarding work carried out by an asbestos removalist, and enquiries or complaints regarding asbestos in the workplace, phone 1800 136 089 or visit www.workcover.vic.gov.au

National Association of Testing Authorities www.nata.asn.au

For a NATA-accredited laboratory in your area that can identify asbestos, phone 9329 1633.

Useful websites

Mesothelioma Applied Research Foundation

www.curemeso.org

This is a US website. It has some excellent information both for patients, their families and health professionals.

Malignant mesothelioma

www.cancer.org/cancer/malignantmesothelioma/index

Information from the American Cancer Society.

International Mesothelioma Interest Group (IMIG)

<http://imig.org/>

This website is designed to support, inform and provide a forum for iMig members, those who do research in mesothelioma and those who care for patients with mesothelioma.

Useful books

Lean on me by Lorraine Kember

L Kember Publications. Detailed information, doctor's recommendations, book excerpts and ordering available online at www.cancerthroughacarerseyes.jkwh.com

This book describes an emotional journey as Lorraine supports her husband, who has mesothelioma. The book has writings from Lorraine's diary and poems. She describes the sense of helplessness she felt after his diagnosis. Lorraine covers pain and managing symptoms. Her strength grows as she comes to realise that there is so much she can do to help to improve her husband's quality of life.



Glossary: what does that word mean?

Some of the words listed here are used in this booklet; others are words you are likely to hear used by doctors and other health professionals who will be working with you.

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

advanced cancer Cancer that has spread and/or is unlikely to be cured.

alternative therapy Approaches to cancer treatment, often unproven and sometimes harmful, used instead of conventional (medical) cancer treatments.

anaesthetic A drug that is taken to stop a person feeling pain. A 'local' anaesthetic numbs part of the body; a general anaesthetic causes temporary loss of consciousness.

benign Not cancerous. Benign cells do not spread like cancer cells.

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

cells The 'building blocks' of the body. A human is made of billions of cells, which are adapted for different functions. Cells are able to reproduce themselves exactly, unless they are abnormal or damaged, as are cancer cells.

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

chest cavity The area enclosed by the ribs, above the diaphragm.
diaphragm A sheet of muscle that divides the chest cavity from the abdomen. It is used in breathing.

clinical trials Carefully designed research studies that investigate a new test, treatment or medical procedure in people. A trial may look at the

safety, side effects and how well a treatment works in comparison to standard treatment.

complementary therapy Therapy used alongside medical treatment to help manage symptoms and side effects.

diagnosis The process of finding out about a person's illness by considering their signs and symptoms, medical background and results of diagnostic tests.

extrapleural pneumonectomy Surgery to remove a diseased lung, part of the pericardium (membrane covering the heart), part of the diaphragm (muscle between the lungs and the abdomen), and part of the parietal pleura (membrane lining the chest).

genes The tiny factors that control the way the body's cells grow and behave. Each person has a set of many thousands of genes inherited from both parents.

lungs The two spongy organs within the chest cavity, made up of very large numbers of tiny air sacs.

lymph nodes Small, bean-shaped structures which are part of the lymphatic system. The lymphatic system is part of the immune system, which protects the body against infection and parasites. It is a network of small lymph nodes connected by very thin lymph vessels, which branch into every part of the body. The lymph nodes filter the lymph to remove bacteria and other harmful agents, such as cancer cells.

malignant Cancerous. Malignant cells can spread (metastasise) and can eventually cause death if not treated.

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

metastases Also known as 'secondaries'. Tumours or masses of cells that develop when cancer cells break away from the original (primary) cancer and are carried by the lymphatic and blood systems to other parts of the body.

palliative treatment/care Treatment aimed at providing relief from symptoms when cure is no longer possible.

peritoneal Affecting the peritoneum, the tissue that lines the abdominal wall and pelvic cavity.

pleura Membranes that line the chest wall and cover the lungs.

pleural cavity A space between the two layers of the pleura.

pleurectomy Surgery to remove part of the pleura (a thin layer of tissue that covers the interior wall of the chest cavity).

primary cancer The original cancer. At some stage, cells from the primary cancer may break away and be carried to other parts of the body, where secondary cancers may form.

prognosis An assessment of the course and likely outcome of a person's disease (also known as 'outlook').

radiotherapy The use of radiation, usually x-rays or gamma rays, to destroy cancer cells or injure them so that they cannot grow or multiply. Radiotherapy can also harm normal cells, but they are usually able to repair themselves.

staging Investigations to find out how far a cancer has progressed. This is important in planning the best treatment.

tissue A collection of similar cells.

tumour A new or abnormal growth of tissue on or in the body.

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Cancer information in your language

For the cost of a local call (except from mobiles), you can talk confidentially to a Cancer Council nurse with the help of an interpreter.

Simply follow these steps:

1. Call **13 14 50**, Monday to Friday 9 am – 5 pm. 
2. Say the language you need.
3. Wait on the line for an interpreter (may take up to 3 minutes).
4. Ask the interpreter to contact the Cancer Council Victoria Helpline on 13 11 20.