Australian Government

Australian Institute of Health and Welfare

AIHW

Dementia in Australia 2021

Summary report

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The Australian Institute of Health and Welfare is a major national agency whose purpose is to create authoritative and accessible information and statistics that inform decisions and improve the health and welfare of all Australians.

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Contents

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 2021

It is estimated between **386,200 and 472,000** Australians are living with dementia

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

1 in 12 Australians aged 65 and over has dementia

2 in 3 Australians with dementia live in the community

Over **27,800 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 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

Overall, dementia is the **3rd leading cause of disease burden** in Australia

Dementia is the **leading cause of disease burden** in Australians aged 75 and over

Services and spending for dementia

Over 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 who completed a comprehensive assessment to use aged care services had dementia

Between 2012–13 and 2019–20 there was a **43% increase** in the number of scripts dispensed for **dementia-specific medications**

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 **134,900 and 337,200** 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 her husband (Dan) has 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, he's fit [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 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 [are] 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 [in] 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

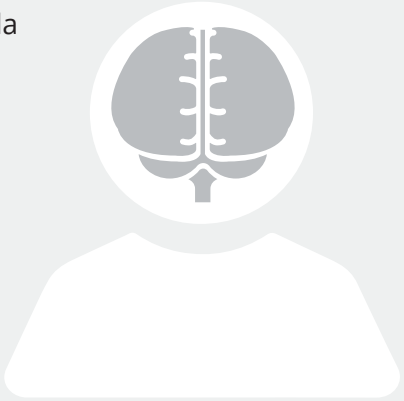
Dementia is a leading cause of death and burden of disease in Australia. It is estimated that between 386,200 and 472,000 Australians have dementia in 2021 and, with Australia's ageing population, this number is expected to rise to more than 849,300 by 2058. Although dementia can affect people under 65 years of age, 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/contents/about.

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).

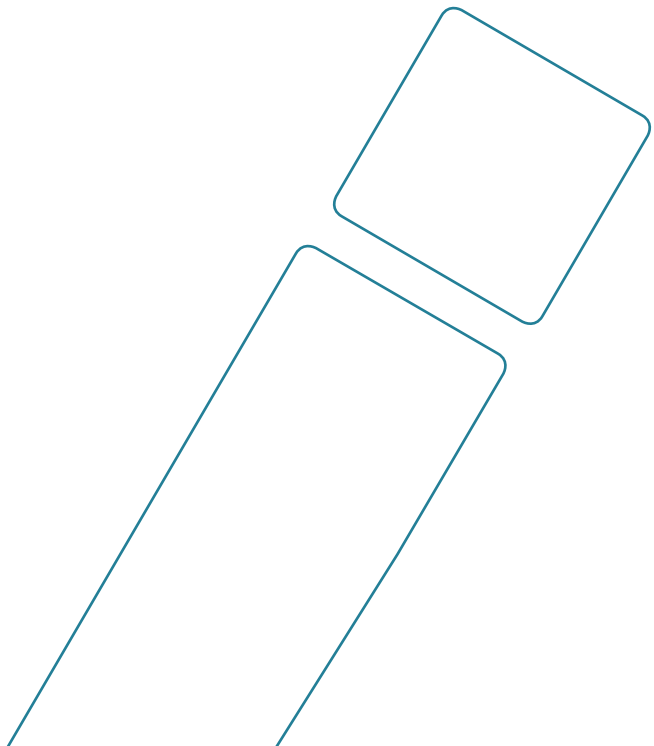
Types of dementia

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).

