Australian Government
Australian Institute of Health and Welfare

Dementia in Australia

Web report | Last updated: **28 Mar 2024** | Topic: Dementia

About

Dementia is a significant and growing health and aged care issue in Australia that has a substantial impact on the health and quality of life of people with the condition, as well as for their family and friends. This online report provides a comprehensive picture of dementia in Australia, including the latest statistics on dementia prevalence, burden of disease, deaths, expenditure, as well as the use of health and aged care services among people with dementia and information on carers of people with dementia.

Dementia in Australia has been published as a web report since 2021. This report is updated bi-annually to include the latest data from a range of sources. For more information, see Data sources.

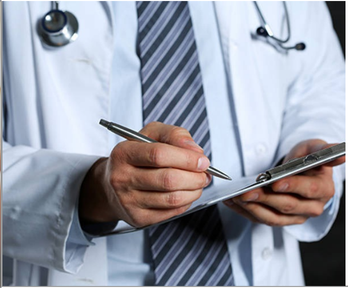
Cat. no: DEM 2

Latest dementia statistics

In 2023, it is estimated that **411,100** Australians are living with dementia

Dementia prevalence rates among First Nations people is estimated to be **3-5 times as high** as the rate for Australians overall

Dementia was the **2nd leading cause of death** in Australia in 2021



In 2023, dementia was the **2nd leading cause of burden of disease** in Australia

Around **2 in 3** Australians with dementia were **living in the community** in 2022

54% of people living in **permanent residential aged care** had dementia in 2021–22

$3.7 billion of Australia's health and aged care **expenditure** was spent directly on dementia in 2020–21

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

Contents of this report

Summary

- Treatment, management and support
- Carers
- Dementia data gaps
- Where do I go for more information?

Australian stories about living with dementia

Australian stories about living with dementia

- Carrie's story: A diagnosis of dementia can impact the affected person, their friends, families and carers. Read Carrie's story about becoming a carer to her husband, while also raising a young family.
- Len's story: Dementia has a deep impact on Aboriginal and Torres Strait Islander communities. Learn about Len, an Aboriginal elder, who returned to his community after being diagnosed with Alzheimer's disease.
- Martina's story: Living with the early stages of dementia can be challenging. Read about Martina's experience with being diagnosed with Lewy body dementia and how her life has changed since.
- Lucy's story: Dementia can also impact young people. Lucy shares how she is able to keep doing what she enjoys after being diagnosed with a rare type of dementia common in her family.
- Jim's story: Many people with dementia prefer to live independently in the community. Jim has Alzheimer's disease and lives at home on his own. Read about how the COVID-19 pandemic has affected him, his family and the services he receives.

Understanding dementia

Understanding dementia

- What puts someone at risk of developing dementia?
- How is dementia diagnosed?
- Less common dementias
- What care and support is available to people with dementia?

Population health impacts of dementia

Population health impacts of dementia

- Prevalence of dementia
- Incidence of dementia
- Deaths due to dementia
- Dying due to dementia compared to dying with dementia
- Burden of disease due to dementia
- Dementia burden due to risk factors

Carers and care needs of people with dementia

Carers and care needs of people with dementia

- How do care needs of people with dementia differ by place of residence?
- Carers of people with dementia
- Impact of the caring role on carers
- Employment and financial impact on carers
- Carers unmet needs

Health services used by people with dementia

Health services used by people with dementia

- Primary health care services
- Prescriptions for dementia-specific medications
- Antipsychotics and other medications dispensed to people with dementia
- Prescribers of dementia-specific medications
- Hospital care
- Hospitalisations due to dementia
- Hospitalisations with dementia

Aged care and support services used by people with dementia

Aged care and support services used by people with dementia

- Overview of Australia's aged care system
- Aged care assessments

- Community-based aged care
- Residential aged care
- Overview of dementia support services and initiatives
- National Dementia Support Program and Dementia Friendly Communities
- Behaviour support programs
- What carer support services are available?

Dementia in priority groups

Dementia in priority groups

- Understanding dementia among First Nations people
- Population health impacts of dementia among First Nations people
- Burden of disease due to dementia among First Nations people
- Hospital care for First Nations people with dementia
- Aged care service use by First Nations people with dementia
- First Nations-specific health and aged care programs and caring roles among First Nations people
- Dementia among people from culturally and linguistically diverse backgrounds
- Cultural and linguistic diversity among Australians who died with dementia
- Dementia among people with intellectual disabilities
- Dementia among veterans
- Dementia in the LGBTIQ+ community
- Younger onset dementia
- Population health impacts of younger onset dementia
- Health services used by people with younger onset dementia
- Aged care and support services available to people with younger onset dementia

Health and aged care expenditure on dementia

Health and aged care expenditure on dementia

- Expenditure on aged care and support services
- Total health expenditure including hospital services and out-of-hospital services

Behaviours and psychological symptoms of dementia

Behaviours and psychological symptoms of dementia

- What are behaviours and psychological symptoms of dementia?
- National dementia behaviour support programs
- Behaviours captured in aged care assessments
- Data gaps and limitations in understanding BPSD

National policy response to dementia

National policy response to dementia

Australian stories about living with dementia

Carrie's story
A diagnosis of dementia can impact the affected person, their friends, families and carers. Read Carrie's story about becoming a carer to her husband, while also raising a young family.

Martina's story
Living with the early stages of dementia can be challenging. Read about Martina's experience with being diagnosed with Lewy body dementia and how her life has changed since.

Len's story
Dementia has a deep impact on Aboriginal and Torres Strait Islander communities. Learn about Len, an Aboriginal elder, who returned to his community after being diagnosed with Alzheimer’s disease.

Lucy's story
Dementia can also impact young people. Lucy shares how she is able to keep doing what she enjoys after being diagnosed with a rare type of dementia common in her family.

Jim's story

Many people with dementia prefer to live independently in the community. Jim has Alzheimer’s disease and lives at home on his own. Read about how the COVID-19 pandemic has affected him, his family and the services he receives.

Summary

Dementia is an Australia's health topic

- Health of older people | 28 Jun 2023
- Stroke | 14 Dec 2023
- Burden of disease | 14 Dec 2023

On this page

Dementia is a term used to describe a group of conditions characterised by gradual impairment of brain function, which may impact memory, speech, cognition (thought), personality, behaviour, and mobility.

There are many forms of dementia, the most common being Alzheimer's disease – a degenerative brain disease caused by nerve cell death resulting in shrinkage of the brain. It is also common for an individual to have multiple types of dementia, known as 'mixed dementia'. While the likelihood of developing dementia increases with age, dementia is not an inevitable or normal part of the ageing process. Dementia can also develop in people under 65, referred to as younger onset dementia, and in children, which is known as childhood dementia.

Dementia is a significant and growing health and aged care issue in Australia that has a substantial impact on the health and quality of life of people with the condition, as well as their family and friends. As the condition progresses, the functional ability of an individual with dementia declines, eventually resulting in the reliance on care providers in all aspects of daily living. There is currently no cure for dementia but there are strategies that can assist in maintaining independence and quality of life for as long as possible.

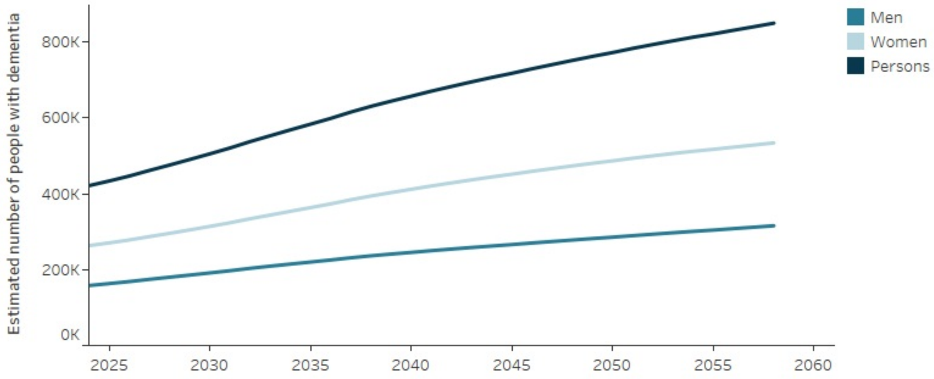
How common is dementia?

In 2023, it was estimated that there were 411,100 (AIHW estimate) Australians living with dementia. Based on AIHW estimates, this is equivalent to 15 people with dementia per 1,000 Australians, which increases to 84 people with dementia per 1,000 Australians aged 65 and over. Nearly two-thirds (63%) of Australians with dementia are women.

With an ageing and growing population, it is predicted that the number of Australians with dementia will more than double by 2058 to 849,300 (533,800 women and 315,500 men) (Figure 1).

Figure 1: Australians living with dementia between 2024 and 2058: estimated number by sex and year

This figure shows the increasing estimated prevalence of dementia between 2010 and 2058.



The trend of sum of Prevalence for Year. Color shows details about Sex. The data is filtered on Year, which keeps 36 of 49 members.

Source: The AIHW estimates were derived using prevalence rates from the 2015 World Alzheimer report and Withall et al. 2014, and the ABS Series B population projections.
http://aihw.gov.au

Measuring dementia prevalence

The exact number of people with dementia in Australia (the ‘prevalence’) is currently not known. Estimates vary because there is no single authoritative data source for deriving dementia prevalence in Australia and different approaches are used to generate estimates. For more information, see What is being done to improve dementia prevalence estimates in Australia?

The Organisation for Economic Co-operation and Development (OECD) estimated that in 2021, the prevalence of dementia in Australia was 13.2 cases per 1,000 population. This estimate is slightly less than the OECD average of 15.0 per 1,000 population, ranking 12th lowest out of 38 countries (OECD 2023).

For data by age, sex, geographic and socioeconomic area, see Prevalence of dementia.

Risk factors

A range of factors are known to contribute to the risk of developing dementia and may affect the progression of symptoms. Some risk factors can’t be changed, such as age, genetics and family history. However, there are health behaviours that can increase or decrease the risk of developing dementia (known as ‘modifiable risk factors’).

High levels of education, physical activity and social engagement are all protective against developing dementia, while obesity, smoking, high blood pressure, hearing loss, depression and diabetes are all linked to an increased risk of developing dementia (Livingston et al. 2017).

For more information about risk factors, see What puts someone at risk of developing dementia?

Impact

Dementia is the second leading cause of death in Australia

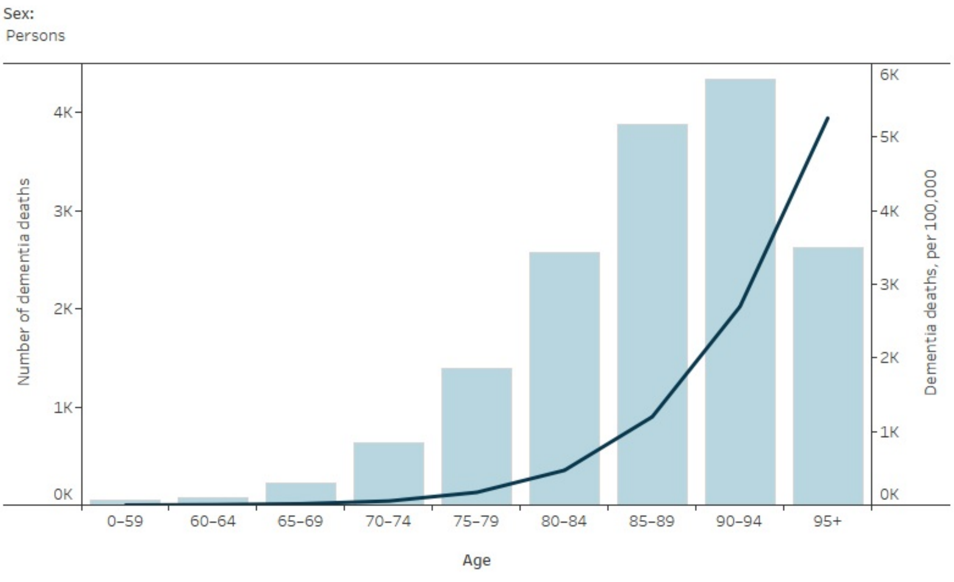
In 2021, dementia was the second leading cause of death in Australia, accounting for just under 15,800 deaths (or 10% of all deaths). Dementia was the leading cause of death for women and the second leading cause for men, after coronary heart disease.

The number of deaths due to dementia increased from 10,780 deaths in 2012 to 15,800 deaths in 2021. The age-standardised rate, which accounts for differences in the age and sex structure of a population, rose between 2012 and 2021, from 38 to 41 deaths per 100,000 Australians. The rate of deaths due to dementia by age and sex was highest among men and women aged 95 and over, reaching just over 4,000 and 5,700 per 100,000 population, respectively (Figure 2).

For more information, see Deaths due to dementia.

Figure 2: Deaths due to dementia: number and age-specific rates, by age and sex, 2021

This figure shows that age-specific death rates increased with age, with women having higher rates than men.



Notes
1. Age-specific rates are expressed per 100,000 population.
2. This analysis is only based on the underlying cause of death and not on associated causes of death.
Source: AIHW analysis of the National Mortality Database.
https://www.aihw.gov.au

Impact of COVID-19 on people with dementia

People with pre-existing chronic conditions, such as dementia, have a greater risk of developing severe illness from COVID-19. Fatal COVID-19 outbreaks have involved many people with dementia. Pre-existing chronic conditions were reported on death certificates for 11,075 deaths due to COVID-19, registered by 30 April 2023 in Australia. Of these deaths, over 30% had dementia (including Alzheimer’s disease) recorded (ABS 2023). COVID-19 was an associated cause of death for a further 677 deaths due to dementia (including Alzheimer’s disease).

For more information on COVID-19 deaths released by the Australian Bureau of Statistics (ABS), see COVID-19 Mortality in Australia: Deaths registered until 31 January 2024.

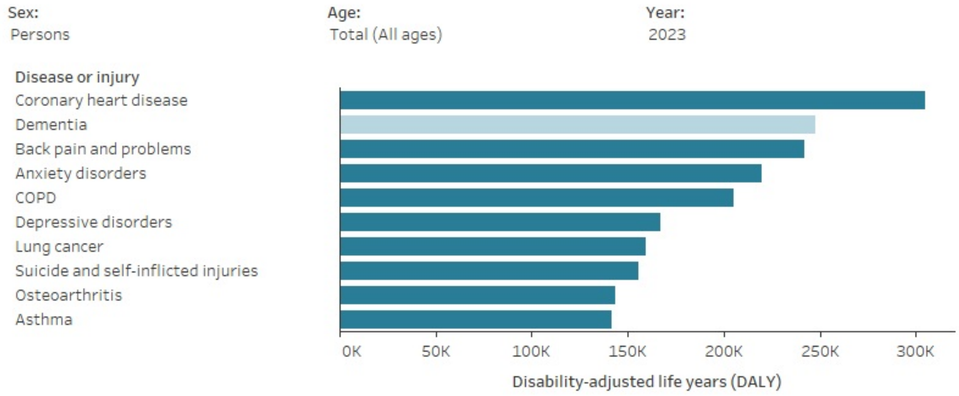
Dementia is a leading cause of burden of disease

Burden of disease refers to the quantified impact of living with and dying prematurely from a disease or injury and is measured using disability-adjusted life years (DALY). One DALY is equivalent to one year of healthy life lost.

Dementia was the second leading cause of burden of disease in Australia in 2023, behind coronary heart disease. However, it was the leading cause of burden for women as well as for Australians aged 65 and over. The total burden of dementia was almost 248,000 DALY, with 59% of burden attributable to dying prematurely and 41% from the impacts of living with dementia (Figure 3).

Figure 3: Leading 10 causes of disease burden (DALY) in Australia, by sex and age, 2015, 2018, 2022 and 2023

This figure shows that dementia was the second leading cause of disease burden in Australia, and was the leading cause of disease burden for women.



Notes
1. COPD refers to Chronic obstructive pulmonary disease.
2. COVID-19 is a disease of the respiratory system, caused by the coronavirus SARS-CoV-2.
3. Conditions that were grouped into residual categories in the Australian Burden of Disease Study 2023 (such as 'Other musculoskeletal conditions') are not included in the rankings.
4. Lower respiratory infections include influenza and pneumonia.
5. Due to rounding, estimates for all persons for some diseases does not equal the sum of male and female estimates.

Source: AIHW Australian Burden of Disease Database http://www.aihw.gov.au

Around 43% of the overall dementia burden in 2018 could have been avoided if exposure to 6 lifestyle risk factors (overweight including obesity, physical inactivity, tobacco smoking, high blood pressure in midlife, high blood plasma glucose levels, and impaired kidney function) were reduced.

For detailed information on burden attributable to specific risk factors, see Burden of disease due to dementia.

Treatment, management and support

Primary health care services

Services provided by general practitioners (GPs) and other medical specialists are crucial in diagnosing and managing dementia. If a GP suspects dementia, they typically refer the patient to a qualified specialist, such as a geriatrician, or to a memory clinic for a comprehensive assessment (Dementia Australia 2020).

How is dementia diagnosed?

There is no single conclusive test available to diagnose dementia, and obtaining a diagnosis often involves a combination of comprehensive cognitive and medical assessments.

Identifying the type of dementia at the time of diagnosis is important to ensure access to appropriate treatment and services. However, there are many forms of dementia with symptoms in common, often making diagnosis a lengthy and complex process involving multiple health professionals – see How is dementia diagnosed?

Data on GP and specialist services across Australia are a major enduring gap for dementia monitoring. However, recent advancements in data linkage have enabled the examination of these services – see Primary health care services.

In 2020–21, around half of all services claimed under the Medicare Benefits Scheme (MBS) by people with dementia were for GP consultations (42% for people in the community and 58% for people living in permanent residential aged care).

The second most common MBS service used by people with dementia were pathology services, accounting for 32% of services among those living in the community, and 29% among those living in permanent residential aged care.

Among people with dementia living in the community, more than 70% of people aged 65–84 years had at least one specialist visit in 2020–21. Specialist attendances including general medicine, geriatric medicine, neurology and psychiatry were more common among people with dementia compared to people without dementia living in the community.

Among people living in permanent residential aged care, specialist and allied health service use was generally lower among people with dementia compared to people without dementia.

For information about patterns of health service use among people with younger onset dementia see Younger onset dementia: new insights using linked data.

Dementia-specific medications

Although there is no cure for dementia, there are 4 medications subsidised through the Pharmaceutical Benefits Scheme and Repatriation Pharmaceutical Benefits Scheme, that may alleviate some of the symptoms and slow the progression of Alzheimer's disease.

In 2021–22, there were over 658,000 prescriptions dispensed for dementia-specific medications to just under 68,700 Australians with dementia aged 30 and over. There was a 51% increase in scripts dispensed for dementia-specific medications between 2012–13 and 2021–22.

People with dementia may experience changed behaviours, such as aggression, agitation and delusions, commonly known as behaviours and psychological symptoms of dementia. Non-pharmacological interventions are recommended to manage these symptoms, but antipsychotic medicines may be prescribed as a last resort.

In 2021–22, antipsychotic medications were dispensed to about one-fifth (20%) of the 68,700 people who had scripts dispensed for dementia-specific medication.

For information on medicine types, see Prescriptions for dementia-specific medications.

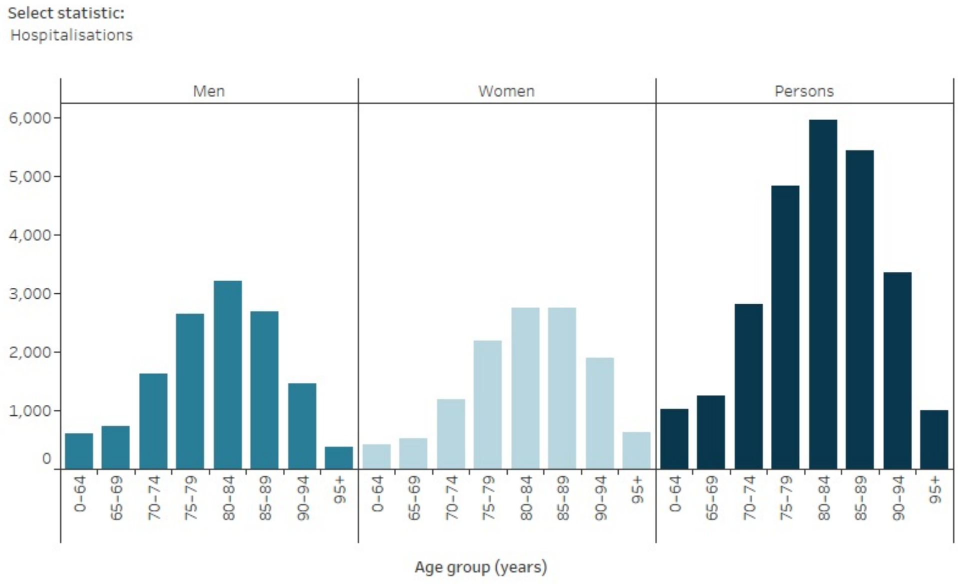
Hospitalisations

In 2021–22, there were more than 11.6 million hospitalisations in Australia (AIHW 2023). Of these, dementia was the main reason for admission for about 25,700 hospitalisations, which is equivalent to 2 out of every 1,000 hospitalisations.

For people with dementia, the average length of stay was more than 5 times as long as the average for all hospitalisations (15 days and 2.7 days, respectively). Of the hospitalisations due to dementia, 63% of patients were aged 75–89, with the number of hospitalisations increasing with age up to 80–84 years, then decreasing in the older age groups (Figure 4).

Figure 4: Hospitalisations due to dementia, by age and sex, 2021–22

This figure shows various measures for hospitalisations due to dementia, including number, rate, bed days and length of stay.



See the technical notes for further information, available at https://www.aihw.gov.au/reports/dementia/dementia-in-aus/contents/technical-notes
Source: AIHW analysis of National Hospital Morbidity Database.
http://www.aihw.gov.au

Data presented in this section refer to hospitalisations *due* to dementia, that is, when dementia was recorded as the principal diagnosis. However, understanding hospitalisations *with* dementia, that is, all hospitalisations with a record of dementia, whether as the principal and/or additional diagnosis, also provides important insights into the wide-ranging conditions that can lead people living with dementia to use hospital services.

For information on hospitalisations with dementia, as well as data by state and territory and dementia type, see Hospital care.

Aged care services

Aged care services are an important resource for both people with dementia and their carers. Services include those provided in the community for people living at home (home support and home care), and residential aged care services for those requiring permanent care or short-term respite stays.

In 2021–22, there were over 242,000 people living in permanent residential aged care, and more than half (54% or about 131,000) of these people had dementia.

For detailed information on the services and initiatives available, see Aged care and support services used by people with dementia.

How do people with dementia access aged care services?

The My Aged Care system coordinates access to a range of government-subsidised services for older Australians who require care and assistance. After an initial screening, an aged care assessment is completed to establish an individual's needs and types of services that may help.

In 2021–22, just over 37,100 Australians who completed an aged care assessment (either a comprehensive or home support assessment) had dementia recorded as a health condition. This equates to 9.3% of people who completed an aged care assessment that year. Of the aged care assessments undertaken by people with dementia, just over 4 in 5 (81%) were comprehensive assessments (for people with complex and multiple care needs).

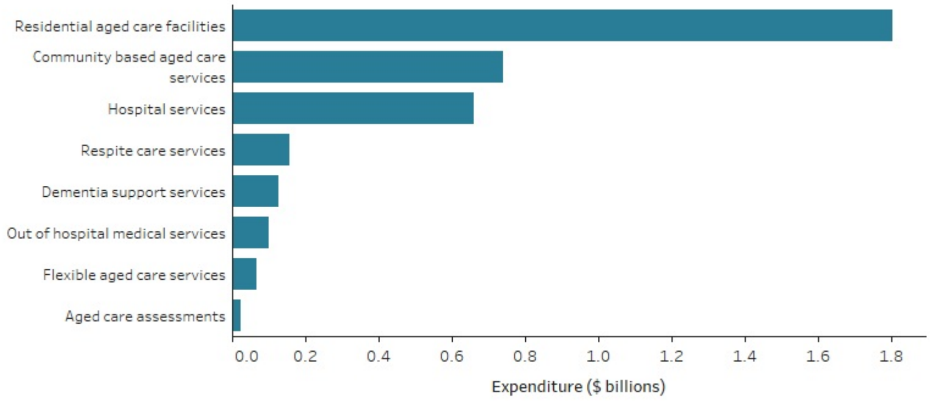
Health and aged care expenditure on dementia

Australia's response to dementia requires economic investment across health, aged care and welfare sectors. It is estimated that almost $3.7 billion of health and aged care spending in 2020–21 was directly attributable to the diagnosis, treatment and care of people with dementia.

Residential aged care services accounted for the largest share of expenditure (49% or $1.8 billion), followed by community-based aged care services (20% or $741 million) and hospital services (18% or $662 million) (Figure 5).

Figure 5: Health and aged care spending directly attributable to dementia by broad service area, 2020–21

This figure shows how the $3 billion dollars of dementia expenditure was divided across 8 broad health and aged care service areas.



Notes
1. 'Respite care services' include residential respite care and community-based respite care.
2. 'Out of hospital medical services' include general practice, diagnostic imaging, specialist, allied health and pathology services as well as pharmaceuticals.
3. 'Flexible aged care services' include the Transition Care Program and the National Aboriginal and Torres Strait Islander Flexible Aged Care program.
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.
Source: See technical notes for data sources and methods used to derive estimates for each of the service areas/programs.
https://www.aihw.gov.au

For detailed information of spending on aged care, health, hospital and support services, see Health and aged care expenditure on dementia.

Carers

The level of care required for people with dementia depends upon individual circumstances, but likely increases as dementia progresses. Carers are often family members or friends of people with dementia who provide ongoing, informal assistance with daily activities.

The AIHW estimates that in 2023 there were at least 140,900 informal primary carers of people with dementia. Among primary carers of people with dementia, 3 in 4 (75%) were female and 1 in 2 (50%) were caring for their partner with dementia.

Caring can be a rewarding role with 38% of primary carers of people with dementia reporting feeling closer to the care recipient.

Caring can also be physically, mentally, emotionally, and economically demanding. According to the ABS Survey of Disability, Ageing and Carers (SDAC) 2018, among carers of people with dementia:

- 1 in 2 (47%) provided an average of 60 or more hours of care per week
- 3 in 4 (76%) reported one or more physical or emotional impacts of the role
- 1 in 4 (23%) reported that they needed more respite care to support them
- 1 in 2 (52%) experienced financial impacts since taking on the role.

Further findings from this survey can be found in Carers and care needs of people with dementia.

Dementia data gaps

Australia's dementia statistics are derived from a variety of sources including administrative data, survey data and epidemiological studies. As each data source has incomplete coverage of people with dementia, it is difficult to accurately report how many Australians are living with dementia. This limits the ability to examine impacts of dementia on individuals with the condition, their carers and support networks, as well as the community and national health and aged care systems more broadly.

For more information, see Dementia data gaps and opportunities and the National Dementia Data Improvement Plan 2023–33.

Diagnosing dementia

Estimating the incidence (new dementia cases in a given period) and prevalence (total cases) of dementia in Australia is vital to evaluating the current and future impacts of the condition, as well as for policy and service planning. There are several factors in the diagnostic process that affect our ability to estimate the number of Australians living with dementia, including:

- an often lengthy diagnosis process for reasons such as not recognising symptoms, a delay in seeking help, limited access to specialists or complexity of diagnostic processes
- no single conclusive diagnostic assessment for dementia
- lack of national GP or specialist data collections with dementia-specific diagnostic information.

There are ongoing efforts to improve the accuracy of these estimates, such as through the utilisation of data linkage, electronic health records and the development of a national dementia clinical quality registry.

Childhood dementias

Around 1% of all dementia diagnoses in Australia are childhood dementia caused by over 70 rare genetic disorders (Childhood Dementia Initiative 2020). Most cases of childhood dementia are fatal before adulthood (Dementia Support Australia 2022).

There are limited data available on childhood dementia both within Australia and internationally. Increased awareness and research of childhood dementia is needed to improve the quality of life for children with dementia.

Impact on health, aged care and social systems

Dementia statistics within Australia are largely sourced from hospital, aged care and cause of death data, likely providing a skewed view towards moderate and severe dementia. There are considerable gaps in primary health care data and data about use of services by people with dementia living in the community. Further, there is a lack of timely data on dementia disease expenditure. Without this information, it is difficult to determine the demand for dementia services and plan for economic costs to health and social systems.

Understanding patient experiences of people with dementia and their carers is important to assess the quality of care within the health and aged care systems. There is a lack of information on these experiences, and improvements are needed to understand these qualitative aspects to improve quality of care and outcomes for those living with dementia.

For more information, see the National Dementia Data Improvement Plan 2023–33.

Carers

There are considerable gaps in national data on carers of people with dementia in Australia. The ABS SDAC 2018 provides the most up-to-date national information on carers. However, this survey is limited to collecting self-reported information from co-resident carers only for people with dementia and, further, likely under-identifies the number of people with dementia (particularly people with mild dementia living in the community). As a result, it is challenging to comprehensively understand how many Australians provide care to people with dementia and what their unmet needs may be.

Dementia in population groups of interest

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 specific population groups are limited and further research is needed.

First Nations people

Among Aboriginal and Torres Strait Islander (First Nations) people, the rate of dementia is estimated to be 3–5 times as high as rates for Australia overall. However, improvements are needed in the representation of First Nations people in key datasets to support better dementia prevalence estimates.

There are also limited data on Indigenous-specific health and aged care services. Improving data in these areas will help to identify how dementia is understood and managed by First Nations people and improve the development of culturally appropriate and effective policies and services.

Due to sampling issues, data on First Nations carers of people with dementia and/or carers of First Nations people with dementia are not available as part of the ABS SDAC.

People from culturally and linguistically diverse backgrounds

For people from culturally and linguistically diverse (CALD) backgrounds, attitudes towards, as well as access to, aged care and support services need to be considered.

Based on the ABS SDAC 2018, 1 in 2 (47%) people with dementia who were born in non-English–speaking countries and were living in the community relied upon informal assistance only (compared to 1 in 3 (30%) people who were born in English speaking countries). This may reflect a preference for informal care or may be due to challenges in accessing suitable services. Gaps in data limit the understanding of how individual CALD communities may differ in their experiences of disease, attitudes surrounding dementia and carers, and access to and utilisation of services.

For information on population groups of interest that may benefit from a more specific focus within dementia care, see Dementia in priority groups.

Where do I go for more information?

- For more AIHW reports on this topic, visit Dementia.
- For detailed dementia statistics, see chapters of Dementia in Australia.
- For dementia information, education, advocacy and resources, see Dementia Australia.
- For support services and information, see Dementia Support Australia.
- For information on ageing and carers from the Australian Bureau of Statistics, see Disability, Ageing and Carers, Australia: summary of findings, 2018.
- For information on the Australian adult population’s attitudes and knowledge of dementia and dementia risk reduction, see Australia’s Dementia Awareness Survey.

References

ABS (Australian Bureau of Statistics) (2019) *Disability, Ageing and Carers, Australia: Summary of Findings, 2018- Explanatory notes*, ABS website, accessed 19 January 2022.

ABS (2023) *COVID-19 Mortality in Australia: Deaths registered until 30 April 2023*, ABS website, accessed 19 June 2023.

AIHW (2023) *Admitted patient care 2021–22: Australian hospital statistics*, AIHW website, accessed 29 June 2023.

Childhood Dementia Initiative (2020) *Childhood Dementia: the case for urgent action*, Childhood Dementia website, accessed 19 January 2022.

Dementia Support Australia (2022) *Childhood Dementia Support*, Dementia Support Australia website, accessed 19 January 2022.

Livingston G, Sommerlad A, Orgeta V, Costafreda SG, Huntley J, Ames D et al. (2017) ‘Dementia prevention, intervention, and care’, *The Lancet*, 390:2673–734, doi:10.1016/S0140-6736(17)31363-6.

OECD (Organisation for Economic Co-operation and Development) (2023) *Health at a Glance 2023: OECD Indicator*, 2023 edn, OECD Publishing, doi:10.1787/19991312.

Australian stories about living with dementia

The following stories are based on interviews with Australians living with dementia and their carers. We would like to thank these people for sharing their stories and Dementia Australia for interviewing these people on behalf of AIHW.

The stories provide a greater understanding of dementia and show the diverse experiences of living with dementia. Click on a story below to learn more about how dementia has impacted their lives.

Carrie's story

A diagnosis of dementia impacts the affected person, as well as their friends and families. When Carrie's husband was diagnosed with younger onset frontotemporal dementia, she became his carer while also raising their young children.

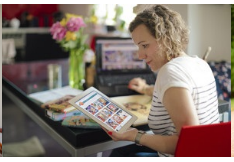
Len's story

Dementia has a deep impact on Aboriginal and Torres Strait Islander communities. After Len was diagnosed with Alzheimer's disease, Len and his partner Sue returned to their family and community in a remote part of Australia.

Martina's story

Living with the early stages of dementia can be challenging. After being diagnosed with Lewy body disease, Martina needed to access home-based support services to help her with daily living, and health services to manage her symptoms.

Lucy's story



Although not as common, dementia also impacts young people. Lucy shares how she is able to continue doing what she enjoys, like studying and being creative, after being diagnosed with a rare genetic form of dementia.

Jim's story

Many people with dementia prefer to live independently in the community. Jim has Alzheimer’s disease and lives at home on his own. When his area went into lockdown due to COVID-19, Jim's family made sure he kept busy during lockdown.

These stories are based on interviews with Australians living with dementia and their carers. To protect the privacy of participants, names and other identifying characteristics have been changed. Images are not representative of the individuals in the stories.

