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Australian Institute of Health and Welfare

AIHW

Dementia in Australia

Summary report 2022

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Dementia in Australia at a glance

These dementia statistics are sourced from the latest available data in the respective data collections.

Living with dementia in 2022

It is estimated that **401,300** Australians are living with dementia

The number of people with dementia is predicted to reach more than **849,300** by 2058

1 in 12 Australians aged 65 and over has dementia

2 in 3 Australians with dementia live in the community

More than **28,400 Australians** aged under 65 are living with younger onset dementia

2 in 5 Australians aged 90 and over have dementia

Burden of disease and deaths due to dementia

Dementia is the **2nd leading cause of death** in Australia and the leading cause of death for women

Dementia is the **5th leading cause of death** in Aboriginal and Torres Strait Islander people aged 65 and over

Dementia is the **2nd leading cause of disease burden** in Australia

As well as **the leading cause** in Australians aged 65 and over

Services and spending for dementia

More than half of people living in permanent residential aged care have dementia

623,300 scripts for **dementia-specific medications** were dispensed to almost **64,600 Australians** in 2019–20

People hospitalised for dementia **stayed 5 x longer** than the average hospitalisation

1 in 6 people who completed a comprehensive assessment to use aged care services had dementia

Between 2012–13 and 2019–20, the number of scripts dispensed for **dementia-specific medications rose 43%**

In 2018-19, $3 billion was spent on health and aged care directly for dementia; **$1.7 billion** was for permanent residential aged care

Caring for people with dementia

It is estimated between **137,600 and 354,200** people provide consistent unpaid care for someone with dementia

1 in 3 informal/unpaid carers who also had jobs reduced their working hours to provide greater care

Half of unpaid carers provide on average **60+ hours** of care every week

1 in 4 primary carers reported that more **respite care** was needed to support them

A personal account of living with dementia – Carrie and Dan's story

Carrie* is 42. She has two kids, aged 10 and 7, and a husband (Dan) with dementia.

A few years ago, life for her family changed dramatically when she noticed changes in her husband's behaviour. Dan seemed distant with Carrie and their children. Close family members thought Dan might be depressed but Carrie didn't think things were right.

One day, Dan couldn't find words at all. They went to see a neurologist and Dan was diagnosed with younger onset frontotemporal dementia, which affects a person's behaviour and moods. Carrie says most people don't understand the type of dementia Dan has.

> *'... they're looking at him, that he's a fit man [and it doesn't look] like [anything is] wrong ... It doesn't make any sense to people ... they say he's great. He's talking really well. But they don't see that he can go 3 days without saying a word to me or he hasn't said my name in 6 months.'*

Carrie and her family have faced many challenges since the diagnosis, and one of the hardest was telling the kids.

'You live with the uncertainty ... of a prognosis. And you try and explain it ... and their little hearts broke, I'll never forget it, it was devastating.'

Since his diagnosis, Dan left work and can no longer drive. Carrie now organises everything for the family while also working full time. She took on the caring role because Dan is her husband. Carrie says:

> *'we have 2 young children ... I want them to see that ... when you love someone you look after them and I wouldn't deny him the opportunity to see them for as long as he can.'*

Carrie's biggest support network has been her family, Dan's parents, and the Younger Onset Dementia Support Coordinator at Dementia Australia.

Carrie says when she sees other families doing 'normal' things – like going camping, riding bikes and kicking the football with their children – she realises just how different her life is.

‘I would get really really cranky when you see a family at the park … kids are playing on the swings and the dads pushing them … I always thought he would make an awesome Dad when they are teenagers because he would take them skiing … I just imagined I could see him with the kids out in the snow … that just can’t happen now … so it’s just changed things.’

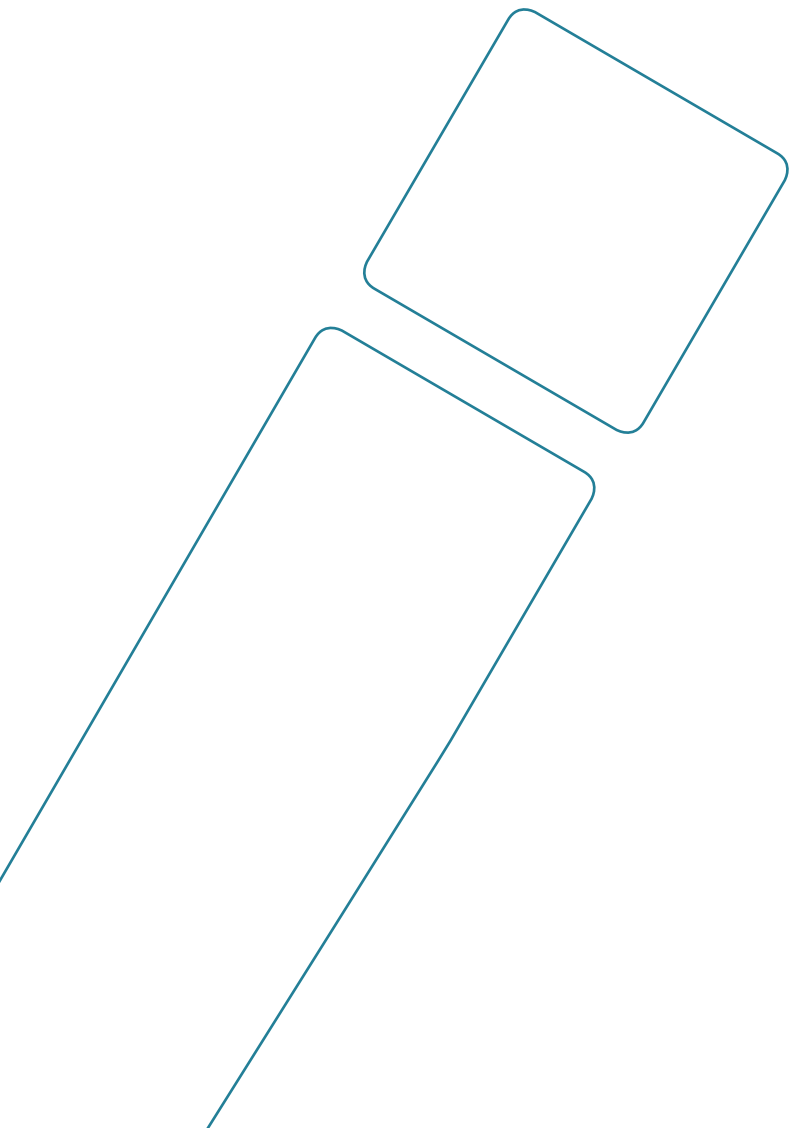
But they are lucky, and lucky to be in a good financial situation.

‘We’ve done some bucket-list trips and have some more planned and we’re making some great memories for the kids. And it’s sort of fun to do that stuff when you are young rather than your 60s or 70s …

> *we have had a lovely life together and we will continue to have a lovely life together. This has just thrown a bit of a curveball … so while it’s awful living with an uncertain prognosis, every day we’re lucky. He’s still here and he gets to see the kids more and they get to see him and do things.’*

*This case study is based on an interview with a carer of person who has dementia. This personal account is not necessarily representative of the circumstances of other carers or people with dementia or the challenges they may face, but it is our hope that it will give readers a greater awareness and understanding of the diversity of people’s experiences with dementia.

Names and identifying characteristics have been changed. Image is not representative of the individuals in the story.



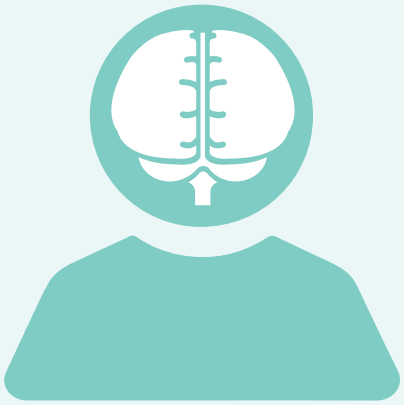
Introduction

Dementia is a leading cause of death and burden of disease in Australia. It is estimated that 401,300 Australians were living with dementia in 2022 and, with Australia's ageing population, this number is expected to rise to more than 849,300 by 2058. Although dementia can affect people aged under 65, it primarily affects older Australians.