Modifiable risk factors

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	

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

Non-modifiable risk factors

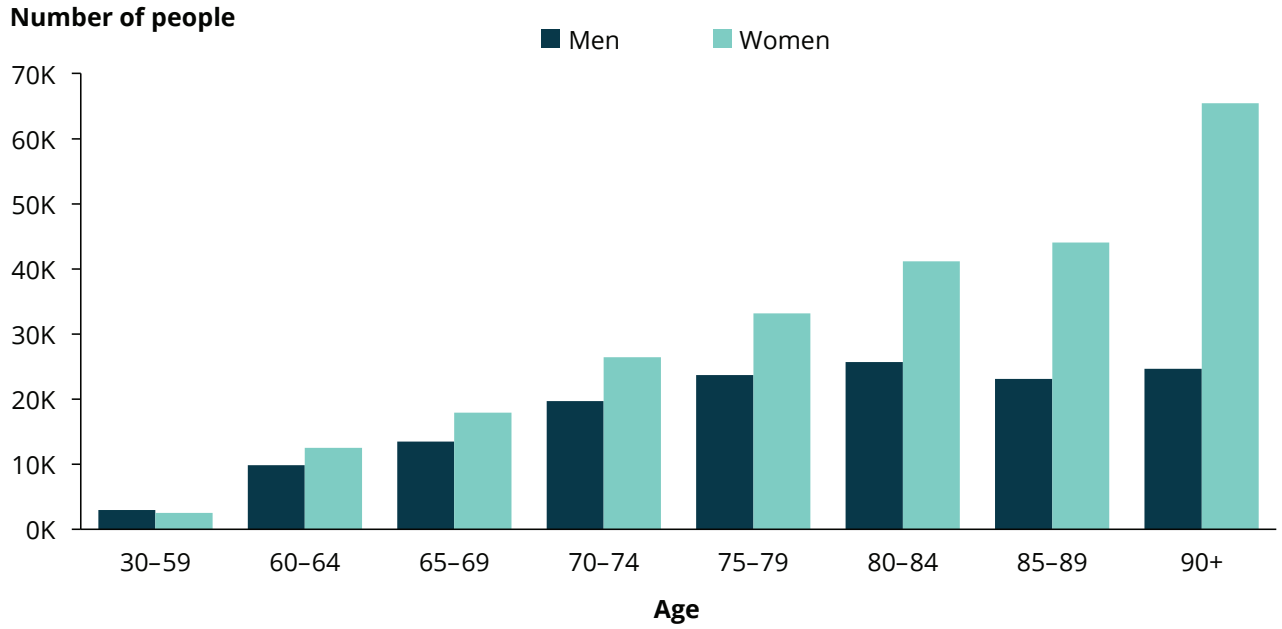
Age—the risk of developing dementia doubles every 5 or 6 years for people aged over 65	Family history of the condition	Genetic mutations

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 2021, it's estimated between 386,200 and 472,000 Australians have dementia

Using the AIHW estimates for the number of people with dementia, nearly two-thirds of the 386,200 Australians with dementia in 2021 were women and one third were men (243,200 women and 143,000 men). Overall, this is equivalent to 15 people with dementia per 1,000 Australians (18 per 1,000 for women and 11 per 1,000 for men).



The number of people with dementia rises quickly with age. It is estimated that among Australians in 2021:

- **1 in 12** Australians **aged 65 and over** have dementia
- **2 in 5** Australians **aged 90 and over** have 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 17 for more information on dementia among Indigenous Australians.

Dementia data gaps

As 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. Detailed estimates by age and sex were derived using AIHW prevalence estimates.

There is work underway to improve the accuracy of estimates of the number of Australians with dementia and new approaches to determining dementia prevalence will likely supersede the estimates shown in this report in coming years.

How do we compare with other countries?