Australian stories about living with dementia

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

A few years ago, her life, and the lives of her family, changed dramatically. She had noticed some changes in her husband's behaviour. He seemed distant with her and their children.

'[It was]…making me question why he wanted to get married and have kids if he didn't seem to have any interest in us, what we were doing or interest in planning anything together. His mum kept saying that he was depressed and needed to see his GP, [but] he denied being depressed. He denied feeling that way and was quite happy and content with how things were going. But I 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 can affects a person's behaviour and moods. On hearing the diagnosis:

'I was shocked. I think I almost vomited on the neurologist and the social worker because it wasn't what I expected, it was worse. I just thought that [condition] would be really, really difficult to manage with a young family. I was worried Dan would become inappropriate around family and friends. He's such a kind person, kind, smart and fun. I thought if he changes so much and that's all people remember him by, that will be devastating.'

> 'And so [after the diagnosis] you leave without a treatment plan. You leave with the number for the NDIS [National Disability Insurance Scheme], and Dementia Australia, and you're told to go home and make the most of it.'

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.'

'… it was the last thing I expected … [I] thought it was going to be another type of dementia or Parkinson's [disease]… not the behavioural variant... to me, that was the worst one.'

People who have the behavioural variant of frontotemporal dementia experience changes in their behaviour, personality and emotional responses. Symptoms vary from person to person. Some people become selfish and start to lack empathy, while others may start exhibiting embarrassing behaviours. Frontotemporal dementia is a progressive and fatal condition. See Understanding dementia for more information on the different types of dementia.

Since his diagnosis, Dan left work and can no longer drive. Carrie says Dan admits in hindsight 'He was probably having some problems with work. So we were lucky with him that we was diagnosed quickly before his performance at work became an issue and he lost his job or … got into strife with doing something wrong at work [due to his behaviour changes].'

For Carrie, life is now a juggling act:

> 'The pressure comes on me being the only driver, being [the] only one to organise everything. So I do all the household management, including finding, booking and organising carers, managing the NDIS, plan holidays, birthdays, Christmas etc. and I work full time.'

'I also do all the school stuff for the kids. So I could complain or I can suck it up. And there's no point sitting in a corner crying, [it] doesn't get me anywhere…I'm just lucky that I was raised to be strong, I guess, and I'm a bit of an organiser. So I just get on with it and the kids are great to have around him … they keep him busy, and they keep him on his toes.' (see Carers of people with dementia for more information on the impact of the caring role).

She took on the caring role because Dan is her husband. 'My vows, it's my wedding vows and, you know, in sickness or health, for better or worse. We also have 2 young children… I want them to see that when you love someone you look after them. I also would not deny him the opportunity to see them for as long as he can and vice versa. Prior to his diagnosis, I contemplated divorce many, many times. Now that we've got a diagnosis, it all makes sense. I need to care for him and give him the life we promised each other when we married.'

Carrie says most people don't understand the type of dementia Dan has.

> '… they're looking at him, that 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 [that] he hasn't said my name in 6 months. They also don't see the lack of initiative, the falls, the choking on food and fluids, the difficulty he has controlling the TV. I think the kids and I probably protect him a bit and make life pretty easy for him.'

Carrie's biggest support network has been her family, Dan's parents, and Dementia Australia.

'After speaking to Dementia Australia, I just was on a high for days, because the things they suggested, things that we discussed, they just make sense.'

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, and at times her life can seem unfair.

'I can't watch families at the park or families hanging out together doing stuff, it makes me feel like I'm missing out on something, and it's no one's fault. I always thought Dan would really shine when the kids were older, as he would take them skiing and bushwalking, all of the activities he loves so much. He can't do that with them anymore.'

But Carries admits they are lucky. They are also financially secure through Dan's income protection insurance and they have access to his superannuation.

'We have 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 …'

> 'When Dan proposed to me, I said to him we will have a lovely life together, we still do. We will continue to have a lovely life together, it's just not going to be forever. The diagnosis has 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 with us and he gets to see the kids do more and more.'

For anyone whose loved one has just been diagnosed with dementia, Carrie advises:

'Get the right people around you. There are people who you just need to let go of in your life because they are not helpful. They may never be helpful! Keep in touch with Dementia Australia. They have the right people, services and advice to help you navigate through this condition. Then you need to be kind to yourself. Remember that you are allowed to lose it sometimes, that's okay. Because it's hard sometimes.'

*****This case study is based on an interview with a carer of a 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. Images are not representative of individuals in the story.

Australian Government
Australian Institute of
Health and Welfare

Australian stories about living with dementia

Len* is an Aboriginal elder from a remote community in central Australia. He has spent most of his adult life working in various remote Aboriginal and Torres Strait Islander communities. He is currently living with Alzheimer's disease.

Len and his partner and carer, Sue*, moved away from their home when their place got too much for them to handle. They moved in with family members and for the next few years, there were 4 generations living in the same household. It was a wonderful time but Len started to miss his country and his people. So he decided to return to his community and live in aged care, while Sue rented a unit nearby. But Len was unsettled.

'Of course [the community] wasn't how he remembered,' Sue said. 'There was only a couple of family members left there, the old people that we particularly worked with had passed and the 2 nephew sons that were there said they had had enough of it and were going to [a regional town].'

Len has since moved out of aged care and is back living with Sue. Together they moved closer to their family as it was too far for them to visit. She says prior to Len being diagnosed with dementia, she had started to notice small changes in his behaviour.

> 'Things that he normally did he suddenly had lost interest in or just wasn't doing any more – like he used to play solitaire on the computer but he stopped doing that. He was quite a good bush mechanic and he stopped doing that.'

Another time he bought a new set of tools when he already had the same set of tools at home. He did that 3 times.

Sue says not being able to read and write has made it a lot more difficult to manage his dementia.

'We can't leave out reminder notes and things like that, like you could with someone that can [read]. And sometimes you think, "Now, is this just cultural stuff or is it the dementia?" Like this morning he is looking at the back with the palm tree and he calls it a pine tree … straight away someone else would probably think, "well that's dementia." But I know that that's what he was doing long beforehand, and it's him muddling up English with his [Indigenous] language a bit. Also he's going back to talking [in his] language more … here at home.'

Sue says that in remote communities' people with dementia tend to be accepted into the community. 'As long as their behaviour wasn't affecting anyone else, it was sort of just ''that's him'', and that's the way they are, and that was accepted.'

'Or anyone whose behaviour becomes a bit bizarre or really abnormal, people would say they are in 'rama rama', meaning they not thinking properly in their heads.'

> 'Most of the ones in the remote areas are still sort of living in the community with families and managing, but not always managing all that well either.'

Sue says Len has 'been seen by an ngankari (a traditional healer) which he likes to see and he has seen them in the past'.

One of the things Len was really missing was sitting down with his own people to chat. ‘That’s something he’s sort of done all his life. Even when he was working, he always went around and sat with the old fellows’. So she got in touch with an Aboriginal community service organisation that provides a meeting place and activities and they now go there twice a week. It’s been an important connection for both of them.

See Dementia among First Nations people for more information on the impact of dementia in Aboriginal and Torres Strait Islander communities.

*****This case study is based on an interview with a carer of an Indigenous 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. Images are not representative of individuals in the story.

Australian stories about living with dementia

Martina* started seeing the first signs of dementia a couple of years ago when it started to affect her ability to drive, which was an important part of her job.

‘I started to forget where I was when I was driving… I was falling, I was tripping, I was just not really being aware of my own self. I didn’t feel like myself.’ About 8–12 months later, she was diagnosed with Lewy body disease – a type of dementia that has similarities with Alzheimer’s disease and Parkinson’s disease. Symptoms of Lewy body disease may include fluctuating mental states, confusion, issues with concentration, difficulty judging distances (which leads to falls), hallucinations and tremors.

Although Martina knew things weren’t quite right, she says family and friends didn’t seem to be aware of it at the time. Martina can no longer drive and had to hand in her licence. Other than that, she and her partner of 15 years live day by day and try not to worry about it too much.

> ‘When I was first diagnosed I thought “Oh that's it I'll be in a nursing home”. But as time goes along I've just learned to cope with it and thought “Ah well if that's the case, I'll just keep going and keep looking forward to the future.”’

Martina lives in a rural part of Australia. She would have to travel to see a specialist, but at this stage she hasn’t needed to. Her local GP is just 5 minutes away and she has no trouble getting an appointment when she needs one.

‘I have great help here and feel well supported... I get help through the NDIS [National Disability Insurance Scheme] and help and support through my home care package as well.’ This includes assistance with day-to-day life, such as house cleaning, as well as help with health services, such as physiotherapy.

Dementia Australia helped to organise the home care package and, for the moment, she is getting the assistance she needs. Home Care Packages provide community-based care to people with greater or more complex care needs (see Aged care and support services for people with dementia for more information on aged care services available to eligible Australians).

‘I’m actually not too worried about it [dementia] any more,’ she says.

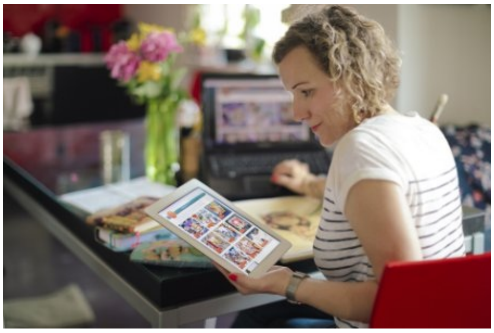
*****This case study is based on an interview with a person who has dementia. This personal account is not necessarily representative of the circumstances of other people with dementia or the challenges they may face, but it is our hope that it will give readers a greater awareness and understanding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

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

Australian stories about living with dementia

Lucy* is in her early 40s and was diagnosed with a rare type of dementia about 2 years ago. She is currently studying and has a background in science and research.

There is a strong link between the type of dementia Lucy was diagnosed with and a family history of dementia, with some people carrying a gene mutation that passes the condition onto their children.



Lucy says many people in her family have been affected by dementia.

’We had seen a lot of people in the family getting dementia and dying from it and we didn't know exactly what it was…until my father went to a research group and they actually [did] the testing…And as soon as I was able to get the testing done…I found out that I also was carrying a mutation.’

Lucy was already beginning to show symptoms when she got the results of the genetic testing, but it took about 9 months to see a neurologist who specialises in dementia and receive a formal diagnosis.

‘As soon as I got to a neurologist that actually understood dementia I got a diagnosis on the spot. [The neurologist] said it was very early. He has never diagnosed anybody with this dementia that early.’

In a lot of ways, Lucy says dementia hasn’t affected her life too much. She is still able to do many of the same things as before – study, get good grades, and do the creative things she enjoys. But it does make some things more difficult.

‘I still have [a] lot of abilities to do things but the biggest issue with me is... stamina. I'm very fine when I first wake up but… towards the end of the day…I just don't have energy left. I can easily get distracted … I come to the end of the day and I haven't started or haven't finished the original task.'

> 'Those type of things [are] very much part of the dementia itself. It’s not as if dementia has completely changed who I am [but] it does add those extra things [that] just makes it a little bit harder. I have to work harder.’

Lucy gets most of the support she needs through the National Disability Insurance Scheme (NDIS).

’Because I’m not in [the] age care age, I am getting the NDIS instead… I have a cleaner come in fortnightly and I have someone do my yard work… I also have support workers who take me to different activities that are outside the distance that I feel safe to drive.‘

The NDIS provides support for people aged under 65 who have a significant, ongoing disability. Through this scheme individuals are provided with funding in order for them to access a range of support services and programs, including supports that assist people with daily personal activities, making home modifications to suit their needs, programs that enable and encourage participation in work or social activities, and funding towards therapeutic services.

Lucy’s mum cares full-time for her dad who also has dementia, so Lucy wanted to get access to NDIS services to relieve some of the pressure on her family.

She says it’s hard to know what the future will hold, or predict what sort of support she might need down the track.

> ’As my dementia progresses I [will] definitely need more help. Having my NDIS plan is good because if something bad comes we can always organise better things or extra things.’

See Aged care and support services for people with dementia for more information on support services available to eligible Australians with dementia.

***** This case study is based on an interview with a person who has dementia. This personal account is not necessarily representative of the circumstances of other 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. Images are not representative of individuals in the story.

Australian stories about living with dementia

Jim* was diagnosed with Alzheimer's disease almost 20 years ago and, with the support of his family and a network of carers and services, is still able to live at home on his own.

His daughter, Ingrid*, says her father has a wonderful team of carers, which has been central to Jim to remain living at home. Keeping Jim physically, mentally and socially active has also been an important factor.

'We are quite fortunate. I think it's partly attributed to my sister being persistent in him keeping involved in activities. We got him into a busier schedule than what he had before.'

> 'He learned bingo, table tennis, exercise class and indoor bowls. We found he's obsessed with Find-A-Word puzzles! It goes to show that you CAN teach an old dog with dementia new tricks!'

Jim's family and carers would often take him out to their local seniors' social club so that Jim could socialise and take part in the clubs' activities. But when Jim's area went into lockdown due to COVID-19, all social club activities were cancelled. During this time, Jim's family devised activities for him to do at home to keep him busy. Lockdowns due to COVID-19 have resulted in rapid declines in cognitive ability, worsening of dementia symptoms and/or onset of new symptoms, and increased rates of depression and anxiety among people with dementia (see this article for more information). Ingrid says keeping Jim active during this time was important for his health and wellbeing.

'I went to the charity shops, I got him puzzles. I got him a bingo thing for home. So, he would call out the numbers himself with someone. We also got board games like Connect 4 and snakes and ladders, and dominoes. And quoits,' Ingrid says.

'We just increased what is available at home… keeping [Jim] active that way. But yes, he has been getting into jigsaws…He got really fixated. He would do them for hours.'

As Jim lives alone he was still able to have formal carers visit during lockdown periods. The family also made sure that Jim was involved with household tasks like emptying the dishwasher, hanging out his washing, checking his letterbox and preparing food.

Ingrid says that when her father was first diagnosed, the biggest challenge was knowing what services are available so that he can remain living at home for as long as possible. As Jim has a Department of Veterans' Affairs (DVA) gold card, they found that he has access to a range of entry level home care services, including domestic assistance, respite care and home and garden maintenance through DVAs programs (see Dementia among veterans for more information on veterans with dementia).

Ingrid says that small changes made to the family home has also greatly improved her dads' independence and quality of life.

'So we've ordered equipment [for Jim] like a rail for his bed…one of those mats with the alarms so when he stands up at night, [the alarm] will tell the carer. They had put in rails like for the stairway, outside… and the front tiles outside, were a bit slippery. So putting a coating on there and painting, you know, white line on the steps… it's been good [for Jim].'

> 'If it gets to the point where he is… needing 24/7 care…or he is more bed bound, and we can't handle it, and we can't get carers to come to his house, then there is the different version of a residential aged care we will try to find for him, where they only have about 5 clients and it's more like a normal house.'

When Jim was first diagnosed, Ingrid says learning more about their fathers' condition was helpful.

'So we [my sisters and I], back in the early days, we did a course [on dementia]. The elderly person had their group and then we went with the carers group… [It was] good learning more about dementia.'

*****This case study is based on an interview with a family member of a person with Alzheimer's disease, which is the most common form of dementia. This personal account is not necessarily representative of the circumstances of other 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.

Understanding dementia

Dementia is not a single specific disease, but rather there are many types of dementia with symptoms in common. These are caused by a range of conditions impacting brain function. It is commonly associated with memory loss but can affect speech, cognition, emotional control, behaviour and mobility (WHO 2023).

Identifying the type of dementia at the time of diagnosis is important to ensure the person receives appropriate treatment and services, and to be better informed about their condition, treatment options and prognosis. However, it is not always straight forward to correctly diagnose the type of dementia based on a person’s symptoms (see How is dementia diagnosed? for more information). If you would like any more information about any of the types of dementia listed in this section, see the Dementia Australia website.

The most common types of dementia include:

- Alzheimer’s disease – a degenerative brain disease caused by nerve cell death resulting in shrinkage of the brain.
- Vascular dementia – mainly caused by haemodynamic (blood flow to the brain) disorders (for example, strokes), thromboembolism (small blood clots that block small blood vessels in the brain), small blood vessel disease in the brain and bleeding into or around the brain.
- Dementia with Lewy bodies – caused by the 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 – caused by progressive damage to the frontal and/or temporal lobes of the brain (Dementia Australia 2022; Draper 2013).

For information on the less common types of dementia, see Less common dementias.

It is common to have multiple types of dementia at once – known as ‘mixed dementia’ – with the most common combination being Alzheimer’s disease and vascular dementia. An increased risk of developing dementia is also linked to the presence of other conditions (such as Parkinson’s disease, Huntington’s disease and Down syndrome), prolonged substance abuse and traumatic brain injuries.

Irrespective of the type of dementia, a person with dementia will experience declining health and ability to live independently. However, the progression of dementia varies considerably from person to person. As the condition progresses, a person with dementia will require increasing care, eventually in all aspects of daily living.

The likelihood of developing dementia increases with age, however, dementia is not an inevitable or normal part of the ageing process. Dementia can also develop in people aged under 65, referred to as ‘younger onset dementia’. There is currently no cure for dementia but there are strategies to manage dementia symptoms that can assist in maintaining independence and quality of life for as long as possible.

Need more information?

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
- The Dementia Guide by Dementia Australia
- 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)
- My Aged Care (for information on, and applying for access to government-subsidised aged care services).

References

Dementia Australia (2022) *Types of dementia*, Dementia Australia website, accessed 5 September 2023.

Draper B (2013) *Understanding Alzheimer's disease and other dementias*, Jessica Kingsley Publishers, London.

WHO (World Health Organization) (2023) *Dementia*, WHO website, accessed 22 February 2024.

Understanding dementia

There are a number of factors that can increase a person's likelihood of developing dementia. Some risk factors can be avoided or reduced (known as 'modifiable risk factors') and others cannot be changed (known as 'non-modifiable risk factors'). As there is currently no cure for dementia, minimising modifiable risks is currently the best way to prevent dementia (Livingston et al. 2020; Prince et al. 2014). Having one or more of these risks factors does not mean you will definitely develop dementia, rather it increases the individual chance of dementia developing.

Non-modifiable risk factors

Ageing is the main risk factor for dementia. While dementia can occur in people aged under 65, the risk of developing dementia doubles every 5 or 6 years for people aged over 65. However, it is not known whether or not this increasing risk continues at the same rate past the age of 90 due to challenges with diagnosis in this age group – more research is required (Corrada et al. 2010; Gardner et al. 2013; Slavin et al. 2013). Other non-modifiable risk factors for dementia include: a family history of the condition, and other genetic mutations or variations (namely, the apolipoprotein E (APOE) ε4 gene and Down syndrome). For more information on dementia among people with Down syndrome, see Dementia among people with intellectual disabilities.

Modifiable risk factors

Modifiable risk factors for dementia include a number of cardiovascular and lifestyle factors (often associated with other chronic diseases) as well as a number of social factors. For certain risk factors, a person's age when exposed to that risk plays a role in their likelihood of developing dementia. For other risk factors, it does not matter when a person is exposed – the level of increased risk remains the same.

It is estimated that 40% of new cases of dementia could be avoided if the majority of the modifiable risk factors for dementia were eliminated (Livingston et al. 2020). Additionally, a 20% reduction in exposure to 7 key risk factors – diabetes, hypertension in midlife, obesity in midlife, physical inactivity, depression, smoking, and low educational attainment – could lead to a 15% reduction in the prevalence of Alzheimer's disease by 2050 (Norton et al. 2014).

Modifiable risk factors recognised as having strong evidence for their association with increased risk of developing dementia include:

- low levels of education in early life
- obesity in midlife
- hypertension in midlife
- hearing loss in midlife
- tobacco smoking
- excessive alcohol consumption
- physical inactivity
- high cholesterol
- high levels of homocysteine – an amino acid produced when proteins are broken down
- atrial fibrillation
- diabetes
- depression
- social isolation
- air pollution
- traumatic brain injury (Anstey et al. 2019; Livingston et al. 2020).

Further information on the dementia burden in Australia due to a number of modifiable risk factors is described in Dementia burden due to risk factors.

There are a number of other risk factors that may be associated with an increased risk of developing dementia. However, the evidence of association is weaker than for the risk factors listed above. They include various lifestyle and biomedical factors (such as prolonged stress, diet, inadequate sleep and various health conditions) and environmental risks (Anstey et al. 2019). Further research is needed to determine if these are associated with an increased risk of dementia.

Protective factors

The World Health Organization has developed recommendations on the types of interventions that should be adopted to reduce risks associated with cognitive decline and dementia. These include a number of cognitive, behavioural, social and pharmacological interventions aimed at improving health overall and reducing exposure to known modifiable risk factors associated with dementia (WHO 2023).

Protective factors for dementia include:

- undertaking regular physical activity and eating a healthy, balanced diet
- maintaining a healthy weight
- quitting smoking and reducing alcohol intake

- maintaining an active social life
- keeping mentally stimulated
- managing other health conditions, such as hypertension, hearing loss, diabetes and depression (WHO 2019).

A person at any age can reduce their risk of developing dementia (and other health conditions) by making some or all of these lifestyle changes. As further research on risk factors for dementia is undertaken, the list of recognised risk and protective factors will be updated.

Assess your dementia risk

Dementia Australia provides further information and a range of resources on reducing your risk of dementia.

Researchers at The University of NSW (UNSW) and Neuroscience Research Australia (NeuRA) have developed the Cognitive Health and Dementia Risk Assessment Tool (CogDrisk) which uses the latest evidence to help people understand their dementia risk profile. The Cognitive Health and Dementia Risk Assessment only takes 20 minutes to complete and provides you with an individualised report that can be discussed with your doctor.

References

Anstey K, Ee N, Eramudugolla R, Jagger C and Peters R (2019), 'A systematic review of meta-analyses that evaluate risk factors for dementia to evaluate the quantity, quality and global representativeness of evidence', *Journal of Alzheimer's Disease,* 70:S165–S186, doi:10.3233/JAD-190181.

Corrada MM. Brookmeyer R, Paganini-Hill A, Berlau D and Kawas CH (2010) 'Dementia incidence continues to increase with age in the oldest old: the 90+ study', *Annals of Neurology,* 67(1):114–21, doi:10.1002/ana.21915.

Gardner RC, Valcour V and Yaffe K (2013) 'Dementia in the oldest old: a multi-factorial and growing public health issue', *Alzheimer's Research & Therapy,* 5:27, doi:10.1186/alzrt181.

Livingston G, Huntley J, Sommerlad A, Ames D, Ballard C, Banerjee S et al. (2020) 'Dementia prevention, intervention, and care: 2020 report of the Lancet commission', *The Lancet Commission,* 396(10248):413-446, doi:10.1016/S0140-6736(20)30367-6.

Norton S, Matthews FE, Barnes DE, Yaffe K and Brayne C (2014) 'Potential for primary prevention of Alzheimer's disease: an analysis of population-based data', *Lancet Neurology,* 13(8):788–794, doi:10.1016/S1474-4422(14)70136-X.

Prince M, Albanese E, Guerchet M and Prina M (2014) *World Alzheimer report 2014 – dementia and risk reduction: an analysis of protective and modifiable factors*, Alzheimer's Disease International, accessed 10 July 2023.

Slavin MJ, Brodaty H and Sachdev PS (2013) 'Challenges of diagnosing dementia in the oldest old population', *Journal of Gerontology Series A: Biological Sciences and Medical Sciences,* 68(9):1103–1111, doi:10.1093/gerona/glt051.

WHO (World Health Organization) (2019) *Risk reduction of cognitive decline and dementia: WHO guidelines*, WHO website, accessed 22 February 2024.

WHO (2023), *Dementia*, WHO website, accessed 22 February 2024.

Understanding dementia

It is important to diagnose dementia early, as it allows for timely access to information and advice, medical management and support services. An early diagnosis also allows for future planning of care options, living arrangements and sorting of legal and financial affairs. However, early symptoms of dementia are often either not recognised, attributed to being a 'normal' part of ageing or may be denied by the person experiencing the symptoms, or by their family and carers.

There is no single conclusive test available to diagnose dementia. As such, obtaining a diagnosis is also often a long process and involves comprehensive cognitive and medical assessments. The time taken to receive a confirmed diagnosis may also vary according to the person's symptoms and who is conducting the assessments.

There is no single pathway to obtaining a diagnosis. However, a visit to a general practitioner (GP) is often the first step. According to Dyer et al. (2016), based on the Clinical practice guidelines and principles of care for people with dementia in Australia, GPs are recommended to undertake an initial assessment for a person suspected of having dementia. For more information on the process of diagnosing dementia see Diagnosing dementia | Dementia Australia.

Progression of dementia

Symptoms of dementia vary from person to person, and for individuals, from day to day. There are also particular symptoms associated with certain types of dementia. However, in all cases the progressive nature of dementia will eventually result in cognitive and physical decline. The rate of decline will vary due to personal characteristics (age, number and type of other co-existing conditions), type and severity of dementia, age at diagnosis and the person's environment (such as care and living arrangements and access to health services).

Due to the variations in symptom presentation and progression, there are many models used to classify dementia severity. However dementia progression can often be grouped into 3 stages (mild, moderate and advanced dementia).

Mild dementia

Mild dementia is defined by cognitive impairment and poor performance on objective cognitive assessments that represent a decline from the past. However, as opposed to more severe forms of dementia, the person retains independence in basic activities of daily living.

The onset of symptoms may be gradual and can include:

- forgetfulness and confusion
- irritability and appearing more apathetic
- poor judgement and decision making
- disinterest in activities
- vision or speech problems
- behavioural changes
- a decline in higher order or more complex activities of daily living such as understanding finances, planning, and organisation.

As signs are subtle, dementia may not be recognised or instead be attributed to old age.

Moderate dementia

Symptoms in this stage are more distinct and impact on instrumental activities of daily living such as driving and preparing meals. In addition to the symptoms in mild dementia, symptoms for moderate dementia may include:

- increased forgetfulness and confusion
- inappropriate or uncharacteristic behaviours
- increased fear and paranoia.

These experiences often cause distress for the person with dementia, and their family and friends.

Advanced dementia

This is the final stage in which health and functional ability decline and the person becomes dependent on others for activities of daily living (for example dressing, bathing and toileting).

The person may experience:

- severe memory loss
- problems with communication
- difficulty swallowing
- incontinence
- decreased mobility or complete immobility in the final months or weeks of life.

Most people in advanced stages of dementia require extensive care, often from permanent residential aged care services.

References

Dyer SM, Laver K, Pond CD, Cumming RG, Whitehead C and Crotty M (2016) 'Clinical practice guidelines and principles of care for people with dementia in Australia', *Australian Family Physician*, 45(12):884–889.

Understanding dementia

Dementia can manifest as a symptom of other diseases, infection or injury.

The number of people in Australia living with these less common types of dementia is not known. There are some data on hospitalisations and deaths where rarer dementia types are recorded, however, these are limited and should be interpreted with caution as coding of dementia type can be inconsistent and can vary by region of residence (AIHW 2023b; Waller et al. 2021).

Parkinson's disease dementia

Parkinson's disease, Parkinson's disease dementia, and dementia with Lewy bodies are three overlapping disorders that are forms of Lewy Body disease. They share similarities in the ways by which they damage the brain at the cellular level and in the symptoms a person may experience. For more information, see Lewy body disease.

Globally, the prevalence of Parkinson's disease has been increasing (GBD 2016 Neurology Collaborators 2019) and an estimated 20%–40% of people with Parkinson's disease also have dementia (Åström et al. 2022).

In Australia:

- prevalence estimates for Parkinson's disease vary widely (Deloitte Access Economics 2015; Parkinson's NSW 2024)
- in 2021, among people who had dementia recorded as an associated cause of death, *Parkinson's disease* was the leading underlying cause of death (UCOD) for men aged 65–74, and the fourth leading UCOD overall (almost 830 people)
- between 2003 and 2023, the rate of fatal burden of disease (years of life lost) due to Parkinson's disease increased by 57% for men and 24% for women (AIHW 2023a)
- *Dementia in Parkinson's disease* was recorded as the dementia type in 1.7% of hospitalisations due to dementia (2.4% for men, 1.0% for women) in 2021–22
- *Lewy Body dementia* was recorded as the dementia type in 2.6% of hospitalisations due to dementia (3.3% for men, 1.8% for women) in 2021–22.

See Hospitalisations by type of dementia and Leading underlying causes of death.

Dementia due to the effect of alcohol and other substances

The use of alcohol and other harmful substances can have long-term impacts on brain health (Dementia Australia 2018). In 2021–22, *Dementia due to the effect of substances* was recorded as the dementia type in 1.1% of hospitalisations due to dementia (1.6% for men, 0.6% for women).

For more information, see Alcohol related dementia.

Huntington's disease

Huntington's disease is an inherited genetic condition that progressively affects the nervous system and causes dementia. It can occur at any age, but people usually start experiencing symptoms in young-middle aged adulthood. For more information, see Huntington's disease.

According to a recent Australian report (Layton and Brusco 2020):

- the prevalence rate of Huntington's disease was estimated at 8.4 per 100,000 people (about 2,160 people)
- about 830 people diagnosed with Huntington's disease were receiving a National Disability Insurance Scheme (NDIS) package on 31 December 2019
- about 40 people with Huntington's disease moved into permanent residential aged care per year between 2013–14 and 2017–18.

Due to low numbers, *Dementia in Huntington's disease* is currently grouped under *Other dementias* in the Dementia in Australia data. Work is underway to provide more detailed data where possible.

HIV associated dementia

The human immunodeficiency virus (HIV) can infect brain cells, causing cognitive impairment. The most severe form of impairment is called HIV associated dementia. Since the introduction of combination antiretroviral therapy, HIV associated dementia is rare in high income countries, affecting 2–8% of people living with HIV (Saylor et al. 2016).

For more information, see HIV associated dementia.

Due to low numbers, *Dementia in HIV* is currently grouped under *Other dementias* in the Dementia in Australia data. Work is underway to provide more detailed data where possible.

Creutzfeldt-Jakob disease

Creutzfeldt-Jakob disease (CJD) is a very rare degenerative brain disease that causes dementia. CJD usually develops spontaneously (called sporadic CJD), but other forms of the disease can be genetically inherited or acquired from external sources.

For more information, see the CJD Support Group Network.

CJD is the most common of the human prion diseases. In Australia, an average of 35 new cases of human prion disease were reported each year between 1993 and 2022 (Stehmann et al. 2023). There has been an increase in the number of cases of sporadic CJD reported over time, likely due to a combination of an ageing population and improved detection.

Due to low numbers, *Dementia in CJD* is currently grouped under *Other dementias* in the Dementia in Australia data. Work is underway to provide more detailed data where possible.

Chronic Traumatic Encephalopathy dementia

Chronic Traumatic Encephalopathy (CTE) is a type of dementia caused by repeated head injuries. These injuries may occur while playing sport, or through other forms of head impact such as violent assault, family and domestic violence, frequent falls, or during military service.

For more information, see Chronic Traumatic Encephalopathy dementia.

There is a lack of data on the prevalence and impact of CTE and its causes. Data development initiatives include the National Sports Injury Data Strategy, the Australian Sports Brain Bank and the Australian Veterans Brain Bank.

Childhood dementia

Childhood dementia results from progressive brain damage and is caused by over 100 rare genetic disorders (Elvidge et al. 2023). Collectively, childhood dementia has an estimated incidence rate of 84.3 per 100,000 births (1 in 2,900 births) and an expected prevalence rate of 5.3 per 100,000 persons in high and upper-middle income countries (Elvidge et al. 2023).

For more information, see the Childhood Dementia Initiative.

Data on childhood dementia are not currently reported in Dementia in Australia. Work is underway to address this data gap.

References

Åström D, Simonsen J, Raket L, Sgarbi S, Hellsten J, Hagell P, Norlin JM, Kellerborg K, Martinez-Martin P and Odin P (2022) 'High risk of developing dementia in Parkinson's disease: a Swedish registry-based study', *Scientific Reports*, 12(1):16759, doi:10.1038/s41598-022-21093-8.

AIHW (Australian Institute of Health and Welfare) (2023a) *Australian Burden of Disease Study 2023*, AIHW, Australian Government, accessed 13 February 2024.

AIHW (2023b) *Geographical variation in health service use by people living with dementia*, AIHW, Australian Government, accessed 12 February 2024.

Deloitte Access Economics (2015) *Living with Parkinson's disease: an updated economic analysis*, Parkinson's Australia, accessed 12 February 2024.

Dementia Australia (2018) *Think ahead – harmful substance use and the brain*, Dementia Australia, accessed 13 February 2024.

Elvidge K, Christodoulou J, Farrar M, Tilden D, Maack M, Valeri M, Ellis M, Smith NJC and the Childhood Dementia Working Group (2023) 'The collective burden of childhood dementia: a scoping review', *Brain*, 146(11):4446–4455, doi:10.1093/brain/awad242.

GBD 2016 Neurology Collaborators (2019) 'Global, regional, and national burden of neurological disorders, 1990–2016: a systematic analysis for the Global Burden of Disease Study 2016', *Lancet Neurology*, 18(5):459–480, doi:10.1016/S1474-4422(18)30499-X.

Layton N and Brusco N (2020) *Peer support for the Huntington's community... by the Huntington's community, 'Huntington's Community Connect' Part 1: Gap Analysis Report*, Monash University, accessed 12 February 2024.

Parkinson's NSW (2024) *What is Parkinson's?*, Parkinson's NSW website, accessed 12 February 2024.

