



# Mesothelioma Learning Module

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Section 1

# Mesothelioma

# What is Mesothelioma?

Mesothelioma is a rare cancer with a terminal prognosis caused by asbestos exposure. Accounting for fewer than 1% of all cancers, it affects the mesothelial cells, which make up the mesothelium, the membrane that lines the outer surface of most organs. Malignancy develops slowly, with a latency period ranging from 10–50 years.<sup>1</sup>

## What is Asbestos?

A mineral with fibrous crystalline structures that has been mined and used by humans for thousands of years for its pliability, strength and insulative qualities. Often referred to as the 'Hidden Killer', asbestos fibres are 200 times thinner than human hair and have no taste or smell.

Asbestos was nationally banned in Australia in 2003. Australia has one of the highest incidence rates of mesothelioma in the world, with 642 new cases reported to the Australian Mesothelioma Registry in 2020. This is an unfortunate consequence of the booming asbestos mining industry and widespread use of asbestos-containing products in the last century.<sup>2,3</sup>

## Who is at risk of mesothelioma?

Mesothelioma potentially affects anyone who has been exposed to asbestos. It is preventable, therefore raising awareness is an important aspect of asbestos related disease management.



### Occupational exposure

Occupational exposure primarily happens in a workplace setting. People who worked with the raw material or with asbestos-containing products are at the highest risk of developing mesothelioma.

1 Shavelle R, Vavra-Musser K, Lee J, Brooks J. [Life expectancy in pleural and peritoneal mesothelioma](#). *Lung Cancer International*. 2017; 2017:1-8.

2 Musk AB, Klerk N, Brims FJ. [Mesothelioma in Australia: A Review](#). *Medical Journal of Australia*. 2017;207(10):449-452.

3 Australian Institute of Health and Welfare. [Mesothelioma in Australia 2020](#). Updated October 28 2021.



### **Environmental exposure**

Asbestos is a naturally occurring mineral, therefore people who are exposed to the natural dust in the ground, live near old asbestos mines or exposed at home are at risk of developing mesothelioma.



### **Secondhand exposure**

Household members of people working with asbestos containing products can be exposed. This includes the partners, children and siblings who for example washed the dust covered clothing of workers or cleaned workspaces that has resulted in exposure to asbestos/dust fibres and have developed mesothelioma.



### **Renovation exposure**

There is a growing body of evidence that more people are being diagnosed with mesothelioma as a result of non-occupational exposure to asbestos fibres and dust during DIY home renovations and demolitions. Most homes built before 1990 are likely to contain asbestos products. This applies also to farm and rural properties.

# Types of Mesothelioma

The most common site of mesothelioma is in the pleura, and this is what this module will focus on. Other sites include the peritoneum, pericardium, and tunica vaginalis.

## Pleural Mesothelioma

Pleural Mesothelioma affects the thoracic pleura that lines the lungs, chest wall, diaphragm, and heart. It is the most common type, accounting for approximately 90% of mesothelioma cases. The median overall survival rate is 15 months with approximately 10% of patients surviving 5 years after diagnosis.<sup>4</sup>



Video: [Anroav]. (2009, September 24). Asian Ban Asbestos Video, English [Video]. Youtube. <https://www.youtube.com/watch?v=whIIUZMKcV0>

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4 Musk AW, Olsen N, Alfonso H, et al. Predicting survival in malignant mesothelioma. *European Respiratory Journal*. 2011;38(6):1420-1424.

## Peritoneal Mesothelioma

Accounts for approximately 10% of cases with a median survival rate of 1–5 years. It affects the peritoneum (lining of the abdominal cavity) and the membrane that covers the organs of the abdomen and pelvis, including the stomach, bowel, liver, kidneys, uterus and ovaries.<sup>5</sup>

Patients present with diffuse, extensive spread throughout the abdomen. Common symptoms may include:

- ▶ Swollen or painful abdomen
- ▶ Ascites
- ▶ Loss of appetite and weight loss
- ▶ Nausea/vomiting
- ▶ Constipation/Diarrhea

Due to the rarity of peritoneal mesothelioma and the non-specific symptoms that patients present with, it is usually diagnosed late when the disease burden is extensive.

Treatment includes:

- ▶ Systemic Chemotherapy and/or immunotherapy
- ▶ Cytoreductive surgery and Hyperthermic Intraperitoneal Chemotherapy (CRS + HIPEC)

Cytoreductive surgery is a complex abdominal surgery that involves the stripping of the peritoneal lining. In addition, some patients may require organ resections if there is disease spread and or obstruction. Hyperthermic Intraperitoneal Chemotherapy involves the heating of chemotherapy drugs to 42–43 degrees Celsius which is continuously irrigated within the peritoneal cavity for 60–90 minutes intraoperatively.

Cytoreductive surgery is complex, and the patient requires a continual multidisciplinary approach to their care. Critical management of potential complications is imperative; they may include post-operative septic shock, anastomotic leaks, wound breakdown, and intra-abdominal collections.<sup>6</sup>

5 Kim J, Bhagwandin S, Labow DM. [Malignant peritoneal mesothelioma: A Review](#). *Annals of Translational Medicine*. 2017;5(11):236–236.

6 García-Fadrique A, Mehta A, Mohamed F, Dayal S, Cecil T, Moran BJ. [Clinical presentation, diagnosis, classification and management of Peritoneal Mesothelioma: A Review](#). *Journal of Gastrointestinal Oncology*. 2017;8(5):915–924.

