Living with pleural mesothelioma



What is mesothelioma?

Mesothelioma is a type of cancer that typically develops as a result of exposure to asbestos. It affects the mesothelium, a thin layer of tissue covering internal organs of the body including the lung cavity (pleura), heart sac (pericardium) and abdominal cavity (peritoneum). The mesothelium supports and protects the body's organs while also providing a source of lubrication helping the organs to move and function. The two main types of mesothelioma are pleural and peritoneal. Australia has one of the highest rates of mesothelioma in the world¹. Each year, approximately 700 to 800 people are diagnosed with mesothelioma¹.

Exposure to asbestos may result in the development of a number of different lung conditions, such as asbestosis, pleural thickening, pleural plaques, pleural effusion and rounded atelectasis, as well as lung cancer and mesothelioma. Mesothelioma is considered a type of occupational lung disease if it develops due to exposure to asbestos in the workplace.

What is pleural mesothelioma?

Pleural mesothelioma affects the pleura, which is the outer lining of the lungs. It typically develops as a result of inhalation of asbestos fibres into the lungs, which embed themselves into the mesothelium. As the body's immune system tries to eradicate the asbestos fibres, it causes permanent scarring and hardening of the surrounding tissue. As the disease progresses, cancer cells can spread locally throughout the lung cavity, causing thickening in the lining of the lungs or it can spread outside of the lungs (metastasise) to other parts of the body. Pleural mesothelioma is the most common type of mesothelioma, accounting for approximately 90 per cent of all mesotheliomas.

Symptoms

It typically takes many years for mesothelioma to develop after exposure to asbestos. Generally, the latency period, or the time it takes for the disease to develop, can range between 20 and 60 years, but most commonly develops around 40 years after asbestos exposure. In 2020, the median age at diagnosis was 75 years¹.

Common symptoms of pleural mesothelioma include:



Shortness of breath



Cough



Chest pain



Weight loss for no apparent reason



Loss of appetite



Fatigue

Many people also present with fluid on the lungs, known as pleural effusion.

Diagnosis

Mesothelioma can be difficult to diagnose. This is because symptoms are often vague and characteristic of other lung diseases or ageing. Mesothelioma may be suspected by your doctor following discussions about your medical and occupational history, particularly if you report exposure to asbestos.

To confirm diagnosis, referral to a respiratory specialist or occupational specialist doctor is required. Further discussions about your previous or current exposure to asbestos may be had, including the type of work performed, the frequency and time of your exposure and protective measures used to reduce or manage exposure, such as Personal Protective Equipment (PPE). Your doctor will also ask about other lifestyle factors, such as smoking and/or vaping history, including any exposure to second-hand smoke.

In addition to the discussions with your GP and specialist, the following diagnostic tests may be performed:



Physical examination



PET scan



Lung-function (breathing) tests



Biopsy – this is the main test used to diagnose mesothelioma and confirm the type of mesothelioma a patient has



Chest X-ray



CT scan



Blood test



Sputum cytology test

After mesothelioma has been diagnosed, further tests will be performed to determine the stage (extent) of the disease, and whether it has spread.

Prognosis

Mesothelioma behaves differently for every person. For some people, the disease can remain stable for many years whereas it may progress more rapidly for others. You may have periods of relatively good health when symptoms are well controlled, as well as periods where symptoms need to be managed with more intensive treatment.

The course of the disease is influenced by many factors, such as the size of the tumour/s and stage of the disease, your symptoms and the type of treatment you are able to have, as well as your general health. Information about your prognosis is best provided by your specialist doctor.

Management

Currently, there is no cure for mesothelioma. However, there are treatment and management strategies which may slow the progression of the disease and help improve your quality of life. Your treating healthcare team will work with you to determine the most appropriate options for you, including lifestyle changes.

Current treatment options

Treatment usually includes chemotherapy, radiotherapy, immunotherapy, or a combination of all three. Your treating healthcare team will discuss the different types of treatment options with you and recommend the most appropriate one for you.



Chemotherapy

Anti-cancer medication given intravenously through a drip or orally, which aims to kill cancer cells.



Radiotherapy (or radiation therapy)

Uses high-energy targeted radiation to kill cancer cells by targeting their DNA, typically done several times per week for a number of weeks.



Immunotherapy

Medication, given intravenously through a drip, that assists the body's own immune system to fight cancer.



Pleurodesis

Type of surgery for people who develop pleural effusions (fluid on the lungs), which helps prevent the fluid from coming back and causing breathlessness.



Surgery

In some cases, removal of all or part of the tumour may be possible in combination with other treatments.

CLINICAL TRIALS

As research in this area evolves, so too do treatments for this disease. Talk to your treating healthcare team about whether you may be eligible for any clinical trials.

Care and support



SUPPORTIVE CARE

Living with mesothelioma can significantly impact your physical health, as well as your mental health and emotional wellbeing. It's important to access support early, whether it's from a trusted friend, family member or healthcare professional. Seeking support can help you and your family navigate your 'new normal' and provide you with steps you can take to proactively care for and manage your physical and mental health.

There are many avenues of support available for people living with mesothelioma. Your GP can provide you with a Chronic Disease Management Plan with a Team Care Arrangement, helping you access subsidised allied health support, such as a dietitian, physiotherapist or occupational therapist. They can also assist with the provision of a Mental Health Treatment Plan, helping you access subsidised visits with a psychologist or social worker.



PALLIATIVE CARE

Palliative care is another beneficial support pathway to explore. Palliative care is designed to improve your quality of life by identifying your physical, emotional and social needs. It seeks to provide a comprehensive, patient-centred model of care, and is beneficial for people of any age to help navigate living with mesothelioma. It is encouraged to discuss palliative care options with your treating healthcare team early on in your diagnosis, to ensure you have access to holistic allied health support and help to self-manage your mesothelioma symptoms and/or treatment side effects. Family members and carers can also benefit from palliative care support and advice.



PEER SUPPORT

Participating in peer support can also be very beneficial for your emotional health. There are a number of online support groups, as well as telephone and face-to-face groups, that can connect you with others living with mesothelioma. Peer support provides you with an opportunity to talk directly to someone who understands, share your experience and ask questions.

EXTERNAL LINKS

Asbestos Diseases Foundation of Australia Inc. (ADFA)	adfa.org.au
Asbestos Disease Support Society (ADSS)	adss.org.au
Asbestos Diseases Society of Australia Inc. (ADSA)	asbestosdiseases.org.au
The Australian Asbestos Network	australianasbestosnetwork.org.au
Asbestosis & Mesothelioma Association of Australia (AMAA)	asbestosassociation.com.au
Bernie Banton	berniebanton.com.au
Asbestos Council of Victoria Gippsland Asbestos Related Diseases Support Inc (ACV / GARDS)	gards.org
Asbestos Diseases Society of South Australia (ADSSA)	adssa.org.au
Asbestos Free Tasmania	
Foundation (AFTF)	asbestosfreetasmania.org.au
	asbestosfreetasmania.org.au avasa.asn.au

LUNG FOUNDATION AUSTRALIA SERVICES



Information and Support Team



Lung disease information resources



Education webinars



Support groups



Peer-to-peer connections



Referral to pulmonary rehabilitation and Lungs in Action exercise programs



E-newsletter

REFERENCE

1. https://www.aihw.gov.au/reports/cancer/mesothelioma-in-australia-2020/summary

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