Saylor D, Dickens A, Sacktor N, Haughey N, Slusher B, Pletnikov M, Mankowski J, Brown A, Volsky D and McArthur J (2016) 'HIV-associated neurocognitive disorder – pathogenesis and prospects for treatment', *Nature Reviews Neurology*, 12(4), 234–248, doi:10.1038/nrneurol.2016.27.

Stehmann C, Senesi M, Sarros S, McGlade A, Lewis V, Eller L, Barber D, Simpson M, Klug G, McLean C, Masters C and Collins S (2023) 'Creutzfeldt-Jakob disease surveillance in Australia: update to 31 December 2022', *Communicable Diseases Intelligence*, 47, doi:10.33321/cdi.2023.47.37.

Waller M, Buckley R, Masters C, Nona F, Eades S, Dobson A (2021) 'Deaths with Dementia in Indigenous and Non-Indigenous Australians: A Nationwide Study', *Journal of Alzheimer's Disease*, 81(4):1589–1599, doi:10.3233/JAD-201175.

Understanding dementia

Ongoing management and support for people with dementia as well as their family, friends and carers is essential. Management is based on treating symptoms through a combination of interventions aimed at maintaining quality of life and promoting and maintaining functional and social independence. Refer to Aged care and support services used by people with dementia for more information on the variety of services available to people with dementia and their family, friends and carers.

Upon diagnosis, health and aged care professionals are recommended to provide people with dementia and their family/friends/carers with further information to ensure they are equipped with the correct information to make suitable arrangements. This includes discussing dementia resources and support services, as well as the implications of dementia on a person's financial and legal decision making (including enduring guardianship, power of attorney and development of advance care plans) (Dyer et al. 2016).

There are a number of interventions which do not involve medications (referred to as non-pharmacological interventions) to manage dementia and maximise quality of life, with the adoption of these based on the individual's ability, preferences and access to services. These include: implementing care management plans tailored to the individual (person-centred care models); providing cognitive and behavioural training and therapies (including alternative therapies such as music or animal-assisted therapies); rehabilitation and re-enablement (the process of a person regaining skills, confidence and independence); engaging in physical and social activities tailored to people with dementia; and designing and modifying homes and communities that support independence. There is still little research and evidence on the impact and effectiveness of non-pharmacological interventions to manage dementia.

People diagnosed with Alzheimer's disease may be prescribed dementia-specific medications to treat their symptoms, which are subsidised by the Australian Government through the Pharmaceutical Benefits Scheme (PBS). Other types of medications may be used to treat a number of behavioural and psychological symptoms of dementia (such as depression or agitation) (Dyer et al. 2016). Information on dispensing patterns of dementia specific medications is detailed in Prescriptions for dementia-specific medications.

Promoting a healthy lifestyle through a balanced diet and suitable exercise, as well as ongoing management of other health conditions are also recommended to assist in maximising quality of life and functional independence.

Need more information?

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
- The Dementia Guide by Dementia Australia
- 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)
- My Aged Care (for information on, and applying for access to government-subsidised aged care services).

References

Dyer SM, Laver K, Pond CD, Cumming RG, Whitehead C and Crotty M (2016) 'Clinical practice guidelines and principles of care for people with dementia in Australia', *Australian Family Physician*, 45(12):884–889.

Population health impacts of dementia

It is vital for health-care professionals and policymakers to understand how many people are living with, and dying from dementia in Australia, and how this may vary for different subgroups of the population. This information enables better policy and service planning for the current and future impact of dementia on the health of Australians and Australia's health-care, aged care and social systems.

The following pages present statistics and information on:

- Prevalence of dementia (number of people with dementia)
- Incidence of dementia (number of new cases of dementia)
- Deaths due to dementia (where dementia was the underlying cause of death)
- Dying *due* to dementia compared to dying *with* dementia
- Burden of disease due to dementia
- Dementia burden due to risk factors.

These pages also present the current data landscape for reporting on the population health impact of dementia and ways this may be improved in the future.

Refer to the Prevalence data tables, Mortality data tables and Burden of disease data tables for the underlying data presented in these pages.

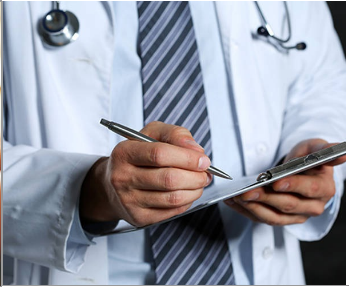
See Dementia in priority groups for more information on the population health impacts of dementia among different population groups, including among First Nations people and people from culturally and linguistically diverse backgrounds.

Key statistics

In 2023, it was estimated that **411,100** Australians were living with dementia

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

Dementia was the **second leading cause of death** in Australia in 2021, accounting for 10% of all deaths that year



Dementia was the **second leading cause of disease burden** in Australia in 2023, behind coronary heart disease

Australian Government
Australian Institute of
Health and Welfare

Population health impacts of dementia

Key statistics

It is estimated that **411,100** Australians were living with dementia in 2023

2 in 3 people with dementia are thought to be **living in the community**

The number of Australians with dementia is projected to more than **double by the year 2058**

There are ongoing efforts to improve the accuracy of estimates of the number of Australians with dementia

It is estimated that in 2023 there were 411,100 Australians living with dementia. However, the exact number of people with dementia is currently not known as there is no single authoritative data source for deriving dementia prevalence in Australia.

This page presents dementia prevalence, as estimated by the Australian Institute of Health and Welfare (AIHW):

- by sex and age in 2023
- by place of residence in 2022 (that is, living in the community versus living in cared accommodation)
- for each year between 2024 and 2058
- by states/territories, remoteness, socioeconomic and small geographic areas in 2022.

It also presents how the prevalence rate of dementia in Australia compares with other countries.

Expand the headings below for information on the available data sources and methodologies to estimate dementia prevalence. Refer to the Prevalence data tables for the underlying data presented in this page.

See Population health impacts of dementia among First Nations people and Dementia among people from culturally and linguistically diverse backgrounds for more information on the challenges involved in estimating dementia prevalence among these groups.

What data are currently available for reporting on dementia prevalence?

Australia’s dementia statistics are derived from a variety of data sources of varying quality, including administrative data (such as data on medications dispensed, hospital visits, aged care services, and causes of death), survey data (such as the Australian Bureau of Statistics (ABS) Survey of Disability, Ageing and Carers (SDAC)) and epidemiological studies (both Australian and international). As each data source has incomplete coverage of people with dementia, major studies have used a number of different approaches to estimate the prevalence of dementia in Australia. For example:

- The *Economic cost of dementia* report by the National Centre for Social and Economic Modelling estimated dementia prevalence using a pooled data set of Australian longitudinal studies for people aged 65 and over, which included cases of ‘probable dementia’ and mild cognitive impairment (Anstey et al. 2010; Brown et al. 2017). This resulted in an estimated 413,000 people living with dementia in Australia in 2017, higher than what was estimated by AIHW for the same year.
- The 2019 Global Burden of Disease Study estimated dementia prevalence through a systematic review of surveys and epidemiology studies, as well as administrative data. An updated literature review for the period 2016–2017 found 38 new studies were in scope for calculating prevalence of dementia at the global, regional, and country level (GBD 2019). This resulted in an estimated 301,000 people living with dementia in Australia in 2017, lower than what was estimated by AIHW for the same year.

Given the wide range of dementia prevalence estimates reported, improvements in dementia data are needed to truly understand the number of people with dementia in Australia.

What methods were used to estimate dementia prevalence for this report?

Taking into consideration the strengths and limitations of available data sources and methodologies, the AIHW has produced revised dementia prevalence estimates for Australia. Our approach in this report is based on the methodology used in the AIHW 2012 *Dementia in Australia* report to estimate prevalence but has incorporated new data. The prevalence of dementia among Australians aged 60 and over was estimated using data from a systematic review of worldwide dementia prevalence conducted by Alzheimer's Disease International for the *World Alzheimer report 2015* (ADI 2015). Prevalence estimates for those aged under 60 were derived from a recent Australian study (Withall et al. 2014). Therefore, the dementia prevalence estimates presented in this report supersede those published by AIHW in the 2012 *Dementia in Australia* report. See Methods for more details on the methodology used to calculate dementia prevalence estimates.

What is being done to improve dementia prevalence estimates in Australia?

There are ongoing efforts to improve the accuracy of dementia prevalence estimates in Australia. As a result, the approach used to estimate the prevalence of dementia in this report will likely be superseded in coming years as findings from these initiatives become available. See *3: Dementia prevalence and incidence* of the National Dementia Data Improvement Plan 2023–2024 for information on current developments and future activities aimed at improving dementia prevalence data.

How many people have dementia in Australia?

The AIHW estimates that in 2023 there were around 411,100 people living with dementia in Australia, including nearly 257,500 women and 153,700 men. This is equivalent to 15 people with dementia per 1,000 Australians (19 per 1,000 women and 12 per 1,000 men).

New health condition question in the 2021 Census

In the 2021 Census, a new long term health condition question was asked, which captured whether a person had one or more of a select group of health conditions. One of these select conditions was dementia (including Alzheimer's).

For the purposes of the census, long-term conditions are conditions that:

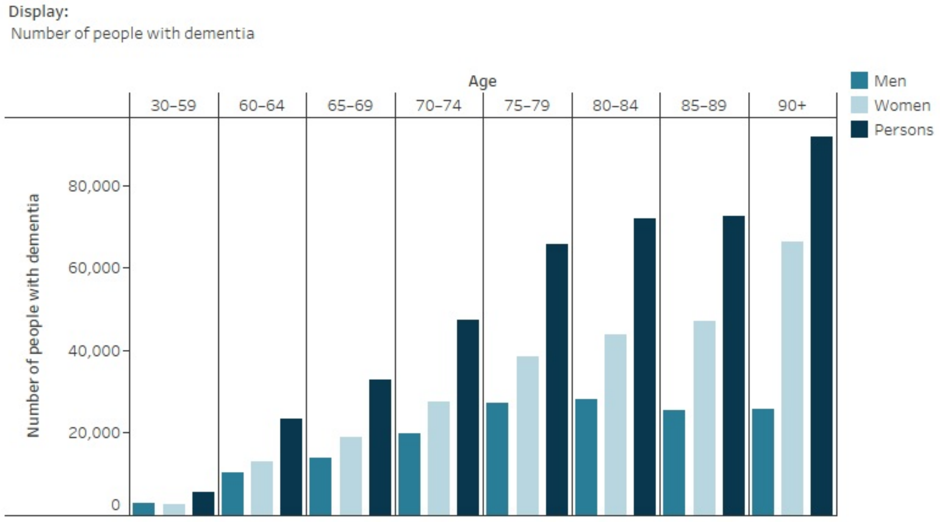
- the respondent has been told they have by a doctor or nurse
- have lasted, or are expected to last, for 6 months or more
- may recur from time to time
- are controlled by medication, or
- are in remission (ABS 2022).

The first results of the census were released on 28 June 2022, and they showed that 189,162 people living in Australia self-reported a dementia diagnosis (78,154 males and 111,003 females). While the ABS advises that their health surveys (the National Health Survey and the National Aboriginal and Torres Strait Islander Health Survey) continue to capture the prevalence of these conditions more accurately, work has commenced to better understand how the new census estimate aligns with other dementia diagnosis information, as well as how these data can be used to improve how we understand and monitor dementia prevalence in Australia.

The rate of dementia rises quickly with age – from less than one person with dementia per 1,000 Australians aged under 60, to 71 per 1,000 Australians aged 75–79, and then to 429 per 1,000 Australians aged 90 and over. Interestingly, the rates are similar for men and women in the younger age groups, but quickly diverge with increasing age. For the oldest age group, the rate of dementia among women is 1.4 times the rate of men (479 per 1,000 women and 337 per 1,000 men) (Figure 2.1).

Figure 2.1: Prevalence of dementia in 2023: estimated number and rate, by age and sex

Bar chart shows that the number of people with dementia and the rate of dementia both increase with age. The rate of dementia is higher in women than men in each age group, with the difference greatest among those aged 90 and over.



Note: The AIHW dementia prevalence rates were applied to the ABS 2023 June 30 estimated resident population (ERP).
Source: The AIHW estimates were derived using prevalence rates from the 2015 World Alzheimer report and Withall et al. 2014.
http://www.aihw.gov.au

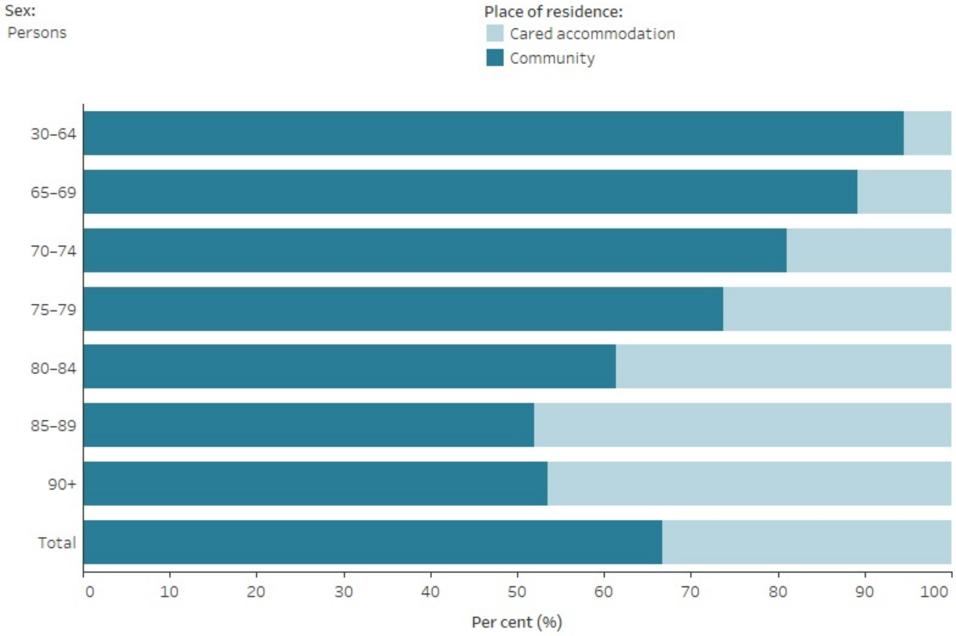
67% of people with dementia live in the community

Based on AIHW estimates, there were an estimated 267,700 people with dementia living in the community (as opposed to cared accommodation) in 2022 (102,200 men and 165,500 women). This equates to 67% of all people with dementia living in the community (68% of men and 66% of women with dementia) (Figure 2.2).

As people with dementia age, they are more likely to move into residential aged care homes and so the proportion living in the community decreases with increasing age. The majority of people with younger onset dementia (aged less than 65) were living in the community (95% or 26,900 people). Among the older age groups, just over half of people with dementia lived in the community (52% of people with dementia aged 85–89 or 36,400 people and 54% aged 90 and over, or 49,300 people). This decrease was more substantial among women than men.

Figure 2.2: Australians living with dementia in 2022: estimated percentage by age, sex and place of residence

Stacked bar graph shows that younger people with dementia are more likely to live in the community, while older people with dementia are more likely to live in cared accommodation.



Note: Cared accommodation includes people in hospitals, residential aged care facilities, aged care hostels, cared components of retirement villages and other 'homes', such as a group home for people with disability.
Source: The AIHW estimates were derived using prevalence rates from the 2015 World Alzheimer report and Withall et al. 2014, and AIHW analysis of 2021–22 Aged Care Funding Instrument data and the ABS 2018 Survey of Disability, Ageing and Carers confidentialised unit record file.
http://www.aihw.gov.au

It is often assumed that people with dementia require care at all times. However, with the appropriate help and support, people with dementia can live independently in their own home, often until their dementia has advanced and care needs become greater.

According to the Survey of Disability, Ageing and Carers (SDAC), of the people with dementia who lived in the community in 2018, 86% lived in private dwellings with other people, while 14% lived alone. Men were more likely to have been living with other people (91%) than women (81%) (Table S2.3). Further information on the SDAC can be found in the Technical notes.

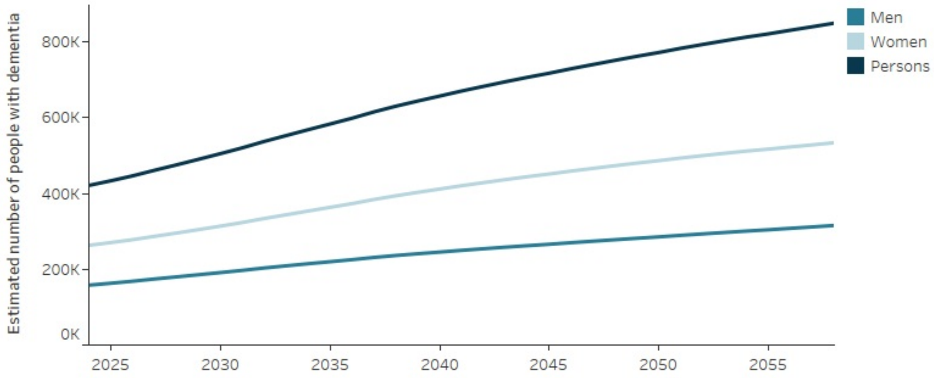
The number of Australians with dementia is projected to more than double by the year 2058

With Australia's population expected to continue growing and ageing into the future, the number of people with dementia is also expected to rise. Applying the AIHW-derived prevalence rates discussed above to ABS population projections for each year to 2058, it is estimated the number of people with dementia in Australia will more than double over this period – from just over 411,100 in 2023 to 849,300 in 2058 (around 315,500 men and 533,800 women) (Figure 2.3).

This trend is driven by the projected continued growth and ageing of Australia's population, as the condition is increasingly common in older age. As demographic projections over long periods carry a large degree of uncertainty and this approach assumes that the incidence of dementia (that is, no changes in the rate of new dementia cases in future years) and mortality rates for dementia remain the same, these estimates should be interpreted with caution. In particular, recent findings suggest that the official estimated resident population for Australia is less accurate as age increases, especially among those aged 100 and over (Wilson and Temple 2020). Refer to table S2.4 for more details on the estimated dementia prevalence by age and sex between 2010 and 2058.

Figure 2.3: Australians living with dementia between 2024 and 2058: estimated number by sex and year

Line graph showing that the estimated number of people with dementia in Australia is expected to increase in the future, due to the projected continued growth and ageing of Australia's population.



The trend of sum of Prevalence for Year. Color shows details about Sex. The data is filtered on Year, which keeps 36 of 49 members.

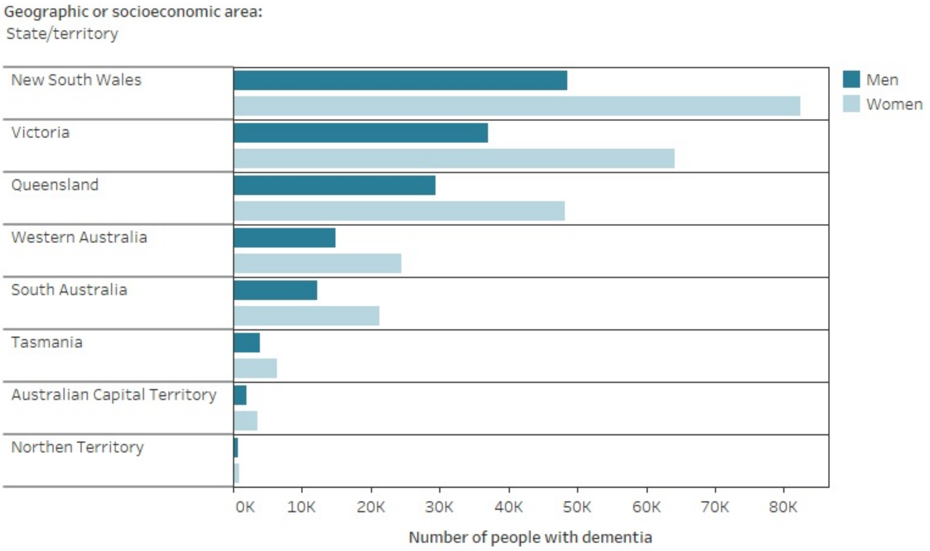
Source: The AIHW estimates were derived using prevalence rates from the 2015 World Alzheimer report and Withall et al. 2014, and the ABS Series B population projections.
http://aihw.gov.au

How does dementia prevalence vary by geographic and socioeconomic areas?

Given the lack of suitable data to accurately estimate dementia prevalence at the national level, it isn't surprising that estimating dementia prevalence at a finer disaggregation is even more difficult. However, the derived age-specific and sex-specific national prevalence rates can be used to illustrate the impact of different age structures and population sizes on how the number of people with dementia varies across Australia. Dementia prevalence has been estimated by applying these rates to state/ territory, remoteness, socioeconomic area, primary health network (PHN) and Statistical Area Level 2 (SA2) populations.

Figure 2.4: Australians living with dementia in 2022: estimated number by sex, and geographic or socioeconomic area

Bar graph showing the numbers of men and women with dementia were highest in the ost populous states, New South Wales, Victoria and Queensland, and in Major cities, but were spread evenly across socioeconomic areas. The number of women with dementia is higher than men across all areas shown.



Note: Due to the lack of data on the variability of dementia prevalence rates by geographic and socioeconomic areas, dementia prevalence estimates were calculated by applying the AIHW national age- and sex-specific dementia prevalence rates to the population of each geographic or socieconomic area.
Source: The AIHW estimates were derived using prevalence rates from the 2015 World Alzheimer report and Withall et al. 2014.
http://aihw.gov.au

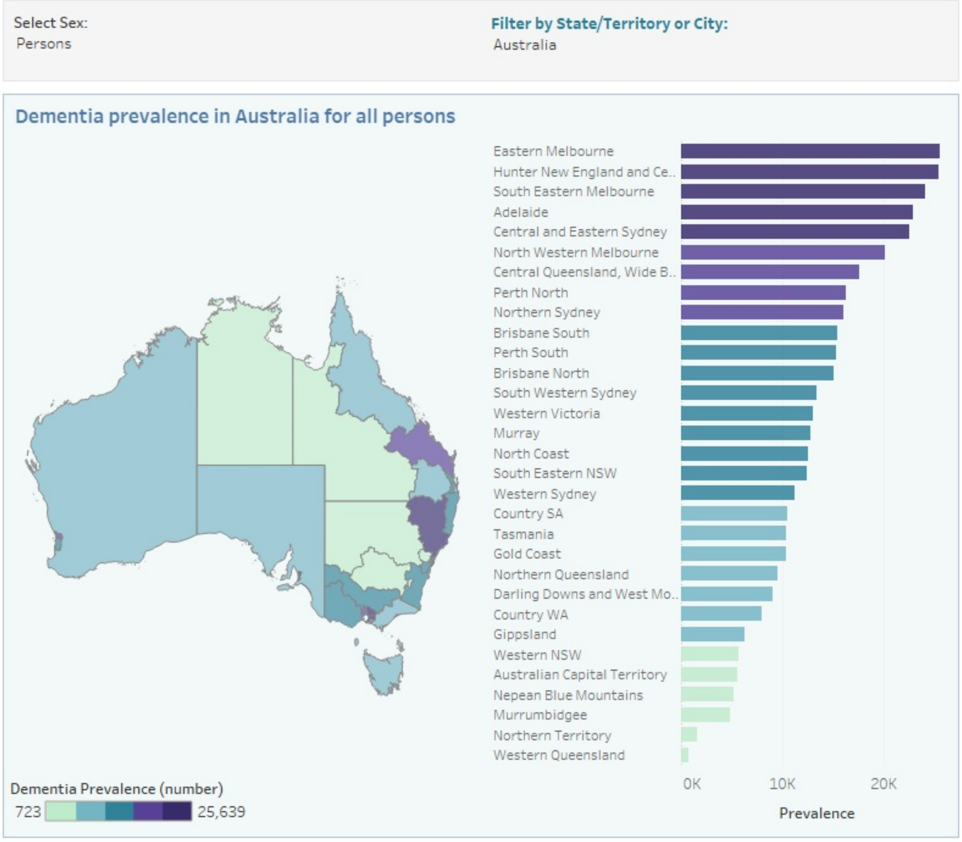
A report using nationwide clinical data from 569 general practices found that dementia was similarly present across socioeconomic and remoteness areas in Australia (NPS MedicineWise 2020). These data provide important insights on those people in the community with diagnosed dementia who attend a regular general practice.

Figure 2.5 shows the estimated number of people with dementia by sex and PHN. There are 31 PHNs across Australia which closely align with the state and territory local hospital networks. The PHN with the highest estimated number of people with dementia is Eastern Melbourne (over 25,600 people), while the lowest is Western Queensland (723 people). Due to the way these prevalence estimates are calculated, PHNs with larger, older populations will have a larger number of estimated people with dementia.

Prevalence estimates by statistical area 2 (SA2) are available in supplementary data table S2.9.

Figure 2.5: Australians living with dementia in 2022: estimated number by sex and primary health network (PHN)

This visualisation includes a map of Australia and shows that Eastern Melbourne had the highest number of estimated dementia prevalence while Western Queensland had the lowest.



Select Sex: Persons

Filter by State/Territory or City: Australia

Note: Due to the lack of data on the variability of dementia prevalence rates by small geographic areas, dementia prevalence estimates were calculated by applying the AIHW national age- and sex-specific dementia prevalence rates to the population of each geographic area.
Source: The AIHW estimates were derived using prevalence rates from the 2015 World Alzheimer report and Withall et al. 2014.
https://www.aihw.gov.au

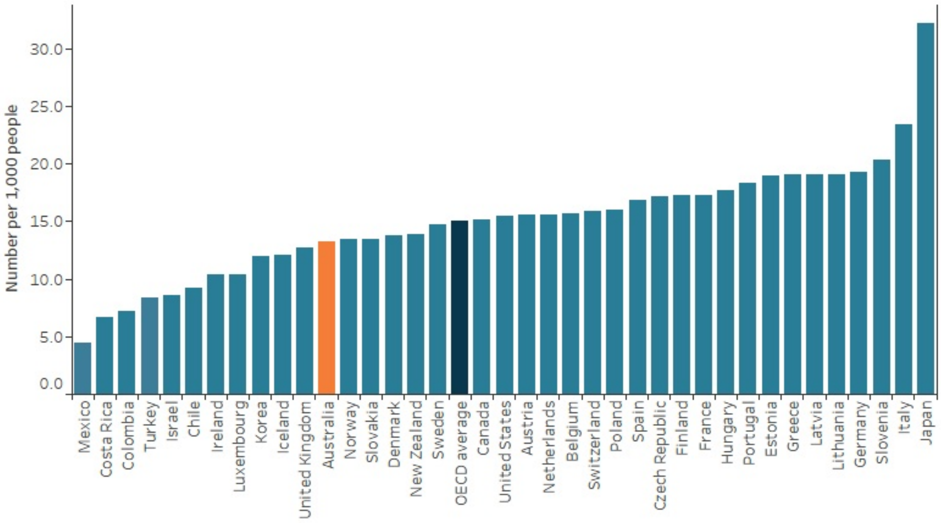
International comparisons of dementia prevalence

International comparisons of dementia prevalence statistics are a useful starting point for learning how other nations with similar population profiles are experiencing dementia. The Organisation for Economic Co-operation and Development (OECD) publishes dementia prevalence rate estimates for OECD countries that provide a useful comparison for Australia as most are considered developed, high-income countries. The 2021 OECD dementia prevalence rates were slightly lower to the estimates presented in this report, but used a different methodology and data source. The OECD rates were based on the regional prevalence rates published in the Institute for Health Metrics and Evaluation (IHME) Global Burden of Disease (GBD) study 2019 and were subject to varying quality of information across regions, so they should only be used for international comparisons.

The OECD estimated that the prevalence of dementia in Australia was 13.2 cases per 1,000 population in 2021, slightly less than the OECD average of 15.0 per 1,000 population and ranking 12th lowest out of 38 countries (Figure 2.6). Mexico had the lowest rate, just over one third of the Australian rate at 4.5 per 1,000 population, whereas Japan's rate was highest at 32.2 per 1,000 population (OECD 2023). These are unadjusted prevalence rates, meaning that much of the variation in dementia prevalence across countries is due to differences in population age structures, with ageing OECD nations tending to have higher prevalence rates.

Figure 2.6: People living with dementia in Organisation for Economic Co-operation and Development (OECD) member countries in 2021: estimated rate by country

Bar graph showing that the estimated rate of dementia in Australia was slightly lower than the average rate for OECD countries.



Sum of F2 for each F1. Color shows details about F1.

Source: Organisation for Economic Co-operation and Development (OECD) analysis of data from the Institute for Health Metrics and Evaluation (IHME) Global Burden of Disease Study.
http://aihw.gov.au

References

ABS (Australian Bureau of Statistics) (2022) *Health: census*, ABS, Australian Government, accessed 1 July 2022.

ADI (Alzheimer's Disease International) (2015) *World Alzheimer report 2015: the global impact of dementia: an analysis of prevalence, incidence, cost and trends*, Alzheimer's Disease International, accessed 17 August 2022.

Anstey KJ, Burns RA, Birrell CL, Steel D, Kiely KM and Luszcz MA (2010) 'Estimates of probable dementia prevalence from population-based surveys compared with dementia prevalence estimates based on meta-analyses', *BMC Neurology*, 10(1):62, doi:10.1186/1471-2377-10-62.

AIHW (Australian Institute of Health and Welfare) (2012) *Dementia in Australia*, AIHW, Australian Government, accessed 17 August 2022.

Brown L, Hansnata E and La HA (2017) *Economic cost of dementia in Australia 2016–2056*, University of Canberra, accessed 17 August 2022.

GBD (Global Burden of Disease) 2019 Diseases and Injuries Collaborators (2019) 'Global burden of 369 diseases and injuries in 204 countries and territories, 1990–2019: a systematic analysis for the Global Burden of Disease Study 2019', *The Lancet*, 396:1204–1222, doi:10.1016/S0140-6736(20)30925-9.

IHME (Institute for Health and Metrics and Evaluation) (2020) *GBD Results* [data set], healthdata.org, accessed 16 January 2024.

NPS MedicineWise (2020) *General Practice Insights report July 2018 – June 2019*, NPS MedicineWise, accessed 17 August 2022.

OECD (Organisation for Economic Co-operation and Development) (2023) 'Health at a Glance 2023: OECD indicators', 2023 edn, *OECD Publishing*, doi:10.1787/19991312.

Wilson T and Temple J (2020) 'The rapid growth of Australia's advanced age population'. *Journal of Population Research*, 37:377–389, doi:10.1007/s12546-020-09249-7.

Withall A, Draper B, Seeher K and Brodaty H (2014) 'The prevalence and causes of younger onset dementia in Eastern Sydney, Australia', *International Psychogeriatrics*, 26(12):1955–1965, doi:10.1017/S1041610214001835.

Population health impacts of dementia

Understanding the number of new dementia cases in a given period, also known as the incidence of dementia, is important for responding to the changing and growing challenges that dementia poses. The issues and gaps discussed in the Prevalence of dementia page are also applicable to dementia incidence data. Estimating dementia incidence requires even more information, such as date of diagnosis and whether a diagnosis was made close to symptom onset.

Emerging evidence suggests the incidence rate of dementia is declining in several high-income countries due to improvements in the prevention and management of vascular risk factors for dementia (i.e. high blood pressure and cardiovascular disease) (Roehr et al. 2018). This decline has been seen despite rising cases globally of other risk factors for dementia, such as diabetes and obesity. It isn’t clear whether a declining incidence applies to Australia as we do not know the net effects of changing dementia risk factors coupled with an ageing population. For example, Australia’s obesity rates are among the highest of OECD nations but its mortality rate due to coronary heart disease lies just below the OECD average (AIHW 2020).

Given the unique and changing profile of Australia’s population and the lack of Australian-specific studies on dementia incidence, we have chosen not to present national dementia incidence estimates. Recent and emerging work to improve dementia prevalence and incidence estimates provide a good prospect for the availability of these statistics in coming years.

Emerging Australian work to better understand dementia incidence

The following 3 examples illustrate the important knowledge that can be gained from population-wide, high-quality data on dementia incidence.

The Sydney Memory and Ageing Study

This ongoing population-based longitudinal study has provided important information about dementia incidence among older community-dwelling adults (aged 70–90) since 2005. The study provides high-quality information by using reliable, standardised assessments of mild cognitive impairment and dementia among older Australians. Of those adults in the study with no cognitive impairment, 9.5% developed dementia over 6 years. Of participants with mild cognitive impairment, 4.7% developed dementia 2 years later (Lipnicki et al. 2017).

45 and Up Study

The 45 and Up Study is the largest ongoing study of healthy ageing in the southern hemisphere. A cohort of about a quarter of a million participants from the 45 and Up Study has been linked to health administrative data such as hospitals and prescription data, to ascertain dementia incidence rates. Recent estimates place the age-adjusted incidence rate of dementia at 16.8 cases per 1,000 person years for people aged 65 and over (Welberry et al. 2020).

NHMRC-funded dementia research grants

The National Health and Medical Research Council (NHMRC) through the then National Institute for Dementia Research has funded research grants exploring the utility of linked health administrative data (such as hospitals and deaths data) and electronic health records, to better identify dementia and develop new methodological approaches to estimate dementia prevalence and incidence (NHMRC 2019).

The NHMRC has also funded the development of a dementia clinical quality registry to directly collect data for the diagnosis and management of dementia by the Australia Dementia Network, which could be used in the future to estimate dementia incidence using high-quality clinical data (NHMRC 2019).

References

AIHW (Australian Institute of Health and Welfare) (2020) *International comparisons of health data*, AIHW, Australian Government, accessed 02 August 2021.

