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australian mesothelioma registry

Mesothelioma in Australia

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Australia has one of the highest incidence rates of mesothelioma in the world. This rare and aggressive cancer has no cure, and between 700 and 800 people are diagnosed each year. The average time between diagnosis and death is around 11 months according to Australian Institute of Health and Welfare (AIHW) analysis of all mesothelioma diagnoses and deaths recorded in the Australian Mesothelioma Registry (AMR) as at September 2018.

What is mesothelioma?

Mesothelioma is a form of cancer in the mesothelium—the protective lining on the inside of body cavities and the outside of internal organs, such as the lungs, heart and bowel. Despite most commonly occurring in the chest, mesothelioma is not lung cancer. It is generally accepted that the primary cause is exposure to asbestos (fibres/dust). Australia banned the use of all forms of asbestos in 2004. However, before this, it was used in more than 3,000 products in the construction industry, in industrial plants and equipment, and in ships, trains and cars (ASEA 2018). Its legacy means a large amount of asbestos still remains in buildings and other infrastructure, and thousands of different products containing asbestos are still in use today.

'Asbestos' is a group of naturally occurring fibrous silicate materials that do not readily break down and are resistant to fire and chemical corrosion. Asbestos fibres are so small that they are invisible to the naked eye and can be inhaled into the lungs (AMR as at September 2018).

On average, 2 people are diagnosed with mesothelioma in Australia each day.

Males are 4 times as likely to be diagnosed as females.

The average time from diagnosis to death is 11 months.

Symptoms of mesothelioma typically appear 20–40 years after a person has been exposed to asbestos—it has one of the longest latency periods of all diseases.

AIHW

The Australian Mesothelioma Registry

The AMR collects information on new cases of mesothelioma diagnosed in Australia from 1 July 2010, to better understand the relationship between asbestos exposure and mesothelioma, assist the development of policies to best deal with asbestos still present in our environment, and to provide sound information to policy makers and researchers.

State and territory cancer registries notify the AMR of new cases—notifications include demographic and diagnosis information and are collected and stored in accordance with the *Privacy Act 1988*. The AMR also collects information from consenting patients on their possible asbestos exposure history. Clinicians are approached to provide advice on each patient's suitability to participate in the exposure data collection. Information on potential occupational and non-occupational exposure, and the types of work and circumstances that most likely led to exposure, are collated. The AMR has been managed by the AIHW since 2017 (previously, it had been managed by Cancer Institute New South Wales since 2010). This report presents the latest available information from the AMR, supplemented by data from the National Mortality Database (NMD) and the Australian Cancer Database (ACD).

How many people are diagnosed with mesothelioma?

In total, 710 new cases of mesothelioma were reported to the AMR with a date of diagnosis during 2017 (Table 1). Because not all cases are reported in the same year in which they are diagnosed, the number of cases for recent years can be expected to rise as more notifications are received. Between 2011-2017, on average, four times as many males were diagnosed as females—which is expected because the majority of cases are from exposure in the type of environments in which males more commonly work.

Table 1: Number of people diagnosed with mesothelioma by year and sex, 2011 to 2017