This summary report presents some of the key findings and concepts from the *Dementia in Australia* online compendium, which is available at https://www.aihw.gov.au/reports/dementia/dementia-in-aus/

Additional findings, interactive data and information about dementia, support services and aged care programs can be found in the online report. Important information about data sources and methodologies to derive statistics are also explained in the online report.

What is dementia?



Dementia is not a single specific condition. Rather, it is an umbrella term for a large number of conditions that gradually impair brain function. Dementia may result in impairments or changes with: cognition, language, memory, perception, personality, behaviour, and mobility and other physical impairments.

The likelihood of developing dementia increases with age but it is not an inevitable part of ageing. Dementia that develops in people aged under 65 is referred to as 'younger onset dementia'. To date, there is no known cure for dementia but there are strategies to manage symptoms, which can help people with dementia maintain independence and quality of life for as long as possible.

While the onset of dementia is typically gradual, the progression of dementia varies. It is often described in terms of 3 stages:

- **Mild dementia** – difficulties with a number of areas such as memory, planning, organisation and personal care, but the person can still function with minimal assistance.
- **Moderate dementia** – difficulties become more severe and increasing levels of assistance are required to help the person maintain functioning in their home and in the community.
- **Severe or advanced dementia** – almost total dependence on care and supervision by others.

The progression of dementia will vary from person to person due to: their personal characteristics (such as their age and whether they have other health conditions), what type of dementia they have, how severe it is and how old they were when they were diagnosed, and their environment (such as whether they have suitable care arrangements and can access health services).

Types of dementia

Identifying the type of dementia a person has at the time of diagnosis is important to ensure they receive appropriate treatment and services, and are better informed about their condition, treatments and prognosis. Having multiple types of dementia at once is common and is referred to as 'mixed dementia'.

The main types of dementia include:

- **Alzheimer's disease:** a degenerative brain disease caused by nerve cell death resulting in shrinkage of the brain.
- **Vascular dementia:** a disease that is mainly caused by issues with blood flow to the brain (such as a stroke) or bleeding into or around the brain.
- **Dementia with Lewy bodies:** a disease caused by degeneration and death of nerve cells in the brain due to the presence of abnormal spherical structures, called Lewy bodies, which develop inside nerve cells.
- **Frontotemporal dementia:** a disease that is caused by progressive damage to the frontal and/or temporal lobes of the brain.

Dementia is also associated with other conditions (such as Parkinson's disease, Huntington's disease and Down syndrome), prolonged substance abuse and severe brain injuries.

A number of factors may increase your risk of developing dementia

Some risk factors for dementia cannot be avoided (such as ageing) but many others can be minimised. Risk factors that can be avoided or reduced – such as physical inactivity – are called modifiable risk factors. Risk factors that cannot be avoided are called non-modifiable risk factors. Some modifiable risk factors may increase your risk of dementia at a specific stage in your life. For example, high blood pressure is thought to be a risk factor for dementia only in mid-life (between the ages of 35 and 64).

Risk factors for dementia			
Hearing loss in mid-life*	Depression	Traumatic brain injury*	Tobacco smoking
Low levels of education in early life	Obesity in mid-life	High blood pressure in mid-life	Social isolation
Excessive alcohol consumption	Diabetes	Physical inactivity	Air pollution
High cholesterol	Atrial fibrillation* irregular heartbeat	High homocysteine levels – an amino acid due to protein breakdown	
Age – the risk of developing dementia doubles every 5 or 6 years for people aged over 65**		Family history of the condition**	Genetic mutations**

*Some but not all cases of hearing loss, atrial fibrillation and traumatic brain injury are potentially modifiable.

**Non-modifiable risk factors.

But you can reduce your risk of developing dementia by ...

Undertaking regular physical activity

Keeping mentally stimulated

Eating a healthy, balanced diet

Reducing your alcohol intake

Maintaining an active social life

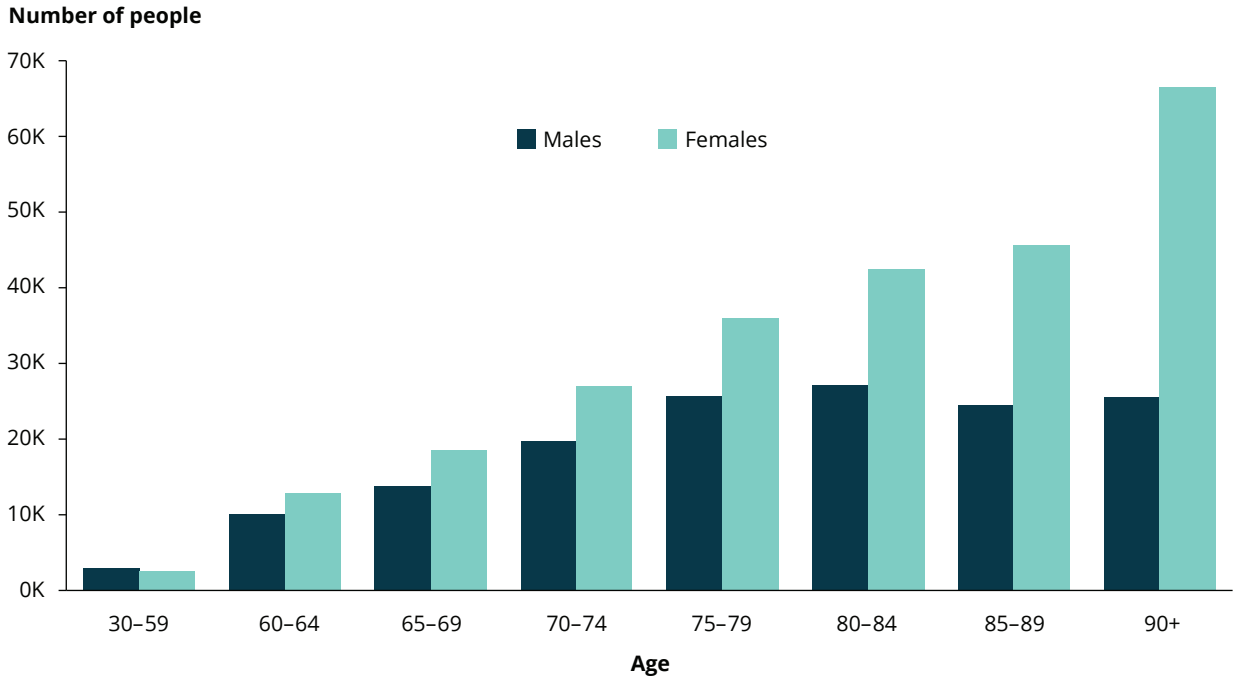
Maintaining a healthy weight

Quitting smoking

Managing health conditions

In 2022, it's estimated that 401,300 Australians have dementia

Using the AIHW estimates for the number of people with dementia, nearly two-thirds of the 401,300 Australians with dementia in 2022 were women (251,700) and one-third were men (149,600). Overall, this is equivalent to 15 people with dementia per 1,000 Australians (19 per 1,000 for women and 12 per 1,000 for men).



The number of people with dementia rises quickly with age. It is estimated that among Australians in 2022:

- **1 in 12** Australians **aged 65 and over** had dementia
- **2 in 5** Australians **aged 90 and over** had dementia

Among Indigenous Australians, the rate of people with dementia is estimated to be 3–5 times as high as the Australian population overall (Radford et al. 2017; Russell et al. 2020). See page 19 for more information on dementia among Indigenous Australians.

Dementia data gaps

There is no single authoritative data source that can provide an accurate estimate of the number of Australians living with dementia. Estimates vary substantially across studies and may differ to what is shown in this report. This report presents the overall number of Australians with dementia as a range – the minimum estimate was produced by AIHW and the maximum estimate produced by the National Centre for Social and Economic Modelling. The AIHW prevalence estimates are used when presenting estimates by age and sex.

Work is under way to improve the accuracy of dementia estimates and new approaches will likely supersede the estimates shown in this report in coming years.