Lipnicki DM, Crawford J, Kochan NA, Trollor JN, Draper B, Reppermund S, Maston K, Mather KA, Brodaty H and Sachdev PS (2017) 'Risk factors for mild cognitive impairment, dementia and mortality: The Sydney Memory and Ageing Study', *Journal of the American Medical Directors Association*, 18(5):388–395, doi:10.1016/j.jamda.2016.10.014.

NHMRC (National Health and Medical Research Council) (2019) *Boosting dementia research grants*, NHMRC website, accessed 02 August 2021.

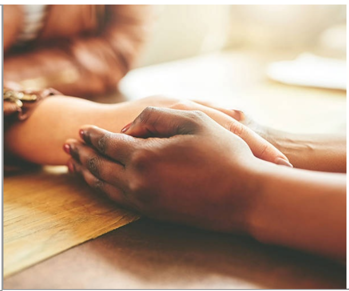
Roehr S, Pabst A, Luck T and Riedel-Heller SG (2018) 'Is dementia incidence declining in high-income countries? A systematic review and meta-analysis', *Clinical Epidemiology*, 10:1233, doi:10.2147/CLEP.S163649.

Welberry HJ, Brodaty H, Hsu B, Barbieri S and Jorm LR (2020) 'Measuring dementia incidence within a cohort of 267,153 older Australians using routinely collected linked administrative data', *Scientific Reports*, 10:8781, doi:10.1038/s41598-020-65273-w.

Population health impacts of dementia

Key statistics

Dementia was the **second leading cause of death** in Australia in 2021, accounting for 10% of all deaths



Women aged 75 or over accounted for **over 60%** of deaths due to dementia in 2021

Deaths due to dementia increased from 10,800 deaths in 2012 to **15,800 deaths** in 2021

Coronary heart disease was the leading underlying cause of death when dementia was an associated cause of death

Dementia is a progressive condition that leads to reduced life expectancy. However, time from diagnosis to death is highly variable. Survival time is affected by age, sex, dementia type and severity at diagnosis, among other factors (Brodaty et al. 2012). In addition, dementia is not always the direct cause of death as the condition often impairs an individual's physical health and their ability to cope with other diseases (Dementia Australia 2019).

The mortality statistics presented here are derived from the National Mortality Database and, unless otherwise specified, refer to cases where a death was due to dementia, also known as the 'underlying cause of death'. The National Mortality Database holds records for deaths in Australia from 1964 and comprises information about causes of death and other characteristics of the person, such as sex, age at death, area of usual residence and First Nations status. Causes of death were coded using the 10th version of the International Statistical Classification of Diseases and Related Health Problems (ICD-10), an international standard agreed by the World Health Organization for defining and reporting causes of death. Refer to the Technical notes for further information on death data and the codes used to classify dementia in the National Mortality Database.

Refer to the Mortality data tables for underlying data presented in these pages.

Dementia is a leading cause of death in Australia

In 2021, dementia was the second leading cause of death in Australia after coronary heart disease, and was the leading cause of death for women. There were a total of 15,800 deaths due to dementia, with more women than men dying due to the condition (around 10,100 and just over 5,700 deaths, respectively). This corresponds to dementia causing 10% of all deaths in Australia in 2021 (or 13.1% of all deaths among women and 6.9% of all deaths among men).

Figure 3.1 shows the leading 5 causes of death for Australians in 2021, by age and sex. Dementia becomes an increasingly common cause of death with increasing age, and was the leading cause of death for persons aged 75 and over. This was driven by the fact that dementia was the leading cause of death for women aged 75 and over. For men aged 75 and over, dementia was the second leading cause of death after coronary heart disease.

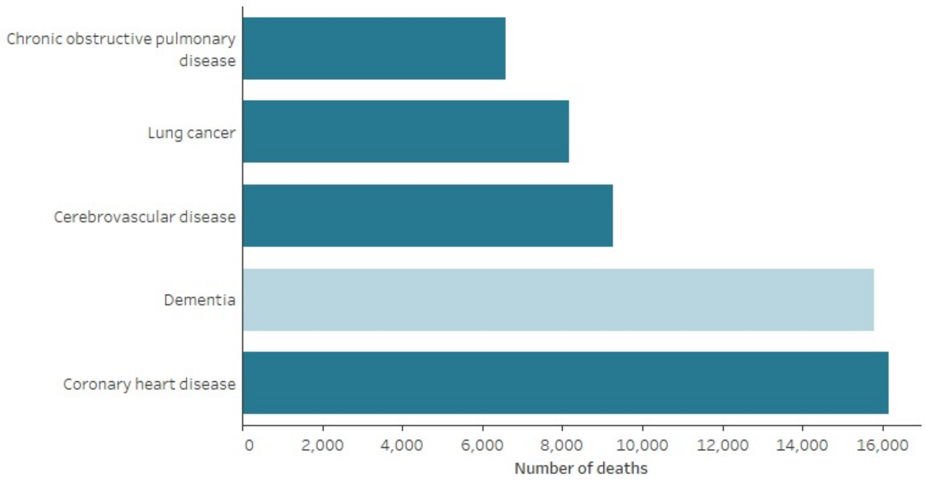
Details on the total number of deaths and the age-specific rate of deaths per 100,000 population are displayed when the mouse is hovered over each leading cause of death.

Figure 3.1: Leading causes of death in Australia in 2021, by age and sex

Figure 3.1 shows that dementia becomes an increasingly common cause of death with increasing age, and was the leading cause of death for persons aged 75 and over.

Sex:
Persons

Age group:
All ages



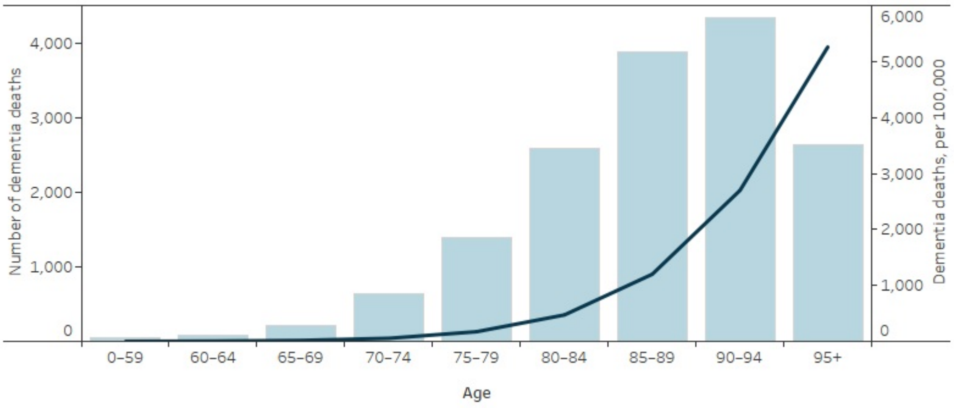
Note: This analysis is only based on the underlying cause of death and not on associated causes of death.
Source: AIHW analysis of the National Mortality Database.
https://www.aihw.gov.au

Figure 3.2 presents more details on deaths due to dementia by age and sex in 2021. The rate of deaths due to dementia among those who died aged 75–79 was 175 and 171 deaths per 100,000 population for men and women, respectively. The rate increased to just over 4,000 and 5,700 per 100,000 population for men and women aged 95 and over, respectively. The majority of deaths due to dementia occurred among men and women aged 85–94 years.

Figure 3.2: Deaths due to dementia in 2021: number and age-specific rates, by age and sex

This figure shows the increasing number and rate of deaths due to dementia, with most deaths occurring among people aged between 85 and 94.

Sex: Persons



Notes
1. Age-specific rates are expressed per 100,000 population.
2. This analysis is only based on the underlying cause of death and not on associated causes of death.
Source: AIHW analysis of the National Mortality Database.
https://www.aihw.gov.au

Box 3.1: Provisional dementia deaths in more recent years

The current Dementia in Australia report includes mortality data up to and including 2021. This data includes the latest available coroner and doctor certified deaths data which are compiled and provided to the AIHW by the ABS. In response to the COVID-19 pandemic, the ABS started reporting provisional mortality statistics.

The latest provisional mortality estimates indicate an upward trend in deaths due to dementia. Over the year to date in 2023, deaths due to dementia were above the baseline average in the years of 2017–2019, and in 2021, and above the number of deaths recorded at a similar point in 2022 (ABS 2023).

Provisional mortality data includes deaths certified by doctors only and does not include deaths referred to the coroner (around 15% of total deaths). Therefore, data released provisionally is subject to change and should be interpreted with caution. However it does provide an early indication of emerging mortality patterns in Australia.

Deaths due to dementia have increased over the 2012–2021 period

The number of deaths due to dementia increased from 10,800 deaths in 2012 to 15,800 deaths in 2021 (Figure 3.3). This increase was seen for both men and women. Each year more women than men died due to dementia. As age is the biggest risk factor for dementia, the increase in the number of Australians dying from dementia is in part a reflection of more Australians living to older ages.

The rate of deaths due to dementia increased from 47 to 61 deaths per 100,000 population between 2012 and 2021 (Table S3.3). However, a large part of this increase was due to Australia's increasingly ageing population. When accounting for changes in the Australian population over time, the age-standardised rate of deaths due to dementia between 2012 and 2021 increased slightly from 38 to 41 deaths per 100,000 population.

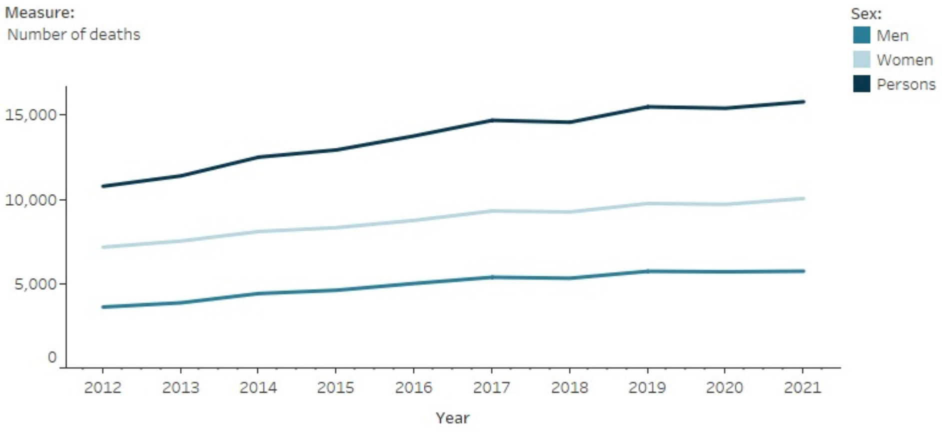
Over the period 2012 to 2021, age-standardised death rates increased slightly for both men (from 34 to 37 deaths per 100,000) and women (from 39 to 43 deaths per 100,000). The increase in the number of deaths due to dementia may not be entirely explained by Australia's increasingly ageing population, and the prevalence of dementia may have also changed over the period from 2012 to 2021.

Other factors that may have contributed to changes in the number and rate of deaths due to dementia over the last decade include:

- Changes in ICD-10 instructions for coding deaths data have resulted in the assignment of some deaths to *Vascular dementia* (F01) where previously they may have been coded to *Cerebrovascular diseases* (I60–I69).
- Legal changes allowing veterans and members of the defence forces to relate death from vascular dementia to relevant service and an accompanying promotional campaign targeted at health professionals, are thought to have increased the number of dementia deaths among this group (ABS 2015).

Figure 3.3: Deaths due to dementia in Australia over the period 2012 to 2021: number and age-standardised rate by sex

This figure shows the number and age-standardised rates of men, women and people who died due to dementia in Australia between 2012 and 2021.



Notes
1. Death rates due to dementia have been standardised to the 2001 Australian Standard Population and are expressed per 100,000 population.
2. This analysis is only based on the underlying cause of death and not on associated causes of death.
Source: AIHW analysis of the National Mortality Database.
https://www.aihw.gov.au

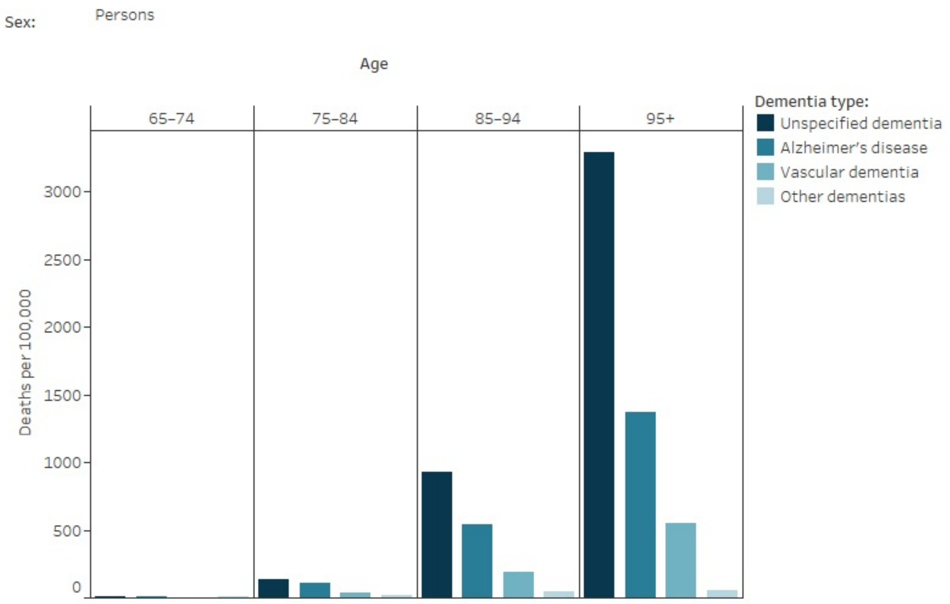
How are dementia types coded in death certificates?

Although the National Mortality Database contains information on specific types of dementia, this information is not always systematically recorded on death certificates. Coding changes and variations in certification practices have likely resulted in an increase in deaths coded to dementia (ABS 2015). Descriptions in death certificates may indicate dementia but not a particular type of dementia, and in these cases, the type of dementia would be recorded as *Unspecified dementia*. These influencing factors should be kept in mind when interpreting deaths by dementia type.

In 2021, for people aged 65 and over, the most common specific dementia types recorded were *Alzheimer's disease* (just over 5,000 deaths) and *Vascular dementia* (1,700 deaths). *Unspecified dementia*, that is, when the type of dementia was not known, was recorded for 8,300 deaths (Table S3.4). Together, *Frontotemporal dementia, Lewy body dementia* and *Dementia due to the effects of substance use,* accounted for 660 deaths. Interestingly, as age increased, so did the age-specific rate of deaths classified as due to *Unspecified dementia* (Figure 3.4). This may be due to challenges in diagnosing and reporting dementia among older individuals who have other comorbidities, and similar trends have been found in other recent studies (Gao et al. 2018; PHE 2016).

Figure 3.4: Deaths due to dementia in 2021: age-specific rates, by sex and dementia type

This figure shows that *Unspecified dementia* was responsible for the highest rate of deaths, followed by *Alzheimer's disease* and *Vascular dementia*.



Notes
1. Due to confidentiality issues, rates are not shown for people aged 0–64 years.
2. Age-specific rates are expressed per 100,000 population.
3. The category 'Other dementias' include: Frontotemporal dementia; Lewy body dementia; and Dementia due to the effect of substance use.
Source: AIHW analysis of the National Mortality Database.
https://www.aihw.gov.au

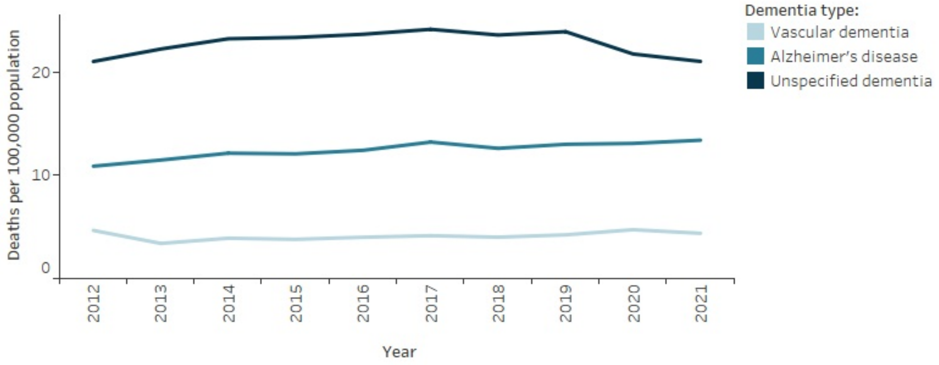
Emerging work in Australia to better understand dementia typing in deaths data

Over the 2012–2021 period, the age-standardised rate of deaths due to *Unspecified dementia* increased from 21 to 24 deaths per 100,000 people between 2012 and 2016, then remained steady before decreasing to 22 deaths per 100,000 people in 2020. The age-standardised rate of deaths decreased again in 2021 to 21 deaths per 100,000 people (Figure 3.5). Crude rates of deaths per 100,000 due to *Unspecified dementia* followed a similar trend (Table S3.5). The reasons for this trend are not well understood.

The Australian Bureau of Statistics (ABS) and the University of Queensland are currently analysing changes in how dementia deaths have been certified by doctors over time. This analysis will also examine the interaction between certified terms and the application of ICD mortality coding rules as well as differences across jurisdictions. This work will be valuable to understand what is driving changes in dementia typing over time and how data users should interpret coding changes over time, and may lead to recommendations that could improve the specificity of dementia types in future data sets. Recommendations will also be provided to certifiers on how recording of dementia deaths can be improved (NHMRC 2019).

Figure 3.5: Deaths due to dementia over the period 2012 to 2021: age-standardised rates, by dementia type

This figure shows the age-standardised rates of deaths due to dementia in Australia between 2012 and 2021 by type of dementia (*Alzheimer's disease*, *Unspecified dementia*, *Vascular dementia)*.



Notes
1. Death rates due to dementia over the 2012–2021 period have been standardised to the 2001 Australian Standard Population and are expressed per 100,000 population.
2. This analysis is only based on the underlying cause of death and not on associated causes of death.
Source: AIHW analysis of the National Mortality Database.
http://www.aihw.gov.au

Geographic and socioeconomic area variations

Figure 3.6 shows age-standardised rates of death due to dementia in 2021 by sex, and by different geographic areas and socioeconomic groups. After adjusting for population differences, the age-standardised rate of deaths due to dementia:

- varied across states and territories – ranging from 36 deaths per 100,000 population in Victoria to 50 per 100,000 population in the Northern Territory

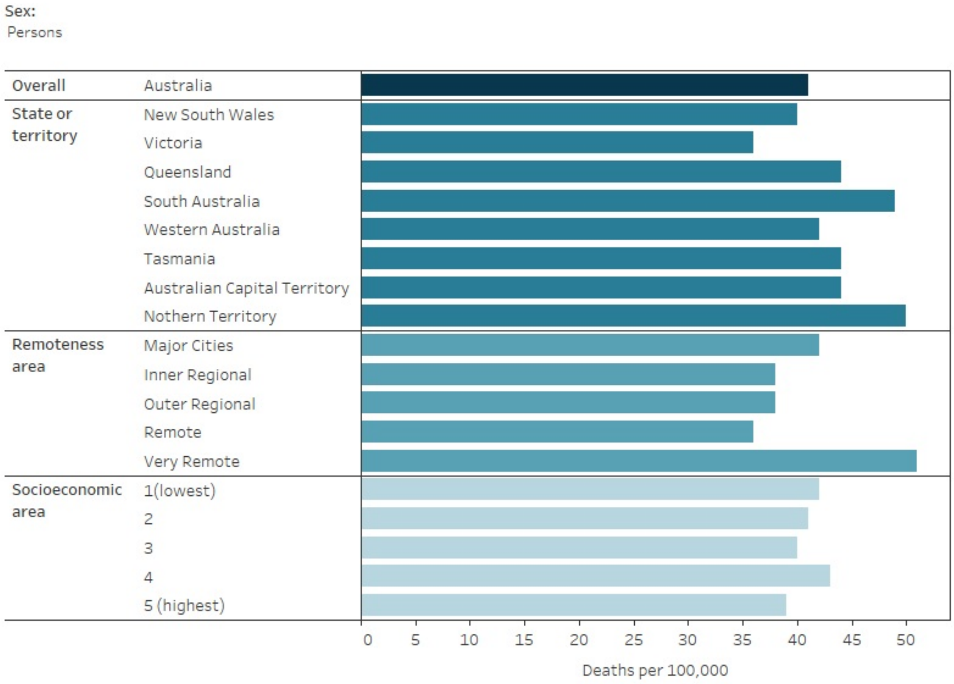
- varied by remoteness – the rate was highest in *Very remote* (51 deaths per 100,000 population) and lowest in *Remote* areas (36 per 100,000 population)
- was relatively similar across socioeconomic areas – ranging between 39–43 deaths per 100,000 population (Figure 3.6).

Recent evidence points to the high variability of appropriate dementia care across Australia as well as of dementia awareness among healthcare and aged care workers, which could be impacting where people with dementia die, and when and how dementia deaths are coded (Royal Commission 2019). Information on factors such as place of death, if captured comprehensively, may help to shed some further light on end-of-life care in Australia.

Details on the rate of deaths per 100,000 population are included in Table S3.6.

Figure 3.6: Deaths due to dementia in 2021: age-standardised rates, by sex, and by geographic and socioeconomic areas

This figure shows that dementia death rates varied by state or territory, as well as by remoteness areas, but were similar across socioeconomic areas.



Notes
1. Death rates due to dementia for the categories above have been standardised to the 2001 Australian Standard Population and are expressed per 100,000 population.
2. This analysis is only based on the underlying cause of death and not on associated causes of death.
Source: AIHW analysis of the National Mortality Database.
https://www.aihw.gov.au

Box 3.2: Where do deaths due to dementia occur?

Place of death, the location or setting in which an individual dies, is an important indicator for end-of-life care. Place of death is currently recorded on either a Death Registration Form or the Medical Certificate of Cause of Death, and it is mostly captured as free text that can vary significantly across jurisdictions (ABS 2021).

In 2021, the ABS released the results of a pilot study in which they developed and applied a methodology to assign a place of death to deaths occurring in 2019, based on data sourced from the Deaths Registration Form and the Medical Certificate of Cause of Death. Deaths were assigned to one of five categories:

- Home/residence
- Residential aged care facility
- Hospital/medical service area
- Other
- Unspecified.

Details of the methodology of assignment can be found on the ABS website.

In 2019, the majority of deaths due to dementia (including Alzheimer's disease) occurred in a residential aged care facility (77%), with 20% occurring in a hospital or medical service area, and 2.5% occurring in a home or residence. Compared with the other selected causes of death examined, dementia had the highest proportion of deaths occurring in aged care facilities and the lowest occurring in hospitals or medical service areas. This is likely reflective of the higher proportion of people with dementia who reside in aged care facilities at end of life due to disease progression and complex care needs.

References

ABS (Australian Bureau of Statistics) (2015) *Causes of death, Australia, 2013*, ABS, Australian Government, accessed 11 July 2022.

ABS (2021) *Classifying Place of Death in Australian Mortality Statistics*, ABS, Australian Government, accessed 11 July 2022.

ABS (2023). *Provisional Mortality Statistics*. ABS, Australian Government, accessed 12 July 2023.

Brodaty H, Seeher K and Gibson L (2012) 'Dementia time to death: a systematic literature review on survival time and years of life lost in people with dementia', *International Psychogeriatrics,* 24(7):1034–1045, doi:10.1017/S1041610211002924.

Dementia Australia (2019) *The later stages of dementia*, Dementia Australia, accessed 1 August 2021.

Gao L, Calloway R, Zhao E, Brayne C, Matthews FE and Medical Research Council Cognitive Function and Ageing Collaboration (2018) 'Accuracy of death certification of dementia in population-based samples of older people: analysis over time', *Age and Ageing,* 47(4):589–594, doi:10.1093/ageing/afy068.

NHMRC (National Health and Medical Research Council) (2019) *Boosting dementia research grants*, NHMRC, Australian Government, accessed 1 August 2021.

PHE (Public Health England) (2016) *Data analysis report: dying with dementia*, PHE, UK Government, accessed 17 August 2022.

Royal Commission (Royal Commission into Aged Care Quality and Safety) (2019) *Interim Report: Neglect*, Royal Commission, Australian Government, accessed 17 August 2022.

Population health impacts of dementia

The discussion about dementia deaths among Australians has so far been restricted to deaths *due to* dementia, that is, where dementia was recorded as the underlying cause of death (UCOD). In addition to the underlying cause of death, the National Mortality Database contains information on up to 19 associated causes of death (ACOD) – that is, other causes that were instrumental or significantly contributed to the death. Given people with dementia often have other health conditions and there can only be one underlying cause of death recorded, it is important to also account for all other cases where Australians died *with* dementia (where dementia was recorded as either the underlying cause or an associated cause of death).

In 2021, around 15,800 people died *due to* dementia (nearly 10,100 women and just over 5,700 men). In comparison, around 29,100 people died *with* dementia (just over 17,300 women and nearly 11,800 men). This is an important difference as people who have dementia often have other health conditions, which may cause their death rather than dementia (Table S3.7).

Leading underlying causes of death

In 2021, the leading underlying causes of death for people who had dementia recorded as an associated cause of death were:

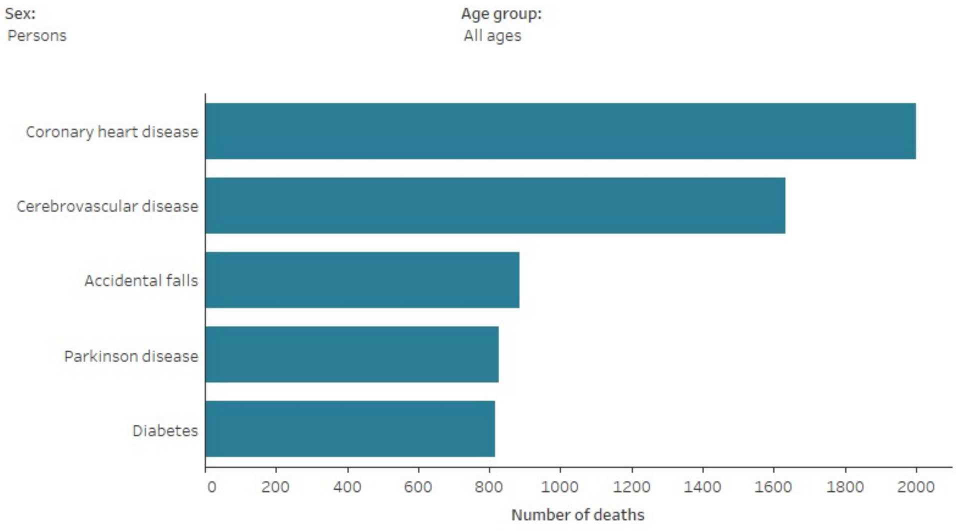
- coronary heart disease (2,000 deaths)
- cerebrovascular disease (just over 1,600 deaths)
- accidental falls (almost 900 deaths)
- Parkinson’s disease (almost 830 deaths)
- diabetes (almost 820 deaths) (Figure 3.7).

As a person may have multiple types of dementia, it is possible for a person to have dementia recorded as both the underlying and associated cause of death. For example, a person may have *Alzheimer’s disease* as the underlying cause and *Vascular dementia* as an associated cause of death. Among the 13,700 people who died with at least one type of dementia recorded as an associated cause, almost 440 (3.2%) also had dementia recorded as the underlying cause of death (Table S3.9).

The leading underlying causes of death were fairly similar for men and women where dementia was an associated cause, but varied somewhat with increasing age – *Accidental falls* was more common with increasing age, whereas deaths due to *Diabetes* decreased with increasing age.

Figure 3.7: Leading 5 underlying causes of death in 2021 when dementia was an associated cause of death, by sex and age

This figure shows the leading 5 underlying causes of death in Australia by sex and age in 2021, when dementia was an associated cause of death.



Note: Due to low numbers, values are not shown for people aged 0–64 years.
Source: AIHW analysis of the National Mortality Database.
http://www.aihw.gov.au

Trends in coding of dementia as the underlying cause of death versus an associated cause of death

Between 2012 and 2021 the age-standardised rate of deaths where dementia was the underlying cause of death increased slightly from 38 to 41 deaths per 100,000 population. In contrast, the rate of deaths where dementia was an associated cause of death decreased from 44 to 36 per 100,000 population over the same period (Figure 3.8).

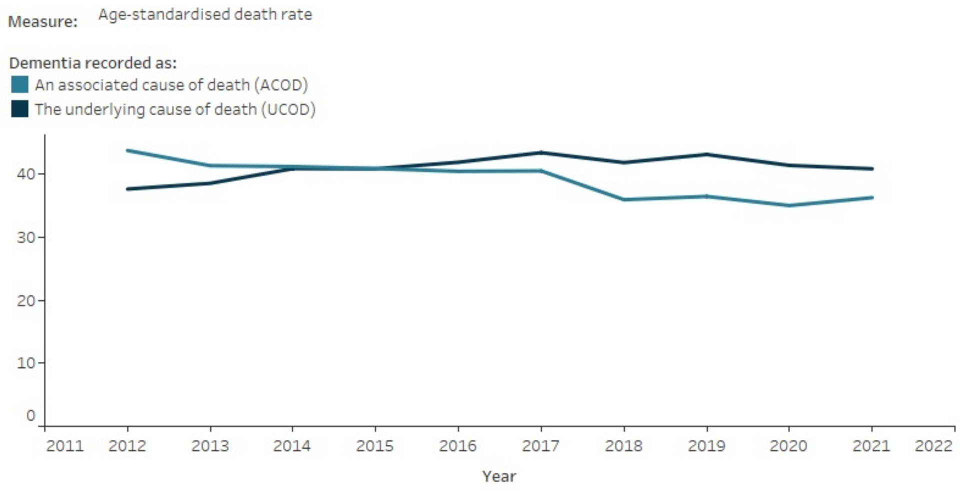
While we cannot be certain why this is occurring, it may be due to various factors:

- Australians are living longer and are more likely to be dying from dementia than from other conditions. Notably, there have been decreases in fatal heart attacks and strokes over time. This is resulting in dementia being increasingly attributed as the underlying cause of death, whereas in the past it was more likely to be recorded as an associated cause of death or not recorded at all.
- Over time, dementia awareness could have significantly improved among health professionals who record and code cause of death information, leading to an increase in dementia being recorded as the underlying cause of death.
- Changes to coding rules implemented from 2013 have meant that *Unspecified dementia* is more likely to be recorded as the underlying cause of death rather than as an associated cause of death among people who die with dementia and other specific conditions (including *Pneumonitis due to food and vomit*). This resulted in an increase in the number of deaths with *Unspecified dementia* as an underlying cause (ABS 2015).

Details on the rate of deaths per 100,000 population are included in Table S3.10.

Figure 3.8: Dementia-related deaths in Australia in 2012–2021: number and age-standardised rates, by whether dementia was recorded as the underlying cause of death (UCOD) or an associated cause of death (ACOD)

This figure shows that the rate of deaths with dementia increased as an underlying cause of death and decreased as an associated cause of death between 2012 and 2021.



Notes
1.Death rates related to dementia over 2012–2021 are expressed as the number of deaths per 100,000 population, and have been standardised to the 2001 Australian Standard Population. This means they have been adjusted to have the same age distribution at each year.
2. The UCOD category in this graph is equivalent to the definition used in this page for deaths *due to* dementia. However, the ACOD category in this graph is not equivalent to deaths *with* dementia, since deaths *with* dementia also includes cases where dementia was only listed as the UCOD and not an ACOD.
Source: AIHW analysis of the National Mortality Database.
https://www.aihw.gov.au

References

ABS (Australian Bureau of Statistics) (2015) *Causes of death, Australia, 2013*, ABS, Australian Government, accessed 17 August 2022.

Population health impacts of dementia

Burden of disease analysis measures the combined impact of living with illness and injury (non-fatal burden) and dying prematurely (fatal burden). The fatal and non-fatal burden summed together is referred to as the total burden, measured using disability-adjusted life years (DALY). One DALY is equivalent to one year of healthy life lost. Burden of disease allows for comparisons of all diseases, illness and injury, by taking into account not only the number of people affected but the severity and duration of illness, as well as the age of people who died (AIHW 2023).

The Australian Burden of Disease Study (ABDS) 2023 provides the most up-to-date information on the burden of disease in Australia at a national level. Burden of disease estimates for the Australian population in 2023 are presented in the *Australian Burden of Disease Study 2023* report.

The ABDS 2018 provides the most up-to-date information for burden of disease estimates by state and territory, remoteness and socioeconomic area, as well as estimates of disease burden attributable to risk factors (AIHW 2021). Detailed estimates from the Australian Burden of Disease Study 2018 can be found at Disease burden: interactive data and Risk factors: interactive data.

Refer to Burden of disease due to dementia among First Nations people for information based on these latest available estimates.

Refer to the Burden of disease data tables for the underlying data presented in these pages.