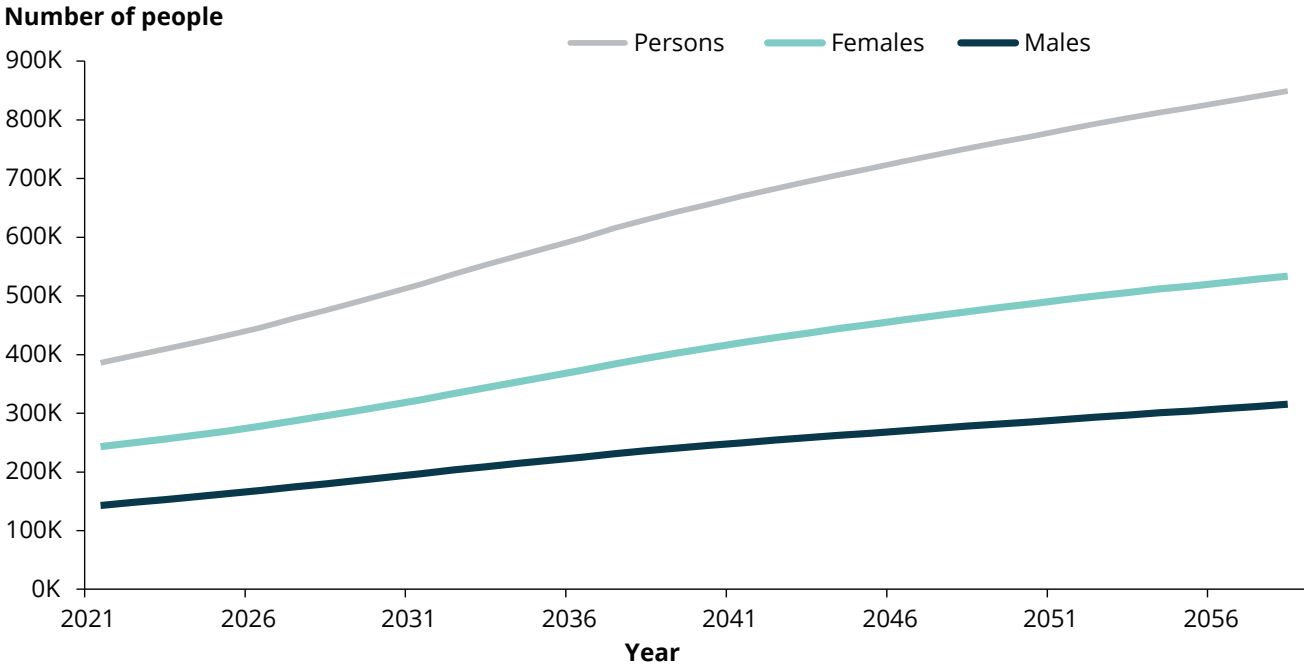
The Organisation for Economic Co-operation and Development (OECD) estimated that 14.6 in every 1,000 Australians were living with dementia in 2019. Although the OECD dementia prevalence rates for Australia were similar to the AIHW estimates presented in this report, it is important to remember that different methodologies and data sources were used. The rate of dementia in Australia ranked 17th lowest out of 36 countries. Mexico had the lowest rate, at 7.6 per 1,000, population and Japan had the highest rate at 24.8 per 1,000 (OECD 2019).

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 386,200 in 2021 to 849,300 in 2058 (533,800 women and 315,500 men).



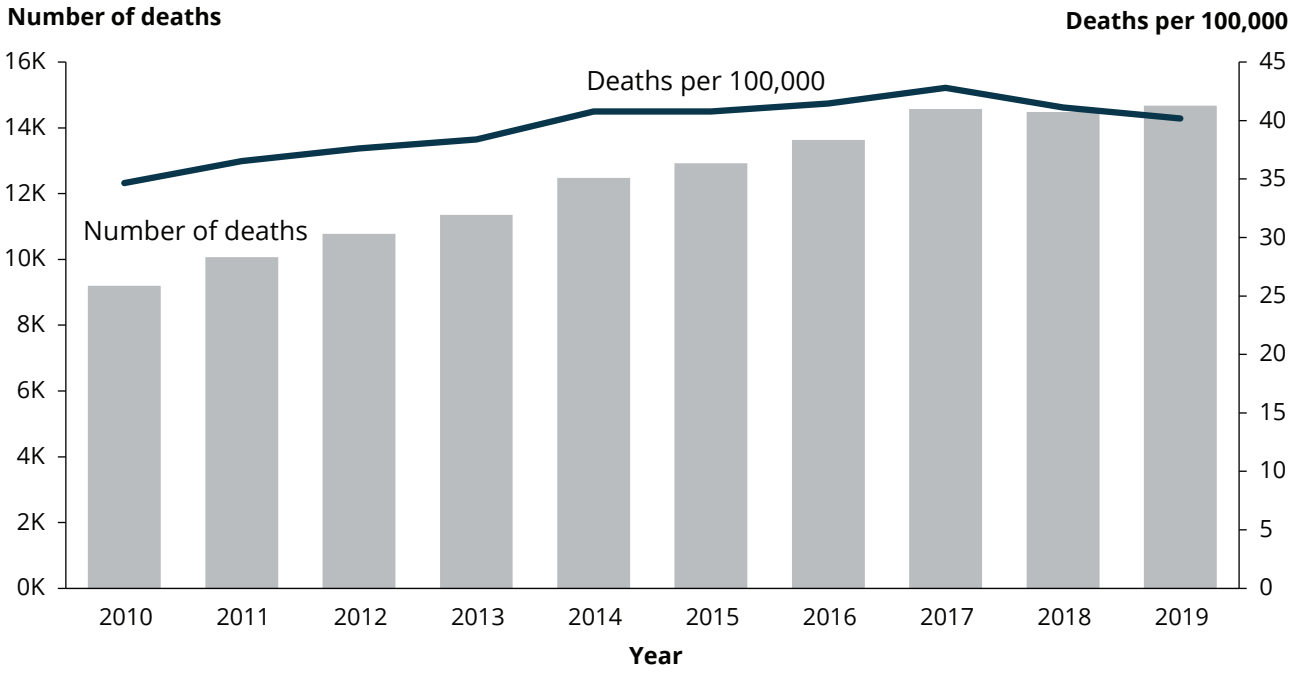
Until there is a cure or significant advancements in treatment, the best way to reduce the prevalence of dementia in the future is to minimise exposure to risk factors that increase the likelihood of developing dementia in later life (Livingston et al. 2017; Prince et al. 2014).