How do we compare with other countries?

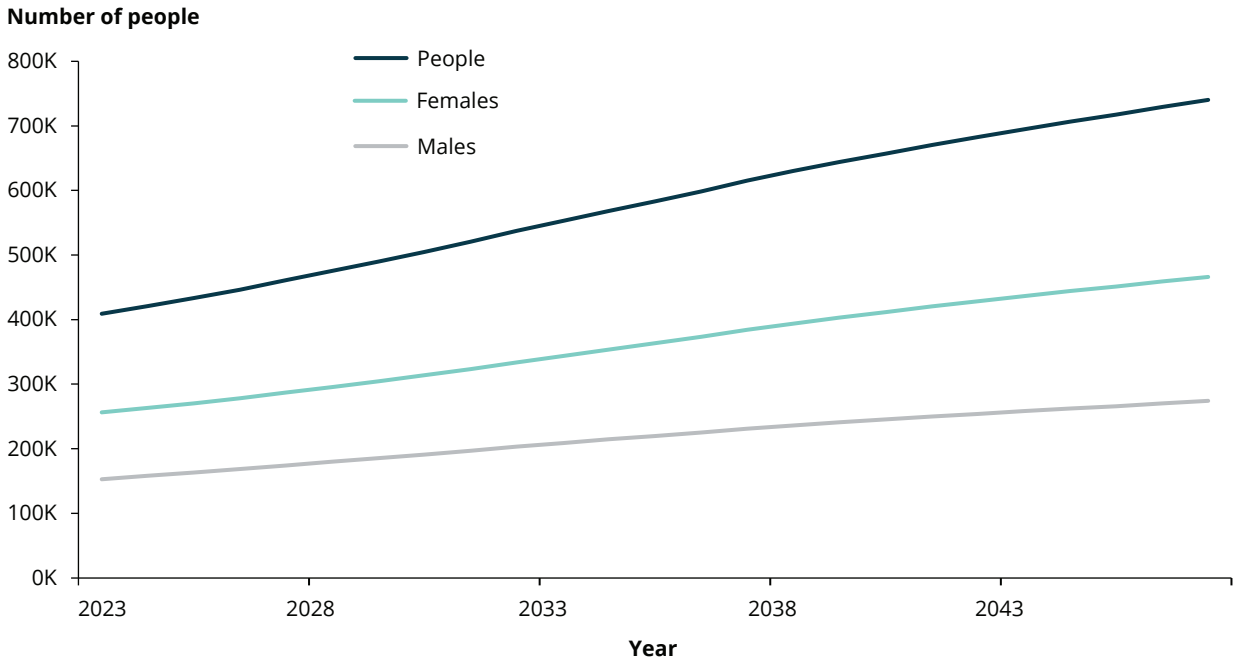
The Organisation for Economic Co-operation and Development (OECD) estimated that 15 in every 1,000 Australians were living with dementia in 2021. Although the OECD prevalence rates were similar to the AIHW estimates presented in this report, it is important to remember that different methodologies and data sources were used. In the OECD estimates, the rate of dementia in Australia ranked 19th lowest out of 38 countries. Mexico had the lowest rate, at 7.7 per 1,000, population and Japan had the highest rate at 27 per 1,000 (OECD 2021).

Much of the variation in the rate of dementia across countries is due to their different population age structures, with higher rates generally found in ageing OECD nations.

The number of Australians with dementia is predicted to more than double by 2058

Dementia poses a substantial heath, aged care and social challenge, and with Australia's ageing and growing population, it is predicted to become an even bigger challenge in the future.

The number of Australians with dementia is predicted to more than double by 2058 – from around 401,300 in 2022 to 849,300 in 2058 (533,800 women and 315,500 men).



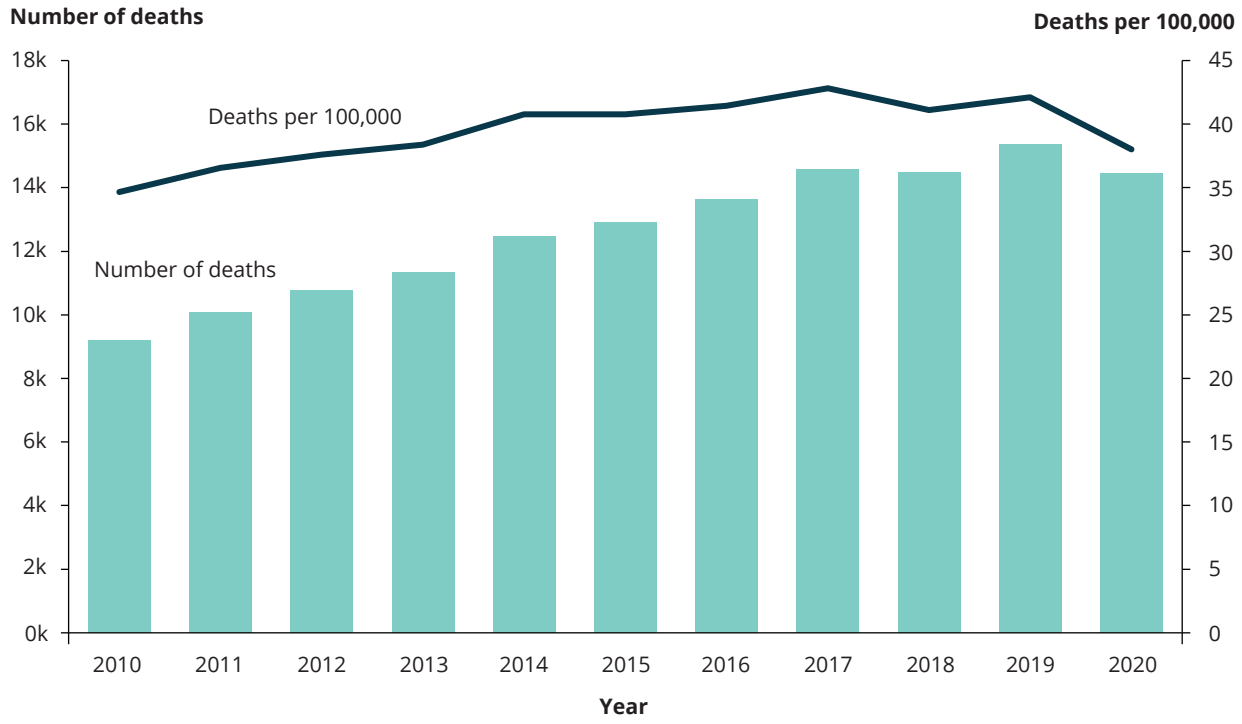
Until there is a cure or significant advancements in treatment, the best way to reduce the prevalence of dementia in the future is to minimise exposure to risk factors that increase the likelihood of developing dementia in later life (Livingston et al. 2017; Prince et al. 2014).

International studies have found that the rate of dementia is declining in countries where the prevention and management of high blood pressure and cardiovascular disease has improved in recent years (Roehr et al. 2018). As Australia has improved cardiovascular disease treatment and management, and reduced the prevalence of other major risk factors for dementia (such as tobacco smoking), the rate of new cases of dementia may stabilise or fall in the future. As there are current issues with monitoring the incidence of dementia in Australia, it is unclear whether incidence rates of dementia in Australia have increased, stabilised or decreased over time.

Dementia is the 2nd leading cause of death in Australia

Dementia was responsible for almost 14,500 deaths in 2020 – 9.6% of all deaths that year. It was the 2nd leading cause of death in Australia, behind coronary heart disease and the leading cause of death among women (around 9,100 deaths in 2020).

The number of deaths due to dementia rose from 9,200 deaths in 2010 to 15,400 deaths in 2019 and fell slightly in 2020 (14,500 deaths). The rate of deaths rose from 42 per 100,000 people in 2010 to 61 per 100,000 people in 2019 and fell slightly in 2020 (56 per 100,000 people). However, the changes in these rates over time may be due to an ageing population. Age-standardised rates, which control for the age and sex structure of the population, provide a better understanding of the true disease trend over time. The age-standardised rate rose between 2010 and 2019, from 35 to 42 deaths per 100,000 Australians, and fell slightly in 2020 to 38 per 100,000 people. This decrease is likely driven by the COVID-19 pandemic (AIHW 2021).