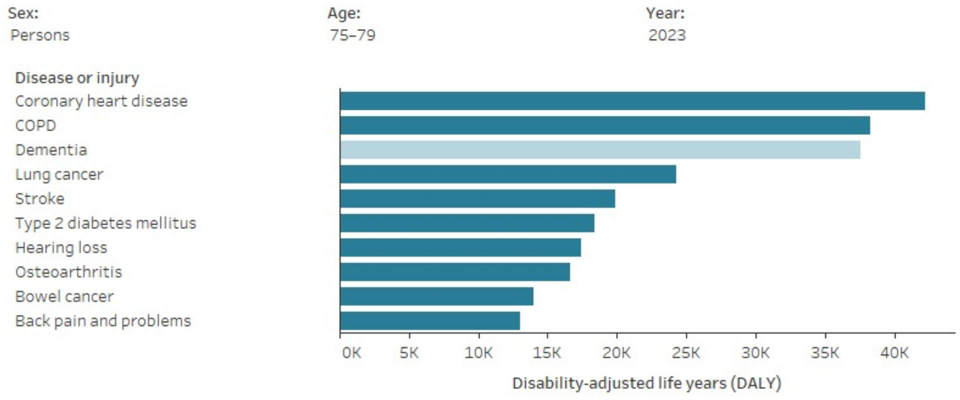
Dementia is a leading cause of disease burden in Australia

In 2023, dementia was the second overall leading cause of burden of disease and injury in Australia, behind coronary heart disease. Dementia was responsible for 4.4% of the total burden of disease in Australia, equivalent to around 248,000 healthy years of life lost (DALY), or 6.4 DALY per 1,000 people. Dementia was the leading cause of disease burden for females overall, 150,000 DALY of the total burden was due to dementia. In comparison, dementia was the fourth leading cause of disease burden for men (97,400 DALY).

Age is the biggest risk factor for dementia, and its ranking as a leading cause of disease burden increased as age increased. Dementia was the leading cause of burden for women as well as for all Australians aged 65 and over. This was largely due to the high disease burden among women, whereas for men dementia was only the leading cause of disease burden in 3 age groups. See Figure 4.1 for further information on the leading causes of disease by age group.

Figure 4.1: Leading 10 causes of disease burden (DALY) in Australia in 2015, 2018, 2022 and 2023: by sex and age

Figure 4.1 is a bar graph showing the leading causes of disease burden with filters for age, year and sex. For 2023 dementia is generally the leading cause of disease burden in older age groups (over 80) for all sexes.



Notes
1. COPD refers to Chronic obstructive pulmonary disease.
2. COVID-19 is a disease of the respiratory system, caused by the coronavirus SARS-CoV-2.
3. Conditions that were grouped into residual categories in the Australian Burden of Disease Study 2023 (such as 'Other musculoskeletal conditions') are not included in the rankings.
4. Lower respiratory infections include influenza and pneumonia.
5. Due to rounding, estimates for all persons for some diseases does not equal the sum of male and female estimates.
Source: AIHW Australian Burden of Disease Database http://www.aihw.gov.au

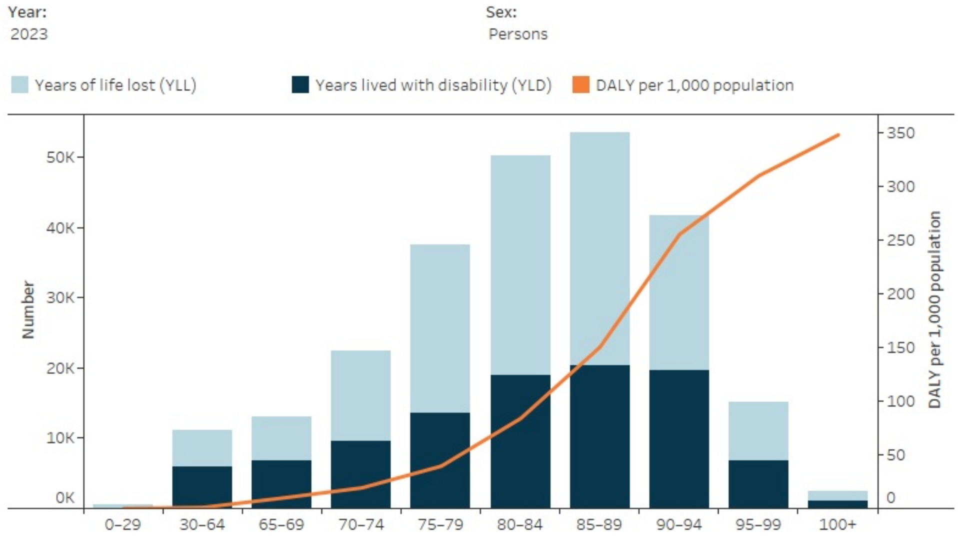
The fatal burden, or *years of life lost* (YLL) is the difference between a person's age at death, and the age at which that person would have expected to live to according to an aspirational life table. Fatal burden for dementia was calculated based on deaths where dementia was the underlying cause of death. It does not include deaths where dementia was an associated cause of death. For more information see Dying due to dementia compared to dying with dementia.

Over half (59%) of the total burden due to dementia was from dying prematurely (about 145,000 YLL). The proportion of burden due to dying prematurely was higher in males (64% or 62,000 YLL) compared with females (55% or 83,000 YLL) (Table S4.3).

Conditions that cause deaths at younger ages (such as Sudden Infant Death Syndrome) have a much higher number of YLL per death than conditions like dementia, which cause death at older ages (as there are more years of life to lose). So while the number of YLL decreases with increasing age, as there were more people dying due to dementia in the older age groups, the number of YLL due to dementia increases with increasing age. The number of *disability-adjusted life years* or DALY (which is the sum of the *years of life lost* (YLL) and *years lived with disability* (YLD)) was greatest between ages 80 and 94, peaking slightly younger in men (age 80–84) compared with women (age 85-89) (Figure 4.2). From age 95 onwards there was a sharp decline in the number of DALY due to a smaller population at this age. However, the rate of DALY due to dementia continued to increase with increasing age.

Figure 4.2: Dementia burden in Australia in 2015, 2018, 2022 and 2023 by sex and age: number (YLL, YLD) and age-specific rate (DALY per 1,000 people)

Figure 4.2 is a bar graph showing the number of years life lost (YLL) and year lived with disability (YLD) with a line graph over the top showing the age-standardised rate of disability-adjusted life years (DALY). The highest YLL and YLD are between the 75 to 94 years of ages for all sexes and the DALY rate increases with age peaking at the oldest age group (100+).



Source: AIHW Australian Burden of Disease Database http://www.aihw.gov.au

Burden due to dementia increased between 2015 and 2023

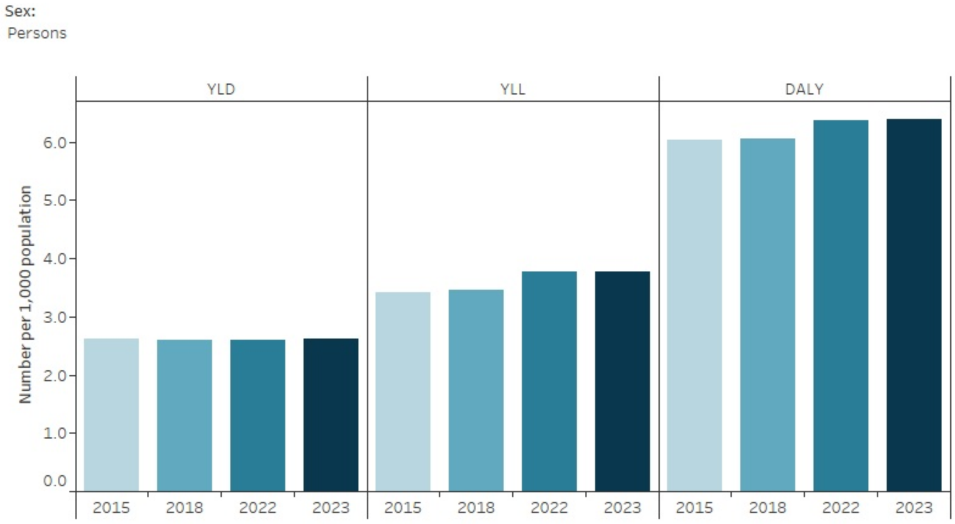
Dementia has risen from the third leading cause of disease burden in 2015 (behind coronary heart disease and back pain and problems) to be the second leading cause in 2023 (behind coronary heart disease).

There was a slight increase in the age-standardised rate of total burden due to dementia between 2015 and 2023, from 6.0 DALY to 6.4 DALY per 1,000 people, due to an increase in fatal burden (from 3.4 YLL to 3.8 YLL per 1,000 people) (Figure 4.3). Due to the lack of high-quality data on dementia prevalence (number of people with dementia) and associated disease severity in Australia, the same prevalence and severity rates were used to estimate the non-fatal burden due to dementia in 2015, 2018, 2022 and 2023. As such, there is no change in the YLD rates between 2015 and 2023.

Improvements in estimating dementia prevalence will assist in future calculations of the burden of disease due to dementia in Australia. For more information on the work that is being done to improve dementia prevalence estimates for Australia refer to Prevalence of dementia.

Figure 4.3: Dementia burden in Australia in 2015, 2018, 2022 and 2023, by sex: age-standardised YLL, YLD and DALY per 1,000 people

Figure 4.3 shows 3 bar graphs comparing the dementia burden across 4 different years. The YLL, YLD and DALY are similar between different years.



Note: Rates were age-standardised to the 2001 Australian Standard population and are expressed as per 1,000 population.
Source: AIHW Australian Burden of Disease Database. http://www.aihw.gov.au

Dementia burden differed across population groups

The disease burden experienced in a population (both the amount and types of disease) are influenced by a number of geographic and socioeconomic factors, such as income, education, employment and access to health and social support services.

In the ABDS 2018, remoteness areas are based on an area's relative distance to services and divided into 4 areas:

- *Major cities*
- *Inner regional*
- *Outer regional*
- *Remote/Very remote* areas.

Socioeconomic areas are presented as quintiles and based on a number of socioeconomic characteristics (such as household income, employment and education levels) of the area where a person lives. Quintile 1 represents the 20% of the population living in areas with the greatest overall level of disadvantage whereas Quintile 5 represents the 20% living in areas with the least overall level of disadvantage.

In 2018, the age-standardised DALY rate due to dementia varied by geographic and socioeconomic group (Figure 4.4):

- The Northern Territory had the highest rate of dementia burden (8.9 DALY per 1,000 people), and was much higher than the national rate (6.1 DALY per 1,000 people).
  - This is likely due to a combination of factors including, the Northern Territory having a younger demographic and greater proportion of First Nations people compared with other states and territories, as well as increased prevalence of a number of known risk factors for dementia compared with other states and territories.
- Western Australia had the lowest rate of dementia burden of all the states and territories (4.7 DALY per 1,000 people).
- *Major cities* had the highest rate of dementia burden (6.3 DALY per 1,000 people) and *Outer regional* and *Remote/ Very remote areas* had the lowest rates (5.8 and 5.7 DALY per 1,000 people, respectively).
- People who lived in the lowest socioeconomic area (Quintile 1) had the highest rate of dementia burden (6.6 DALY per 1,000 people), and the rate of dementia burden decreased with each increasing socioeconomic quintile.

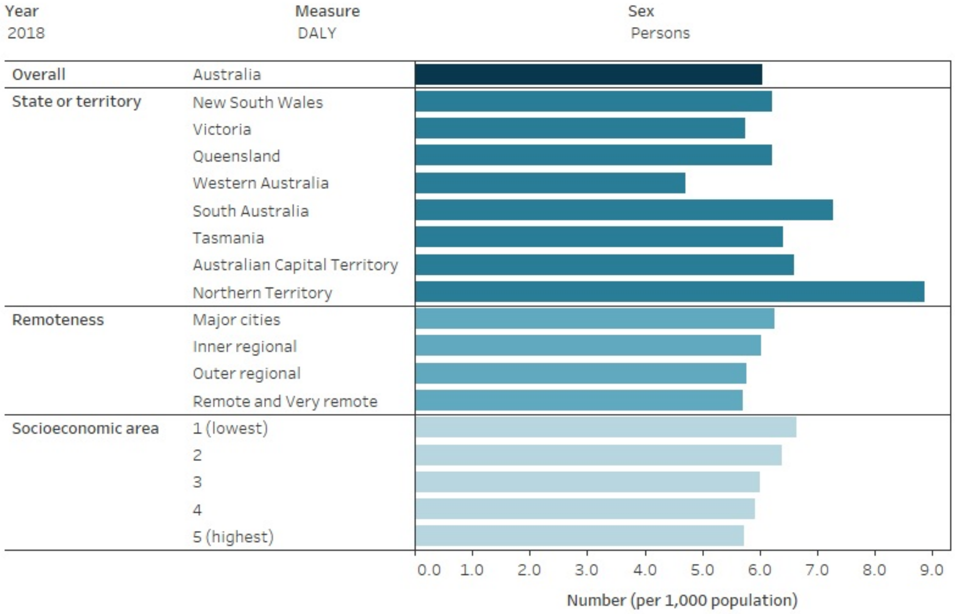
Between 2011 and 2018, changes in the rate of dementia burden varied by state. The rate declined for the Northern Territory, Tasmania and Western Australia (by between 0.5 to 1.0 DALY per 1,000 people); rose for the Australian Capital Territory, New South Wales and Queensland (by between 0.6 to 0.8 DALY per 1,000 people); and remained relatively steady for Victoria.

The rate of burden rose for all remoteness areas and by a similar amount between 2011 and 2018; whereas, it was either steady or rose only slightly for most socioeconomic areas, with the exception of the lowest socioeconomic area which increased from 5.6 to 6.6 DALY per 1,000 people.

Note, patterns in state and territory YLD rates differ to the state and territory prevalence estimate patterns shown in Prevalence of dementia. For burden of disease analyses, prevalence estimates were derived by applying the state and territory proportions of deaths due to dementia to the national prevalence estimates, and then multiplying by the associated disability weights (measure of health loss) to obtain YLD estimates for dementia.

Figure 4.4: Dementia burden in 2011, 2015 and 2018, by geographic and socioeconomic areas and sex: DALY, YLL and YLD per 1,000 people

Figure 4.4 is a bar graph showing that in 2018, dementia DALY rates were highest rates in the Northern Territory, *Major cities* and the lowest socioeconomic area, and were lowest in Western Australia, *Outer regional and Remote/ Very remote areas* and the highest socioeconomic areas. Between 2011 and 2018, dementia DALY rates decreased for the Northern Territory, Tasmania and Western Australia and increased for the Australian Capital Territory, New South Wales, and Queensland, as well as for all remoteness areas. In 2011, dementia DALY rates were similar across socioeconomic areas, but between 2011 and 2018, dementia DALY rates increased for the lowest socioeconomic areas only.



Note: Rates were age-standardised to the 2001 Australian Standard Population and are expressed as per 1,000 population.
Source: AIHW Australian Burden of Disease Database.
http://www.aihw.gov.au

References

AIHW (Australian Institute of Health and Welfare) (2021) *Australian Burden of Disease Study 2018: Interactive data on disease burden*, AIHW, Australian Government, accessed 12 December 2022.

AIHW (2023) *Australian Burden of Disease Study 2023*, AIHW, Australian Government, accessed 28 February 2023.

Population health impacts of dementia

Disease burden due to risk factors is known as the attributable burden. It is measured as the number of healthy years of life lost that could have been avoided if exposure to the risk factor had been reduced or completely avoided.

The Australian Burden of Disease Study (ABDS) 2018 estimated the dementia burden attributable to 6 modifiable risk factors, including:

- tobacco use
- overweight and obesity
- physical inactivity
- high blood pressure in midlife (35–64 years)
- high blood plasma glucose
- impaired kidney function.

Note, this is not an exhaustive list of risk factors linked to dementia (for example, low education levels – an established risk factor for dementia – is not included) and only includes risk factors measured in the ABDS 2018. The list of risk factors and measures of additional risk (relative risks) were based on those used in recent Global Burden of Disease studies and a number of epidemiological studies. For more information on the complete list of established risk factors for dementia refer to What puts someone at risk of developing dementia?.

43% of the dementia burden was attributable to 6 risk factors

Overall, 43% of the dementia burden in 2018 was attributable to the 6 risk factors combined, equivalent to 84,800 DALY. This estimate takes into account the complex pathways and interactions between risk factors, such as the relationship between physical inactivity, overweight and obesity, and high blood pressure in midlife. However, this work does not incorporate the impact of age as a separate risk factor for dementia. Age is the main risk factor for dementia but because it is not a modifiable risk factor, it is not included in this report.

When looking at each risk factors' contribution to the total burden due to dementia (Figure 4.5):

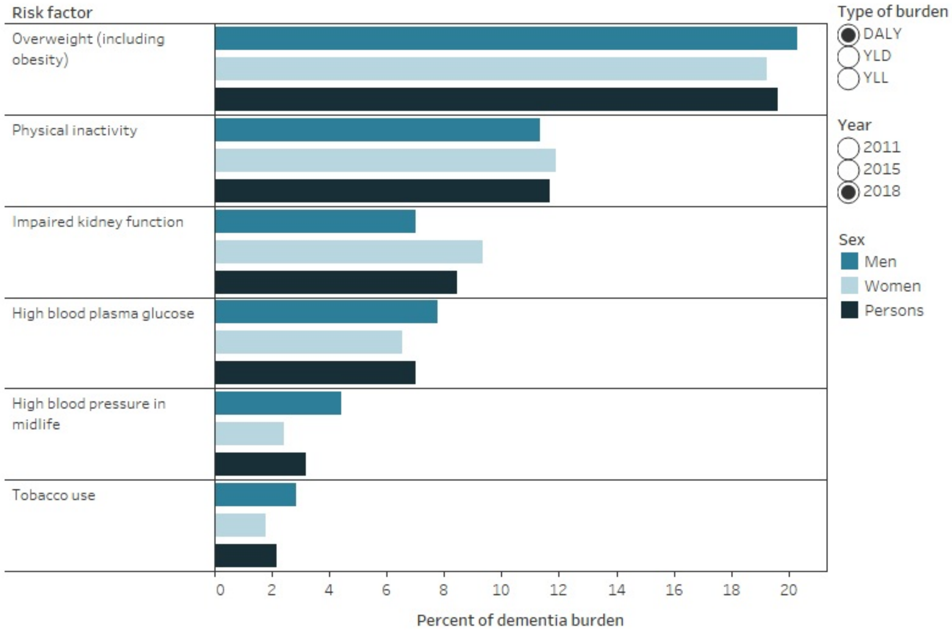
- 20% was attributable to overweight and obesity (38,900 DALY)
- 12% was attributable to physical inactivity (23,100 DALY)
- 8.4% was attributable to impaired kidney function (16,700 DALY)
- 7.0% was attributable to high blood plasma glucose (13,900 DALY)
- 3.2% was attributable to high blood pressure in midlife (6,300 DALY)
- 2.2% was attributable to tobacco use (4,300 DALY).

While there was little difference in the proportion of dementia burden attributable to the 6 risk factors between men and women, the number of attributable DALY was often lower in men compared with women. This is due to women overall experiencing a greater amount of burden due to dementia than men.

Between 2011 and 2018, the proportion of dementia burden attributable to the 6 risk factors combined increased by 2%. However, this varied when looking at each risk factor. The proportion of dementia burden attributable to high blood pressure in midlife and tobacco use decreased (by 22% and 10%, respectively) whereas this increased for overweight and obesity (by 9.0%) and high blood plasma glucose (3.5%). For impaired kidney function and physical inactivity, this was stable over time.

Figure 4.5: Dementia burden in Australia attributable to specific risk factors in 2011, 2015 and 2018, by sex: percentage of DALY, YLL and YLD

Figure 4.5 is a bar graph showing the percentage of years of life lost, years lived with disability and disability-adjusted life years (DALY) due to dementia that were attributable to specific risk factors in Australia by sex in 2011, 2015 and 2018. Risk factors include tobacco use, overweight and obesity, physical inactivity, high blood pressure in midlife (35–64 years), high blood plasma glucose and impaired kidney function. Overall, overweight and obesity was the greatest contributor to disability-adjusted life years due to dementia, followed by physical inactivity. There was little difference in the proportion of dementia DALY attributable to the 6 risk factors by sex. Between 2011 and 2018, the proportion of dementia DALY attributable to overweight and obesity and high blood plasma glucose increased, whereas this decreased for high blood pressure in mid-life and tobacco use.



Source: AIHW Australian Burden of Disease Database.
http://www.aihw.gov.au

How do risk factors impact dementia burden by age?

The amount of dementia burden attributable to each risk factor varied by age. This is due to age differences in both exposure to the risk factor, as well as the burden of dementia by age. The attributable dementia burden was estimated in all ages, except for high blood pressure in midlife, which was estimated for burden due to dementia in people aged 65 and over.

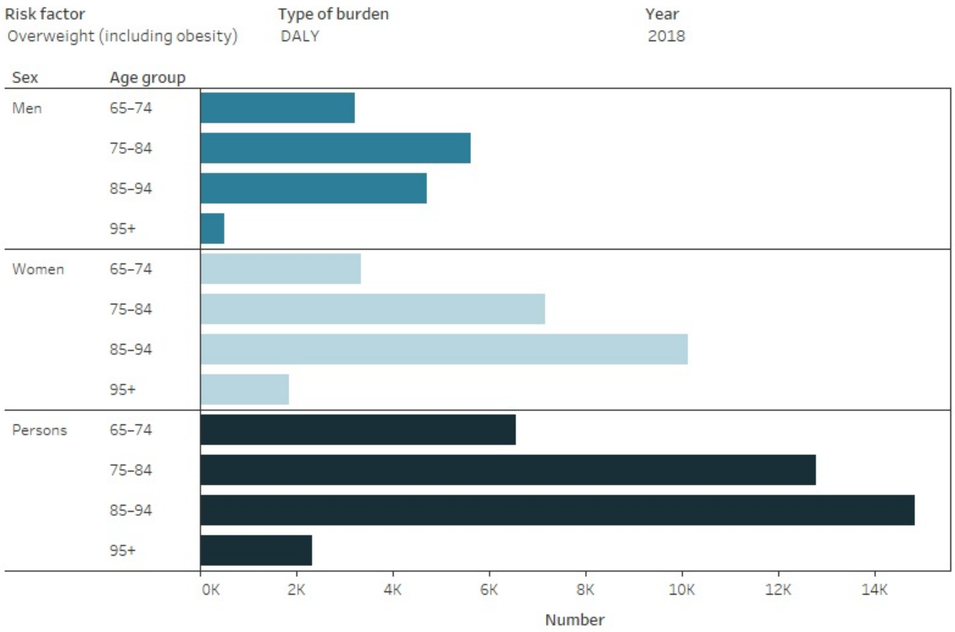
The dementia burden attributable to each risk factor (besides tobacco use) was greatest in people aged 85–94 (Figure 4.6). Dementia burden attributable to tobacco use was greatest in a slightly younger age group (people aged 75–84).

For most risk factors, the total dementia burden attributable to each risk factor was higher in women than men aged 85 and over. However, among those aged 65–74, the dementia burden attributable to each risk factor was generally higher in men than women.

Between 2011 and 2018, there was little difference between age groups in changes to the proportion of the dementia burden attributable to high blood pressure in midlife, overweight and obesity and physical inactivity. However, the proportion attributable to high blood plasma glucose and impaired kidney function either increased or decreased depending on the age group. This suggests there were age-specific changes in the exposure to these 2 risk factors between 2011 and 2018.

Figure 4.6: Dementia burden attributable to specific risk factors in 2011, 2015 and 2018, by age and sex: YLL, YLD and DALY

Figure 4.6 is a bar graph showing the number of years of life lost, years lived with disability and disability-adjusted life years (DALY) due to dementia that were attributable to specific risk factors in Australia by sex and age in 2011, 2015 and 2018. Risk factors include tobacco use, overweight and obesity, physical inactivity, high blood pressure in midlife (35–64 years), high blood plasma glucose and impaired kidney function. Besides tobacco use, the dementia DALY attributable to each risk factor was greatest among those aged 85-94. The dementia DALY attributable to each risk factor was generally higher for females in the older age groups but higher in males in the youngest age groups.



Source: AIHW Australian Burden of Disease Database.
http://www.aihw.gov.au

How do risk factors impact dementia burden by socioeconomic area?

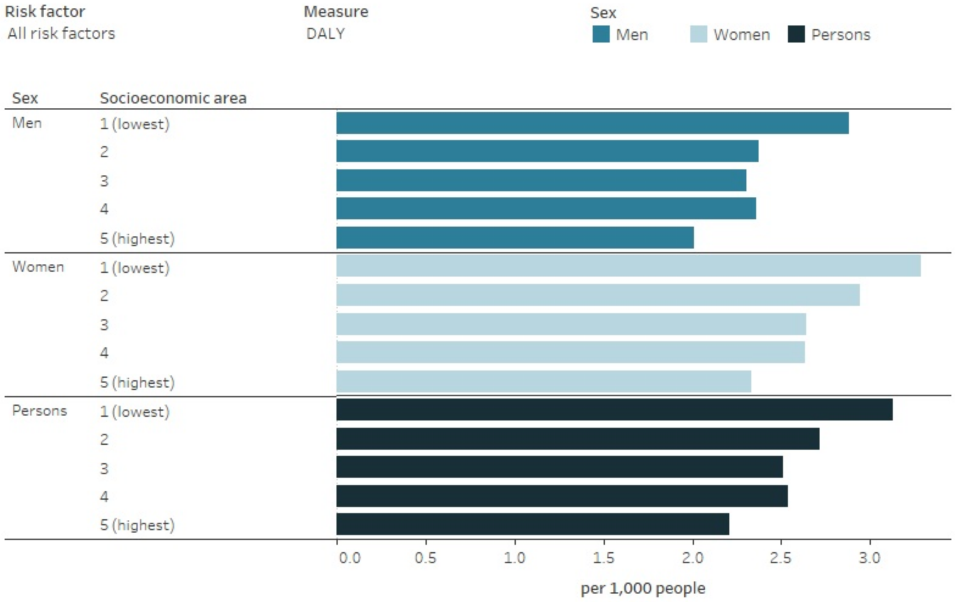
The amount of dementia burden attributable to each risk factor varied by socioeconomic area. Poorer health outcomes are generally observed as greater rates of burden in lower socioeconomic areas. This disparity is influenced by a complex and interrelated set of social and economic factors, including reduced access to health services, lower resource availability, lower levels of education and the influence of uptake of risky behaviours (AIHW 2021).

Taking into account the different age structures in each socioeconomic area, dementia burden attributable to the 6 risk factors combined decreased with increasing socioeconomic area, and was 1.4 times as high in the lowest socioeconomic area (3.1 DALY per 1,000 population) as in the highest area (2.2 DALY per 1,000 population) (Figure 4.7).

The rates of dementia burden attributable to each individual risk factor were consistently higher in the lowest socioeconomic areas than in the highest socioeconomic areas. The greatest difference was seen for tobacco use (2.4 times higher in the lowest socioeconomic area) and high blood plasma glucose (2.2 times higher). In each socioeconomic area, men had higher rates of dementia burden attributable to high blood pressure in midlife and (except for the lowest socioeconomic area) tobacco use than women, and women had higher rates of dementia burden attributable to physical inactivity and impaired kidney function than men.

Figure 4.7: Dementia burden attributable to specific risk factors, by socioeconomic group: age-standardised YLL, YLD and DALY per 1,000 people

Figure 4.7 is a bar graph showing the age-standardised rates of years of life lost (YLL), years lived with disability (YLD) and disability-adjusted life years (DALY) due to dementia that were attributable to specific risk factors in Australia in 2018 for men, women and persons by socioeconomic areas. Risk factors include tobacco use, overweight and obesity, physical inactivity, high blood pressure in midlife (35–64 years), high blood plasma glucose and impaired kidney function. The rates of dementia DALY attributable to each risk factor were consistently higher in the lowest socioeconomic areas than in the highest socioeconomic areas, with the greatest difference seen for tobacco use and high blood plasma glucose. Males had higher rates of dementia DALY attributable to high blood pressure in midlife, high blood plasma glucose levels and tobacco use than females for most socioeconomic areas. Females had higher rates of dementia DALY attributable to physical inactivity and impaired kidney function.



Notes:
1. Rates were age-standardised to the 2001 Australian Standard Population and are expressed as per 1,000 population.

Source: AIHW Australian Burden of Disease Database.

http://www.aihw.gov.au

References

AIHW (Australian Institute of Health and Welfare) (2021) *Australian Burden of Disease Study: impact and causes of illness and death in Australia 2018*, AIHW, Australian Government, accessed 12 December 2022.

Carers and care needs of people with dementia

The level of care required for people with dementia depends on the progression of their dementia and will vary depending on individual circumstances, but the level of care required will increase as the dementia progresses. Carers are people who provide ongoing, informal assistance (help or supervision) to people with disability or older people. Carers play an important role in looking after family members and friends with dementia, and are pivotal in Australia's aged care, health-care, disability and social systems.

The following pages present statistics and information on:

- How care needs of people with dementia differ by place of residence?
- Carers of people with dementia
- Impact of the caring role on carers
- Employment and financial impact on carers
- Carers' unmet needs.

For more information on carers and care needs of people with dementia among different population groups see Dementia in priority groups, including among:

- First Nations people
- people from culturally and linguistically diverse (CALD) backgrounds.

For the underlying data presented in these pages, see data tables.

In 2023, it is estimated there were at least **140,900 unpaid carers** of people with dementia who live in the community

Half of primary carers of people with dementia in 2018 were **caring for their partner** with dementia

57% of primary carers of people with dementia in 2018 were providing **on average 60 or more hours of care** every week

41% of primary carers of people with dementia in 2018 reported that they frequently **felt weary or lacked energy**

Carers and care needs of people with dementia

This page describes how the care needs of people with dementia differ between people living in the community and those living in cared accommodation (such as a residential aged care facility), including differences in:

- level of disability
- average number of co-existing health conditions
- types of co-existing health conditions.

It also includes information on assistance needs and the source of assistance for people with dementia living in the community.

The data presented are from the 2018 Australian Bureau of Statistics' Survey of Disability, Ageing and Carers (SDAC), which surveys a sample of people with dementia in urban and rural areas of Australia living in the community and living in a number of different types of cared accommodation. On this page, 'people with dementia' refers to Australians with dementia in 2018 from the SDAC. Expand the following section, Survey of Disability, Ageing and Carers (SDAC) 2018 and measures of disability, for more information on the SDAC and its limitations for reporting on people with dementia.

Some of the statistics presented in this report are also shown in Aged care and support services used by people with dementia. However, the statistics there are slightly different because they are based on aged care administrative datasets (rather than the SDAC 2018) and are presented for people with dementia who were assessed for using government-subsidised aged care services, and those who are living in permanent residential aged care.

If you are interested in the care needs of people with dementia using aged care services refer to Aged care and support services used by people with dementia.

For demographic information and/or additional information on the assessed needs of people with dementia in Australia refer to Prevalence of dementia and Dementia in priority groups (including First Nations people, people from culturally and linguistically diverse (CALD) backgrounds, people with intellectual disabilities, veterans and the LGBTIQ+ community).

Survey of Disability, Ageing and Carers (SDAC) 2018 and measures of disability

The 2018 SDAC provides detailed information on Australians who belong to one or more of the following groups:

- people with disability
- older people (those aged 65 years and over)
- unpaid carers of people with disability, or a long terms health condition or older people.

The SDAC surveyed people in urban and rural areas of Australia, in 2 distinct groups, referred to in this report as those living in:

- the **community:** includes people living in private dwellings and self-care retirement villages. This is referred to as 'households' in the SDAC.
- **cared accommodation:** includes people living in a cared accommodation facility for a minimum of 3 months where there is 24-hour access to assistance for personal and/or medical needs, and all meals are provided. This includes hospitals, residential aged care facilities, hostels, cared components of retirement villages and other 'homes', such as group homes for people with disability. The vast majority (98%) of people with dementia in cared accommodation in the SDAC were living in residential aged care facilities (government-subsidised and non-government-subsidised facilities) (Table S5.9).

As the SDAC relies on self-reported information about a respondents' health status for those living in the community, the number of people with dementia as reported by the SDAC is likely to be an underestimate. The information on dementia collected by the SDAC requires people to be formally diagnosed, and this diagnosis being reported by the respondent. This may be a particular issue for people with dementia who are living in the community as they either have not yet been formally diagnosed with dementia, are not aware they have it or are unwilling to disclose it. Further, for those who do not have a carer, they may be unable to respond to the survey. The probable underestimate of people with dementia based on the findings of the SDAC should be considered when interpreting the information on people with dementia in this webpage.

In this webpage, there are a number of SDAC estimates where the relative standard errors are between 25% and 50%. These estimates are noted in the figures and should be used with caution.

Disability levels in the SDAC

In the SDAC, respondents with disability include those who have impairments or limitations which restrict their ability to undertake everyday activities, and has lasted, or is expected to last, for at least 6 months. To measure the extent of disability, the SDAC classified limitations into 4 groups based on a persons' experience in undertaking core activities (self-care, communication and mobility):

mild: the person needs no help and has no difficulty with any of the core activity tasks, but uses aids or equipment for core tasks, or has other limitations with core tasks (such as difficulty walking short distances, unable to easily bend over or needs help with using public transport).

moderate: the person needs no help, but has difficulty with a core activity task.

severe: the person sometimes needs help with a core activity task, and/or has difficulty understanding or being understood by family or friends, or can communicate more easily using non-spoken forms of communication.

profound: the person is unable to do, or always needs help with, a core activity task.

A person's overall level of core activity limitation is determined by their highest level of limitation in these activities.

In the SDAC it is not possible to determine if dementia was the only cause of disability. There may be other co-existing conditions contributing to the disability level of a person with dementia. Further, a person with dementia may be considered to have no disability if they are still able to undertake everyday activities.

The SDAC also classified people as having a ‘schooling/employment restriction only' if someone reported no limitations with any of the core activities but reported having difficulty with schooling and/or employment activities. For the purposes of this report, this restriction was not included as a disability level.

More information on the SDAC is found in the Technical notes.