## Pericardial Mesothelioma (membrane around the heart)

A median survival rate of 2 months.<sup>7</sup>

The symptoms are vague and may take many years to present. They may include:

- ▶ Chest pain
- ▶ Cardiac arrhythmias
- ▶ Dyspnoea
- ▶ Right shoulder pain
- ▶ Swelling in lower extremities

Common clinical manifestations include constrictive pericarditis, cardiac tamponade, and heart failure.

Treatment includes:

- ▶ Systemic chemotherapy
- ▶ Pericardiectomy (tumour removal)

Unfortunately, due to the rarity and vague presentation of pericardial mesothelioma, most cases are diagnosed on autopsy after death.

## Tunica Vaginalis Mesothelioma (membrane around the testes)

A median survival rate of 2 years.<sup>8</sup>

Symptoms include:

- ▶ Enlargement of the scrotum
- ▶ Hydrocele (abnormal fluid retention around the testicle)
- ▶ Paratesticular mass

Treatment includes:

- ▶ Chemotherapy
- ▶ Immunotherapy
- ▶ Radiation therapy
- ▶ Orchiectomy (removal of the testicle and spermatic cord).

7 Godar M, Liu J, Zhang P, Xia Y, Yuan Q. [Primary pericardial mesothelioma: a rare entity](#). *Case Rep Oncol Med*. 2013;2013:283601.

8 Akin Y, Bassorgun I, Basara I, Yucel S. [Malignant mesothelioma of tunica vaginalis: an extremely rare case presenting without risk factors](#). *Singapore Med J*. 2015;56(3):e53-e55.



# Cell Types of Mesothelioma

Mesothelioma is classified into three histopathological subtypes; each type has its own unique characteristics that determine how the disease responds to specific oncological treatments.

## Epithelioid

This is the most common subtype, and affects the epithelioid cells. It tends to be slower growing with a median survival of 19 months. Epithelioid mesothelioma is more likely to respond to chemotherapy.<sup>9</sup>

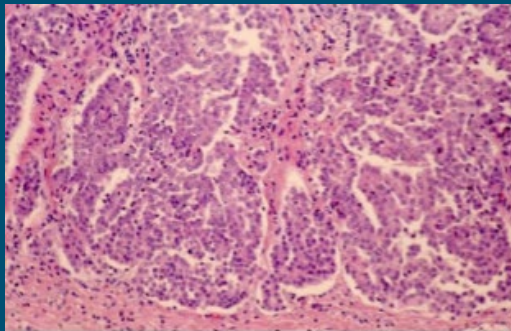


Image: Inai K. (2008). Microphotograph of epithelioid mesothelioma (H&E stain). Papillo-tubular structure is prominent. [Online Image]. [Pathology of mesothelioma](#). 2008;13:60-64.

<sup>9</sup> Asciak, R, George, V, Rahman, NM. [Update on biology and management of mesothelioma](#). *European Respiratory Review*. 2021;30(159).

## Sarcomatoid

Refers to mesothelioma tumours consisting of sarcomatoid cells. This cell type is more aggressive, it typically forms in multiple lesions and is more likely to spread to bone and nearby organs. Previously sarcomatoid mesothelioma was resistant to standard oncological therapy, but recent clinical trials have shown immunotherapy to be the most promising treatment. The median survival is 4 months.<sup>10,11</sup>

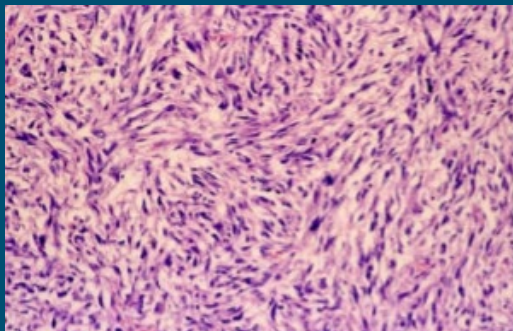


Image: Inai K. (2008). Microphotograph of sarcomatoid mesothelioma (H&E stain). Proliferation of spindle cells mimics true sarcoma. [Online Image]. [Pathology of mesothelioma](#). 2008;13:60–64.

## Biphasic

Also known as mixed mesothelioma, biphasic consists of at least 10% of both epithelioid and sarcomatoid cells. The percentage of epithelioid and sarcomatoid cells will impact the treatment options and prognosis.<sup>12</sup>

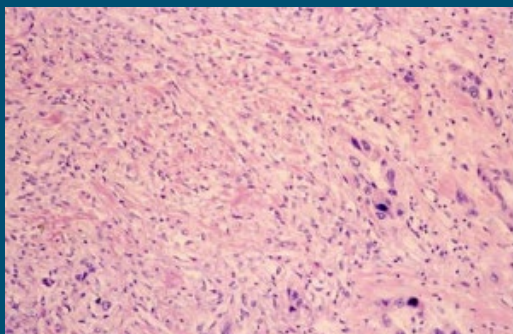


Image: Inai K. (2008). Microphotograph of epithelioid mesothelioma (H&E stain). Microphotograph of biphasic mesothelioma (H&E stain). The features of epithelioid mesothelioma and that of sarcomatoid mesothelioma are mixed within one tumor. [Online Image]. [Pathology of mesothelioma](#). 2008;13:60–64.

10 Asciak, R, George, V, Rahman, NM. [Update on biology and management of mesothelioma](#). *European Respiratory Review*. 2021;30(159).