Note: Rates were age-standardised to the 2001 Australian Standard Population and are expressed as per 100,000 population.

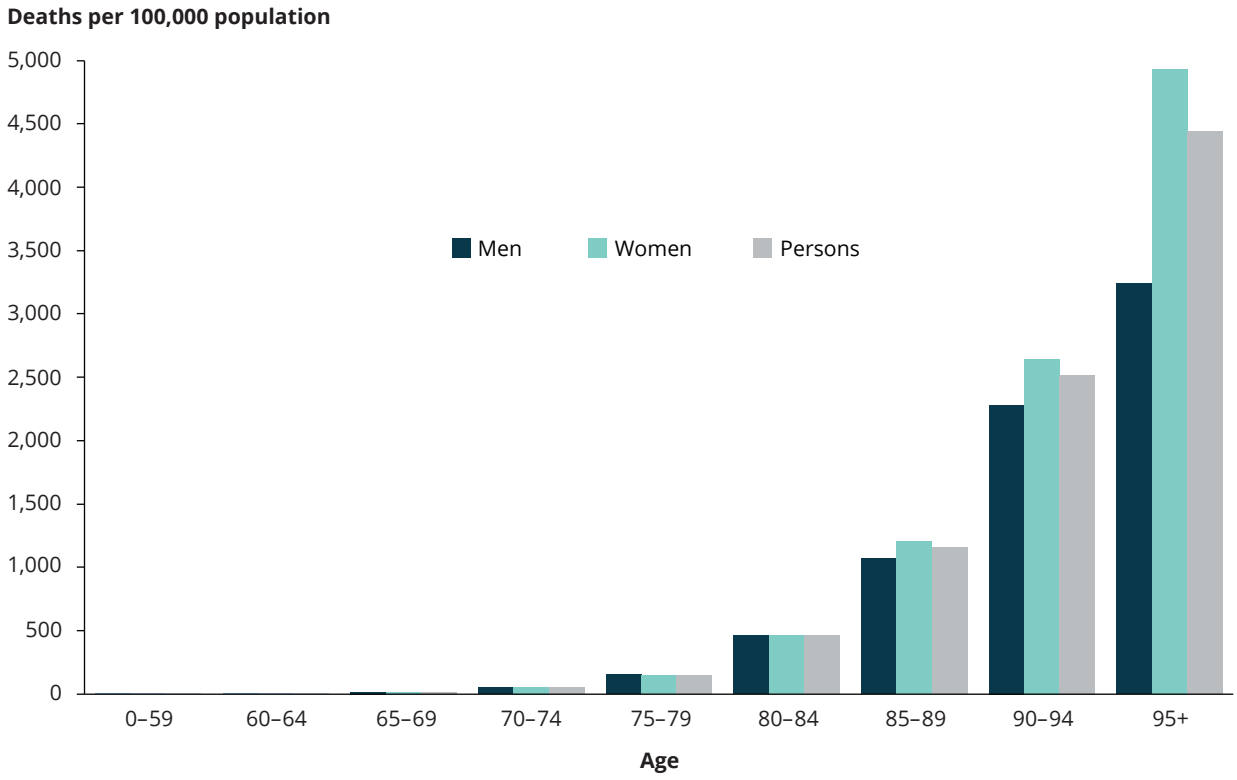
How do deaths vary by age and sex?

	Men	Women
Number of deaths due to dementia in 2020*	**5,300**	**9,100**
Deaths due to dementia per 100,000 Australians in 2020	**42**	**70**
Proportion of all deaths in 2020	**6.8**	**12.6**

*Note that the number of deaths by sex does not add up to the number of deaths for all persons due to rounding.

Most deaths due to dementia in 2020 occurred among those aged 85–94 (around 7,600). The rate of deaths due to dementia increases substantially with age, from about 150 per 100,000 people aged 75–79 to about 4,400 per 100,000 people aged 95 and over.

The rate of deaths due to dementia in 2020 before the age of 85 were similar for men and women. From age 85–89 onwards, the rate for women is increasingly higher than rates among men of the same age. For both men and women, those aged 95 and over had the highest rate of deaths due to dementia.



Dementia is a leading cause of burden of disease

Dementia was the 2nd leading cause of burden of disease in Australia in 2022, behind coronary heart disease.

For Australians of all ages, dementia was the:

- **2nd leading cause of disease burden** (241,500 DALY)
- **5th leading cause in men** (95,900 DALY)
- **leading cause in women** (145,600 DALY)

As the risk of developing dementia increases with age, the disease burden due to dementia is higher for older Australians. Dementia was the leading cause of disease burden in people aged 65 and over.

Of the disease burden due to dementia in Australia in 2022:

59%
was from dying prematurely

41%
was from living with dementia

The 2018 Australian Burden of Disease Study also estimated the attributable burden from 6 established risk factors for dementia – overweight and obesity, physical inactivity, tobacco smoking, high blood pressure in midlife, high blood plasma glucose levels and impaired kidney function.

Around 43% of the overall dementia burden in 2018 could have been avoided if exposure to these 6 modifiable risk factors was avoided or reduced to the lowest level possible.

What is burden of disease?

- Burden of disease measures the combined impact of living with illness and injury (non-fatal burden) and dying prematurely (fatal burden).
- Fatal and non-fatal burden are added together to provide the total burden, measured using disability-adjusted life years (DALY).
- 1 DALY is equivalent to 1 year of healthy life lost.
- Attributable burden is the disease burden attributable to a particular risk factor and could be avoided if the risk factor were removed or reduced to the lowest possible exposure.

Findings from the Australian Burden of Disease Study 2022 are at available at https://www.aihw.gov.au/reports/burden-of-disease/australian-burden-of-disease-study-2022/

How is dementia diagnosed?

There is no single conclusive test to diagnose dementia, and obtaining a diagnosis is often a long process that involves comprehensive cognitive and medical assessments. It is important to diagnose dementia early, as this enables timely access to information, advice, medical management and support services. However, the time taken to receive a confirmed diagnosis varies depending on the person's symptoms and who is conducting the assessments.

General practitioners (GPs) are often the first point of contact when concerns are raised by the patient or the patient's carer, family or friends. If a GP suspects dementia, it is best practice for them to refer patients to qualified specialists (such as a geriatrician or psycho-geriatrician) or memory clinics for a more comprehensive assessment to take place.

Dementia data gaps

There is a lack of up-to-date and robust data on how many people are newly diagnosed with dementia and how many GP and specialist services are used for dementia diagnosis and management. This is because there are no national data on GP and specialist services in Australia that include diagnostic information.

Our understanding of dementia in the GP and specialist settings remains a key data gap for monitoring dementia in Australia. The AIHW is developing a national dementia data improvement plan which will outline activities to address key data gaps in monitoring dementia in Australia.

Linking data to shed a light on use of MBS services

The AIHW examined services claimed under the Medicare Benefits Schedule (MBS) by more than 137,000 Australians living with dementia in 2016–17. This was possible using linked health and aged care data sets. The services examined included GP and specialist attendances, pathology services and diagnostic imaging.

The analysis looked at the differences between people living in residential aged care and those living in the community. It found that:

- For people aged under 80, the number of services used was similar for both groups.
- For people aged 80 and over, the number of services used was greater for those living in residential aged care.
- The rate of services used by people with dementia living in residential aged care rose steeply with age – from 45 services per 1,000 people among those ages 80–84 to 241 services per 1,000 people among those aged 95 and over.

Further details on this study can be found in the detailed Dementia in Australia online report at: https://www.aihw.gov.au/reports/dementia/dementia-in-aus

Almost 64,600 people were dispensed scripts for dementia-specific medications

While there is no cure for dementia, there are 4 medications available under the Pharmaceutical Benefits Scheme (PBS) and Repatriation Pharmaceutical Benefits Scheme (RPBS) for war veterans and their dependants that may help to manage symptoms and slow dementia progression.