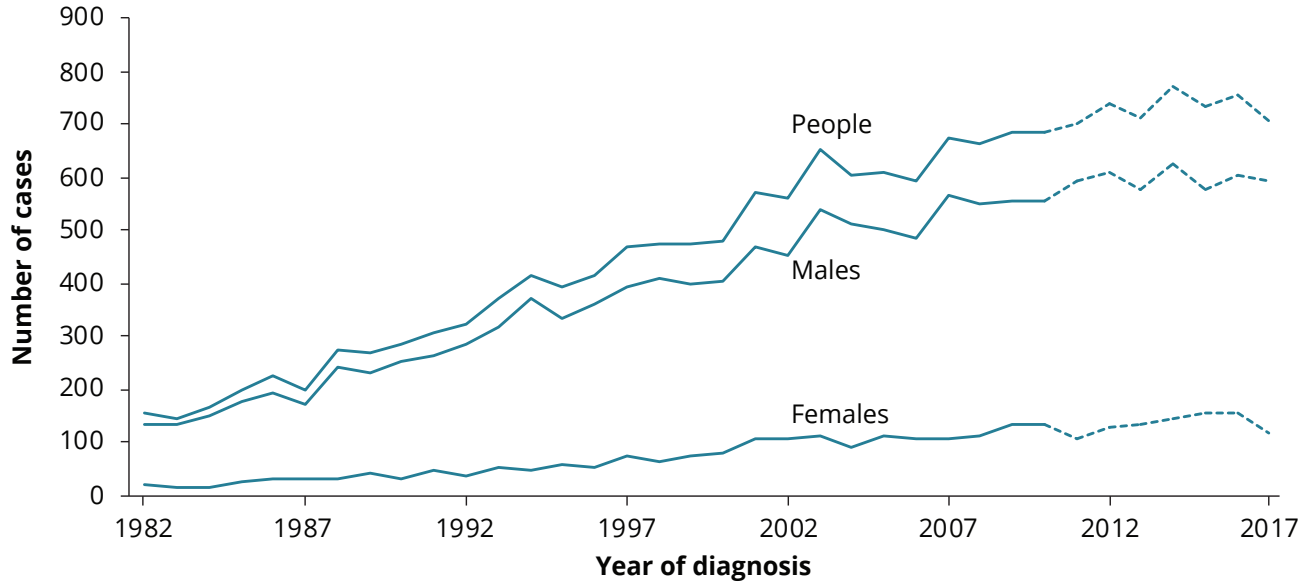
Year of diagnosis	Males	Females	People
2011	596	106	702
2012	610	129	739
2013	576	135	711
2014	625	145	770
2015	576	158	734
2016	604	153	757
2017 (preliminary)	*592*	*118*	*710*

Source: AIHW analysis of AMR data at September 2018.

The number of cases of mesothelioma has risen

As AMR data collection started in July 2010, reporting using AMR data is only possible after that date. However, to produce a longer time series, trends in the number of new cases per year can be reported using data from the ACD for 1982–2010 and the AMR for 2011–2017. The AMR and ACD data on the number of new mesothelioma cases are consistent because state and territory cancer registries provide the same data to both collections. The number of new cases has steadily increased over this period—from 135 for males and 22 for females in 1982, to 592 for males and 118 for females in 2017 (Figure 1). To date, the highest overall number of new cases was in 2014, with 770 cases reported to the AMR.

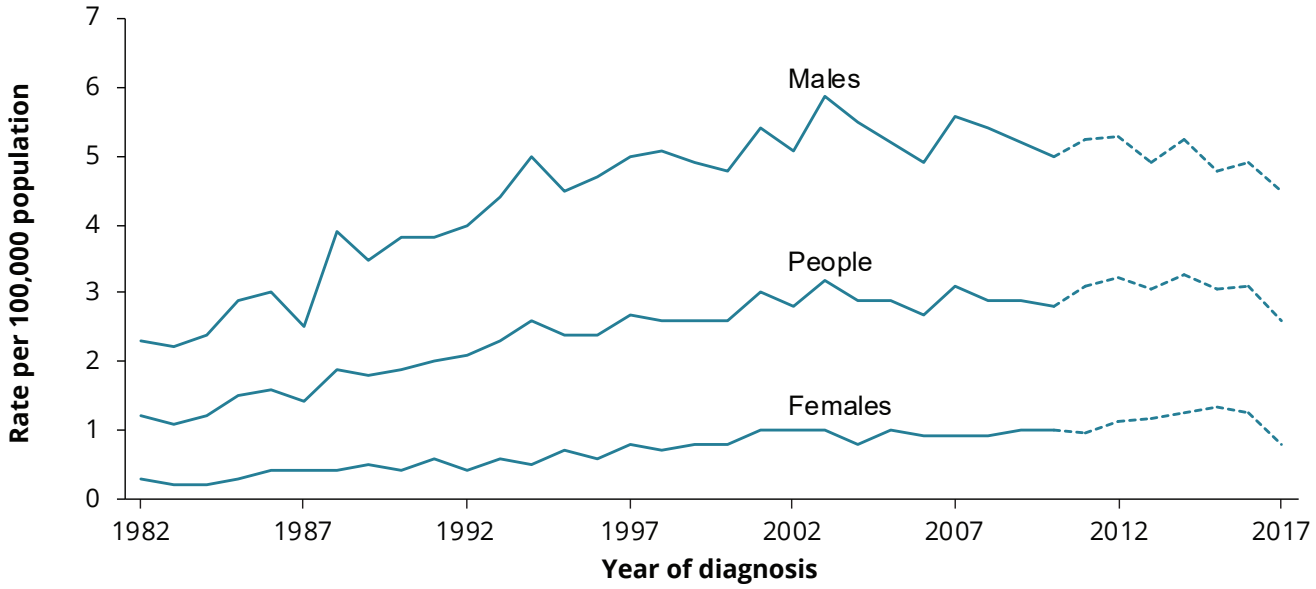
Figure 1: New cases of mesothelioma in Australia, by year and sex, 1982 to 2017