11 Clopton, B et al. [Sarcomatoid mesothelioma: unusual findings and literature review](#). *Journal of Surgical Case Reports*. 2022;2022(11)

12 Røe OD. [Mesothelioma diagnosis and prognosis are we moving beyond histology and performance status towards circulating biomarkers?](#) *Journal of Thoracic Disease*. 2018;10: 1956–1961.



Section 2

# The Patient Journey

# Presenting Symptoms

Early signs of pleural mesothelioma can mimic other diseases, often resulting in delays in presentation and diagnosis. This raises the importance of considering asbestos exposure in patients that present with some or all of these symptoms.

- ▶ Shortness of breath on exertion
- ▶ Chest pain (pleuritic/non-pleuritic)
- ▶ Loss of appetite and weight loss
- ▶ Persistent cough
- ▶ Diaphoresis, especially at night
- ▶ Fatigue and lethargy

Patients usually present to their treating GP or Emergency Department to have symptoms explored and managed.

Initial clinical and radiological examination involves a chest X-Ray that commonly reveals a pleural effusion requiring drainage. Thoracentesis may be required to drain the pleural effusion. Patients will usually notice immediate relief from breathlessness but invariably the fluid reaccumulates over the coming weeks, necessitating further drainage and/or surgical intervention.

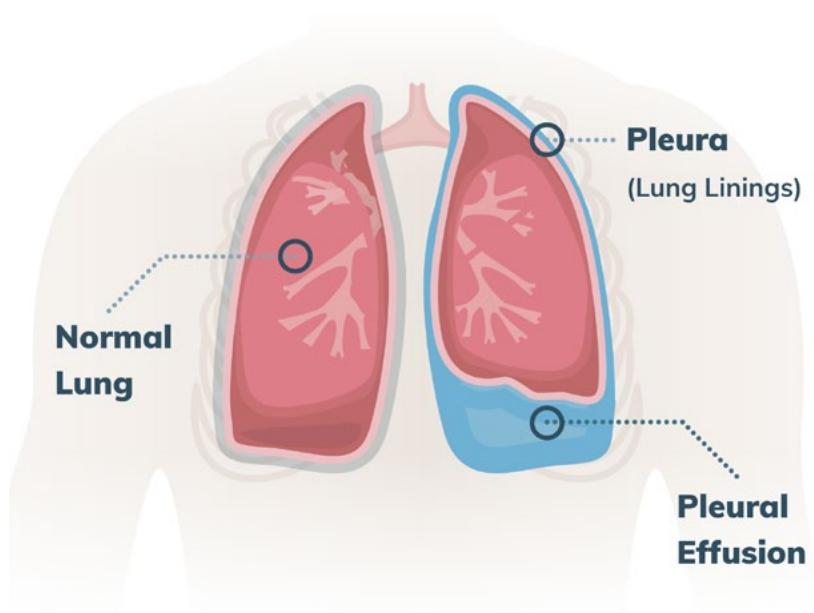


Image: Molinari, L. (2022). [Online Image]. Pleural Effusion & Mesothelioma. <https://www.mesothelioma.com/mesothelioma/symptoms/pleural-effusion/>

# Diagnosis

Getting a diagnosis of pleural mesothelioma can be a difficult and lengthy process because the sequence of interventions varies depending on clinician knowledge, skills and experience. Confirming the histopathological subtype is essential for a definitive diagnosis and treatment plan.

If a pleural effusion is present, a fluid sample can be collected for cytology testing at the time of initial drainage. If that does not yield a result, a tissue biopsy is required. A tissue biopsy can be obtained by either CT-guided biopsy by an interventional radiologist or during Video-Assisted Thoracoscopic Surgery (VATS) performed by a cardiothoracic surgeon.<sup>1,2</sup>

For some patients, at this point, their doctors may have suggested an asbestos-related diagnosis. For others, they will be completely naive to the possibility of a mesothelioma diagnosis.



Watch the video: <https://adri.org.au/education/wp-content/uploads/2023/02/video-meso-diagnosis.webm>

**“I will not let mesothelioma define me”**

— A patient during a Mesothelioma Support group

1 McLean J, McCaughan BC. [Diagnosis and treatment: the journey of a patient with malignant pleural mesothelioma](#). Sydney: The Baird Institute; 2013. 79 p

2 [Guidelines for the Diagnosis and Treatment of Malignant Pleural Mesothelioma](#). Asbestos Diseases Research Institute; Sydney: 2013.

## Who is involved?

The management of patients with mesothelioma is complex. Where possible each case should be presented in a multidisciplinary meeting where medical, surgical and oncological clinical experts review the patient's history, imaging and pathology before deciding on the best pathway of treatment and care. This ensures shared decision making and best practice care.

The patient journey could involve all or some of these health professionals:

- ▶ General Practitioner
- ▶ Radiologist/Interventional Radiologist
- ▶ Respiratory Physician
- ▶ Cardiothoracic Surgeon
- ▶ Medical Oncologist
- ▶ Radiation Oncologist
- ▶ Palliative Care Specialist
- ▶ Cancer Care Coordinator/Nurse
- ▶ Nursing staff in the hospital and community
- ▶ Dietician
- ▶ Social worker
- ▶ Physiotherapist
- ▶ Occupational therapist
- ▶ Exercise Physiologist
- ▶ Clinical Psychologist
- ▶ [Mesothelioma Support Service at ADDRI](#)

### Patient Compensation

Compensation can be sought to cover costs related to loss of employment, financial insecurity, cost of accessing medical treatment and care and unexpected loss of life.