Level of disability

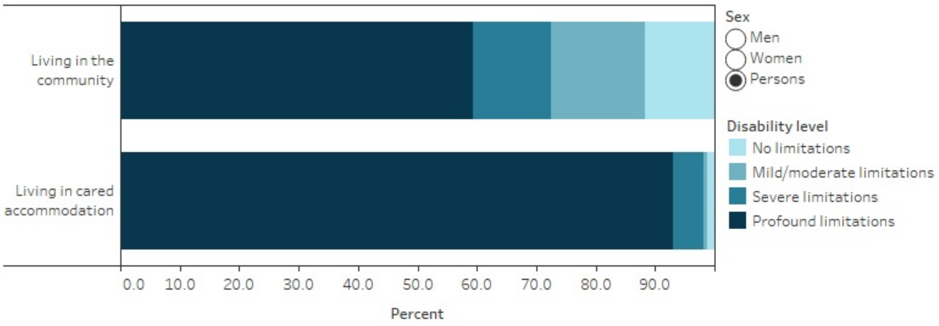
According to the SDAC, in 2018, 59% of people with dementia living in the community and 93% of people with dementia living in cared accommodation were considered to have profound limitations. This means they are unable to do, or always need help with self-care, communication and/or mobility (Figure 5.1). This demonstrates the significant impact dementia has on physical and cognitive functioning, and the need for continued care and support that living in cared accommodation provides.

Among people with dementia living in the community, 58% of men and 61% of women had profound limitations, and 14% of men and 12% of women had severe limitations. A greater percentage of men with dementia living in the community had mild/moderate limitations (18%) compared with women living in the community (13%).

In comparison, the majority of men and women living in cared accommodation had profound limitations (92% and 93%, respectively).

Figure 5.1: Level of disability among people with dementia in 2018: percentage by sex and place of residence

Figure 5.1 is a stacked bar graph showing the percentage of people with dementia by disability level in 2018 (no limitations, mild/moderate limitations, severe limitations and profound limitations) for men, women and persons by place of residence (living in the community or in cared accommodation). Around 92% of men and 93% of women with dementia living in cared accommodation have profound limitations, whereas 58% of men and 61% of women with dementia living in the community have profound limitations. Around 12% of people with dementia living in the community had no limitations and 16% had mild/moderate limitations.



Note: Estimates for men with severe limitations and no limitations living in the community, men with mild/moderate limitations living in cared accommodation and women with mild/ moderate limitations and no limitations living in the community have a relative standard error between 25% and 50% and should be used with caution.
Source: AIHW analysis of the ABS 2018 Survey of Disability, Ageing and Carers confidentialised unit record file.
http://www.aihw.gov.au

Co-existing health conditions

People with dementia often have a number of co-existing health conditions, which can increase or complicate their care needs. Based on the SDAC for the year 2018, we report on co-existing conditions, comparing people living in the community with those living in cared accommodation.

Of those with dementia who reported having multiple health conditions, dementia was reported as the main condition for a greater proportion of people living in cared accommodation (66%) than people living in the community (52%) (Table S5.2).

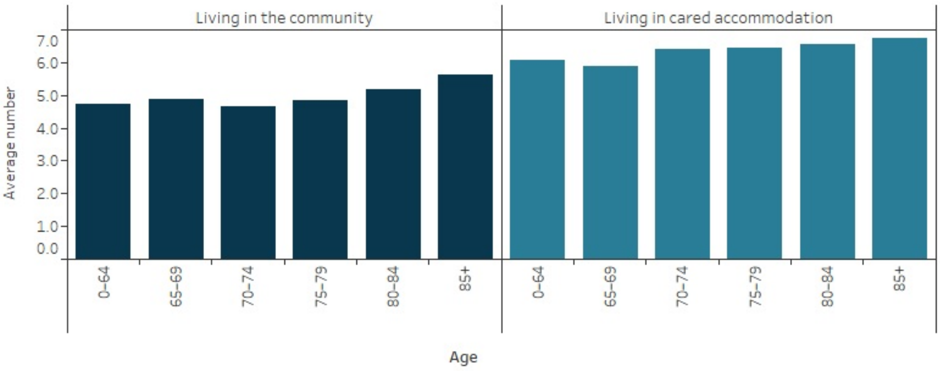
On average, people with dementia living in the community have 5 long-term health conditions

According to the SDAC, people with dementia living in the community had an average of 5.1 long-term health conditions (including dementia) (Figure 5.2). This was lower than for those living in cared accommodation (6.6 conditions). Long-term health conditions are defined as diseases or disorders lasting (or likely to last) for 6 months or more, and conditions that are periodic or episodic in nature (for example, asthma or epilepsy) where the attack or relapse has occurred in the last 12 months (ABS 2019).

There was little difference between men and women with dementia but the average number of conditions generally increased with age, regardless of where they lived. People with younger onset dementia (aged under 65) living in the community had, on average, 4.7 health conditions and those living in cared accommodation had 6.1 health conditions. Among people aged 85 and over with dementia, this increased to 5.6 conditions for those living in the community and 6.8 conditions for those in cared accommodation.

Figure 5.2: Average number of health conditions among people with dementia in 2018: by age and place of residence

Figure 5.2 is a bar graph showing the average number of long term health conditions among people with dementia in 2018 by place of residence and age. The average number of health conditions increased with age both among those living in the community and those living in cared accommodation. In each age group, people with dementia living in cared accommodation had more health conditions on average that those with dementia living in the community.



Note: Average number of health conditions includes dementia as a condition.
Source: AIHW analysis of ABS 2018 Survey of Disability, Ageing and Carers confidentialised unit record file.
http://www.aihw.gov.au

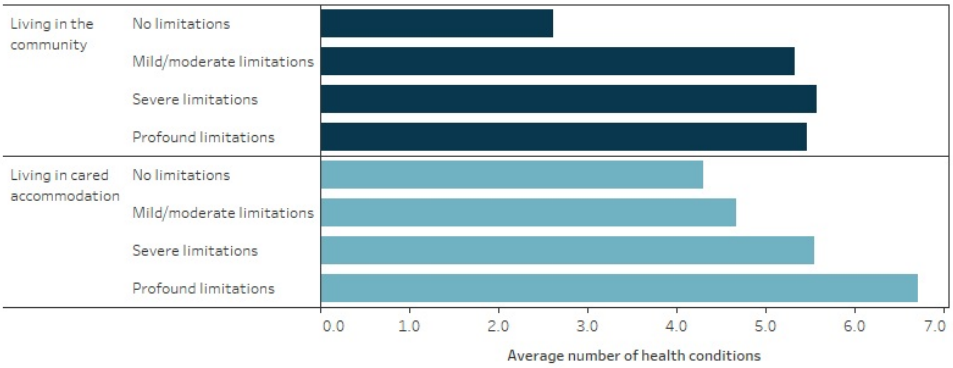
Among people with dementia living in the community, there was little variation in the average number of health conditions across disability levels (with the exception of people with no limitations) (Figure 5.3). Whereas, the average number of health conditions increased with increasing level of disability among people living in cared accommodation.

The average number of health conditions was higher for people with profound limitations living in cared accommodation (average of 6.7) than among people with profound limitations living in the community (average of 5.5 conditions). The majority of people with profound limitations were living in cared accommodation, reflecting their need for extensive care.

The average number of health conditions was fairly similar between people with mild/ moderate or severe limitations living in the community to those in cared accommodation.

Figure 5.3: Average number of health conditions among people with dementia in 2018: by level of disability and place of residence

Figure 5.3 is a bar graph showing the average number of long term health conditions among people with dementia in 2018 by place of residence and disability level. The average number of health conditions increased with increasing level of disability among people living in cared accommodation. For those with dementia living in the community, there was little variation in the average number of health conditions across disability levels (except for people with no limitations, where the average number of health conditions was much lower).



Note: Average number of health conditions includes dementia.
Source: AIHW analysis of ABS 2018 Survey of Disability, Ageing and Carers confidentialised unit record file.
http://www.aihw.gov.au

Common co-existing health conditions

According to the SDAC, the most common co-existing health conditions in people with dementia in 2018 varied by whether they were living in the community or in cared accommodation (Figure 5.4).

Of those with dementia living in the community:

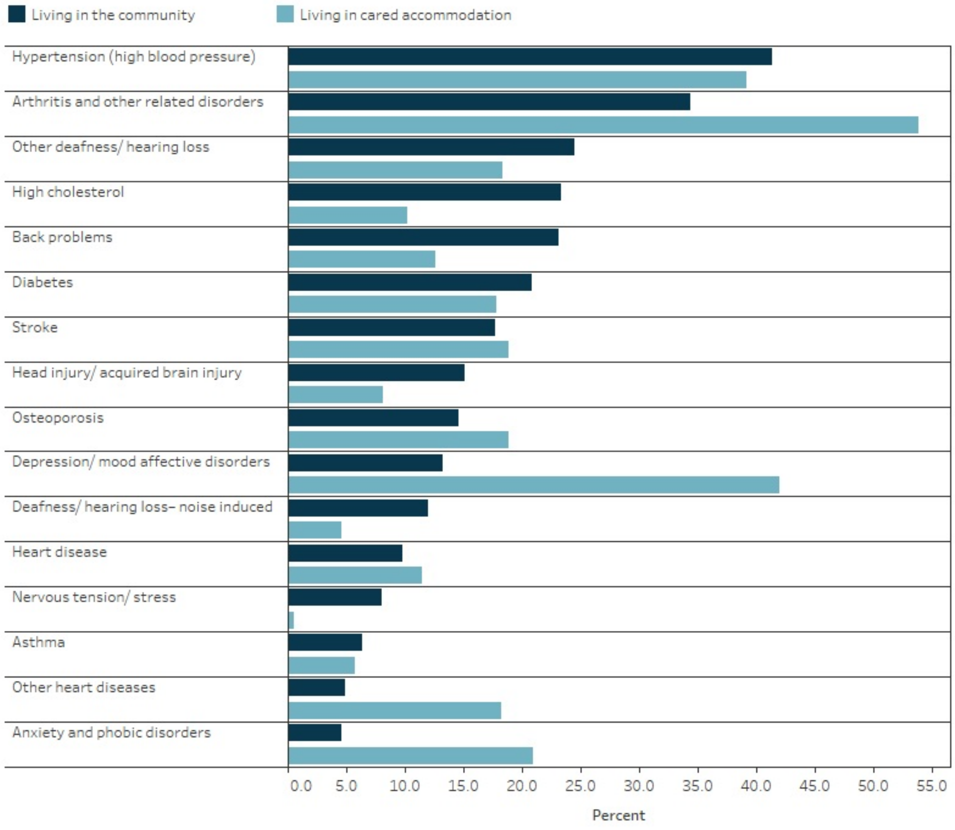
- 41% also had hypertension (high blood pressure) – this was similar to people living in cared accommodation (39%)
- 34% also had arthritis and related disorders – this was lower than those living in cared accommodation (54%)
- 25% also had other hearing loss or deafness (that was not noise induced) – this was higher than those living in cared accommodation (18%)
- 23% also had high cholesterol – this was higher than those living in cared accommodation (10%)
- 23% also had back problems – this was higher than those living in cared accommodation (13%).

Depression and anxiety & phobic disorders were substantially higher among people with dementia living in cared accommodation (42% and 21%, respectively) than in the community (13% and 4.6%, respectively).

Head injury/acquired brain injury, noise induced hearing loss and nervous tension/stress were more common among people with dementia living in the community (15%, 12% and 8.1%, respectively) than in cared accommodation (8.2%, 4.6% and 0.5%, respectively).

Figure 5.4: Common health conditions among people with dementia in 2018: percentage by place of residence

Figure 5.4 is a bar graph showing the percentage of people with dementia in 2018 who had other health conditions by place of residence and health condition. *Hypertension* and *Arthritis & other related disorders* were the most common coexisting health conditions among people with dementia living in the community as well as those living in cared accommodation. *Head injury/acquired brain injury*, *High cholesterol*, *Back problems*, *Noise-induced hearing loss*, and *Nervous tension/stress* were more common among people with dementia living in the community than those in cared accommodation. *Depression/mood affective disorders* and *Anxiety & phobic disorders* were substantially higher among people with dementia living in cared accommodation than in the community.



Notes:
1. Health conditions were based on the International Statistical Classification of Diseases and Related Health Problems, 10th Revision (ICD-10). Refer to the Technical notes for more information on health conditions in the SDAC.
2. As a person may have more than 1 health condition, the percentages will sum to more than 100%.
3. 'Other heart diseases' includes the ICD-10 codes I23-I52; 'Other deafness/ hearing loss' includes the ICD-10 codes H910–912 and H918–919; 'Diabetes' includes the ICD-10 codes E10–E14.
4. Estimates for 'Asthma', ' Other heart diseases' and 'Anxiety and phobic disorders' among people with dementia living in the community have a relative standard error between 25% and 50% and should be used with caution.

Source: AIHW analysis of ABS 2018 Survey of Disability, Ageing and Carers confidentialised unit record file.
http://www.aihw.gov.au

Box 5.1: Information on co-existing health conditions among people with dementia from other data sources

Data on the co-existing health conditions of people with dementia are available from a number of data sources. They include the SDAC, as well as administrative data from aged care services (presented in Aged care and support services used by people with dementia).

Information on co-existing health conditions for all people with dementia who were assessed for the use of government-subsidised aged care services is available from the National Screening and Assessment Form (NSAF) as well as from the Aged Care Funding Instrument (ACFI) for people with dementia living in permanent residential aged care. The profile of co-existing health conditions from these sources was similar to the profile seen using the SDAC for some conditions. However, there are a number of differences that are likely due to variations in how health condition information is collected between these sources, as well as differences in the group of people with dementia examined.

If you are interested in co-existing health conditions among people with dementia using aged care services refer to Aged care assessments and Residential aged care. For more detail on how health condition information is collected from each of these data sources refer to Technical notes.

Assistance needs for people with dementia living in the community

People with dementia often require care in various activities of daily living. This section presents the broad assistance needs of people with dementia living in the community, how needs vary by place of residence and the source of assistance for people with dementia living in the community as reported in the 2018 SDAC.

Carers of people with dementia provides information on the informal carers, who provide support and assistance for people with dementia living in the community, and Residential aged care provides information on assistance needs of people with dementia living in residential aged care.

Broad assistance needs

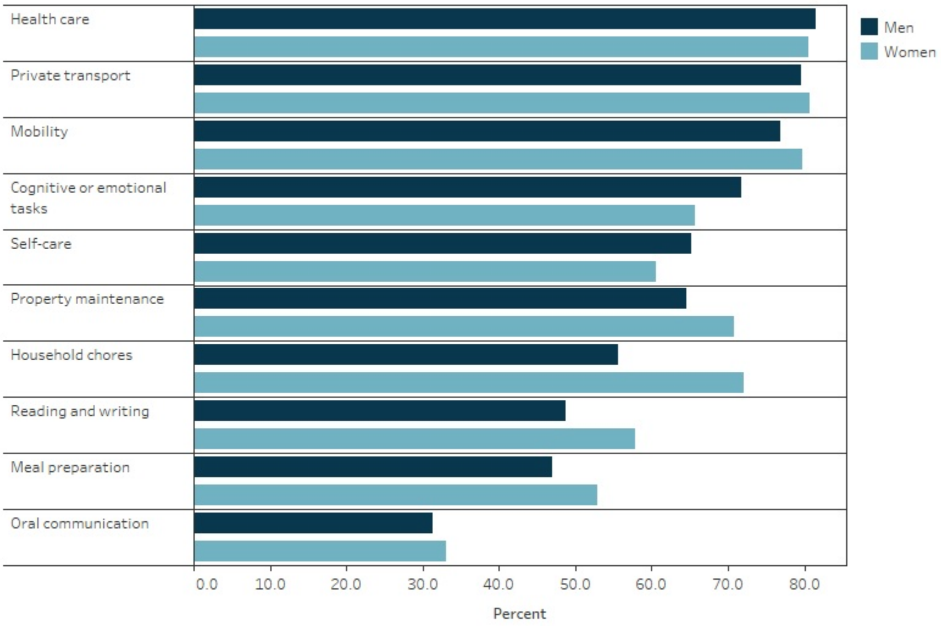
Based on the SDAC, more than three-quarters of people with dementia living in the community who required assistance in 2018 required assistance in 3 activities – health care (81%), private transport (80%) and mobility (78%) (Table S5.6).

When looking at the assistance needs for the 3 core activities individually – self-care, communication and mobility – men and women living in the community were most likely to need assistance with mobility (77% of men and 80% of women) (Figure 5.5).

Women were more likely to need assistance with household chores (56% of men compared with 72% of women). For all other activities, there was little difference in the proportion of men and women living in the community who required assistance.

Figure 5.5: People with dementia living in the community who required assistance in 2018: percentage by sex and activity

Figure 5.5 is a bar graph showing the percentage of people with dementia living in the community who required assistance in 2018 by sex and the type of activity they required assistance with. The majority required assistance with health care, private transport and mobility. Women were more likely to need assistance with household chores, but for all other activities, there was little difference by sex.



Note: Includes people with dementia living in the community only.
Source: AIHW analysis of the ABS 2018 Survey of Disability, Ageing and Carers confidentialised unit record file.
http://www.aihw.gov.au

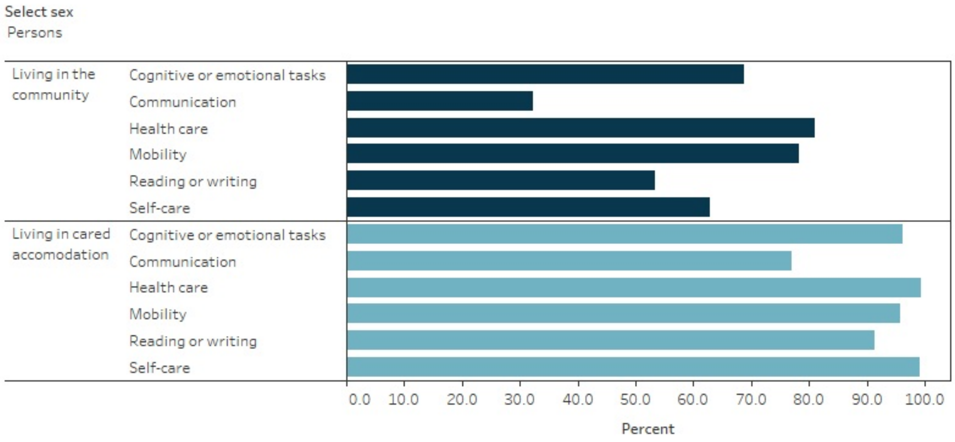
Unsurprisingly, for each activity the proportion of people with dementia who needed assistance was lower for those living in the community than those living in cared accommodation and there was little difference by sex (Figure 5.6). This reflects the greater care needs of people living in cared accommodation, such as permanent residential aged care facilities.

The greatest difference was in the need for assistance with communication; 32% of people with dementia living in the community compared with 77% of those living in cared accommodation. This was followed by assistance with reading or writing (53% in the community and 91% in cared accommodation) and self-care (63% in the community and 99% in cared accommodation).

Note, meal preparation, private transport, property maintenance and household chores are not included as these activities are provided for people living in cared accommodation.

Figure 5.6: People with dementia who required assistance in 2018: percentage by sex, activity and place of residence

Figure 5.6 is a bar graph showing the percentage of people with dementia who required assistance in 2018 by sex, place of residence and the type of activity they required assistance with. The percentage of men and women with dementia who needed assistance in each activity was lower among those living in the community than those living in cared accommodation. There was little difference by sex. The greatest difference was in the percentage who needed assistance with communication, followed by assistance with reading or writing and self-care.



Source: AIHW analysis of the ABS 2018 Survey of Disability, Ageing and Carers confidentialised unit record file.
http://www.aihw.gov.au

Overall source of assistance

Assistance from informal sources (such as family and friends) as well as from formal sources (such as dementia-specific, disability support and/or aged care services) are essential for people with dementia living in the community.

According to the SDAC, over 1 in 3 people with dementia (36%) who were living in the community in 2018 relied on informal assistance only (Table S5.7).

For information on how the source of assistance varies among people with dementia born in non-English speaking countries refer to Dementia among people from culturally and linguistically diverse backgrounds. For information on informal carers of people with dementia refer to Carers of people with dementia.

Source of assistance in core and other activities

The SDAC grouped activities in which people require assistance into 2 groups:

- Core activities – this includes self-care, communication and mobility. People with more severe limitations (severe or profound limitations) require assistance with one or more of these activities.
- Other activities – this includes private transport, property maintenance, household chores, reading or writing, health care, cognitive or emotional tasks, and meal preparation.

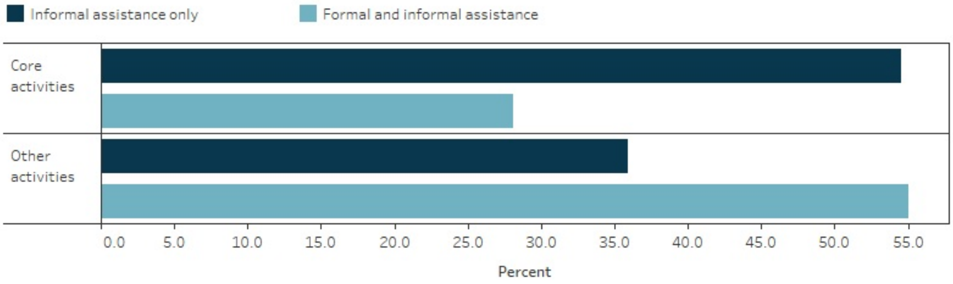
If we look at the source of assistance people with dementia living in the community were receiving by whether this was for core activities or other activities:

- 55% received assistance in core activities from informal sources only – this was higher than the percentage who received informal assistance for other activities (36%).
- 28% received assistance in core activities from a combination of informal and formal sources – this was lower than the percentage who received a combination of informal and formal assistance with other activities (55%) (Figure 5.7).

The high percentage of people with dementia requiring support from informal carers demonstrates the importance and responsibilities that informal carers (such as family and friends) have for caring for an individual with dementia. Refer to Carers of people with dementia for more information on informal carers.

Figure 5.7: People with dementia living in the community who require assistance in 2018: percentage by source of assistance for core and other activities

Figure 5.7 is a bar graph showing the percentage of people with dementia who were living in the community and required assistance in 2018 by source of assistance for core and other activities. Core activities include self-care, communication and mobility. Other activities include private transport, property maintenance, household chores, reading or writing, health care, cognitive or emotional tasks, and meal preparation. Over half of people with dementia who were living in the community and required assistance were receiving support with core activities from informal sources only (such as family and friends). Over one-third were receiving support with other activities from informal sources only.



Notes:
1. Includes people with dementia who live in the community.
2. Core activities includes mobility, self-care and communication.
3. Other activities includes health care, private transport, cognitive or emotional tasks, property maintainence, household chores, reading or writing and meal preparation.

Source: AIHW analysis of the ABS 2018 Survey of Disability, Ageing and Carers confidentialised unit record file.
http://www.aihw.gov.au

References

Australian Bureau of Statistics (ABS) (2019) *Disability, Ageing and Carers, Australia: Summary of Findings, 2018- Explanatory notes*, ABS, Australian Government, accessed 17 January 2020.

Carers and care needs of people with dementia

Key statistics

In 2023, there were at least **140,900 unpaid carers** of people with dementia who live in the community

Half of primary carers of people with dementia in 2018 were **caring for their partner** with dementia

57% of primary carers of people with dementia in 2018 were providing on average **60 or more hours** of care every week

23% of primary carers of people with dementia in 2018 reported that they needed **more respite care**

Carers play an important role in providing care for family members and friends with illnesses or disabilities and are pivotal in Australia's aged care, health-care, disability and social systems. Carers assist and support with a range of daily activities such as self-care, transport, meal preparation and household chores, as well as provide overall supervision and manage behavioural or medical problems. For carers of people with dementia, the type of support and assistance needed will vary depending on individual circumstances but the level of care required will increase as the dementia progresses.

This page provides information on the number of carers of people with dementia in Australia as estimated by the Australian Institute of Health and Welfare (AIHW), and information from the Australian Bureau of Statistics (ABS) Survey of Disability, Ageing and Carers (SDAC) 2018 on:

- Primary carers of people with dementia
- Motivation to take on the caring role
- Time spent in the caring role.

For key carer definitions used in this report see Box 6.1.

For more information on how carer characteristics differ in people from non-English speaking countries, see Dementia among people from culturally and linguistically diverse (CALD) backgrounds. For information on carers among First Nations people, see First Nations-specific health and aged care programs and caring roles among First Nations people.

Box 6.1: Key definitions used in this report

This report relies on a number of definitions from the ABS Survey of Disability, Ageing and Carers (SDAC) 2018. The definition of a ‘carer’ in the SDAC varies depending on the level of care provided:

- **Carer** refers to people who provide any informal assistance (help or supervision) to people with disability or older people (aged 65 and over). The assistance must be ongoing, or likely to be ongoing, for at least 6 months. It excludes people who provide formal assistance (on a regular paid basis, usually associated with an organisation). A carer is either a *primary carer* or *other carer*.
- **Primary carer** refers to carers aged 15 or over who provided the most informal, ongoing assistance with one or more core activity tasks (mobility, self-care or communication) for a person with disability. The assistance must be ongoing, or likely to be ongoing, for at least 6 months. For this report, all primary carers lived in the same household as their care recipient.
- **Other carer** refers to carers who: are aged under 15 – provide informal assistance with one or more core activity tasks but do not provide the most assistance or provide assistance with non-core activities only.

While information on carers in this report refers to people who provide assistance to those living in the community, it is important to note that there are people who provide significant care to family and friends with dementia living in residential aged care facilities.

How many carers of people with dementia are there in Australia?

The number of carers of people with dementia in Australia is unclear. Based on the available data, the AIHW estimates that in 2023, there were at least 140,900 informal carers of people with dementia who live in the community. However, this is likely an underestimate of the true number of carers of people with dementia in Australia. Expand the following section, Knowledge gaps on carers of people with dementia in Australia, for details on data gaps for carers of people with dementia in Australia and how the total number of carers in Australia was estimated for this report.

Knowledge gaps on carers of people with dementia in Australia

There are significant gaps and inconsistencies in national data on carers of people with dementia in Australia.

The ABS Survey of Disability, Ageing and Carers (SDAC) 2018 provides the most up-to-date national information on carers of people with dementia. However, the SDAC is limited in its ability to provide a comprehensive picture as the information collected is restricted to co-resident carers (primary and otherwise) only for people with dementia and it is difficult to adequately identify population groups of interest (such as First Nations people and people of culturally and linguistically diverse backgrounds). Further, the SDAC will likely under identify the number of people with dementia (particularly people with mild dementia living in the community). Refer to Box 5.1 for more information on limitations of reporting on people with dementia from the SDAC.

As a result of these gaps, it is challenging to present a comprehensive national picture on; how many Australians provide care to people with dementia, what the important support mechanisms for carers are, what their unmet needs are, and how the prevalence of carers and their needs may change in the future. Without this information, the ability to plan and make informed decisions on the magnitude and type of support services needed for carers of people with dementia in the future is limited.

Estimating the number of carers of people with dementia

The AIHW estimates that in 2023, there were at least 140,900 carers of people with dementia in Australia who live in the community. The minimum estimate was derived by applying the rate of carers of people with dementia from the SDAC 2018 to the estimated residential population aged 15 and over for the year 2023. However, the SDAC will be an underestimate as only carers who lived in the same household as the care recipient with dementia (co-resident carer) were included. In addition, the SDAC also underestimates the number of people with dementia living in the community.

Primary carers of people with dementia

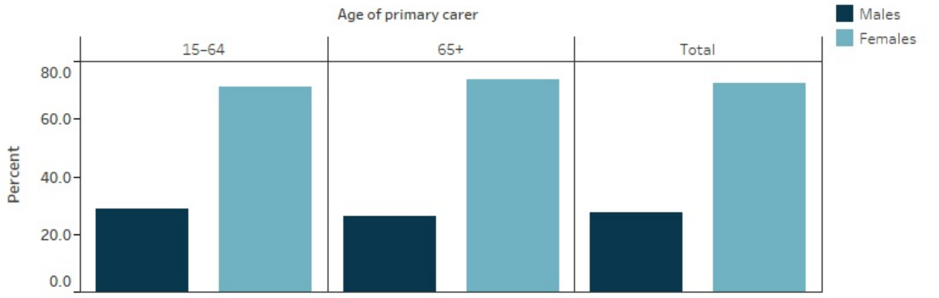
This section presents information from the SDAC on primary carers of people with dementia who live in the same household as the care recipient.

According to the SDAC, in 2018:

- 126,700 people were providing informal care to people with dementia – over half were primary carers (55%, or 70,200 people).
- Almost 3 in 4 primary carers of people with dementia were females (72%).
  - This proportion was similar among carers aged under 65 (71% were female) and carers aged 65 and over (74% were female) (Figure 6.1).
- Half of primary carers were caring for their partner with dementia (50%).
  - The remainder were mostly caring for their parent with dementia (41%) (Table S6.4).

Figure 6.1: Primary carers of people with dementia in 2018: percentage by sex in each age group

Figure 6.1 is a bar graph showing the percentage of primary carers of people with dementia according to the ABS Survey of Disability, Ageing and Carers in 2018 by age and sex of the primary carer. Almost three-quarters of primary carers of people with dementia were female, and this pattern was consistent across primary carer age groups.



Notes:
1. Primary carers are people aged 15 or over who provided the most informal, ongoing assistance (minimum of 6 months) with 1 or more core activities (mobility, self-care and communication) for the care recipient.
2. Estimates for male primary carers in each age group have a relative standard error between 25% and 50% and should be interpreted with caution.

Source: AIHW analysis of 2018 ABS Survey of Disability, Ageing and Carers confidentialised unit record file.
http://www.aihw.gov.au

Motivation to take on the caring role

Based on the SDAC, in 2018 the most common reasons for primary carers of people with dementia to take on the caring role was:

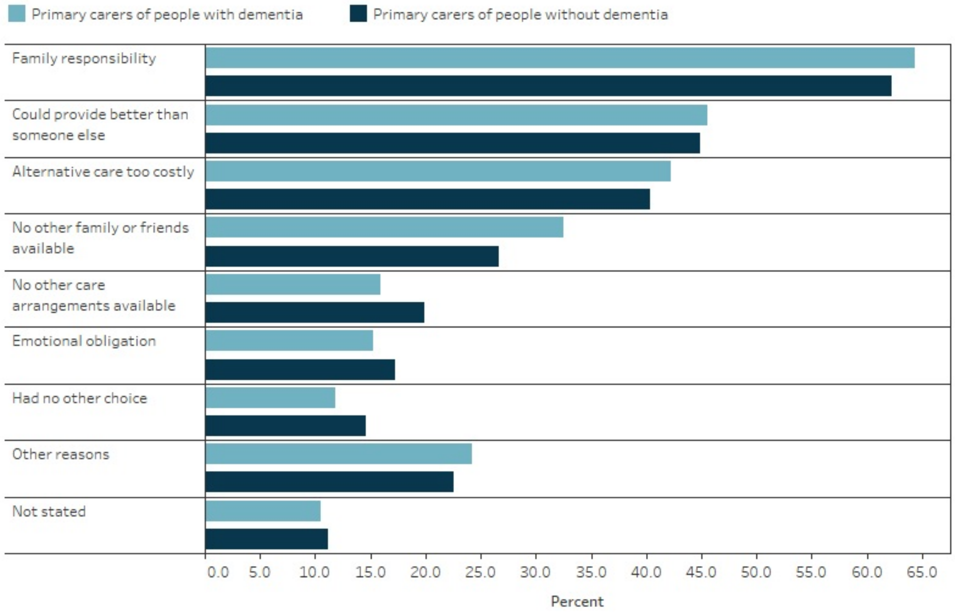
- family responsibility (64%)

- they could provide better care than someone else (46%)
- alternative care is too costly (42%)
- no other family or friends were available (32%) (Figure 6.2).

For most of the common reasons for taking on the caring role, proportions were similar for primary carers of people with dementia compared with primary carers of people without dementia.

Figure 6.2: Primary carers of people with dementia and people without dementia in 2018: percentage by reason for taking on the caring role

Figure 6.2 is a bar graph showing the percentage of primary carers of people with dementia and primary carers of people without dementia in 2018 by their reason for taking on the caring role. Almost two-thirds of primary carers of people with dementia reported that they took on the caring role because it was a family responsibility. Other common reasons included that they could provide better care than someone else, alternative care was too costly and that they had no other family or friends available to help. There were no substantial differences between primary carers of people with and without dementia.



Notes:
1. Primary carers are people who provided the most informal, ongoing assistance (minimum of 6 months) with 1 or more core activities (mobility, self-care and communication) for a person with dementia.
2. As multiple reasons for taking on the caring role may be reported, percentages for each reason will sum to over 100%.
3. Estimates for primary carers of people with dementia where the reason for taking on the caring role was not stated has a relative standard error between 25% and 50% and should be used with caution.

