



What to expect during each stage of treatment and beyond

## Mesothelioma support

For information about mesothelioma, call Cancer Council on **13 11 20**. Qualified cancer nurses at Cancer Council can answer your questions about the effects of cancer, explain what will happen during treatment and link you to support groups and other community resources.

If you need an interpreter, call TIS (the Translating and Interpreting Service) on 13 14 50. For support and advice for carers, call the Carers Association on 1800 242 636.

## 1. Initial investigations and referral

Your general practitioner (GP) will assess your symptoms. The main symptoms are shortness of breath, pain when breathing, chest/shoulder/upper arm pain, loss of appetite, weight loss, and persistent cough or bouts of pneumonia. Your GP will conduct a physical examination and order tests.

**Because mesothelioma usually results from exposure to asbestos a number of years previously, it is important to mention any asbestos exposure that may have occurred in the past to alert your doctor to this risk factor.**

**Tests you may have:**

### Blood tests

To check your overall health, how your blood cells, liver and kidneys are working.

### Chest x-ray

To help identify any abnormalities or fluid build-up in the pleura (the lining of the lungs and chest wall).

### Computed tomography (CT) scan

Computer technology is used to create detailed images of the lungs and the pleura.

Your GP should also discuss your needs (including physical, psychological, social and information needs) and recommend sources of reliable information and support.

If mesothelioma is suspected, you will be referred to a respiratory specialist for further testing. Your GP will provide the specialist with information about your medical history and results of the initial tests.

**It can be helpful to bring a family member or friend with you to your appointments.**

## 2. Diagnosis and staging

The specialist will confirm whether you have mesothelioma by conducting one or more of the following tests:

### Pleural aspiration

A sample of fluid from the chest is taken by a needle and sent to a pathologist for testing. This is often performed with the use of ultrasound imaging.

### Positron emission tomography (PET) scan

This produces a three-dimensional colour image that may show where cancers are located. A small amount of radioactive material is injected and the whole body is scanned.

### VATS or CT guided biopsy

A small tissue sample (a biopsy) is taken from the lungs to examine under a microscope. The sample can be taken by keyhole surgery, called VATS, or using a needle guided by a CT scan.

### Pleuroscopy

Your specialist may look inside your chest using a special telescope and take fluid and samples through a small hole made in your chest while you are under sedation.

**It can be helpful to contact cancer peer support groups and support groups for carers.**

## 3. Treatment

To ensure you receive the best care, your specialist will arrange for a team of health professionals to plan your treatment based on your preferences and needs.

The team will be made up of professionals who have experience managing and supporting a person with mesothelioma. Your specialist will tell you when the team will be discussing your case.

Your team will plan your ongoing care, and should discuss the different treatment options with you including the likely outcomes, possible side effects and the risks and benefits.

You might want to ask for more time before deciding on your treatment, or ask for a second opinion. Your doctor may also suggest you consider taking part in a clinical trial.

Let your team know about any complementary therapies you are using or thinking about trying. Some therapies may not be appropriate, depending on your medical treatment.

**Treatment options:**

**Chemotherapy** may be given to try to shrink the cancer or try and slow its growth. This may be given in combination with radiotherapy or after surgery.

### 3. Treatment cont'd

**Radiation therapy** (also called radiotherapy) can be used as a palliative treatment to ease symptoms of mesothelioma such as shortness of breath, pain or growths which can occasionally appear on the chest wall. It can also be used to prevent cancer re-growing in the chest following surgery.

#### Surgery

The aim of surgery is to confirm the diagnosis and to treat the fluid in the chest to try and prevent it from coming back. This involves sticking the lung to the inside of the chest wall (a pleurodesis). It is important that this surgery is performed by a surgeon who is very experienced in performing lung surgery and performs several operations every year.

#### Watching and monitoring

Often patients have no symptoms either at diagnosis or after the initial surgery. In this case no further treatment is given and your specialist may advise watchful waiting, and deal with symptoms as they arise.

#### Indwelling chest catheter

Very occasionally the fluid build-up cannot be controlled by surgery and a small tube called a chest catheter, is inserted into the pleural space to allow fluid to drain out of the chest into a bottle. The tube can stay in place for some time. A nurse should provide you with information about surgery and adjusting to life with a chest catheter.

**Palliative treatment** can be used at different stages to relieve various symptoms and help to improve your quality of life.

For more information about treatment and treatment side effects ask your doctor or **visit** [www.cancer.org.au/about-cancer/types-of-cancer/mesothelioma.html](http://www.cancer.org.au/about-cancer/types-of-cancer/mesothelioma.html)

Your doctor should discuss your needs with you during and after treatment (including physical, psychological, social and information needs) and may refer you to another service or health professional for different aspects of your care.

### 4. After treatment

After treatment is completed, your doctor should provide you with a treatment summary that details the care you received including:

- diagnostic tests performed and their results
- types of treatment used and when they were performed
- treatment plans from other health professionals
- support services provided to you
- contact information for key care providers.

The majority of patients will be discharged into the community and

generally need to see a respiratory specialist for regular follow-up appointments.

You and your GP will receive a follow-up care plan that tells you about:

- the type of follow-up that is best for you
- ways to manage any side effects of treatment, should they occur
- how to get specialist medical help quickly if you think the cancer has got worse.

If you need extra help after treatment, your GP or specialist can discuss your needs with you and refer you to appropriate health professionals and/or community organisations.

### 5. Living with cancer

**Side effects:** Some people experience side effects (for example tiredness) that continue beyond the end of treatment. Side effects sometimes might not begin until months after treatment has finished. For more information about side effects ask your doctor or **visit** [www.cancervic.org.au/about-cancer/survivors/long-term-side-effects](http://www.cancervic.org.au/about-cancer/survivors/long-term-side-effects)

**Advance care plan:** Your doctor may discuss with you the option

of developing an advance care plan. An advance care plan is a formal way of setting out your wishes for future medical care. For more information about advance care planning ask your doctor or **visit** [www.advancecareplanning.org.au/](http://www.advancecareplanning.org.au/)

**Palliative care:** This type of treatment could be used at different stages to help you with pain relief, to reduce symptoms or to help improve your quality of life. For more information about palliative care ask your doctor or **visit** [www.palliativecare.org.au](http://www.palliativecare.org.au)

### 6. Questions of cost

There can be cost implications at each stage of the cancer care pathway, including costs of treatment, accommodation and travel. There can be substantial out-of-pocket costs if you are having treatment in a private health service, even if you have private health insurance. You can discuss these costs with your doctor and/or private health insurer for each type of treatment you may have.

Mesothelioma is caused by exposure to asbestos in the majority of cases. If you can identify how you were exposed to asbestos, including from work, you may be eligible for compensation and support. Each state has different schemes for compensation.

You may also be able to initiate a private claim against the responsible company – it is recommended that you contact a specialist asbestos litigation lawyer that deals with such claims.

If you are experiencing financial difficulties due to your cancer treatment you can contact the social worker at your local hospital.

For more information about cost of treatment **visit** [www.canceraustralia.gov.au/affected-cancer/living-cancer/dealing-practical-aspects-cancer/costs-treatment](http://www.canceraustralia.gov.au/affected-cancer/living-cancer/dealing-practical-aspects-cancer/costs-treatment)

For more information about accommodation and travel costs **visit** [www.cancerCouncil.com.au/get-support/practical-support-services](http://www.cancerCouncil.com.au/get-support/practical-support-services)