In NSW people who develop mesothelioma may be entitled to lodge a claim for compensation via Statutory Law (iCare) or through the courts as a Common Law Claim. Legal entitlements vary according to where and how the exposure to asbestos occurred. Other states and territories have their own differing entitlements.

#### iCare

iCare is an insurance institution that governs the Statutory Body called Dust Diseases Care (DDC). DDC provides compensation to cover financial, healthcare, equipment and domestic support to workers who have a compensable dust disease and or disability as a result of a NSW workplace exposure to asbestos.

## Common Law Claim

A Common Law Claim is lodged by a lawyer experienced in dust disease compensation. It is a claim against the party/parties who manufactured the asbestos products that the person was exposed to. In NSW, people may be entitled to make both a Statutory and Common Law Claim, one is not dependent on the other.

[Click here for information on State and Territory Compensation Schemes](#)

# Treatment

The extent of disease, overall health and patient's wishes will influence treatment plans. Patients with extensive disease may decide not to pursue systemic treatment and instead focus on improving quality of life through symptom management. Patients with limited disease may explore more invasive and complex treatments. Some will enjoy life without treatment for a period under surveillance and others will start immediately.

Mesothelioma treatment impacts both the physical and emotional wellbeing of the patient, therefore the need to monitor for side effects related to their treatment and assess their mental health with referral to social work and psychology is paramount to providing good nursing care.

## Chemotherapy

Since 2003 the standard treatment for pleural mesothelioma has been double chemotherapy with pemetrexed and cisplatin/carboplatin. It remains a standard first line treatment for epithelioid mesothelioma but is less effective for sarcomatoid and biphasic subtypes of mesothelioma.<sup>3,4</sup>

## Immunotherapy

Immunotherapy is a targeted treatment that uses immune checkpoint inhibitors (ICI) to prompt an anti-tumour immune response, allowing T-cells to attack tumour cells. Recent studies have concluded that double immunotherapy using Nivolumab (Opdivo) and Ipilimumab (Yervoy) should be the new standard of care for first line treatment in patients with non-epithelioid mesothelioma and may be of comparable efficacy to chemotherapy in epithelioid disease.<sup>3,5</sup> Prior to 2021 these drugs were not listed on the Pharmaceutical Benefit Scheme (PBS) and the cost to the patient impacted choice and availability. Pembrolizumab (Keytruda) is a single immunotherapy drug that was the basis of initial clinical trials of immunotherapy in mesothelioma care.<sup>5,6</sup>

3 Nowak AK, Jackson A, Sidhu C. Management of advanced pleural mesothelioma—at the Crossroads. *JCO Oncology Practice*. 2022;18(2):116–124.

4 Vogelzang N. J, Rusthoven J. J, Symanowski, J, et al. Phase III study of pemetrexed in combination with Cisplatin versus cisplatin alone in patients with malignant pleural mesothelioma. *Journal of Clinical Oncology*, 2003;21(14);, 2636–2644.

5 Metaxas Y, et al. Pembrolizumab as Palliative Immunotherapy in Malignant Pleural Mesothelioma. *Journal of Thoracic Oncology*, 2018;13(11): 1784–1791.

6 Gray SG, Mutti L. Immunotherapy for mesothelioma: A critical review of current clinical trials and future perspectives. *Translational Lung Cancer Research*. 2020;9(S1).



## Other Therapies

Bevacizumab is an antiangiogenic agent that inhibits the production of tumour blood vessels which limits blood supply, slowing the growth and spread of tumours. Results suggest that Bevacizumab in combination with chemotherapy may be a potentially life-extending treatment as well as beneficial in palliative symptom management.<sup>7</sup>

## Radiation Therapy

Radiation therapy is used to reduce the size and spread of tumours and consequential pain relating to tumour activity. Specialised radiation therapy is used as the third treatment arm of trimodality therapy.

## Clinical trials

As research in mesothelioma evolves, so do treatment options. Current trials are looking at the efficacy of combination chemotherapy and immunotherapy and other targeted therapies in the treatment of mesothelioma. Patients should be informed by their healthcare team of any clinical trials they may be eligible for.

Visit the [Thoracic Oncology Group of Australasia \(TOGA\)](#) for more information on current clinical trials and research.

## Surgery

Surgical intervention aims to control recurrent pleural effusions and optimise lung function by removing the fluid and re-expanding the affected lung. For many patients, surgery to control the fluid will be all they require. Others may require more invasive procedures to reduce disease activity and enable better lung function, and ultimately prolong quality living.

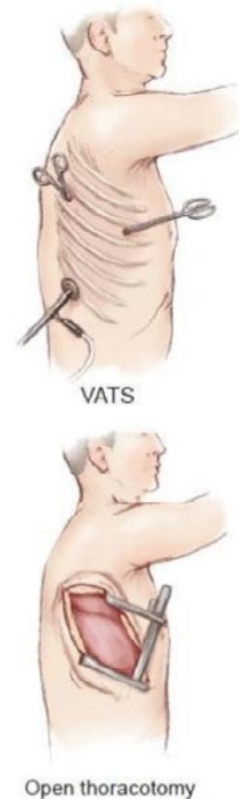
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<sup>7</sup> Zalcman G, Mazieres J, Margery J, et al. [Bevacizumab for newly diagnosed pleural mesothelioma in the mesothelioma Avastin Cisplatin Pemetrexed Study \(MAPS\): A randomised, controlled, open-label, phase 3 trial.](#) *The Lancet*. 2016;387:1405-1414.