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 about 14,700 deaths in 2019—9.5% 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 9,200 deaths in 2019).

The number of deaths due to dementia increased from 9,200 deaths in 2010 to 14,700 deaths in 2019. The age-standardised rate, which accounts for differences in the age and sex structure of the population, rose between 2010 and 2019, from 35 to 40 deaths per 100,000 Australians.



How do deaths vary by age and sex?

Most deaths due to dementia occur among those aged 85–94, and the rate of deaths due to dementia increases substantially with age.

In 2019, the rate of deaths due to dementia among those aged 75–79 was 167 deaths per 100,000 men and 155 deaths per 100,000 women respectively. This increased to about 3,600 and 5,300 deaths per 100,000 for men and women aged 95 and over, respectively.

	Men	Women
Number of deaths due to dementia in 2019*	5,400	9,200
Deaths due to dementia per 100,000 Australians in 2019	38	41
Proportion of all deaths in 2019	6.8	12.4

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

Dementia is a leading cause of burden of disease

Dementia was the 3rd leading cause of burden of disease in Australia in 2018, behind coronary heart disease and back pain.

For Australians of all ages, dementia was the:

- **3rd leading cause of disease burden** (198,000 DALY)
- **6th leading cause in men** (75,300 DALY)
- **Leading cause in women** (122,600 DALY).

As the risk of developing dementia increases with age, the disease burden due to dementia is higher for older Australians.

For Australians aged 75 and over, dementia was the leading cause of disease burden in women and second leading cause of disease burden in men (behind coronary heart disease).

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

56%
was from dying prematurely

44%
was from living with dementia

The 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 summed together to provide the total burden, measured using disability-adjusted life years (DALY).
- 1 DALY is equivalent to 1 year of healthy life lost.

Preliminary findings from the Australian Burden of Disease Study 2018 are at available at https://www.aihw.gov.au/reports/burden-of-disease/burden-of-disease-study-2018-key-findings/contents/about.

How is dementia diagnosed?

There is no single conclusive test available 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 it allows for timely access to information and advice, as well as 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 patients' carer, family or friends. If a GP suspects dementia, it is best practice for GPs 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

Currently, 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.

Focus: Examining services claimed under the Medicare Benefits Schedule by people with dementia

The AIHW examined services claimed under the Medicare Benefits Schedule (MBS) by over 137,000 Australians living with dementia in 2016–17. This was possible using linked health and aged care data sets.

Service usage differed for those who were living in permanent residential aged care compared with those living in the community, but only at older ages:

- for people aged under 80, the number of services used by people who were living in residential aged care was fairly similar to the number used by people who were living in the community
- from age 80 onwards, the number of services used by people living in residential aged care was greater than the number used by people living in the community.