Sources: 1982–2010 (solid graphed line): AIHW 2018b; 2011–2017 (dotted graphed line): AMR data at September 2018.

Data from the ACD and the AMR can also be used to report the incidence rate of mesothelioma (that is, the number of new cases per 100,000 population) over time. Between 1982 and 2003, the mesothelioma incidence rate (adjusted for age) rose for both males (2.3 to 5.9 cases per 100,000 population) and females (0.3 to 1.0 cases per 100,000 population), then remained fairly steady (Figure 2). The overall incidence rate rose over the same period from 1.2 to a peak of 3.2 cases per 100,000 population, but has been constant at around 3 cases per 100,000 population for the most recent years.

Figure 2: Age-standardised incidence rate (per 100,000 population) of mesothelioma in Australia, by year and sex, 1982 to 2017



Note: Incidence rates are age-standardised to the 2001 Australian Standard Population.

Sources: 1982–2010 (solid graphed line): AIHW 2018b; 2011–2017 (dotted graphed line): AMR data at September 2018.

Incidence rates vary by state and territory

In 2017, the incidence rate of mesothelioma for males was higher than for females in all states and territories (Table 2). Western Australia recorded the highest rate (4.9 cases per 100,000 people), while Tasmania recorded the lowest (1.5). The number of cases for 2017 is expected to rise as the AMR receives more notifications.

Table 2: Number and rate (per 100,000 population) by state/territory of diagnosis and sex, 2017

State/territory	Males		Females		People	
	No.	Rate	No.	Rate	No.	Rate
NSW	175	4.5	32	0.8	207	2.6
Vic	125	4.0	29	0.9	154	2.4
Qld	137	5.6	29	1.2	166	3.3
WA	109	8.4	18	1.4	127	4.9
SA	31	3.6	8	0.9	39	2.3
ACT	8	3.9	1	0.5	9	2.2
Tas	7	2.7	1	0.4	8	1.5
NT	0	. .	0	. .	0	. .
Total	**592**	**4.8**	**118**	**0.9**	**710**	**2.9**

. . Rates for the NT are not applicable as there were no reported cases in 2017.