# Surgical Procedures

## Video-assisted thoracoscopic surgery (VATS) with talc pleurodesis

VATS is a minimally invasive thoracic surgery performed with a videoscope inserted into the pleural space. The pleural effusion is drained, allowing the lung to re-expand. Sterile talcum powder is injected into the pleural space which causes inflammation between the visceral pleura and parietal pleura causing them to fuse together (pleurodesis). Usually, a biopsy is collected for analysis and diagnosis.<sup>8,9</sup>



## Thoracotomy with parietal pleurectomy and pulmonary decortication

A posterior thoracotomy is initiated when VATS does not achieve a pleurodesis or for further debulking of tumours that encase the lung (pulmonary decortication) to permit re-expansion of the lung. A parietal pleurectomy is completed where the tumour affected pleura is removed from the chest wall.<sup>8,9</sup>

Images: Cao, C. D'amico, D. Demmy, T. Dunning, J et al. (2016). Comparative incisions for VATs and open thoracotomy in the treatment of non-small-cell lung cancer. [Online Image]. Less is more: a shift in the surgical approach to non-small lung cancer. 2016;4(3).  
Indwelling Pleural Catheter (IPC)

## Indwelling Pleural Catheter (IPC)

When drainage of the pleural effusion via thoracoscopy and thoracotomy will not achieve an optimal clinical outcome or the patient is not an appropriate candidate for surgery, then insertion of an IPC may be considered for the management of a recurrent malignant pleural effusion. The drainage system is designed for intermittent drainage so that the patient can manage the fluid and the symptom of breathlessness at home with community nursing support or by themselves.<sup>8</sup>

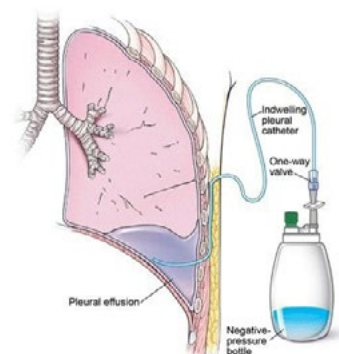


Image: Pangrace, J. (2016). Draining of a Pleural Effusion in the Left Hemithorax. [Online Image]. When should an indwelling pleural catheter be considered for malignant pleural effusion?;83(12) 891-894. <https://www.ccjm.org/content/83/12/891>

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- 8 McLean J, McCaughan BC. Diagnosis and treatment: the journey of a patient with malignant pleural mesothelioma. Sydney: The Baird Institute; 2013.
- 9 Mothoneos J, editor. Understanding Mesothelioma. A guide for people with cancer, their families and friends.: Cancer Council Australia; 2019.

# Trimodality Therapy

A combined approach of induction chemotherapy, followed by radical cytoreductive surgery and then radiation therapy is known as trimodality therapy. Trimodality therapy can improve quality of life and overall survival.

It is only a suitable treatment option for patients who:

- ▶ Are known to have early-stage disease with minimal symptoms
- ▶ Have had a positive clinical response to induction chemotherapy
- ▶ Have nil evidence of lymph node involvement or other cancer disease
- ▶ The surgeon is confident all tumours can be safely removed
- ▶ Are deemed able to live independently with one lung (Pulmonary Function Testing)
- ▶ Are medically and physically fit (Cardiology Assessment)
- ▶ Have the mental strength to endure the prolonged treatment
- ▶ Have a strong support network

Radical surgery is performed with curative intent aiming to achieve complete macroscopic resection. It is offered in New South Wales by one experienced Cardiothoracic Surgeon. There are two radical surgical options.

## Extrapleural Pneumonectomy (EPP)

Involves the removal of the affected lung, parietal pleura, hemi-diaphragm, and pericardium in one piece (en-bloc). The pulmonary lymph nodes are also removed, and the defects around the heart and diaphragm are reconstructed with a layer of gortex mesh.

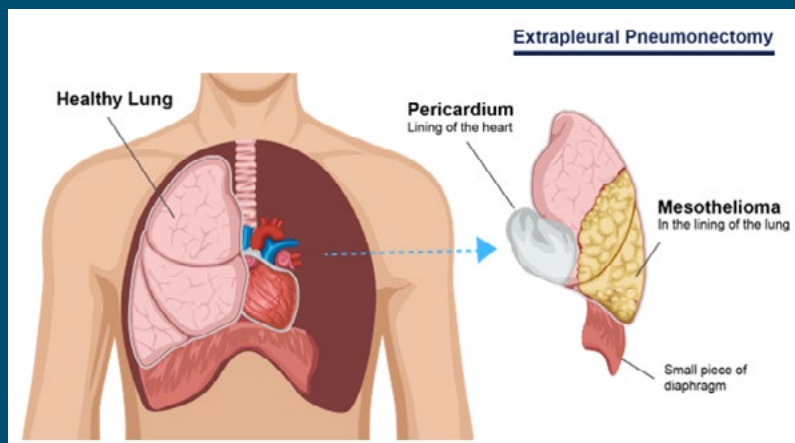


Image: Dryfoos, C. (2022). [Online Image]. Mesothelioma Treatment. <https://www.mesotheliomaveterans.org/treatment/>

## Extended Pleurectomy/Decortication (eP/D)

The total parietal and visceral pleurectomy plus resection of the hemidiaphragm and pericardium as required (the lung remains insitu).