The rate of services used by people with dementia living in residential aged care increased 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 or over.

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

Almost 64,600 people were dispensed scripts for dementia-specific medications in 2019–20

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 over 623,300 prescriptions dispensed for dementia-specific medications to just under 64,600 Australians with dementia aged 30 and over. This is equivalent to 9.7 scripts per person who was dispensed a script for dementia-specific medication. Each script is usually for a month's supply of medication.

Of the just under 64,600 Australians who were dispensed scripts for dementia-specific medications:

- **1 in 3 were aged 85 or over**
- **37,100 were women** and they were dispensed **361,600 scripts**
- **27,400 were men** and they were dispensed **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 increased by 43% between 2012–13 and 2019–20. The increase 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 antipsychotics 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.

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

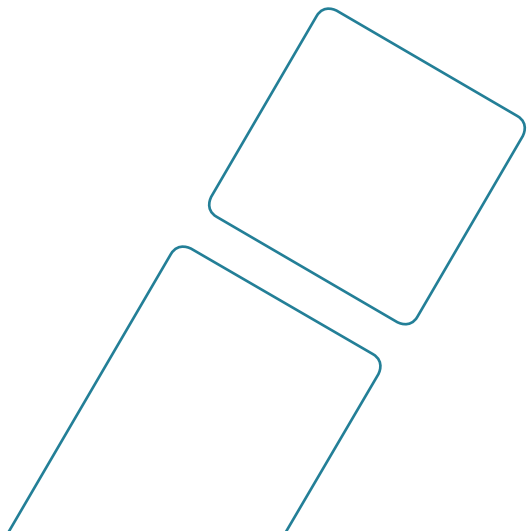
Around 39% of people with scripts dispensed for antipsychotic medications and dementia-specific medications were supplied Risperidone (the only antipsychotic that is currently listed on the PBS for BPSD) followed by Quetiapine (29%) and Olanzapine (24%).

Around 23,200 hospitalisations were due to dementia in 2018–19

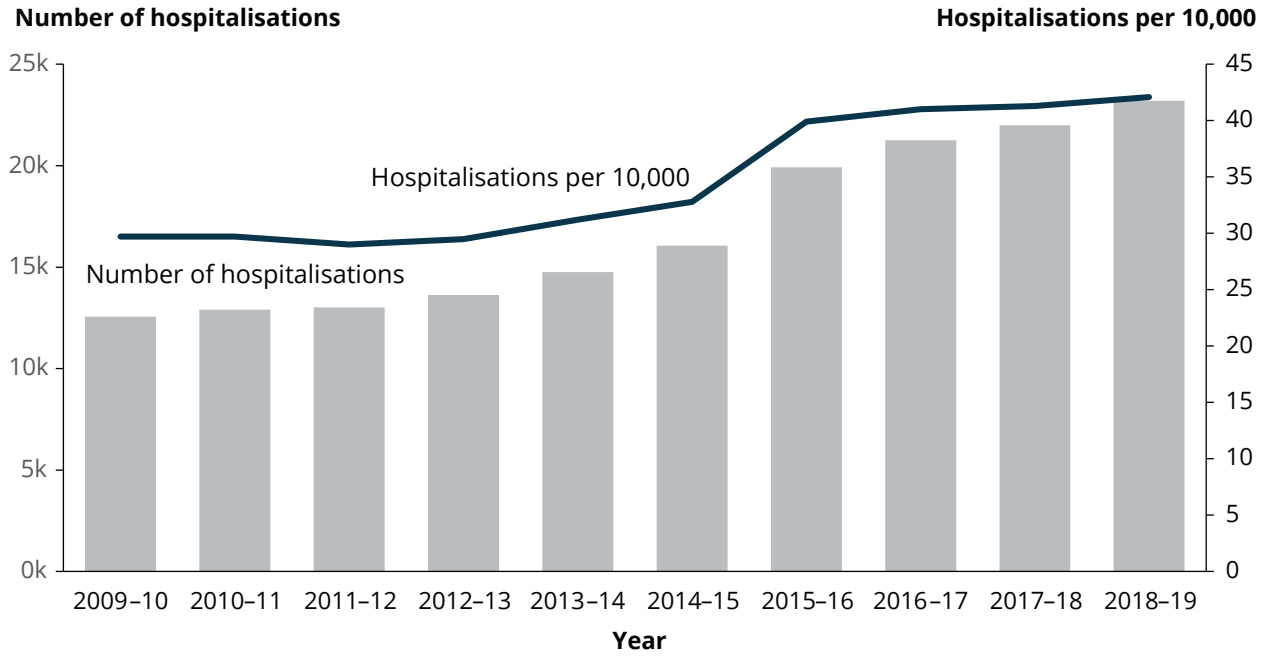
In 2018–19, there were around 23,200 hospitalisations due to dementia (which are hospital admissions where dementia was the principal diagnosis, or the main reason for admission).