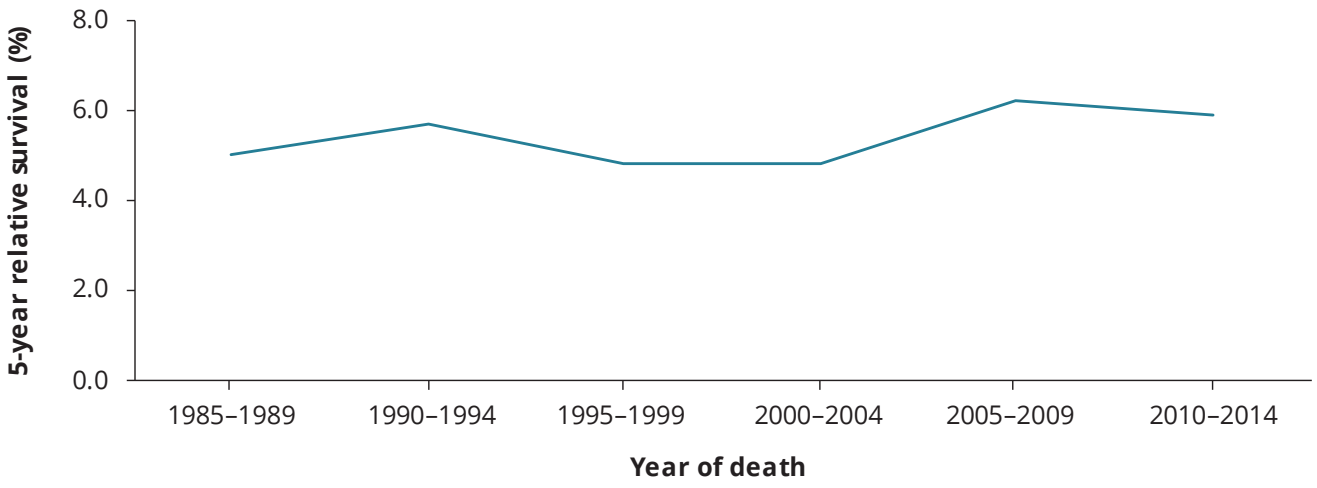
Source: AIHW analysis of AMR data at September 2018.

Patients are less likely to survive mesothelioma than most other cancers

Due to its aggressive nature, mesothelioma has a very poor prognosis. The condition is often diagnosed once it has reached the advanced stages, as early symptoms can go unnoticed or be mistaken as symptoms for other, less serious conditions (Better Health Channel 2018; Cancer Council 2018). Mesothelioma survival rates are very low and this has not changed over time.

Data from the NMD is used to provide information on survival and mortality among people with mesothelioma. Between 1985–1989 and 2010–2014, the 5-year relative survival rate for mesothelioma averaged 5.4%—ranging from 4.8% (1995–1999; 2000–2004) to 6.2% (2005–2009) (Figure 3) (AIHW 2018a). For people with mesothelioma who have already survived 1 year, their 5-year conditional relative survival is 10%, which is low compared with other cancers such as lung (35%), stomach (51%) and kidney (85%) (AIHW 2018b).

Figure 3: Survival rates of people with mesothelioma, 1985–1989 to 2010–2014



Source: AIHW 2018b.

The AMR is linked to the National Death Index (NDI) to determine the number of deaths among people with mesothelioma. In the absence of NDI data, date and cause of death information is provided by state and territory cancer registries.

For 2016, 651 deaths of people with mesothelioma (with any recorded cause of death) were recorded on the AMR (sourced from both the AMR and state and territory cancer registries), at a rate of 2.7 deaths per 100,000 population (Table 3). The number of deaths is expected to increase as more information becomes available. Where cause of death information was available, mesothelioma was the primary (or 'underlying') cause in around 90% of deaths among mesothelioma patients each year.

Table 3: Number and rate (per 100,000 population) of deaths among people with mesothelioma, by year and sex, 2012 to 2016

Year of death	Males		Females		People	
	No.	Rate	No.	Rate	No.	Rate
2012	487	4.3	92	0.8	579	2.5
2013	540	4.7	98	0.8	638	2.7
2014	575	4.9	116	1.0	691	2.9
2015	533	4.5	139	1.2	672	2.8
2016 (preliminary)	*543*	*4.5*	*108*	*0.9*	*651*	*2.7*

Note: The total number of deaths for 2016 are preliminary and are expected to rise as more information becomes available.