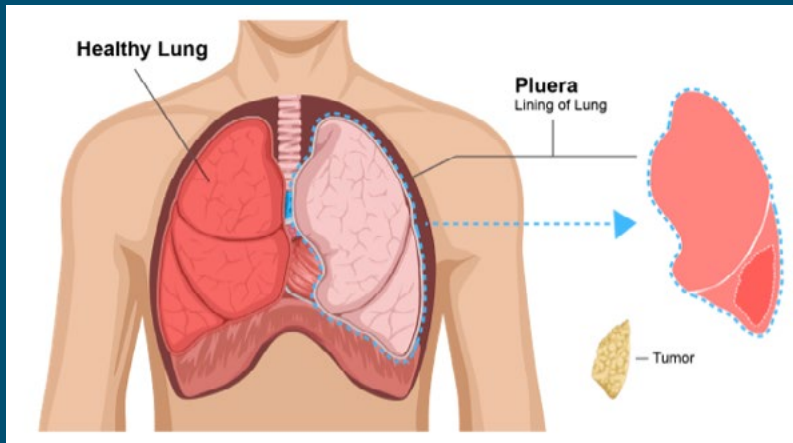


Image: Dryfoos, C. (2022). [Online Image]. Mesothelioma Treatment. <https://www.mesotheliomaveterans.org/treatment/>

## Controversy Around Trimodality Therapy

The role of trimodality therapy across international practices has been debated since the publication of the Mesothelioma and Radical Surgery (MARS) randomised trial which suggested that EPP offers no benefit and possibly harms the patient.<sup>10</sup> In NSW, we see positive patient outcomes and prolonged survival as only those patients that meet the strict criteria mentioned above are offered the surgery. A second trial 'MARS 2' is currently underway comparing eP/D with no eP/D for patients with pleural mesothelioma.<sup>11</sup>

10 Treasure T, Lang-Lazdunski L, Waller D, et al. Extra-pleural pneumonectomy versus no extra-pleural pneumonectomy for patients with malignant pleural mesothelioma: Clinical outcomes of the mesothelioma and radical surgery (MARS) randomised feasibility study. *The Lancet Oncology*. 2011;12(8):763-772.

11 Lim E, Darlison L, Edwards J, et al. Mesothelioma and Radical Surgery 2 (MARS 2): protocol for a multicentre randomised trial comparing (extended) pleurectomy decortication versus no (extended) pleurectomy decortication for patients with malignant pleural mesothelioma. *BMJ Open* 2020;10.

# Recurrent Disease and Disease Progression

Mesothelioma is incurable. All patients—even if there was an initial positive response to treatment—will have disease progression and die. Today, people are living longer with their disease due to advances in oncological treatment and better access to medication.

Mesothelioma was once considered a disease confined to one hemithorax. As people live longer, spread to other organs through the diaphragm and via blood and the lymphatic system are reported and treated.

Second line treatment will depend on the level of disease, overall health of the patient and their wishes. It may include:

- ▶ Retreatment of initial therapy
- ▶ Changing therapy/drugs and combinations (chemotherapy or immunotherapy)
- ▶ Radiation therapy to relieve pain and reduce the size of the tumour regrowth
- ▶ Further surgery
- ▶ Participating in a clinical trial.

Some people may not be suitable for second line treatment or may decline further treatment and instead focus on managing their symptoms and maximising quality of life.

# Symptom Management

Managing symptoms can relate to both the consequence of disease progression and also side effects related to treatment. Nursing care involves comprehensive assessment of both.

## Dyspnoea

96% of patients with mesothelioma experience dyspnoea, it may be a result of:

- ▶ Recurrent pleural effusion
- ▶ Reduction in lung volume—entrapped lung
- ▶ Anxiety
- ▶ Side effects of therapy

Management may include:

- ▶ Further surgical intervention or insertion of a pleural drain to remove fluid
- ▶ Liquid morphine (Ordine)
- ▶ Oxygen therapy may be useful, but is not required by all
- ▶ Psychological support—mindfulness meditation is recognised as a beneficial self-help therapy
- ▶ Chest physio
- ▶ A handheld fan—stimulation of mechanoreceptors or temperature receptors mediated via the trigeminal nerve may alter feedback to the brain and modify perception of dyspnoea
- ▶ Education on positioning and equipment, such as recliner chairs and hospital beds

## Pain

Both a symptom of mesothelioma and a side effect of treatment. It is important to conduct a comprehensive pain assessment to determine the location and severity of pain. Many people may need a combination of medications to achieve good pain control. Referral to palliative care for symptom management is recommended.

## **Weight loss/poor appetite**

Cachexia and malnutrition are common among patients with mesothelioma and are associated with impaired quality of life, reduced tolerance to treatment and increased mortality. Regular malnutrition screening and input from a dietician is essential in managing weight loss and poor appetite. Guidance for the carer around achieving and maintaining adequate dietary intake may be helpful.

## **Fatigue**

Fatigue and lethargy are both a symptom of mesothelioma and a side effect of treatment. It is important the treating team is aware so that it can be treated appropriately. Fatigue is best managed by exercise throughout the day, pacing activities and eating a nutritious diet. You could seek advice from an exercise physiologist or dietician at this point.

## **Psychological Symptoms**

A cancer diagnosis has a significant psychosocial impact on the patient. Anxiety, depression and post-traumatic stress disorders as well as anger, guilt and pressure on relationships are common among patients diagnosed with mesothelioma. Ongoing psychological support is essential in promoting positive patient outcomes and good quality of life. Referral to psychology and counselling services may be considered for these patients.

## **Alternative Therapies**

Some patients may seek alternative treatments to relieve the symptoms of mesothelioma and ease the side effects of chemotherapy and immunotherapy. These may include massage therapy, acupuncture, herbal medicine, and medicinal marijuana. It is essential that the treating specialist is aware of chosen alternative options.