Of the 23,200 hospitalisations due to dementia:

- **12,200 were for men** and **11,000 were for women**
- **63%** of patients were aged between **75 and 89**
- **1 in 3** hospitalisations were for **Alzheimer's disease**
- **13 days** was the average length of stay—this was almost 5 times longer than the average hospitalisation that year (2.7 days).



The rate of hospitalisations due to dementia has increased gradually each year from 2009–10 to 2014–15 (2.1% annual average increase) and from 2015–16 to 2018–19 (1.8% annual average increase). These increases may be due in part 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 2018–19, **78,500 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

awaiting admission to residential aged care

delirium*

* Not induced by alcohol and other psychoactive substances

How do people with dementia access aged care services?

Older Australians who require care and assistance can access a range of government-subsidised services co-ordinated through the My Aged Care system. After an initial screening, an appointment is organised so that an aged care assessment can be completed in order to establish the persons' 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.

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

This equates to 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 women) and **46% were men** (18,900 men)
- The average age for women with dementia was **82** and it was **81** for men
- **3 in 4** assessments were for a **comprehensive assessment**.

The majority of 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 people with dementia accounted for 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—62% of men and 34% of women with dementia were living with their partner at the time of assessment
- Women with dementia were more likely to be living alone at the time of assessment (40%) than men with dementia (20%).

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.

Over half of both women (54% or nearly 85,700) and men (54% or over 46,200) living in permanent residential aged care had dementia. 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 a person's current living arrangements (women tend to live longer than men and thus 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 impact on an individual's care needs.

Many residents with dementia have high care needs:

The Aged Care Funding Instrument (ACFI) is used to allocate funding to residential aged care facilities based on the day-to-day care needs of individual residents, as 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

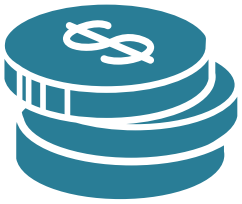
2 in 3 people with dementia (71%) required **high** levels of care in the ***activities of daily living*** domain

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, with the exception of the cognition and behaviour domain, where needs were highest among those with younger onset dementia. This could be in part a result of: severe behavioural and psychological symptoms of dementia being common in dementia types that occur more frequently in younger ages; younger people being more mobile and having fewer co-morbidities; or providers having a different focus when assessing younger peoples' care needs.

$3 billion was spent directly on health and aged care services for dementia in 2018–19

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 dementia 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 (costing $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 vital role in providing assistance and support to those with dementia

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 2021 there are **between 134,900 and 337,200 informal carers of people with dementia** (that is, someone who provides ongoing informal assistance to a person with dementia). This is a conservative estimate based on limited data, and excludes people providing care to those living in permanent residential aged care facilities 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 is a rewarding but demanding role

Caring for a person with a disability, illness or condition can be physically, mentally, emotionally, and economically demanding, and the burden of caregiving is particularly high for those caring for a person with dementia.

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, carers' employment, care recipient and carers' 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 carers work commitments and financial obligations. Over 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.