In 2019–20, there were more than 623,300 prescriptions dispensed for dementia-specific medications to just under 64,600 Australians aged 30 and over with dementia – or 9.7 scripts per person. Each script is usually for a month's supply of medication.

Of these people:

- **1 in 3 were aged 85 or over**
- **37,100 were women (361,600 scripts)**
- **27,400 were men (261,800 scripts)**
- **4 in 5 were prescribed these scripts at least once by a GP**

The number of scripts dispensed for dementia-specific medications rose by 43% between 2012–13 and 2019–20. The rise was greater for men (51%) than women (37%).

What are dementia-specific medications?

Dementia-specific medications can only be prescribed to patients with a confirmed diagnosis of Alzheimer's disease made by a specialist or consultant physician under specific criteria.

Donepezil, Galantamine and Rivastigmine are used for **mild to moderate Alzheimer's disease**. They work by blocking the actions of the enzyme, acetylcholinesterase, which destroys acetylcholine – a major neurotransmitter for memory. The use of these medicines may lead to increased communication between nerve cells and slow dementia progression.

Memantine is used for **moderately severe to severe Alzheimer's disease**. It works by blocking the neurotransmitter, glutamate, which causes damage to brain cells and is present in high levels in people with Alzheimer's disease.

Number of scripts dispensed in 2019–20:

- Donepezil – 409,500 scripts
- Rivastigmine – 76,100 scripts
- Galantamine – 74,500 scripts
- Memantine – 63,300 scripts

Dispensing of anti-psychotics to people with dementia

People with dementia may experience changed behaviours, such as aggression, agitation and delusions, commonly known as behavioural and psychological symptoms of dementia (BPSD). It is not recommended that medications are used to manage these symptoms, but antipsychotic medications may be prescribed as a last resort. However, inappropriate prescribing of antipsychotic medications is a major problem among people living in residential aged care and was a key issue raised in the Royal Commission into Aged Care Quality and Safety (RCACQS 2021).

In 2019–20, of the almost 64,600 Australians who were dispensed scripts for dementia-specific medications:

1 in 5 were also dispensed antipsychotic medications at least once that year

Around 39% of people with scripts dispensed for antipsychotic medications and dementia-specific medications were supplied Risperidone (the only antipsychotic that is currently listed on the PBS for BPSD) followed by Quetiapine (29%) and Olanzapine (24%).

Understanding behaviours and psychological symptoms of dementia

Behaviours and psychological symptoms of dementia (BPSD) refer to a range of non-cognitive symptoms common among people with dementia. Most people with dementia will experience at least one type of BPSD over the course of their illness (Tible et al. 2017). Symptoms may vary in type and severity each day and over the course of illness.

BPSD can have a significant impact on people living with dementia, their carers and family. It been associated with premature admission to residential care, increased hospitalisation, distress for carers, and reduced functional ability for the person living with dementia (Cunningham, Macfarlane & Brodaty 2019).

The Neuropsychiatric Inventory (NPI) is the primary measure of BPSD within clinical settings in Australia. It assesses a wide range of behaviours, rating severity, frequency and carer distress for 12 domains. These include:

- **Delusions:** where client has beliefs that are known to not be true. Examples include insisting that people are trying to harm them or steal from them.
- **Irritability/lability:** where client is irritated or easily disturbed. This includes very changeable moods or abnormal impatience.
- **Hallucinations:** where client has hallucinations such as false visions or hearing false voices.
- **Agitation/aggression:** where client has periods when they refuse to cooperate or won't let people assist them.
- **Depression/dysphoria:** where client appears sad or depressed.
- **Anxiety:** where client is very nervous, worried, or frightened for no apparent reason.
- **Euphoria:** where client has a persistent and abnormally good mood or finds humour where others do not.
- **Apathy:** where client has lost interest in the world around them, or is presenting as apathetic or indifferent.

(continued)

- **Disinhibition:** where client appears to act impulsively without thinking. Examples include doing or saying things that are not usually said/done.
- **Aberrant motor activity:** where client paces, or does things repetitively such as opening closets or draws.
- **Night-time behavioural disturbances:** where client has difficulty sleeping, wandering at night or disturbing carer sleep.
- **Appetite and eating abnormalities:** where client has had changes in appetite, weight, or eating habits (including food preference) (APA 2011).

What support services are available for people affected?

In Australia, there are a range of services available to support people experiencing BPSD, including programs provided by Dementia Support Australia https://www.dementia.com.au and government-subsidised aged care services https://www.myagedcare.gov.au.

Behaviour support provided to more than 8,000 Australians between January and June 2022

Dementia Support Australia (DSA) provides key national support services for people with dementia, their carers and aged care providers. The services can be accessed independently and include:

- **Dementia Behaviour Management Advisory Service (DBMAS):** a mobile workforce of health and allied health professionals who provide support for people living with dementia and their carers, whose wellbeing or care is impacted by the presence of mild to moderate behaviours and psychological symptoms of dementia.
- **Severe Behaviour Response Teams (SBRT):** a mobile workforce of health and allied health professionals who provide support for people living with dementia and their carers, whose wellbeing or care is impacted by the presence of severe behaviours and psychological symptoms of dementia.
- **Needs Based Assessment** program, which determines eligibility for the Specialist Dementia Care Program (SDCP). The SDCP supports people with very severe behavioural and psychological symptoms of dementia who cannot be cared for in a mainstream residential aged care facility.

Between January 2022 and June 2022, DSA reported 7,500 DBMAS referrals and 1,200 SBRT referrals. In this period, clients presented with behaviour symptoms in an average of 5.4 domains out of the 12 Neuropsychiatric Inventory domains upon program intake, and 3.0 upon program exit (an overall reduction of 44%). Clients also recorded a reduction in behaviour severity and carer distress.

Around 25,500 hospitalisations were due to dementia in 2020–21

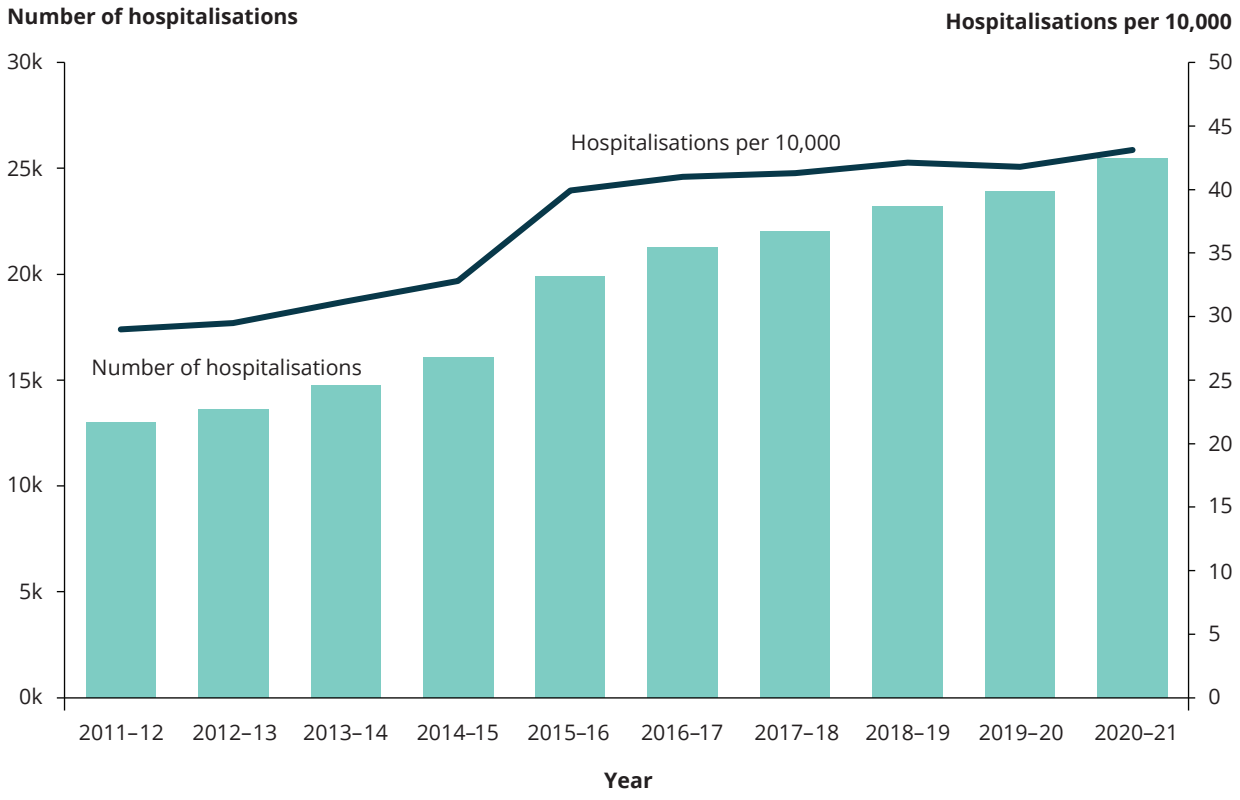
In 2020–21, there were around 25,500 hospitalisations due to dementia (which are hospital admissions where dementia was the principal diagnosis, or the main reason for admission).