# Integrated Palliative and Supportive Care

Transition to integrated palliative and supportive care can be a confusing and traumatic time for patients and their families. Simple kindness can help to diffuse these emotions and may even help to improve patient outcomes.

Research has identified there are six types of kindness in cancer care;<sup>12</sup>

- ▶ **Deep Listening**—whereby clinicians take the time to truly understand the needs and concerns of patients and their families
- ▶ **Empathy**—expressed by clinicians to prevent avoidable suffering
- ▶ **Generous Acts**—that go beyond what patients and families expect of their care team
- ▶ **Timely Care**—that is delivered using a variety of tools and systems that reduce stress and anxiety
- ▶ **Gentle Honesty**—whereby the truth is conveyed directly in well-chosen, guiding words
- ▶ **Support for Family Caregivers**—who's physical and mental well-being are vital components of the care their loved ones receive

The focus on controlling symptoms and improving quality of life becomes the overarching goal. Benefits of early palliative care input include:

- ▶ Symptom management
- ▶ Improving quality of life
- ▶ Recognition of changes to treatment goals
- ▶ Addressing physical, psychological, social, and spiritual needs
- ▶ Encouraging conversations around end of life and advanced care planning
- ▶ Developing a relationship and building rapport with the palliative care team

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12 Berry L, Danaher, TS, Chapman, RA, Awdish, RLA. [Role of Kindness in Cancer Care](#). *Journal of Oncology Practice*. 2017;13(11):744-750.



## Questions to ask

### Have you been introduced to the palliative care team?

There is strong evidence that early palliative care involvement improves symptoms, quality of life and disease outcomes for patients.<sup>13</sup> Remind the patient that even though they may not need assistance from palliative care right now, it is important to connect early to ensure they can access it in the future when they do need it.

### Do you have an advanced care plan?

- ▶ Is your will up to date?
- ▶ Have you appointed a power of attorney to make decisions for you if needed?
- ▶ Do you have an Advanced Care Directive?

End of life wishes need to be considered in alignment with the patient's advanced care directive. This legal document allows the patient to communicate what kind of care and treatment they want leading up to and facing end of life. It is important that this advanced care directive reflects the patient's current situation.

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<sup>13</sup> Kain, DA, Eisenhauer, EA. [Early integration of palliative care into standard oncology care: evidence and overcoming barriers to implementation](#). *Current Oncology*. 2016;23(6):374-377.

# Providing Support

## For the Patient

A mesothelioma diagnosis brings adverse psychological reactions. Initial shock and dismay can lead to anxiety, depression, apathy, difficulty concentrating, discomfort, and social dysfunction. With all the uncertainty that comes with a diagnosis, providing emotional support can help patients to express their fears and struggles and learn new ways to cope with the difficulties they are likely to face. Involvement by a social worker or a psychologist may be helpful at this time.

Avoidance and denial are the predominant coping mechanisms adopted by patients to address feelings of psychological distress. As clinicians, it is essential we understand what is most important to the patient and how we can support them as their goals change throughout their illness.

Patients with mesothelioma are likely to experience functional decline and deterioration. Increased support by allied health and nursing is required to ensure patient safety. The needs of each patient will differ, they may include community nursing to assist with tasks such as showering, education on mobility aids and home modifications.

## For the Carer and Family

Carer support runs parallel with patient care.

Caring for a loved one with mesothelioma may be one of the greatest challenges a caregiver will face in their lifetime. The high symptom burden of mesothelioma leads to significant dependence on caregivers and the poor prognosis generates uncertainty in predicting the trajectory and identifying the needs of the patient. Mesothelioma caregivers experience high levels of emotional morbidity which manifest as feelings of anger, anxiety, depression, isolation and fear of loss. They may feel overwhelmed by conflicted blame and the burden of legal claims.

It is important to check in on carers as well as the patient. Carer support is associated with improved wellbeing and confidence in their ability to provide care at the end of the patient's life and manage after their death.<sup>14</sup>

<sup>14</sup> Harrison M, Darlison L, Gardiner C. [Understanding the experiences of end of life care for patients with mesothelioma from the perspective of bereaved family caregivers in the UK: A qualitative analysis.](#) *Journal of Palliative Care.* 2022;37(2):197-203.

## How we Can Help

The Mesothelioma Support Service at ADDRI addresses the needs of patients with mesothelioma and supports their families. The Registered Nurse driven service utilises a wealth of knowledge and experience by drawing on personal experience, current survivorship research, cancer care networking and carer need research to provide telephone, face-to-face and group meeting support.<sup>15</sup>

The service is available to answer any questions you may have about caring for patients with mesothelioma.

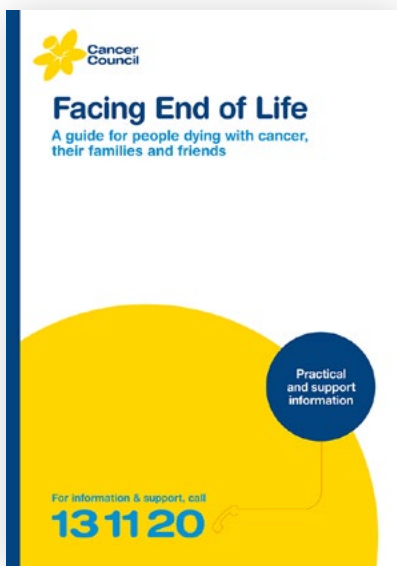
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<sup>15</sup> Lee JT, Mittal DL, Warby A, Kao S, Dhillon HM, Vardy JL. [Dying of mesothelioma: A qualitative exploration of caregiver experiences.](#) *European Journal of Cancer Care*, 2022;31 (5).