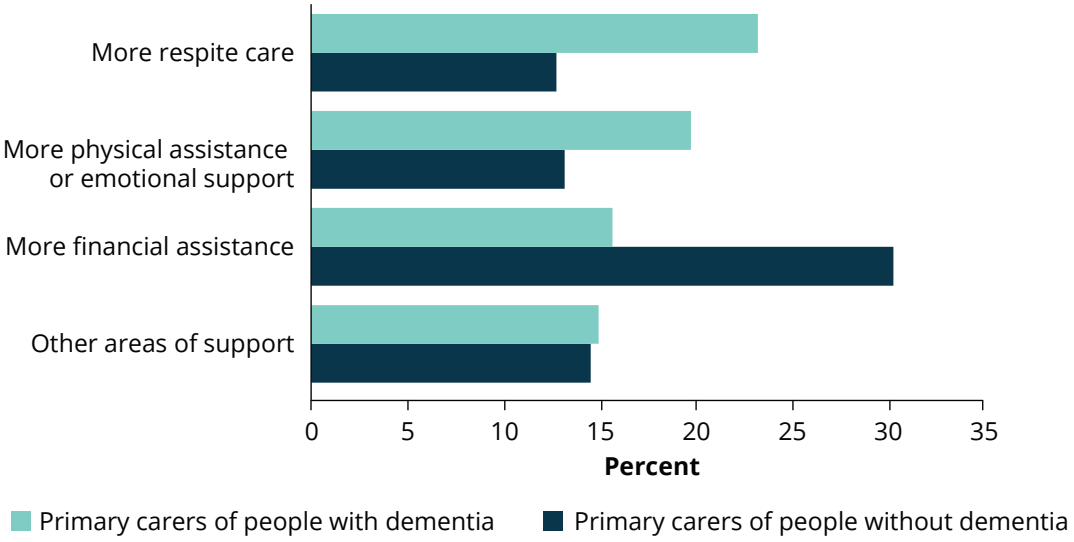
Carers need appropriate support

It is vital 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 Indigenous Australians, 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 Australians with dementia, smaller studies have found higher rates among some groups, when looking at particular age ranges:

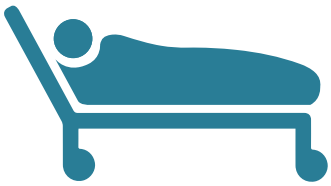
- Rates of dementia for older Indigenous Australians in remote and rural communities tend to be among the highest in the world (Smith et al. 2008; Lo Giudice et al. 2016)
- Across the Northern Territory, the age-adjusted prevalence of dementia for Indigenous Australians aged 45 and over is 6.5%, compared with 2.6% among the non-Indigenous population (Li et al. 2014)
- The prevalence of dementia among Indigenous Australians 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).

Burden of disease and deaths

During 2017–19, 314 Indigenous Australians died due to dementia (196 women and 118 men), and dementia was the fifth leading cause of death among Indigenous Australians aged 65 and over. The number of deaths due to dementia among Indigenous Australians is predicted to rise in the future, primarily due to an increasingly ageing Indigenous population.

The latest burden of disease estimates for Indigenous Australians are for 2011. At that time, the age-standardised rate of disease burden due to dementia was 2.3 times as high among Indigenous Australians (12.8 DALY per 1,000 population) as the burden among other Australians (5.7 DALY per 1,000 population). Among people aged 75 and over, dementia was the leading cause of disease burden for Indigenous women and the third leading cause for Indigenous men (behind coronary heart disease and chronic obstructive pulmonary disease). More recent data estimating the burden of disease for Indigenous Australians are expected in late 2021.

Hospitalisations



In 2018–19, there were 269 hospitalisations due to dementia (where dementia was the principal diagnosis or reason for admission) were the patient identified as an Indigenous Australian.

Of the hospitalisations for Indigenous Australians due to dementia in 2018–19:

- Indigenous men were more likely to be hospitalised due to dementia (25 hospitalisations per 10,000 Indigenous Australians) than Indigenous women (20 per 10,000)
- 12.5 days was the average length of stay, which was similar to the average length of stay for all hospitalisations due to dementia that year (13 days).

Half of Indigenous Australians 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. Over half (52% or almost 1,300 Indigenous Australians) had dementia.