Of these hospitalisations:

- **13,100** were for men and **12,400** were for women
- **62%** of patients were aged between **75 and 89**
- **Around 3 in 10** of hospitalisations were for **Alzheimer's disease**
- **13 days** was the average length of stay – this was **5 times longer** than the average hospitalisation that year (2.6 days)

The age-standardised rate of hospitalisations due to dementia has increased gradually each year from 2011–12 and 2014–15 (4.2% annual average increase) and from 2015–16 to 2020–21 (1.6% annual average). These increases may be partly due to changes in the way dementia is recorded in hospital data (particularly between 2014–15 and 2015–16). Records for dementia in hospital data are also likely to be influenced by the level of education about dementia among health professionals, hospital funding processes and other factors related to care provided in hospitals.

In 2020–21, 39% of hospitalisations due to dementia ended with the patient being discharged home. This was considerably less than for all hospitalisations (93%).



In 2020–21, **77,200 hospitalisations** had dementia listed as a condition that affected a person's hospital care (that is, dementia was not the main reason for admission, but it influenced the provision of care).

Of these, the most common reasons for admission were:

Leg fracture

Problems related to medical facilities and other health care[1]

Delirium[2]

[1] These hospitalisations are where patients are required to stay in hospital longer to rehabilitate or are waiting to transfer to new accommodation. These hospitalisations may be counted as a separate hospitalisation rather than a continuation of a hospitalisation from an acute episode (such as a fracture).

[2] Not induced by alcohol and other psychoactive substances.

How do people with dementia access aged care?

Older Australians who require care and assistance can access a range of government-subsidised services coordinated through the My Aged Care system. After an initial screening, an aged care assessment is done to establish the person's needs and types of services that could help.

There are 2 main types of assessment services depending on the level of care needed:

- **Home Support assessments** – face-to-face assessments provided by Regional Assessment Services for people seeking home-based entry-level support that is provided under the Commonwealth Home Support Programme.
- **Comprehensive assessments** – provided by Aged Care Assessment Teams for people with complex and multiple care needs to determine the most suitable type of care (home care, residential or transition care).

These services are generally provided on the basis of need – there are no age restrictions for eligibility (except for the Commonwealth Home Support Programme). Information on the use of aged care services by people with dementia is not available for all types of aged care, particularly the use of community-based aged care services.

More than 41,000 people with dementia completed an aged care assessment in 2019–20

This is nearly 1 in 10 (9.7%) of all people who completed an aged care assessment (either a home support or a comprehensive assessment) that year.

Among people with dementia who completed an aged care assessment:

- **54% were women** (22,200) and **46% were men** (18,900)
- the **average age** for **women** with dementia was **82** and it was **81 for men**
- **3 in 4** assessments were for a comprehensive assessment.

Most people with dementia (98%) were living in the community at the time of their assessment.

Dementia is a common cause for needing a comprehensive assessment and accounted for nearly 1 in 5 (17%) of all comprehensive assessments completed in 2019–20.

Among people with dementia who completed a comprehensive assessment:

- Men were more likely than women to be living with their partner at the time of assessment (62% compared with 34%, respectively).
- Women with dementia were more likely to be living alone at the time of assessment than men with dementia (40% compared with 20%, respectively).

More than half of people living in permanent residential aged care have dementia

In 2019–20, just under 132,000 (54%) of the 244,000 people living in permanent residential aged care had dementia. The proportion of people with dementia living in permanent residential aged care was the same for women (54% or nearly 85,700) and men (54% or over 46,200). One-third of people under the age of 65 (33% or 2,000) had dementia (also known as younger onset dementia). More men than women had younger onset dementia (1,100 men and 930 women). The likelihood of a person with dementia entering permanent residential care is influenced by a range of circumstances, such as their current living arrangements (women tend to live longer than men so are more likely to be living alone), availability of informal care, and the severity of their dementia.

Depression and mood disorders (47%) and a range of arthritic disorders (45%) were the most common co-existing medical conditions among people with dementia living in permanent residential aged care. Medical conditions were recorded if they affected a resident's care needs.

Many residents with dementia have high care needs:

In 2019–20, the Aged Care Funding Instrument was used to allocate funding to residential aged care facilities based on the day-to-day care needs of individual residents. This was determined by their care needs in 3 key domains: cognition and behaviour, activities of daily living, and complex health care.

4 in 5 people with dementia (81%) required high levels of care in the **cognition and behaviour domain**

2 in 3 people with dementia (71%) required high levels of care in the **activities of daily living domain**

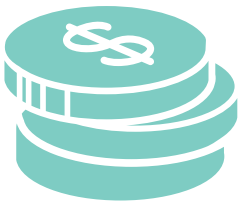
1 in 2 people with dementia (56%) required high levels of care in the **complex health care domain**

The care needs of people with dementia living in permanent residential aged care increased with age, except for the cognition and behaviour domain, where needs were highest among those with younger onset dementia. This could be partly because:

- severe behavioural and psychological symptoms of dementia are common in dementia types that occur more frequently in younger ages
- younger people are more mobile and are less likely to have more than one disease or condition at the same time
- providers have a different focus when assessing younger peoples' care needs.

$3 billion was spent directly on health and aged care services for dementia

Australia's response to dementia requires economic investment across health, aged care and welfare sectors. This involves substantial costs in diagnosis, treatment and care for people with dementia (including supporting a workforce of trained professionals), and support services for people with dementia and their carers.



In 2018–19, $3.0 billion of health and aged care spending was directly attributable to dementia. Spending on residential aged care services accounts for the largest share of this spending (56% or $1.7 billion), followed by community based aged care services (20% or $596 million), which was primarily for the Home Care Packages program ($397 million).

Many people with dementia also have co-existing conditions, some of which may be directly associated with dementia. If these costs were included, the total direct health and aged care system spending for people with dementia (rather than directly attributable to dementia) in 2018–19 would be $9.8 billion.

Health and aged care spending directly attributable to dementia by service area/ program in 2018–19

Service area/ program	Expenditure	Percent (%)
Residential aged care facilities	$1.7 billion	55.6
Community based aged care services	$596 million	19.8
Hospital services	$383 million	12.7
Respite care services	$133 million	4.4
Out of hospital medical services	$99.2 million	3.3
Flexible aged care services	$53.0 million	1.8
Dementia support services	$50.6 million	1.7
Aged care assessments	$21.3 million	0.7
Total	**$3.0 billion**	**100.0**

Notes:

1. 'Respite care services' include residential respite care and community-based respite care.
2. 'Flexible aged care services' include the Transition Care Program and the National Aboriginal and Torres Strait Islander Flexible Aged Care program.
3. 'Out of hospital medical services' include general practice, diagnostic imaging, specialist, allied health and pathology services as well as pharmaceuticals.
4. 'Dementia support services' include the Severe Behaviour Response Teams, the Dementia Behaviour Management Advisory Service, the National Dementia Support Program, the Specialist Dementia Care Program and the Dementia Training Program.

Carers play a crucial role in providing assistance and support

People with dementia become increasingly dependent on carers to maintain their independence and quality of life.