Source: AIHW analysis of ABS 2018 Survey of Disability, Ageing and Carers confidentialised unit record file.
http://www.aihw.gov.au

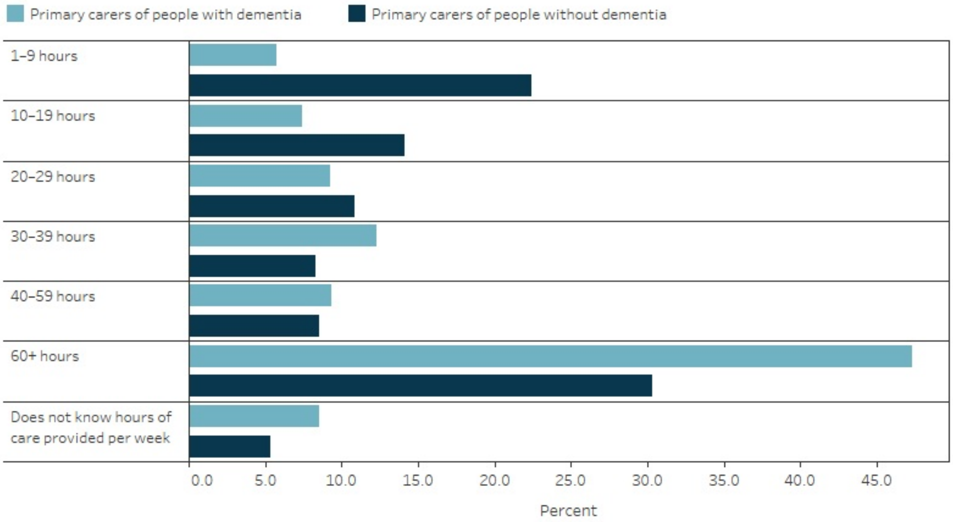
Time spent in the caring role

As dementia progresses, people with the condition require increasing levels of care across all aspects of daily living. This is reflected by the amount of time primary carers of people with dementia spend providing care.

The vast majority (93%) of primary carers of people with dementia provided continuous rather than episodic care, and almost half of primary carers of people with dementia were providing an average of 60 or more hours of care per week (47%) (Figure 6.3). In contrast, the caring intensity was overall lower for primary carers of people without dementia, with 78% providing continuous care and 30% providing on average 60 or more hours of care per week.

Figure 6.3: Primary carers of people with dementia and people without dementia in 2018: percentage by average weekly hours spent caring

Figure 6.3 is a bar graph showing the percentage of primary carers of people with dementia and primary carers of people without dementia in 2018 by average weekly hours spent caring. Just under half of primary carers of people with dementia were providing an average of 60 or more hours of care per week compared with less than one-third of primary carers of people without dementia.



Notes:
1. Primary carers are people who provided the most informal, ongoing assistance (minimum of 6 months) with 1 or more core activities (mobility, self-care and communication) for the care recipient.
2. Estimates of weekly hours spent caring by primary carers of people with dementia (excluding '60+ hours') have a relative standard error of 25% to 50% and should be used with caution.
Source: AIHW analysis of ABS 2018 Survey of Disability, Ageing and Carers confidentialised unit record file
http://www.aihw.gov.au

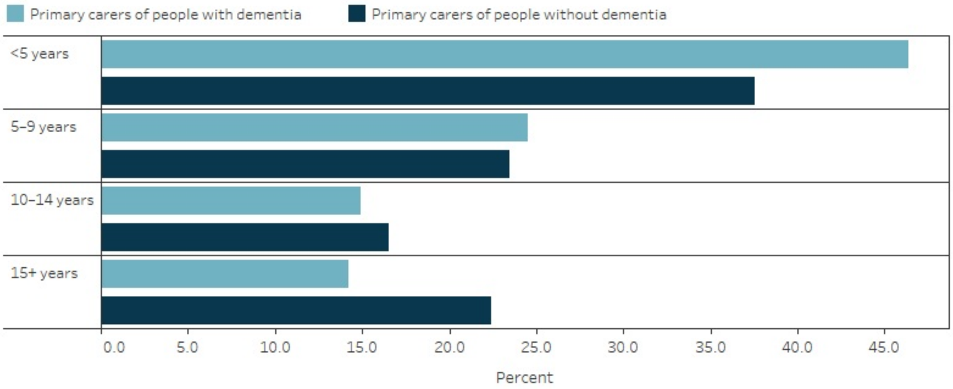
Primary carers of people with dementia had generally spent a shorter period of time providing care than primary carers of people without dementia. Among primary carers of people with dementia:

- 46% had been providing care for less than 5 years. There was no statistical difference compared with primary carers of people without dementia (38%).
- 14% had been providing care for 15 years or more. This was less than for carers of people without dementia (22%) (Figure 6.4).

These differences may be due to the generally late age of onset of dementia, transition into residential aged care for people with dementia when extensive support is required and people with dementia living for a shorter number of years with the diagnosed condition compared to other care recipients without dementia.

Figure 6.4: Primary carers of people with dementia and people without dementia in 2018: percentage by years spent caring

Figure 6.4 is a bar graph showing the percentage of primary carers of people with dementia and primary carers of people without dementia in 2018 by the number of years spent caring. Primary carers of people with dementia had generally spent a shorter period of time providing care than primary carers of people without dementia.



Note: Primary carers are people who provided the most informal, ongoing assistance (minimum of 6 months) with 1 or more core activities (mobility, self-care and communication) for the care recipient.
Source: AIHW analysis of ABS 2018 Survey of Disability, Ageing and Carers confidentialised unit record file
http://www.aihw.gov.au

References

ABS (Australian Bureau of Statistics) (2019) *Disability, Ageing and Carers, Australia: Summary of Findings, 2018- Explanatory notes*, ABS, Australian Government, accessed 10 July 2023.

Carers and care needs of people with dementia

Caring for a person with any type of disability or chronic 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 influencing the level of caregiving burden include the personal characteristics of carers and care recipients, living arrangements, employment and financial situation, and support systems available from formal services and other family and friends.

This page presents information from the Australian Bureau of Statistics Survey of Disability, Ageing and Carers (SDAC) on the impact of caring for a person with dementia on the primary carer's physical and emotional wellbeing, relationships, employment and financial situation in 2018.

Impacts on carers' physical and emotional health and wellbeing

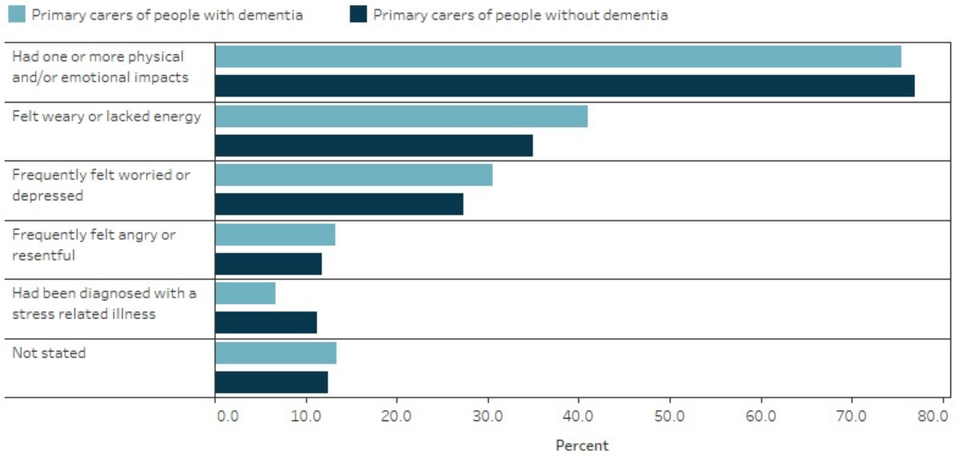
Around 3 in 4 primary carers of people with dementia (75%), as well as primary carers of people without dementia (77%) reported they had 1 or more physical or emotional effects due to the caring role (Figure 6.5).

The most commonly reported impact was that the carer felt weary or lacked energy, reported by 41% of primary carers of people with dementia and 35% of primary carers of people without dementia. Another commonly reported effect was frequently feeling worried or depressed, reported by 31% of primary carers of people with dementia and 27% of primary carers of people without dementia.

The proportion of primary carers who frequently felt angry or resentful and who had been diagnosed with a stress related illness was similar among primary carers of people with dementia (13% and 6.7%, respectively) and primary carers of people without dementia (12% and 11%, respectively).

Figure 6.5: Primary carers of people with dementia and people without dementia in 2018: percentage by physical and emotional impacts of the caring role

Figure 6.5 is a bar graph showing the percentage of primary carers of people with dementia and primary carers of people without dementia in 2018 by the physical and emotional impacts experienced since taking on the caring role. Around three-quarters of primary carers of people with dementia as well as primary carers of people without dementia reported they had 1 or more physical or emotional impacts due to the caring role. The most commonly reported impact by primary carers of people with dementia was feeling weary or lacking energy. In addition, just under one-third of primary carers of people with dementia reported frequently feeling worried or depressed.



Notes:
1. Primary carers are people who provided the most informal, ongoing assistance (minimum of 6 months) with 1 or more core activities (mobility, self-care and communication) for the care recipient.
2. Estimates for primary carers of people with dementia who had been diagnosed with a stress related illness has a relative standard error between 25% and 50% and should be used with caution.

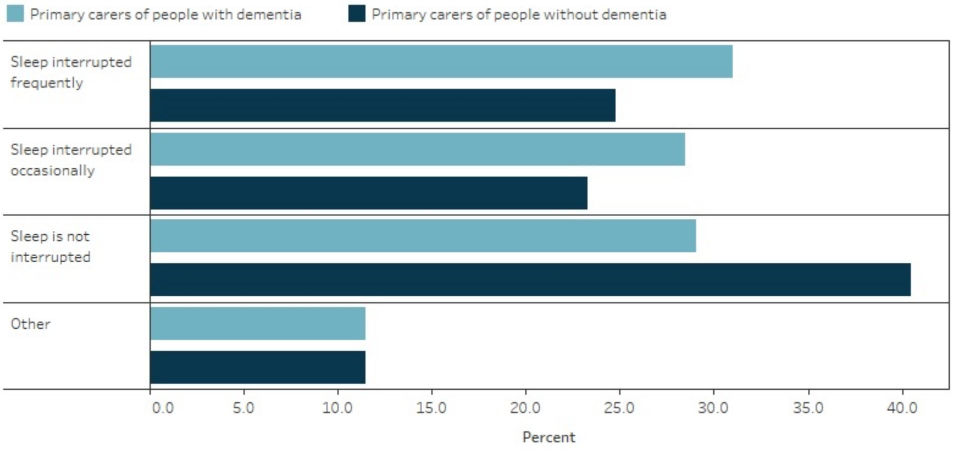
Source: AIHW analysis of ABS 2018 Survey of Disability, Ageing and Carers confidentialised unit record file
http://www.aihw.gov.au

Sleep is essential to improving and maintaining a person's health and wellbeing. However, caring responsibilities can directly impact the length and quality of a carer's sleep.

Among primary carers of people with dementia, 31% reported their sleep was interrupted frequently and 29% reported their sleep was interrupted occasionally due to the caring role. By comparison, 25% of primary carers of people without dementia reported their sleep was interrupted frequently and 23% reported their sleep was interrupted occasionally. There was also no statistical difference in the percentages between primary carers of people with dementia and primary carers of people without dementia (Figure 6.6).

Figure 6.6: Primary carers of people with dementia and people without dementia in 2018: percentage by sleep disturbances due to the caring role

Figure 6.6 is a bar graph showing the percentage of primary carers of people with dementia and primary carers of people without dementia in 2018 by whether they experienced sleep disturbances since taking on the caring role. Almost one-third of primary carers of people with dementia reported their sleep was interrupted frequently and almost one-third reported their sleep was interrupted occasionally due to the caring role. Primary carers of people without dementia were less likely to report their sleep was interrupted frequently or occasionally.



Notes:
1. Primary carers are people who provided the most informal, ongoing assistance (minimum of 6 months) with 1 or more core activities (mobility, self-care and communication) for the care recipient.
2. 'Other' includes 'Not stated' and 'Sleep interrupted but frequency not stated'.
3. The estimate for 'Other' for primary carers of people with dementia has a relative standard error of 25% to 50% and should be used with caution.

Source: AIHW analysis of ABS 2018 Survey of Disability, Ageing and Carers confidentialised unit record file.
http://www.aihw.gov.au

Impact of the caring role on carers' relationship with the care recipient, family and friends

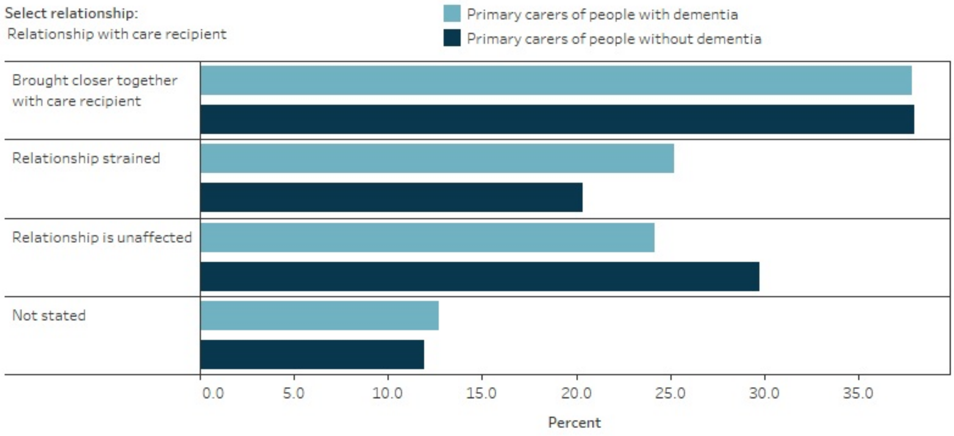
The caring role can have both positive and negative impacts on the relationship between the carer and the recipient of care, as well as on the carer's relationship to others.

Primary carers of people with dementia most commonly reported that the caring role:

- brought them closer to the care recipient (38% of primary carers of people with dementia). This was reported similarly by primary carers of people without dementia (38%)
- resulted in them spending less time with other family members who live in the same house (14%). This was reported similarly by primary carers of people without dementia (15%)
- resulted in them losing touch with friends (34%). This was reported less by primary carers of people without dementia (24%) (Figure 6.7).

Figure 6.7: Primary carers of people with dementia and people without dementia in 2018: percentage by impact of the caring role on others

Figure 6.7 is a bar graph showing the percentage of primary carers of people with dementia and primary carers of people without dementia in 2018 by the impact of the caring role on the carer's relationship with the care recipient, family and friends. Primary carers of people with dementia and people without dementia most frequently reported that the caring role brought them closer to the care recipient but that it resulted in them spending less time with other family members who live in the same house. Compared to primary carers of people without dementia, primary carers of people with dementia more frequently reported that taking on the caring role had resulted in them losing touch with their friends.



Notes:
1. Primary carers are people who provided the most informal, ongoing assistance (minimum of 6 months) with 1 or more core activities (mobility, self-care and communication) for the care recipient.
2. Estimates for primary carers of people with dementia for the following responses: 'Not stated' (for each relationship type), 'Circle of friends has changed', 'Less time to spend with them','Brought closer together', 'Relationship strained or affected in another way' have a relative standard errors between 25% and 50% and should be used with caution.

Source: AIHW analysis of ABS 2018 Survey of Disability, Ageing and Carers confidentialised unit record file.

http://www.aihw.gov.au

Carers and care needs of people with dementia

For primary carers who were/are in paid employment, the demands of caring for a person with dementia may affect their work commitments and arrangements. Changes in employment may then also have an impact on their financial situation. This pages focuses on the employment status and financial impact of the caring role on primary carers of working-age (aged 15 to 64) in 2018, from the Australian Bureau of Statistics Survey of Disability, Ageing and Carers (SDAC).

Around 53% of primary carers of people with dementia (and 71% of primary carers of people without dementia) were of working-age in 2018 (Table S6.20). Primary carers of people with dementia were more likely to be unemployed or not in the labour force (75%) than primary carers of people without dementia (59%).

Among working-age primary carers of people with dementia:

- 80% of carers who were currently unemployed or not in labour force did not want to be employed now that they were in the caring role – this was slightly higher than for primary carers of people without dementia (74%).
- 33% of carers who were employed had to reduce their weekly work hours – this was similar among primary carers of people without dementia (37%).
- 52% experienced a financial impact since taking on the caring role.
  - 24% had a decrease in income – this was similar among primary carers of people without dementia (27%).
  - 28% had extra expenses – this was also similar among primary carers of people without dementia (28%).
- 34% reported that their income was not affected by taking on the caring role – this was similar among primary carers of people without dementia (31%) (Table S6.14).

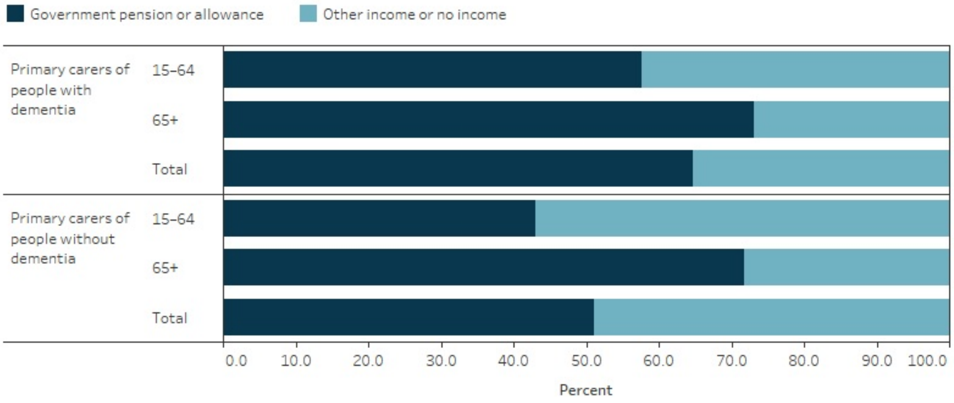
Main source of income

Primary carers of people with dementia were more likely to rely on government benefits as their main source of income (65%) than primary carers of people without dementia (51%) (Figure 6.8). See Box 6.2 for more information on government benefits available to eligible informal carers.

This difference was more substantial among primary carers of working age – 58% of primary carers of people with dementia relied on government benefits as their main source of income, compared with 43% of primary carers of people without dementia. There was less difference in the main source of income among primary carers aged 65 and over, likely due to the availability of the Age Pension to Australians aged 65 and over.

Figure 6.8: Primary carers of people with dementia and people without dementia in 2018: percentage by main source of income and carer age group

Figure 6.8 is a bar graph showing the percentage of primary carers of people with dementia and primary carers of people without dementia in 2018 by the main source of income and carers age. Primary carers of people with dementia were more likely to rely on government benefits as their main source of income than primary carers of people without dementia. This difference was more substantial among primary carers of working age (15 to 64 years). Among primary carers aged 65 and over, the main source of income was fairly similar for those who care for people with dementia and those who care for people without dementia.



Note: Primary carers are people aged 15 or over who provided the most informal, ongoing assistance (minimum of 6 months) with 1 or more core activities (mobility, self-care and communication) for the care recipient.
Source: AIHW analysis of ABS 2018 Survey of Disability, Ageing and Carers confidentialised unit record file.
http://www.aihw.gov.au

Box 6.2: Australian Government benefits available to eligible informal carers

There are a number of government benefits available to eligible Australian residents who provide informal care, where the demands of caring severely restrict or prevent the carer from undertaking substantial paid employment:

- **Carer Payment** is a means-tested income support payment available to informal carers who provide constant care to someone who has a severe disability or medical condition, or an older, frail person.
- **Carer Allowance** is an additional fortnightly payment for people who provide daily care to someone who has either a disability or serious illness, or an older, frail person. It can be paid in addition to wages, or another income support payment.
- **Carer Supplement** is an annual automatic payment to recipients of Carer Allowance and Carer Payment, to help cover costs when caring for someone with a disability.

For carers of adult care recipients (aged 16 and over) a medical report completed by a health professional currently treating the person is required to assess eligibility for the Carer Payment and the Carer Allowance. This report is based on the Adult Disability Assessment Tool, designed to measure the level of care required, irrespective of the condition causing the disability. Information is collected on the amount of help required to undertake activities of daily living (such as mobility, communication, hygiene, eating) as well as a range of cognitive and behavioural areas (Services Australia 2023).

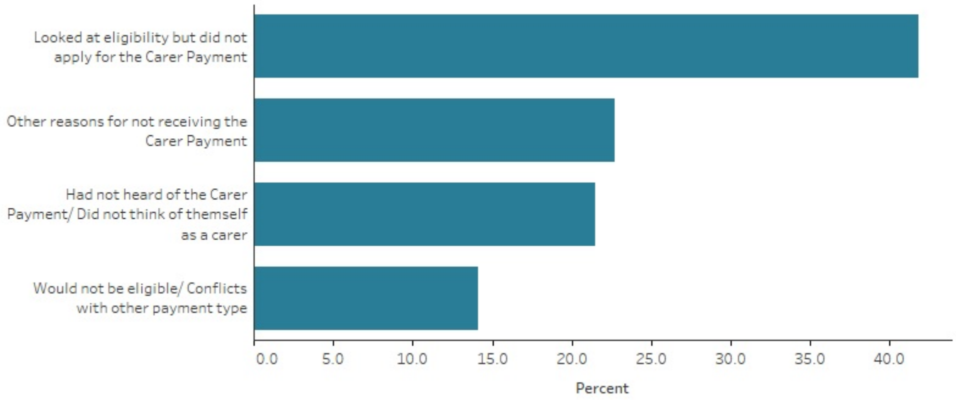
Carer payments

According to the SDAC, almost 1 in 3 primary carers of people with dementia (31%) received the Carer Payment in 2018 (Table S6.16).

Among primary carers of people with dementia who were not receiving the Carer Payment, 42% looked into eligibility but did not receive the payment (Figure 6.9). A further 22% either had not heard of the Carer Payment or did not consider themselves as a carer to apply for this payment, and 14% had looked into receiving this but they were not eligible.

Figure 6.9: Primary carers of people with dementia who did not receive the Carer payment in 2018: percentage by reasons why carers were not receiving the Carer Payment

Figure 6.9 is a bar graph showing the percentage of primary carers of people with dementia who were not receiving the Carer Payment in 2018 by the main reasons why they were not receiving the Carer Payment. Over two-fifths of primary carers of people with dementia who were not receiving the Carer Payment looked into eligibility for the payment but did not apply for it. Just over one-fifth had not heard of the Carer Payment or did not consider themselves as a carer.



Notes:
1. Primary carers are the people who provided the most informal, ongoing assistance (minimum of 6 months) with 1 or more core activities (mobility, self-care and communication) for the care recipient.
2. Excludes primary carers of people with dementia who were receiving the Carer Payment.
3. 'Other reasons for not receiving the Carer Payment' includes that the person did not apply due to their pride, they did not think it was necessary and other non-determined responses.
4. Estimates for the response 'would not be eligible/ conflicts with other payment type' has a relative standard error between 25% and 50% and should be used with caution.

Source: AIHW analysis of ABS 2018 Survey of Disability, Ageing and Carers confidentialised unit record file.
http://www.aihw.gov.au

References

Services Australia (2023) *Payment you can get as a carer*, Services Australia, Australian Government, accessed 10 July 2023.

Carers and care needs of people with dementia

It is vital that informal carers are provided with appropriate support to ensure they can provide adequate care and also to reduce carer burden and stress. This page presents information on the unmet needs of carers in 2018, from the Australian Bureau of Statistics Survey of Disability, Ageing and Carers (SDAC).

Just under 2 in 5 primary carers of people with dementia reported they need assistance or need further assistance with the caring role (38%). This was higher than what was reported by primary carers of people without dementia (27%) (Table S6.18).

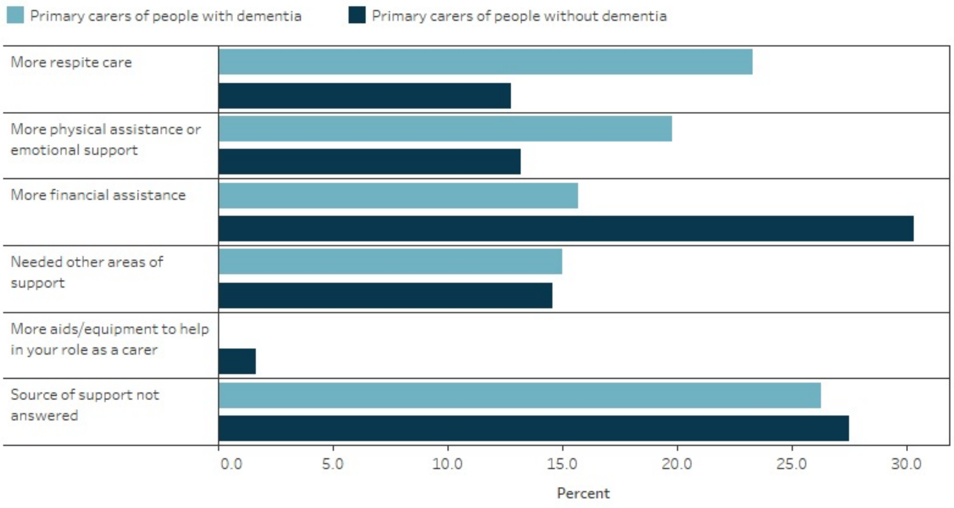
Among primary carers of people with dementia who required more support, the main unmet needs were as follows:

- 23% reported they needed more respite care – this was higher than what was reported by primary carers of people without dementia (13%).
- 20% reported they needed more physical assistance or emotional support– there was no statistical difference compared with primary carers of people without dementia (13%).

However, primary carers of people with dementia were less likely to report that they needed more financial assistance (16%) than primary carers of people without dementia (30%) (Figure 6.10).

Figure 6.10: Primary carers of people with dementia and people without dementia who required more support in 2018: percentage, by main unmet source of support

Figure 6.10 is a bar graph showing the percentage of primary carers of people with dementia and primary carers of people without dementia who required more support in 2018 by the main unmet need for support. The main unmet needs among primary carers of people with dementia were that they needed more respite care, followed by more physical assistance or emotional support. Needing more respite care was reported more frequently by primary carers of people with dementia than primary carers of people without dementia. Primary carers of people with dementia were less likely to report that they needed more financial assistance than primary carers of people without dementia.



Notes:
1. Primary carers are the people who provided the most informal, ongoing assistance (minimum of 6 months) with 1 or more core activities (mobility, self-care and communication) for the care recipient.
2. Analysis restricted to primary carers who reported that they needed more support.
3. Estimates for primary carers of people with dementia for 'More financial assistance', 'Needed other areas of support', and 'Source of support not answered' have a relative standard error between 25% and 50% and should be used with caution.

Source: AIHW analysis of ABS 2018 Survey of Disability, Ageing and Carers confidentialised unit record file.
http://www.aihw.gov.au

Health services used by people with dementia

Services provided by health professionals play a crucial role in the diagnosis, treatment and/or management of dementia.

The following pages present statistics and information on:

- Primary health care services
- Prescriptions for dementia-specific medications
- Antipsychotics and other medications dispensed to people with dementia
- Prescribers of dementia-specific medications
- Hospital care
- Hospitalisations due to dementia
- Hospitalisations with dementia

For the underlying data presented in these pages, see data tables.

Key findings

51% of MBS services used by people with dementia in 2020–21 were for **GP consultations**

There was a **29% increase in scripts** dispensed for dementia-specific medications between 2012–13 and 2021-22

97% of people with dementia living in the community had **at least one GP attendance** in 2020–2021

In 2021–22 there were **25,700 hospitalisations** due to dementia

Health services used by people with dementia

Primary care is often the first contact a person has with the health system and can be delivered in a range of settings, by a range of providers. It may be provided by general practitioners (GPs) within general practice or in an aged care or community setting, or by public or private service providers.

Current and robust data on dementia-specific GP and community-based specialist services are a major data gap in Australia. Advances with data linkage now enable some examination of GP and other community-based medical specialist services utilised by people with dementia. This is possible by linking GP and specialist data with other datasets that have dementia diagnostic information. Data in this section are sourced from linked health and aged care services data in the National Health Data Hub (NHDH), previously referred to as the National Integrated Health Services Information (NIHSI) analytical asset. For more information about the NHDH please refer to the Technical notes.

Current sources of dementia-specific GP consultations

While there is a lack of robust data on dementia-specific GP and community-based specialist services in Australia, the following data sources provide some insight on dementia-specific GP consultations:

- Bettering Evaluation of Care and Health survey (BEACH)
- NPS MedicineWise General Practice Insights report.

For more information on existing data gaps for dementia and future possibilities for filling in these gaps refer to the AIHW reports: Dementia data gaps and opportunities and the National Dementia Data National Dementia Data Improvement Plan 2023–33.

Who was included in this analysis

The analysis focused on people aged 30 and over who used a service in the linked data in 2020–21 and who were alive at the end of the 2020–21 financial year. These people were divided into two main groups:

- **People with dementia**: includes people who had a dementia diagnosis recorded in a hospital admission, emergency department presentation, permanent residential aged care record and/or were prescribed dementia-specific medication between 2010–11 and 2020–21.
- **People without dementia**: includes people who did not have a record of dementia in a hospital admission, emergency department presentation, permanent residential aged care record and were not prescribed dementia-specific medication between 2010–11 and 2020–21.

Both groups were further sub-divided to examine the different health service use of those living in residential aged care compared with those living in the community:

- **Living in residential aged care**: includes people who were living permanently in a residential aged care facility for all, or part of the year in 2020–21.
- **Living in the community**: includes people who were living in the community for all of the year in 2020–21. This may include people who used respite services in a residential aged care facility, as well as people who were living in other supported accommodation.

Results of this analysis should be interpreted with caution due to data limitations.

Dementia diagnostic information is not available in the MBS (Medicare Benefits Schedule data collection) and it is not possible to distinguish between dementia-specific services and services for the management of other health issues.

Identification of people with dementia depends on their use of other health and aged care services (for example, through admission to hospital and dementia being recorded in those data), and the analyses will not include all people with dementia in Australia.

For more information on key data considerations of this analysis, refer to the Technical notes.

The following section presents data on the use of Medicare-subsidised (referred to as MBS – Medicare Benefits Schedule) primary care services in 2020–21 for people living with dementia. Users can explore GP, nursing, specialist and allied health attendances.

For the underlying data presented in these pages, refer to the Primary health care services data tables.

Profile of people with dementia who used an MBS service in 2020–21

In 2020–21, there were 208,000 Australians identified as having dementia in the linked data (referred to as ‘people with dementia’). Of these people, 54% lived in permanent residential aged care and 46% lived in the community. Most people living with dementia identified in the linked data were women (66% of people in permanent residential aged care and 53% of people in the community).

It is known that the types and frequency of health services used change after a person enters permanent residential aged care. For example, general practitioner attendances increase and specialist attendances decrease (AIHW 2022). For this reason, data in this section are presented separately by place of residence.

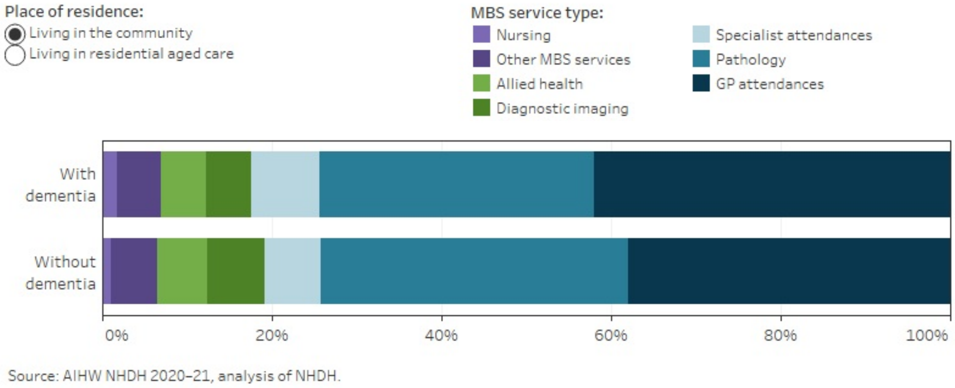
For detailed breakdowns of the age, sex and place of residence for people included in this analysis, see table S7.1.

What MBS services were most commonly used by people with dementia?

GP attendances were the most common MBS service used by people with dementia in 2020–21, followed by pathology services. These MBS services were the most commonly used by people with dementia within each sex and age group for both people living in the community and living in permanent residential aged care (Figure 7.1).

Figure 7.1: MBS services provided to people with dementia in 2020–21: percentage by place of residence

The stacked horizontal bar chart shows a higher proportion of GP attendance in people with dementia than people without dementia, both living in the community and in residential aged care.



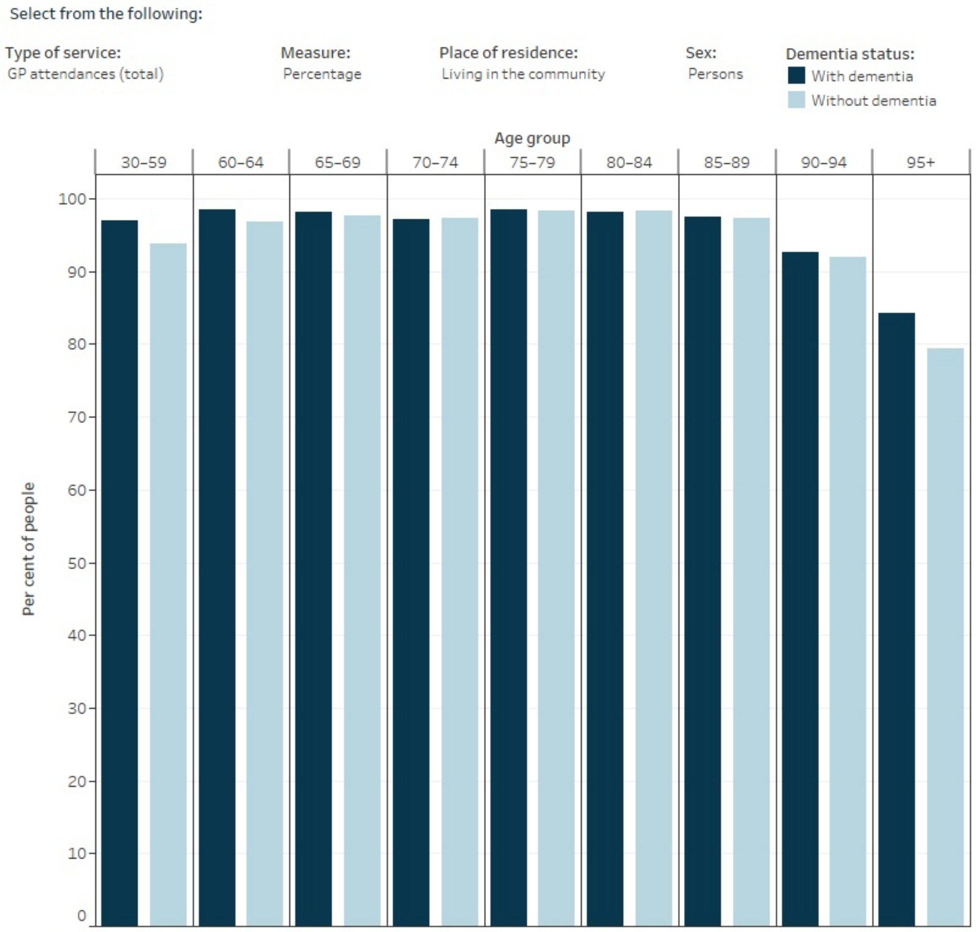
Source: AIHW NHDH 2020–21, analysis of NHDH.