Of the Indigenous Australians with dementia living in residential aged care during 2019–20:

- Indigenous men and women with dementia were older than Indigenous Australians without dementia
- Indigenous Australians with dementia tended to 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 to just under 1,300 in 2019–20.

It is important to note that data presented here on Indigenous Australians living in permanent residential aged care 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 Australians 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 Australians with dementia. ACCHSs 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 vulnerable 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 vulnerable population groups are limited and further research is needed.

The *Dementia in Australia* online report focused on a number of population groups of interest that may benefit from a more specific focus within dementia care, including people with dementia from culturally and linguistically diverse populations.

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, and the population is comprised of a large proportion of people who were born overseas, have a parent born overseas or speak a variety of languages. These groups of people are generally referred to as culturally and linguistically diverse populations.

Cultural and linguistic diversity among people with dementia in Australia largely reflects migration waves to Australia in earlier years, and 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 in earlier years are important to consider for service planning and delivery for people with dementia in Australia, as well as servicing carers of people with dementia.

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

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.

For some cultures, the responsibility of caring for the elderly population falls upon kin. 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, particularly if not provided in their main language spoken.

How does dementia vary across Australia?

There are large differences in the number of people with dementia across Australian states and territories, remoteness and socioeconomic areas.

States and territories	NSW	Vic	Qld	WA	SA	Tas	ACT	NT
Number of people with dementia[(a)]	122,300	94,900	69,700	34,400	30,900	9,300	4,900	1,400
Deaths (per 100,000 population)	42.5	40.6	43.2	38.2	47.0	43.1	43.4	62.0
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)	35.2	47.8	47.6	44.1	40.5	33.1	39.5	64.0
People in permanent residential aged care (per 10,000 population)	307.0	283.3	316.8	306.1	321.7	275.1	306.7	293.2

(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)]	249,900	80,100	33,200	3,300	1,300
Deaths (per 100,000 population)	43.2	40.8	38.9	28.3	30.9
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)	45.9	35.5	38.0	34.9	34.7
People in permanent residential aged care (per 10,000 population)	316.0	290.9	251.7	143.1	116.9

Socioeconomic areas	1 (lowest)	2	3	4	5 (highest)
Number of people with dementia[(a)]	77,800	81,100	71,500	66,100	71,300
Deaths (per 100,000 population)	41.6	43.7	42.1	41.2	41.9
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)	38.7	40.0	46.0	45.8	44.4
People in permanent residential aged care (per 10,000 population)	308.9	323.2	292.5	294.3	292.6

(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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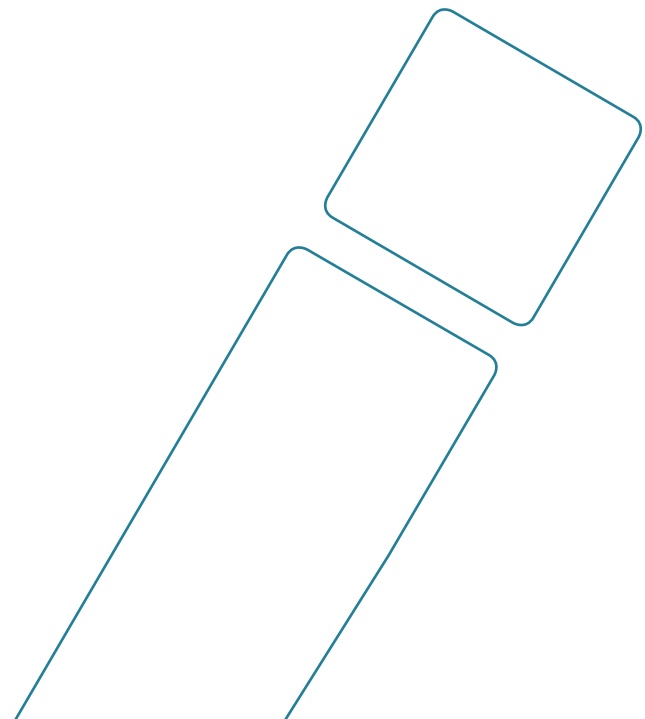

Where can I find out more?

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/contents/about.

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 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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