As dementia progresses, carers are essential in almost all aspects of their daily living. Significant care is also provided by friends and family of people with dementia who live in permanent residential aged care facilities.

The AIHW estimates that, in 2022, there were **between 137,600 and 354,200 Informal carers of people with dementia** (that is, someone who provides ongoing informal assistance). This is a conservative estimate based on limited data and excludes people providing care to those living in permanent residential aged care and paid workers or volunteers arranged by an organisation or formal service.

According to the Australian Bureau of Statistics (ABS) Survey of Disability, Ageing and Carers, in 2018, more than 70,200 people were primary carers of a person with dementia (that is, the carer providing the most informal, ongoing assistance).

Among primary carers of people with dementia, **3 in 4 were female** and **1 in 2 were caring for their partner with dementia**.

Caring can be a rewarding but challenging role

Caring for a person with a disability, illness or condition can be rewarding but also physically, mentally, emotionally and economically challenging.

Factors that may contribute to the demands of providing care include the personal characteristics of carers and care recipients, living arrangements of the carer and care recipient, carer's employment, care recipient and carer's financial situation, and the level of support available from formal services and other family and friends for the care recipient.

According to the ABS Survey of Disability, Ageing and Carers, in 2018, when primary carers of people with dementia were asked about the physical and emotional impact of their caring role:

- **3 in 4 primary carers had 1 or more physical or emotional impacts**
- **2 in 5 primary carers felt weary or lacked energy**
- **1 in 3 primary carers frequently felt worried or depressed.**

The demands of caring for a person with dementia can also affect a carer's work commitments and financial obligations. More than half (52%) of primary carers of people with dementia were affected financially since taking on the caring role – 24% experienced a drop in income and 28% had extra expenses since taking on the caring role.

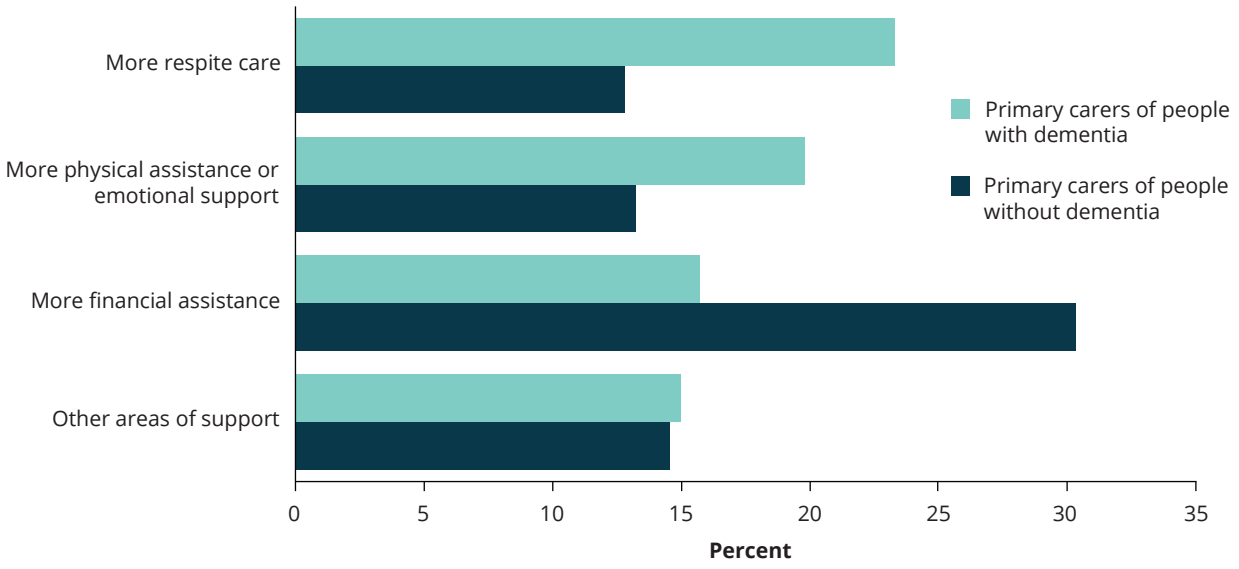
Carers need appropriate support

It is crucial that informal carers are supported effectively so they can provide appropriate care for their loved ones with dementia, as well as look after their own health and wellbeing.

Among primary carers of people with dementia who needed more support:

- **1 in 4 primary carers reported they need more respite care**
- **1 in 5 primary carers reported they need more physical assistance or emotional support.**

By comparison, 1 in 8 primary carers of people without dementia reported that needed more respite care, and 1 in 8 reported that they need more physical assistance or emotional support.



How does dementia affect Aboriginal and Torres Strait Islander people?

Dementia has a deep impact on Aboriginal and Torres Strait Islander people (respectfully referred to as Indigenous Australians) and communities. From receiving a diagnosis, to accessing health and aged care services, Indigenous Australians often face additional challenges. For example, culturally safe health and aged care services are not always available, and health professionals often do not use existing culturally appropriate dementia screening tools to assist with diagnoses.

There are also gaps in our understanding of dementia in Australia's Indigenous people, including a lack of national Indigenous representation in key data, and limited data on Indigenous-specific services that need to be kept in mind when interpreting the findings presented here.

Higher rates of dementia are found in some Indigenous populations

Although there are no national-level estimates of the number of Indigenous people with dementia, smaller studies have found higher rates among some groups. When looking at particular age ranges:

- Rates of dementia for older Indigenous Australians in remote and rural communities tend to be among the highest in the world (Smith et al. 2008; Lo Giudice et al. 2016).
- Across the Northern Territory, the age-adjusted prevalence of dementia for Indigenous people aged 45 and over is 6.5%, compared with 2.6% among the non-Indigenous population (Li et al. 2014).
- The prevalence of dementia among Indigenous people aged 60 and over who live in urban and regional areas is about 3 times as high as the rate for all Australians aged 60 and over (21% and 6.8%, respectively) (Radford et al. 2017).
- A dementia prevalence rate of 14.2% has been estimated among Torres Strait Islanders aged between 45 and 93 years (Russell et al. 2020).

Dementia deaths have risen for Indigenous Australians

Dementia deaths among Indigenous Australians rose by 70% between 2011–15 (296 deaths) and 2016–20 (503 deaths). During 2018–20, 318 Indigenous people died due to dementia (202 women and 116 men), and dementia was the fifth leading cause of death among Indigenous people aged 65 and over (11% of all deaths). The number of deaths due to dementia is expected to continue rising due to the ageing population.

Around 53% of the overall dementia burden could have been avoided

In 2018, dementia was the 19th leading cause of burden of disease among Indigenous Australians, accounting for 3,300 healthy years of life lost, and was the leading cause of burden for Indigenous Australians aged 75 years and over. Indigenous women experienced 56% of the total burden due to dementia.

Of the disease burden due to dementia in Australia in 2018:

56% was from dying prematurely

44% was from living with dementia

The 2018 Australian Burden of Disease Study also estimated the attributable burden from 6 established risk factors for dementia – overweight and obesity, physical inactivity, tobacco smoking, high blood pressure in midlife, high blood plasma glucose levels, and impaired kidney function.

Around 53% of the overall dementia burden in 2018 could have been avoided if exposure to these 6 modifiable risk factors was avoided or reduced to the lowest level possible.

Hospitalisations

In 2020–21, there were 375 hospitalisations due to dementia (where dementia was the principal diagnosis or reason for admission) where the patient identified as an Indigenous Australian.

Of these hospitalisations:

- Indigenous women were more likely to be hospitalised due to dementia (32 hospitalisations per 10,000 Indigenous women) than Indigenous men (28 per 10,000 Indigenous men).
- 14.6 days was the average length of stay, which was slightly higher than the average length of stay for non-Indigenous Australians hospitalised due to dementia that year (12.7 days).

Half of Indigenous people living in permanent residential aged care have dementia

In 2019–20, just over 2,400 people living in permanent residential aged care facilities across Australia identified as being Indigenous. More than half (52% or almost 1,300 Indigenous Australians) had dementia. Of these:

- Indigenous men and women with dementia were older than Indigenous Australians without dementia.
- Indigenous Australians with dementia use permanent residential aged care services at higher rates in more remote areas.