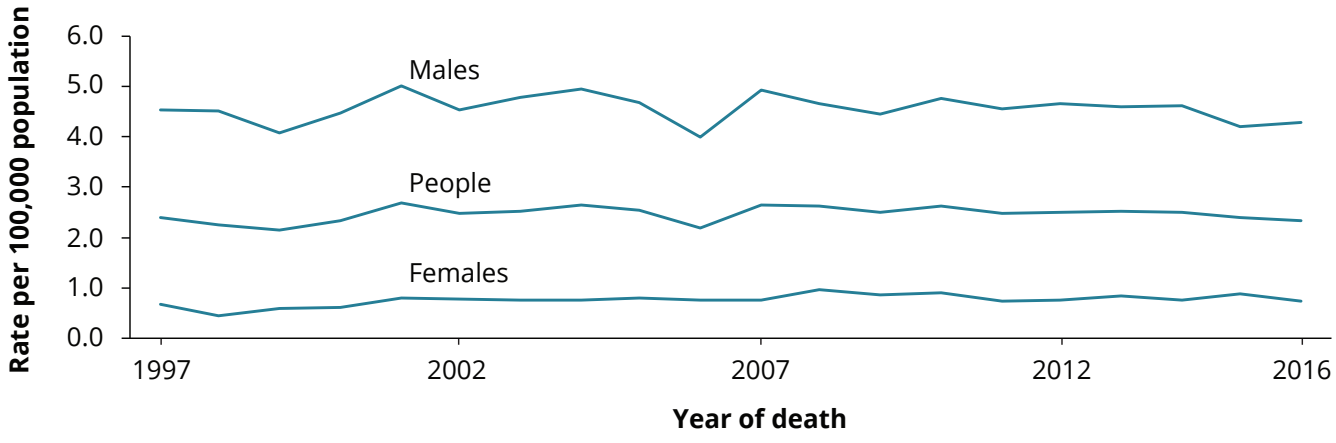
Source: AIHW analysis of AMR data at September 2018.

How has mortality changed over time?

The AMR has insufficient data to report on long-term mortality trends for mesothelioma, so this report uses the NMD.

From 1997 to 2016, mortality rates fluctuated between 2.1 and 2.6 deaths per 100,000 people, after adjusting for age (Figure 4). Rates for males fluctuated considerably more than those for females—the highest rate for males was 5.0 deaths per 100,000 people in 2001 and 2004, and the lowest was 4.0 per 100,000 in 2006. In 2016, the age-standardised mortality rate was 2.3 deaths per 100,000 population and this is expected to rise to 2.7 per 100,000 population in 2018 (AIHW 2018b).

Figure 4: Age-standardised mortality rates (per 100,000 population) for mesothelioma by year of death and sex, 1997 to 2016



Note: Rates are age-standardised to the 2001 Australian Standard Population.

Source: AIHW 2018a.

How does Australia compare?

Mesothelioma is a worldwide health concern—around 125 million people have been exposed to asbestos at work. Globally, the highest incidence rates of mesothelioma in males have been reported in regions within Italy (5.8 per 100,000), Australia (4.7 per 100,000) and the United Kingdom (4.2 per 100,000) (Stayner et al. 2013), although there are many countries for which there is no incidence information. It is estimated that as many as 38,000 people around the world die every year from mesothelioma (Odgerel et al. 2017) —that is, 105 deaths every day.

Asbestos has been banned in about 60 countries, including all countries in the Organisation for Economic Co-operation and Development except Canada, Mexico and the United States of America (ASEA 2018). However, although worldwide use of asbestos has fallen, there is evidence to suggest that its use is rising in many developing countries (Stayner et al. 2013).

Asbestos exposure in people with mesothelioma

Of the 701 people with mesothelioma who have provided occupational and residential information to the AMR since 1 July 2010, 93% (651 people) were assessed as having some level of occupational and/or non-occupational exposure to asbestos (Table 4). Occupational exposures were typically much higher and there was more certainty around them, which is likely to be the cause of the vast majority of cases of mesothelioma identified to date, especially for males. Of these 651 people:

- 80% (524) were male and 20% (127) were female.
- 78% (411) of males indicated some level of occupational exposure, compared with 6.3% (8) of females.
- 94% (119) of females indicated non-occupational exposure, compared with 22% (113) of males.