# End of Life Care

Providing compassionate end of life care that is in accordance with the patient's wishes is an essential component of nursing care. End of life care encompasses many aspects of care, including pain and symptom management and assisting patients and families through the dying process and death.

The most valuable care a nurse can provide for any patient and family facing end of life is support and compassion. This is a very difficult stage and we have found the below resources helpful.



[Download the 'Facing End of Life' booklet \(PDF\)](#)



**The Groundswell  
Project Australia**

## After Death

After the death of a patient, some caregivers describe feelings of abandonment from the abrupt cessation of contact with healthcare professionals. Bereavement support groups are beneficial to carers and families as they offer a place to feel validated and understood, a safe place to express grief and an opportunity to learn about the grieving process.

Referral to a bereavement counsellor/CNC, social worker or psychologist can be beneficial for the family after the death of a patient.

The Mesothelioma Support Service at ADDRI provides support for the bereaved through telephone contact and support groups.



Watch the video: <https://adri.org.au/education/wp-content/uploads/2023/02/video-meso-after-death.webm>

You will find more resources in our [Reading Room](#), but these titles may be valuable to read, or share with the caregivers, at this point.

- ▶ The Certainty Myth, Dr Toni Lindsay
- ▶ Resilient Grieving, Dr Lucy Hone



Section 3

# Resources

# Reading Room

## What is Mesothelioma

- ▶ Shavelle R, Vavra-Musser K, Lee J, Brooks J. Life expectancy in pleural and peritoneal mesothelioma. *Lung Cancer International*. 2017; 2017:1-8.  
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## The Types of Mesothelioma

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<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3697233/>
- ▶ Akin Y, Bassorgun I, Basara I, Yucel S. Malignant mesothelioma of tunica vaginalis: an extremely rare case presenting without risk factors. *Singapore Med J*. 2015;56(3):e53-e55.  
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4371211/>

## The Cell Types of Mesothelioma

- ▶ Asciak, R, George, V, Rahman, NM. Update on biology and management of mesothelioma. *European Respiratory Review*. 2021;30(159).  
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9489032/>

- ▶ Clopton, B et al. Sarcomatoid mesothelioma: unusual findings and literature review. *Journal of Surgical Case Reports*. 2022;2022(11).  
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9675762/>
- ▶ Røe OD. Mesothelioma diagnosis and prognosis are we moving beyond histology and performance status towards circulating biomarkers?. *Journal of Thoracic Disease*. 2018;10: 1956-1961.  
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6036040/>

## Diagnosis

- ▶ Guidelines for the Diagnosis and Treatment of Malignant Pleural Mesothelioma. Asbestos Diseases Research Institute; Sydney: 2013.  
<https://adri.org.au/wp-content/uploads/2018/08/Guidelines-for-the-diagnosis-and-treatment-of-malignant-pleural-mesothelioma.pdf>
- ▶ McLean J, McCaughan BC. Diagnosis and treatment: the journey of a patient with malignant pleural mesothelioma. Sydney: The Baird Institute; 2013. 79 p  
<https://adri.org.au/wp-content/uploads/2017/11/Diagnosis-Treatment-The-Journey-of-a-Patient-with-MPM.pdf>

## Treatment

- ▶ Nowak AK, Jackson A, Sidhu C. Management of advanced pleural mesothelioma—at the Crossroads. *JCO Oncology Practice*. 2022;18(2):116-124.  
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- ▶ Mothoneos J, editor. Understanding Mesothelioma. A guide for people with cancer, their families and friends.: Cancer Council Australia; 2019.  
<https://www.cancer.org.au/assets/pdf/understanding-mesothelioma-cancer-booklet>

## Surgical Procedures

- ▶ McLean J, McCaughan BC. Diagnosis and treatment: the journey of a patient with malignant pleural mesothelioma. Sydney: The Baird Institute; 2013.  
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## Trimodality Therapy

- ▶ Treasure T, Lang-Lazdunski L, Waller D, et al. Extra-pleural pneumonectomy versus no extra-pleural pneumonectomy for patients with malignant pleural mesothelioma: Clinical outcomes of the mesothelioma and radical surgery (MARS) randomised feasibility study. *The Lancet Oncology*. 2011;12(8):763-772.  
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## End of Life Care

- ▶ The Groundswell Project Australia, A BIG LIST of Death Literacy, Planning and Conversation Tools  
<https://www.thegroundswellproject.com/the-big-list>
- ▶ Lee JT, Mittal DL, Warby A, Kao S, Dhillon HM, Vardy JL. Dying of mesothelioma: A qualitative exploration of caregiver experiences. *European Journal of Cancer Care*, 2022;31 (5).  
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9539703/>

## Providing Support

- ▶ Harrison M, Darlison L, Gardiner C. Understanding the experiences of end of life care for patients with mesothelioma from the perspective of bereaved family caregivers in the UK: A qualitative analysis. *Journal of Palliative Care*. 2022;37(2):197-203.  
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9676412/>

## Patient Stories

- ▶ Hear Warren's Story  
<https://www.icare.nsw.gov.au/news-and-stories/warrens-story#gref>
- ▶ Hear Janet's Story  
<https://www.cancer.nsw.gov.au/about-cancer/cancer-stories/janet-s-mesothelioma-story>