The number of Indigenous Australians with dementia living in permanent residential aged care has increased in recent years from just under 1,100 in 2014–15.

It is important to note that data presented here do not include people accessing some government-subsidised Indigenous-specific programs, such as the National Aboriginal and Torres Strait Islander Flexible Aged Care Program.

Indigenous-specific dementia services

Indigenous people can find it difficult to access services that provide culturally appropriate care. This is particularly the case in remote areas.

Aboriginal Community Controlled Health Services (ACCHS) deliver holistic and culturally appropriate health services and are often a first point of contact for Indigenous people with dementia. ACCHS can also refer people to other services, including specialist care, and help people with dementia to navigate the aged care system.

The National Aboriginal and Torres Strait Islander Flexible Aged Care Program aims to provide quality, flexible aged care for older Indigenous Australians in a culturally safe environment. The program operates mainly in regional, remote, and very remote areas, and provides various services, including home and residential care. This program provides aged care to a large number of Indigenous Australians – at 30 June 2020, there were almost 1,300 places available.

How does dementia affect other priority population groups?

Australians living with dementia come from diverse backgrounds and have unique and variable needs for services and support. National data on people with dementia in priority population groups are limited and further research is needed.

This section focuses on current national data available on dementia among people from culturally and linguistically diverse backgrounds. The *Dementia in Australia* online report focuses on a number of other priority population groups that would benefit from better data to reflect dementia and its impacts. These include people with intellectual disabilities, veterans and people from the LGBTIQ+ community.

Understanding dementia among people from culturally and linguistically diverse backgrounds is essential for health and aged care policy and planning

Australia has a long history of immigration. The country's population has a large proportion of people who were born overseas, have a parent who was born overseas, or who speak a variety of languages. These groups are generally referred to as culturally and linguistically diverse populations.

Cultural and linguistic diversity among people with dementia in Australia largely reflects migration waves in earlier years. These waves are evident when looking at the country of birth and year of arrival in Australia of people who died with dementia.

Among people who had dementia recorded on their death certificate between September 2016 and December 2017:

- Those born in Southern, Eastern and North-Western Europe predominantly immigrated to Australia between the late 1940s and the 1960s.
- People born in Asia, the Middle East and Africa more commonly immigrated to Australia after the mid-1960s. For example, 67% of people born in South East Asia (including Vietnam and the Philippines) who died with dementia arrived between 1976 and 1995.

Migration patterns are important to consider for dementia service planning and delivery.

Differences in cultural attitudes towards aged care and support services also need to be considered

For some cultures, the responsibility of caring for the elderly population falls upon family and relatives. There may also be limited understanding of, and/or stigma attached to dementia. It can also be difficult for people to access and use services if they are not designed with culturally and linguistically diverse communities in mind or are not provided in their main language spoken.

According to the ABS Survey of Disability, Ageing and Carers, in 2018:

1 in 2 people with dementia who were born in non-English speaking countries and were living in the community relied on informal care and assistance only.

By comparison, about 1 in 3 people with dementia who were born in English-speaking countries relied on informal care and assistance only.

How does dementia vary across Australia?

There are large differences in the number of people with dementia and death, hospitalisation, burden of disease and aged care rates across Australian states and territories, remoteness and socioeconomic areas. For example, deaths per 100,000 population are highest in the Northern Territory and *Major cities*, and lowest in Western Australia and *Remote* areas. Dementia death rates are the same for people living in the highest and lowest socioeconomic areas. South Australia has the highest rate of people with dementia in permanent residential aged care while Tasmania has the lowest.

States and territories	NSW	Vic	Qld	WA	SA	Tas	ACT	NT
Number of people with dementia[(a)]	128,100	99,000	74,700	38,000	32,800	10,000	5,300	1,500
Deaths (per 100,000 population)	39	38	42	37	49	39	49	55
Burden of disease[(b)]								
DALY per 1,000 population	6.2	5.8	6.2	4.7	7.3	6.4	6.6	8.9
YLL per 1,000 population	3.4	3.2	3.6	3.2	4.1	3.7	3.5	5.5
YLD per 1,000 population [(c)]	2.8	2.5	2.7	1.6	3.2	2.7	3.1	3.4
Hospitalisations (per 10,000 population)	36	41	55	47	50	35	39	58
People in permanent residential aged care (per 10,000 population)	307	283	317	306	322	275	307	293

(a) Due to the lack of data on the variability of dementia prevalence rates by states and territories, dementia prevalence estimates for each state and territory were calculated by applying the AIHW national age- and sex-specific dementia prevalence rates to the population of each. These are based on AIHW methods for estimating dementia prevalence.

(b) Burden of disease measures the impact of living with illness and injury (years of life lost, or YLL) and dying prematurely (years lived with disability, or YLD). Combined this is the disability adjusted life year (DALY). 1 DALY = 1 year of healthy life lost.

(c) For burden of disease analyses, state and territory prevalence estimates were derived by applying the state and territory proportions of deaths due to dementia to the national prevalence estimates. These prevalence estimates were then multiplied by the associated disability weights (measure of health loss) to obtain estimates for the years lived with disability (YLD) due to dementia.

Remoteness areas	Major cities	Inner regional	Outer regional	Remote	Very remote
Number of people with dementia[(a)]	262,100	86,400	35,000	3,300	1,400
Deaths (per 100,000 population)	42	38	37	25	26
Burden of disease[(b)]					
DALY per 1,000 population	6.3	6.0	5.8	5.7 (combined)	
YLL per 1,000 population	3.5	3.4	3.3	3.4 (combined)	
YLD per 1,000 population	2.7	2.6	2.5	2.3 (combined)	
Hospitalisations (per 10,000 population)	46	39	37	35	43
People in permanent residential aged care (per 10,000 population)	316	291	252	143	117
Socioeconomic areas	**1 (lowest)**	**2**	**3**	**4**	**5 (highest)**
Number of people with dementia[(a)]	81,400	86,700	76,100	69,800	75,400
Deaths (per 100,000 population)	39	43	40	40	39
Burden of disease[(b)]					
DALY per 1,000 population	6.6	6.4	6.0	5.9	5.7
YLL per 1,000 population	3.8	3.6	3.4	3.4	3.2
YLD per 1,000 population	2.8	2.8	2.6	2.5	2.5
Hospitalisations (per 10,000 population)	47	44	45	45	39
People in permanent residential aged care (per 10,000 population)	309	323	293	294	293

(a) Due to the lack of data on the variability of dementia prevalence rates by remoteness area and socioeconomic area, dementia prevalence estimates for each remoteness area and socioeconomic area were calculated by applying the AIHW national age- and sex-specific dementia prevalence rates to the population of each. These are based on AIHW methods for estimating dementia prevalence.

(b) Burden of disease measures the impact of living with illness and injury (years of life lost, or YLL) and dying prematurely (years lived with disability, or YLD). Combined this is the disability adjusted life year (DALY). 1 DALY = 1 year of healthy life lost.

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Where can I find out more?

More information can be found in the detailed Dementia in Australia online report, which is available on the AIHW website: https://www.aihw.gov.au/reports/dementia/dementia-in-aus/

If you require more information about dementia, want to know where to seek help if dementia is suspected or want to find out about available support services refer to:

Dementia Australia website: https://www.dementia.org.au/

National Dementia Helpline: **1800 100 500** (a free and confidential service to discuss dementia and memory loss concerns for yourself or others).

Dementia Behaviour Management Advisory Service: **1800 699 799** (if needing help to manage behaviour associated with dementia)

For information on, and applying for access to government-subsidised aged care services, visit the My Aged Care website: https://www.myagedcare.gov.au/

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This *Summary* report presents key findings from the detailed *Dementia in Australia* online compendium and covers a broad range of topics including; prevalence estimates and projections, mortality, burden of disease, care needs of people with dementia, and their use of aged care and health care services. The report also features information on carers of people with dementia, direct health and aged care system expenditure for dementia and dementia among population groups of interest.

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