The occupations that most likely led to asbestos exposure include construction workers, electricians, plumbers, boilermakers, welders and other mechanic and mechanical trades.

Table 4: Number of occupational and non-occupational exposure assessment, by sex, 2010 to 2016

Exposure indicated	Males	Females	People
Both occupational and non-occupational exposure	331	7	338
Occupational exposure only	80	1	81
Non-occupational exposure only	113	119	232
Total occupational and/or non-occupational exposure	*524*	*127*	*651*
Neither occupational nor non-occupational exposure	*30*	*20*	*50*
Total	**554**	**147**	**701**

Source: AMR 2017.

'My late wife Julie had no known work, or adult life history exposure to asbestos fibres/dust. Her only traceable or known exposure was when, during her secondary school years, her father, a refrigeration mechanic, took a job in Burnie Tasmania, and brought home asbestos dust on his work overalls. Julie was an only child and loved her father dearly—and would always greet him as he arrived home. Fifty years on Julie was diagnosed with malignant mesothelioma at the age of 64 years and died 3 years later.'

Rod Smith, Awareness and Support Co-ordinator, Bernie Banton Foundation.

What are the challenges in collecting data and reporting on mesothelioma?

There are several challenges in the collection and reporting of mesothelioma data in Australia, including the following:

- Mesothelioma is a very difficult disease to diagnose, as its symptoms are common to many other illnesses and cancers. If a mesothelioma diagnosis is not established, the AMR is not notified.
- The participation rate in the voluntary components of the AMR is low, with only around 20% of patients diagnosed with mesothelioma taking part. This is partially due to patients dying or being too unwell to participate. Given the low participation rate, it is not known how representative of all mesothelioma patients the people who provide exposure information are. Also, the results of the asbestos exposure assessments consider only the probability of exposure and do not take into account the duration, intensity or frequency of exposure.
- Although state and territory cancer registries fast-track mesothelioma notifications, there is a time lag between a patient's diagnosis, their inclusion in the AMR data set and (if consent is given) when they are interviewed for the AMR's asbestos exposure collection. Reasons for this include the time it takes between diagnosis and notification, including possible delays in confirming a diagnosis, and delays in notifications to cancer registries; and the recruitment processes, which vary between states and territories.

Where do I go for more information?

More information on the AMR is available at <www.mesothelioma-australia.com/home>.
The report *Mesothelioma in Australia 2016: 6th annual report* and previous annual reports are available at <www.mesothelioma-australia.com/publications-and-data/publications>.

People diagnosed with mesothelioma can choose to self-notify by contacting the AMR via email at <amr@aihw.gov.au> or via the toll-free information line on 1800 378 861.

Glossary

age standardisation: A way to remove the influence of age when comparing populations with different age structures. This is usually necessary because the rates of many diseases vary strongly (usually increasing) with age. The age structures of the different populations are converted to the same 'standard' structure, then the disease rates that would have occurred with that structure are calculated and compared.

Australian Cancer Database (ACD): The ACD holds data on all new cases of cancer diagnosed in Australia since 1982.

conditional relative survival: The probability of an individual being alive for a given amount of time (such as 1 or 5 years), provided that they have already survived a specific amount of time after diagnosis.

incidence: The number of new cases (of an illness or event, and so on) occurring during a given period, often expressed as a rate per population.

mortality: The number or rate of deaths in a population during a given time period.

National Death Index (NDI): The NDI is a catalogue of death records used in data linkage for epidemiological studies, and is linked to the AMR to determine the most reliable estimates of mesothelioma mortality.

National Mortality Database (NMD): The NMD holds records for all deaths in Australia since 1964.

non-occupational exposures: Chemical, biological, psychosocial, physical and other factors from places other than the workplace that can potentially cause harm. Examples include contact with asbestos during private house renovations and living in the same home as someone with an asbestos-exposed occupation who came home dusty.

occupational exposures: Chemical, biological, psychosocial, physical and other factors in the workplace that can potentially cause harm.

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