Profiles of types of MBS service use

People with dementia living in the community used an average of 38 MBS services during 2020–21 compared to 22 services for people without dementia. People with dementia living in permanent residential aged care used an average of 45 MBS services, compared to 52 MBS services among people without dementia. Figure 7.2 provides a detailed breakdown of the types of MBS services used in 2020–21, including GP, nursing, specialist, allied health, pathology and diagnostic imaging attendances.

Figure 7.2: MBS service use by type of service, place of residence, sex and age

The vertical bar chart shows the MBS service use among people with and without dementia. The percentage of people who used a service, average number of services per person and total number of services are shown.



Source: AIHW NHDH 2020–21, analysis of NHDH.

Measures of service use

- **Percentage of people who used a service:** 'Percentage' is the proportion of people with at least one service recorded in the linked data in 2020–21. This is also referred to as a rate of service use.
- **Average number of services per person:** The average number of services per person was calculated for people who used the service at least once in 2020–21, referred to in the figures as 'Mean (service users)'.

These measures reflect different aspects of access to services. For example, for people living in the community, more people living with dementia had one or more GP chronic disease management attendances than those without dementia in the age groups 30–80 years. However, among people who used the service, there was little difference in the average number of attendances.

Among people who were living in the community in 2020–21, key findings include:

- Among those who had one or more GP attendances, people with dementia on average had more GP attendances than people without dementia, and this difference was greater in the younger age groups. For example, among those aged 30–59, people with dementia had an average of 17 GP attendances per person compared to 7.3 for those without dementia.
- Half (51%) of people with dementia had a GP chronic disease management attendance compared with 24% of people without dementia (Table S7.2). The proportion of people with a GP chronic disease management attendance was higher than 37% for all age groups among people with dementia.
- Up to one third (32%) of people had a nurse attendance. The proportion was higher for people with dementia compared to without dementia in the younger age groups, and higher for people without dementia compared to people with dementia in the older age groups.
- A higher proportion of people with dementia had at least one specialist attendance (68%) compared to people without dementia (41%) (Table S7.2). This difference was greater in the younger age groups, such as those aged 30–59, where people with dementia who used specialist services at least once, had an average of 4.8 specialist attendances compared to 3.0 for those without dementia.
- Specialist attendances including general medicine, geriatric medicine, neurology and psychiatry were more common among people with dementia compared to people without dementia.
- For those aged under 80 years, allied health, nursing and pathology attendances were more common among people with dementia compared to those without dementia. For those aged 80 years and over, allied health, nursing and pathology attendances were similar or slightly lower for people with dementia.

Among people who were living in permanent residential aged care in 2020–21, key findings include:

- A similar proportion of people with dementia and people without dementia had a GP attendance (96% and 95%, respectively), and among those who had one or more GP attendances, the average number of attendances was also similar (Table S7.2).

- Specialist service use was lower among people with dementia compared to those without dementia, and this trend was consistent across all age groups.
- A higher proportion of people with dementia had geriatric medicine and geriatrician referred plan attendances compared to people without dementia.
- People with dementia typically had lower use of allied health services, pathology and diagnostic imaging compared to people without dementia.
- Across most age groups, people with dementia had a greater average number of nurse attendances than those without dementia. The difference was largest in the youngest age group, where people aged 30–59 with dementia had an average of 6.0 nurse attendances compared to 4.6 for people without dementia.
- The average number of psychiatry services was generally higher among people without dementia except for in the youngest and oldest age groups. People with dementia aged 30–59 had an average of 4.4 attendances per person compared to 3.8 for people without dementia, and 3.3 attendances for people with dementia aged 95 years and over compared to 2.6 for those without dementia.

Assessment and management plans

As there are no specific MBS items for dementia diagnosis and management services, a number of MBS items may be claimed by GPs and other specialists for services involved in diagnosing and managing dementia including:

- Geriatrician Referred Patient Assessment and Management Plans (MBS items 141–147; referred to in figure 7.2 as 'Geriatrician referred plans') are comprehensive assessment and management plan services provided by a consultant physician or specialist in geriatric medicine to patients who have been referred by a GP. These services are for patients aged 65 and over with complex health issues and who are at significant risk of poor health outcomes.
- Chronic Disease Management Items (MBS group A15; referred to in figure 7.2 as 'Chronic disease plans') are management plan services for people with chronic or terminal health conditions, or conditions that require care from a GP and at least 2 other health or care providers.

> Note: As people get older some services, including allied health, can be accessed through My Aged Care which may mean less reliance on Chronic Disease Management items. This should be taken into consideration when comparing the number of Chronic disease plans by age groups in Figure 7.2.

These plans aim to provide comprehensive and up-to-date information on the patient's health priorities, actions for patients to take to manage their condition/s and achieve their health goals, as well as information on health and community services available to the patient. In addition to assessing a patient's current and past medical history, assessments may involve an assessment of physical, psychological (including cognition) and social function, as well as advanced care planning.

References

AIHW (Australian Institute of Health and Welfare) (2020–21) National Health Data System, aihw.gov.au, accessed 10 February 2024.

AIHW (2022) *Younger onset dementia: new insights using linked data*, AIHW, Australian Government, accessed 22 February 2024.

Health services used by people with dementia

While there is currently no known cure for dementia, there are 4 medications available under the Pharmaceutical Benefits Scheme (PBS) and Repatriation Pharmaceutical Benefits Scheme (RPBS, available for eligible veterans, war widows/widowers and their dependants) that may assist in managing dementia symptoms and slow dementia progression. In Australia, these medications are currently only subsidised for people with a diagnosis of Alzheimer's disease (see Box 8.1).

Box 8.1: Dementia-specific medications

There are 4 dementia-specific medications – Donepezil, Galantamine, Rivastigmine and Memantine – currently subsidised under the PBS and RPBS. These medications can be prescribed to patients with a confirmed diagnosis of Alzheimer's disease made by (or in consultation with) a specialist or consultant physician under specific clinical criteria (Drug Utilisation Sub-Committee 2016). In order to continue treatment, patients must demonstrate a clinically meaningful response to the treatment. This may include improvements in the patients' quality of life, cognitive function and/ or behavioural symptoms.

Three of the medications (Donepezil, Galantamine and Rivastigmine) are acetylcholinesterase inhibitors. These types of medications work by blocking the actions of the enzyme acetylcholinesterase, which destroys acetylcholine—a major neurotransmitter for memory.

The Therapeutic Goods Administration (TGA) note the following therapeutic indications for each medication:

- **Donepezil:** indicated for the treatment of mild, moderate and severe Alzheimer's disease.
- **Galantamine:** indicated for the treatment of mild to moderately severe Alzheimer's disease.
- **Rivastigmine** (as hydrogen tartrate)**:** indicated for the treatment of patients with mild to moderately severe Alzheimer's disease.
- **Rivastigmine** (as EXELON PATCH)**:** indicated for the treatment of patients with mild, moderate and severe Alzheimer's disease.

The use of these medicines may lead to increased communication between nerve cells and slow dementia progression (Dementia Australia 2020). Research suggests that these medicines may also benefit people with Lewy body dementia and dementia associated with Parkinson's disease (Noufi et al. 2019), however, these medications are not subsidised in Australia for treating these types of dementia.

Memantine is approved in Australia for the treatment of symptoms of moderately severe to severe Alzheimer's disease (Drug Utilisation Sub-Committee 2016). 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 (Dementia Australia 2020).

This page will be updated to include any future medications that become approved for use and included in the PBS.

This section focuses on dispensing patterns of dementia-specific medications supplied under the PBS and RPBS, as well as a profile of the people who were dispensed scripts for these medicines. As dementia is a condition that primarily affects older people, analyses were limited to prescriptions dispensed to people aged 30 and over. This age limit is consistent with the lower age limit of dementia prevalence estimates for Australia.

It is important to note that information on medication intake and adherence to medication plans is not available. The data presented here relate only to prescriptions dispensed. In addition, the PBS and RPBS do not contain data on dispensing of privately prescribed medications (prescriptions that are not eligible for subsidy under the PBS or RPBS), medications to public hospital in-patients and over-the-counter medications.

Over 658,000 prescriptions were dispensed for dementia-specific medications in 2021–22

In 2021–22, there were over 658,000 prescriptions dispensed for dementia-specific medications to just under 68,700 Australians with dementia aged 30 and over (Figure 8.1). This is equivalent to 9.6 scripts per person who was dispensed a script for a dementia-specific medication in 2021–22. Each script is usually for a month's supply of medicine.

Among those who were dispensed scripts for dementia-specific medications in 2021–22:

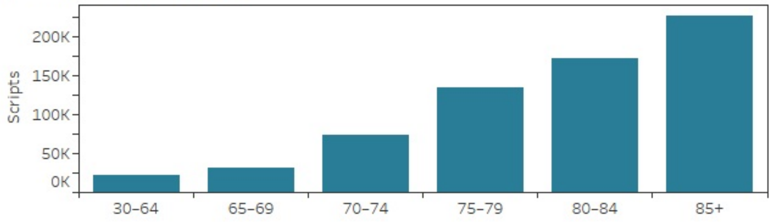
- 43% were men (29,500 men) and 57% were women (39,200 women)
- 1 in 3 people were aged 85 or over
- on average, men were dispensed 9.5 scripts per person and women were dispensed 9.7 scripts per person
- older people were dispensed more scripts on average – increasing from 8.9 scripts per person among those aged under 65 to 9.7 scripts per person among those aged 85 and over.

Figure 8.1: Dementia-specific medications by age and sex in 2021–22: (a) number of prescriptions dispensed and (b) number of people who were dispensed scripts and average number of scripts dispensed, per person

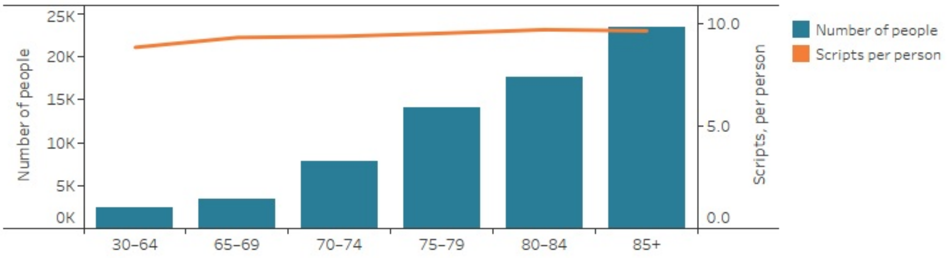
Figure 8.1 shows two graphs on prescriptions dispensed for dementia-specific medications to people aged 30 and over by age and sex in 2021-22. The first is a bar graph showing the number of scripts dispensed by age group. The second is a bar and line graph, with the bar graph showing the number of people who were dispensed scripts for dementia-specific medications and the line graph showing the average number of scripts dispensed per person, both broken down by age groups. The number of prescriptions dispensed, the number of people dispensed scripts and the average number of scripts dispensed per person all increased with age. A greater number of women were dispensed a greater number of scripts than men.

Sex:
Persons

a) Prescriptions dispensed, by age



b) People who were dispensed scripts: number and average number of scripts dispensed, per person, by age



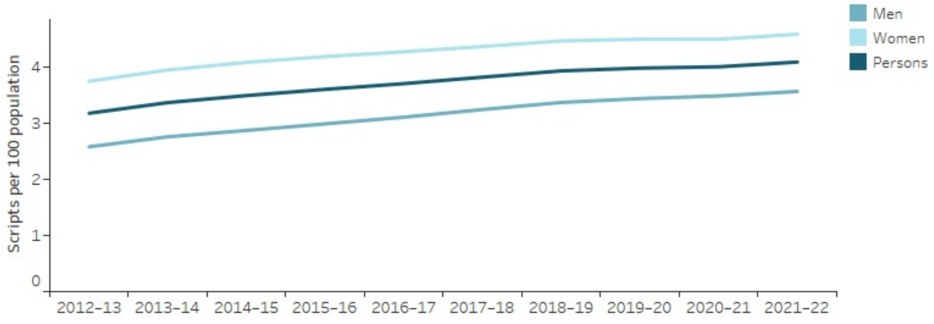
Source: AIHW analysis of PBS data maintained by the Australian Government Department of Health and Aged Care
http://www.aihw.gov.au

Trends in prescriptions for dementia-specific medications dispensed over time

There was a 29% increase in the rate of scripts dispensed for dementia-specific medications to Australians aged 30 and over between 2012–13 and 2021–22. There was a greater increase in the number of scripts dispensed to men (38%) than women (22%) (Table S8.2).

Figure 8.2: Scripts dispensed for dementia-specific medications: crude rate by sex between 2012-13 and 2021-22

Figure 8.2 is a line graph showing the crude rate of people who were dispensed scripts for dementia-specific medications by sex between 2012–13 and 2021-22. The rate of people who were dispensed scripts for dementia-specific medications increased slightly from 3.2 people per 100 population in 2012–13 to 4.1 people in 2021-22. The rate of women dispensed scripts was slightly higher than for men each year, but the increase over time was similar for both men and women.



Note: Rates are expressed as per 100 population for people aged 30 and over.
Source: AIHW analysis of PBS data maintained by the Australian Government Department of Health and Aged Care
http://www.aihw.gov.au

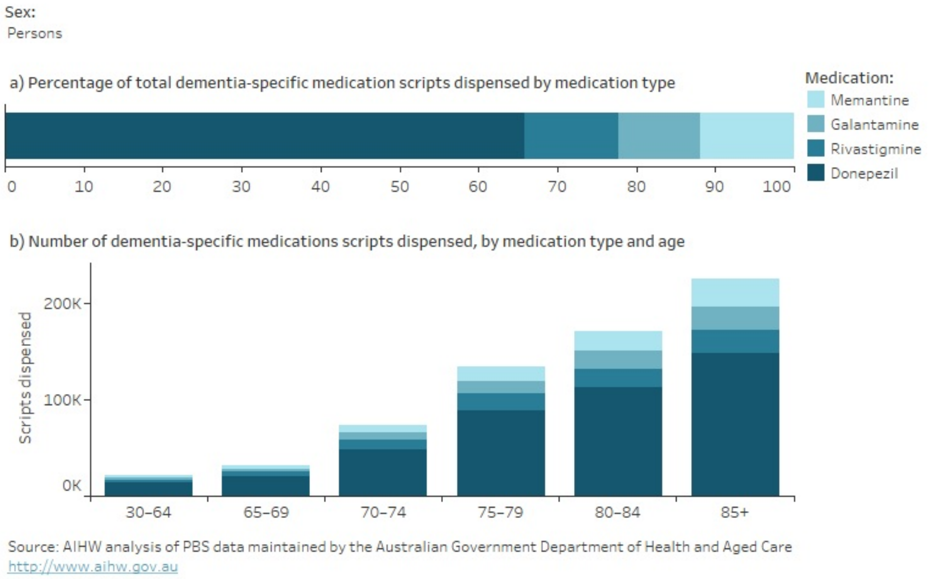
Donepezil was the most commonly dispensed dementia-specific medication

Donepezil was the most commonly dispensed dementia-specific medication in 2021–22, accounting for over 433,000 prescriptions or 66% of all scripts dispensed for dementia-specific medications (Figure 8.3). Each of the other dementia-specific medications (Rivastigmine, Memantine and Galantamine) accounted for between 10-12% of all scripts dispensed.

Women were dispensed a greater number of scripts than men for each of the 4 dementia-specific medications. Donepezil was the most commonly dispensed medication in each age group in both men and women. Rivastigmine was the second-most commonly dispensed medication to men and women in most age groups under 85. For people aged 85 and over, Memantine was the second-most dispensed medication.

Figure 8.3: Dementia-specific medications, by medication type and sex in 2021-22: (a) percentage of all scripts dispensed by medication type and (b) number of scripts dispensed by medication type and age

Figure 8.3 shows two graphs on the prescriptions dispensed for dementia-specific medications, by the four types of dementia-specific medications and sex in 2021-22. The first graph is a stacked bar graph showing the percentage of all scripts dispensed by medication type. The second graph is a stacked bar graph showing the number of scripts dispensed by medication type and age. Around two-thirds of prescriptions dispensed for dementia-specific medications were for Donepezil, and this was the most commonly dispensed medication in each age group in both men and women. Women were dispensed a greater number of scripts than men for each of dementia-specific medication.



Source: AIHW analysis of PBS data maintained by the Australian Government Department of Health and Aged Care
http://www.aihw.gov.au

Differences by state and territories

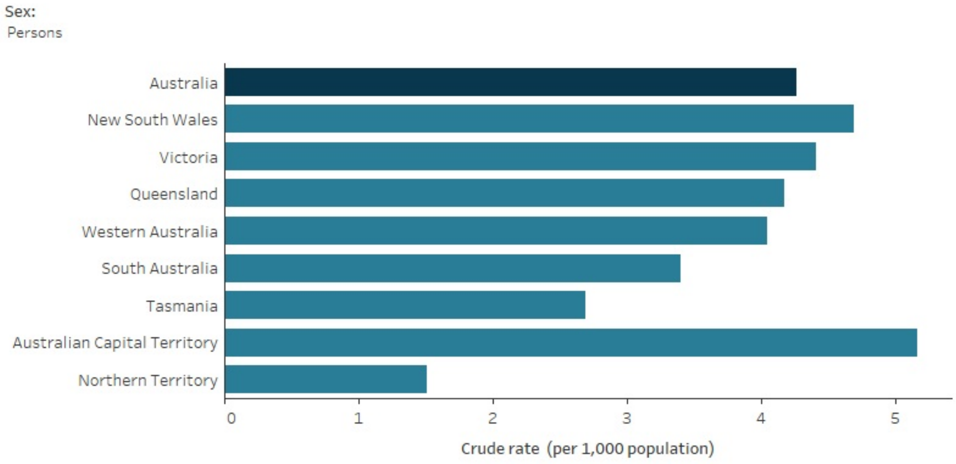
The number of people who were dispensed scripts for dementia-specific medications per 1,000 people varied by state and territory in 2021–22, but was consistently higher among women than men in each state and territory. In Australia overall, there were 4.3 people dispensed scripts for dementia-specific medications per 1,000 people.

The rates of men and women who were dispensed scripts for dementia-specific medications were lowest in the Northern Territory (0.5 and 0.6 people per 1,000 men and women, respectively). The highest rates among men and women were in the Australian Capital Territory (4.7 and 5.6 people per 1,000 men and women, respectively), followed by New South Wales (4.3 and 5.1 people per 1,000 men and women, respectively) (Figure 8.4).

It is important to note that drugs distributed by the government’s Remote Area Aboriginal Health Services (RAAHS) program are not included in PBS data. This may be a factor in the Northern Territory’s low dispensing rates.

Figure 8.4: People who were dispensed scripts for dementia-specific medications in 2021-22: crude rate by sex and state/territory

Figure 8.4 is a bar graph showing the crude rate of people who were dispensed scripts for dementia-specific medications by sex and state and territory in 2021-22. The rates of men and women who were dispensed scripts for dementia-specific medications were lowest in the Northern Territory and highest in the Australian Capital Territory.



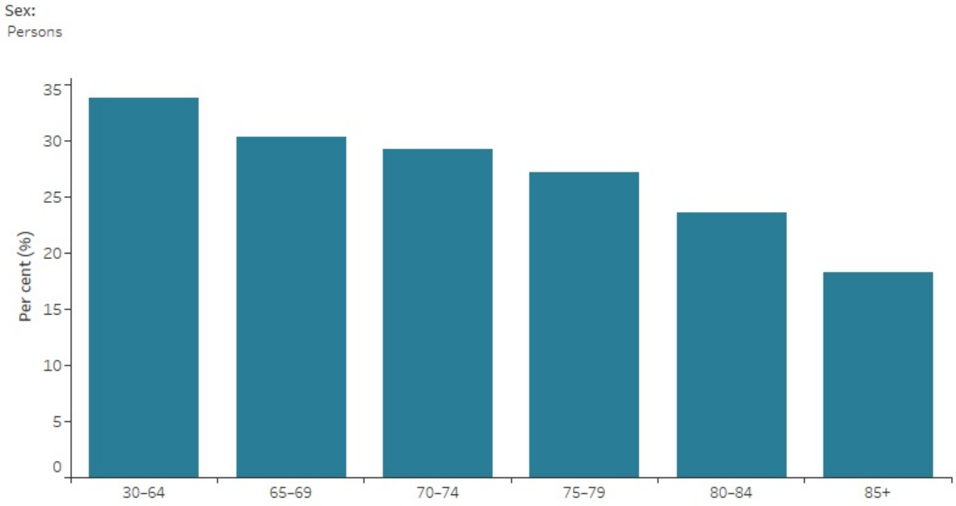
Notes
1. Rates are expressed as per 1,000 population for people aged 30 and over.
2. State is based on the address of the patient as last advised to Medicare.
Source: AIHW analysis of PBS data maintained by the Australian Government Department of Health and Aged Care.
http://www.aihw.gov.au

1 in 4 people who were dispensed scripts for dementia-specific medications, were dispensed these medications for the first time

In 2021–22, 1 in 4 people (24% or over 16,400 people) who were dispensed scripts for dementia-specific medications were dispensed these medications for the first time (Table S8.5). The proportion who were dispensed scripts for dementia-specific medications for the first time varied by age: 1 in 3 people (34%) aged under 65 were dispensed this for the first time (Figure 8.5). This decreased to almost 1 in 5 people (18%) among those aged 85 and over.

Among those who were dispensed scripts for dementia-specific medications for the first time, the most commonly dispensed type of medication received throughout the year was Donepezil (69%), followed by Rivastigmine (14%), Memantine (11%) and Galantamine (6.8%) (Table S8.6).

Figure 8.5: People who were dispensed dementia-specific medications for the first time in 2021–22 by sex: percentage by age
Figure 8.5 shows a bar graph displaying the percent of people who were dispensed prescriptions for dementia-specific medications for the first time by age and sex in 2021-22. The proportion who were dispensed scripts for dementia-specific medications for the first time decreased with increasing age.



Note: This figure refers to the percentage of people who were dispensed scripts for dementia-specific medication for the first time out of all people who were dispensed scripts for dementia-specific medication that year.
Source: AIHW analysis of PBS data maintained by the Australian Government Department of Health and Aged Care
http://www.aihw.gov.au

References

Drug Utilisation Sub-Committee (2016) *Medicines for Alzheimer disease*, PBS website, accessed 10 July 2023.

Dementia Australia (2020) *Drug treatments & dementia*, Dementia Australia website, accessed 10 July 2023.

Noufi P, Khoury R, Jeyakumar S and Grossman GT (2019) 'Use of Cholinesterase Inhibitors in Non-Alzheimer's Dementias', *Drugs & Aging*, 36:719–731, doi:10.1007/s40266-019-00685-6.

Health services used by people with dementia

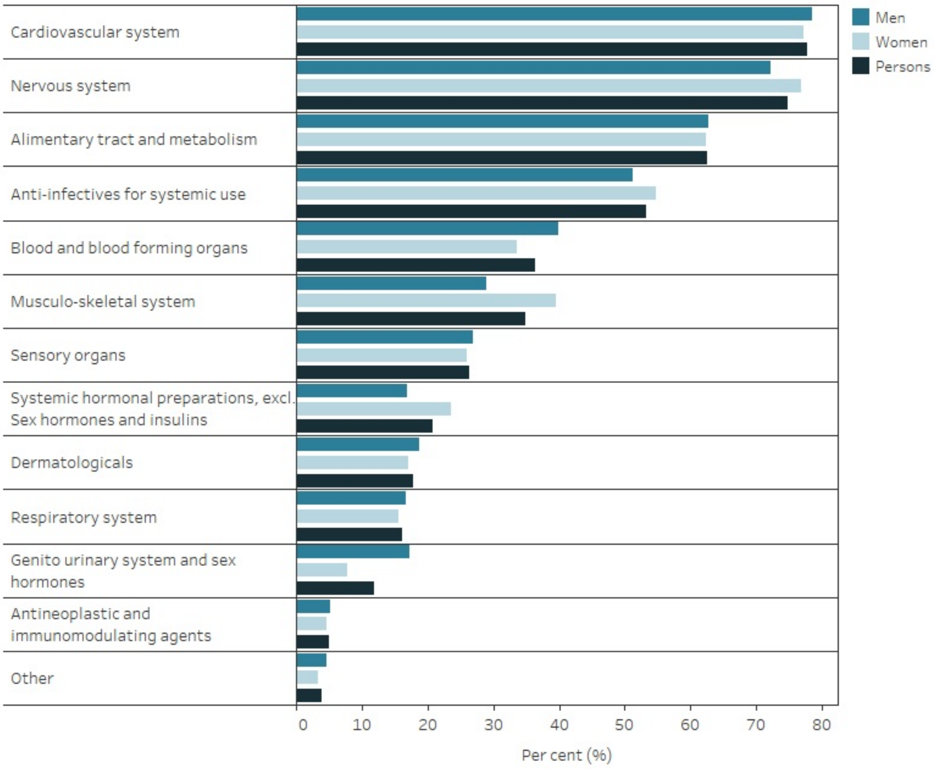
What other medications were dispensed to people who were dispensed scripts for dementia-specific medications?

As people with dementia often have other co-existing conditions, they are likely to be prescribed a range of other medicines. Figure 8.6 shows the types of other medications dispensed to people who were dispensed dementia-specific medications in 2021–22, grouped at the highest level (Anatomical Therapeutic Chemical classification 1 (ATC1)). Refer to the Technical notes for further detail on the Anatomical Therapeutic Chemical classification and the grouping of medications by level.

The most common group of other medications dispensed was for cardiovascular system medications (dispensed at least once to 79% of men and 77% of women who were dispensed dementia-specific medication). This was followed by nervous system medications (72% of men and 77% of women) and, alimentary tract and metabolism medications (63% of men and 62% of women).

Figure 8.6: People who were dispensed scripts for dementia-specific medications in 2021–22: percentage who were dispensed scripts for other medications at least once, by sex and medications' Anatomical Therapeutic Chemical (ATC) group

Figure 8.6 is a bar graph showing the percentage of people dispensed dementia-specific medications who were also dispensed other medications in 2021-22, by medication type and sex. The medications are grouped at the highest Anatomical Therapeutic Chemical classification level. Around three-quarters of men and women who were dispensed scripts for dementia-specific medications were also dispensed medications for the cardiovascular system, and nervous system. Men were less likely than women to be dispensed nervous system medications, anti-infectives for systemic use, musculoskeletal system medications, and systemic hormonal preparations. However, men were more likely than women to be dispensed medications for the cardiovascular system, alimentary tract and metabolic, blood and blood forming organs, sensory organs, dermatologicals, respiratory system, genitourinary system and sex hormones and for antineoplastic and immunomodulating agents.



Notes
1. The Anatomical Therapeutic Chemical (ATC) group 'Other' includes ATC1 groups P, V and ATC Not defined.
2. Medications are counted if they are dispensed once in 2021-22.
3. The groups are ranked based on total persons.
Source: AIHW analysis of PBS data maintained by the Australian Government Department of Health and Aged Care
http://www.aihw.gov.au

The most common subgroup of other medications was psychoanaleptics, dispensed at least once to 52% of people who were dispensed scripts for dementia-specific medications (Figure 8.7). These medications are used to treat depression and other neurological and mental disorders. The next most common subgroups were:

- antibacterials for systemic use (51%; used to treat a range of bacterial infections)
- lipid modifying agents (51%; used to lower high levels of fats in the blood, such as cholesterol)

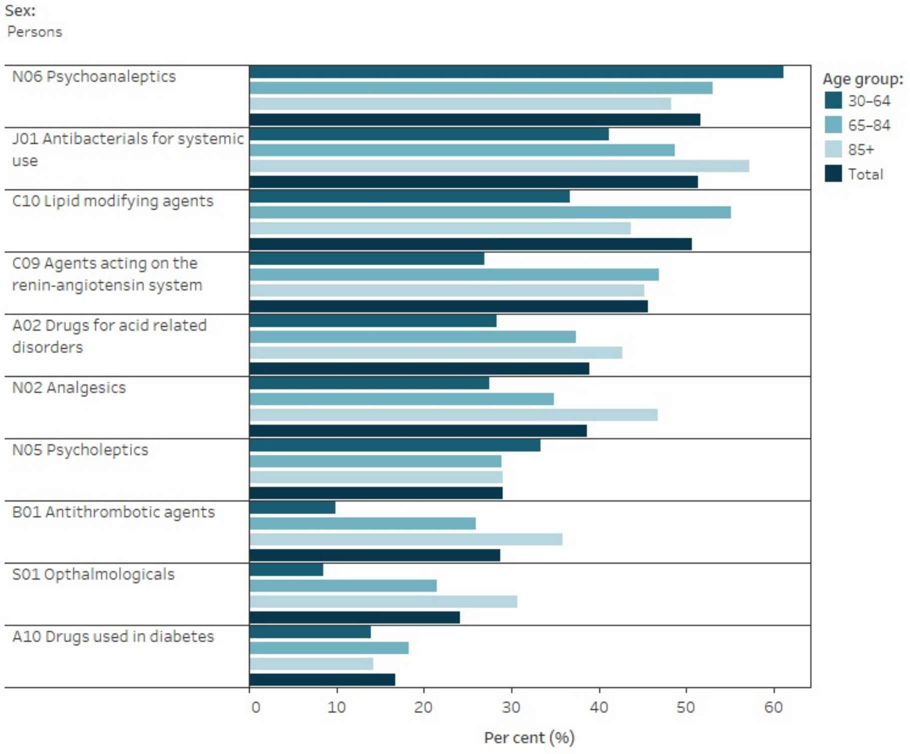
- agents acting on the renin-angiotensin system (46%; used for hypertension)
- drugs for acid related disorders (39%; used to neutralise stomach acidity and relieve heartburn, indigestion or stomach upset).

There were notable differences by sex and age in the most common medications dispensed at least once to people who were dispensed scripts for dementia-specific medication.

Psychoanaleptics were dispensed to a larger proportion of those with younger onset dementia (aged under 65) compared with people aged 85 and over (61% compared with 48%). However, most other medications were dispensed to a greater proportion of those aged 85 and over, with the greatest differences seen with antithrombotic agents (36% compared with 9.8% of people aged 30–64) and opthalmologicals (31% compared with 8.5%).

Figure 8.7: People who were dispensed scripts for dementia-specific medications in 2021-22: percentage who were dispensed scripts for other medications, by Anatomical Therapeutic Chemical (ATC) sub-group, age and sex

Figure 8.7 is a bar graph showing the percentage of people dispensed dementia-specific medications who were also dispensed other medications in 2021-22, by medication type, age and sex. The medications are grouped at the second highest Anatomical Therapeutic Chemical classification level. Over half (52%) were dispensed scripts for psychoanaleptics, which are used for depression and other neurological and mental disorders. Half of people were dispensed scripts for antibacterials for systemic use, which are used to treat a range of bacterial infections. Men were more likely than women to be dispensed scripts for lipid modifying agents, agents acting on the renin-angiotensin system, psycholeptics, antithrombotic agents and drugs used in diabetes. However, women were more likely than men to be dispensed scripts for psychoanaleptics, antibacterials, drugs for acid related disorders, analgesics, and opthalmologicals. While the majority of medications were dispensed to greater proportions of older people who were dispensed dementia-specific medications, psychoanaleptics were dispensed to a larger proportion of those with younger onset dementia (aged under 65) compared with people aged 85 and over.



Notes
1. Only the leading 10 medication subgroups are presented (ranked based on total persons).
2. Medications are counted if they are dispensed at least once in 2021-22.
Source: AIHW analysis of PBS data maintained by the Australian Government Department of Health and Aged Care
http://www.aihw.gov.au

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). To manage these symptoms, non-pharmacological interventions are recommended, but medical professionals may prescribe antipsychotic medicines to people with dementia with BPSD as a last resort. However, inappropriate prescribing of antipsychotic medicines is a major problem among people living in residential aged care and a key issue raised in the Royal Commission into Aged Care Quality and Safety (Royal Commission 2021) (see Box 8.2 for more information). Risperidone is the only antipsychotic that is currently listed on the PBS for BPSD.

In 2021–22, antipsychotic medications (which are part of the psycholeptics group) were dispensed to about one-fifth (20%) of the 68,700 people who had scripts dispensed for dementia-specific medication (Figure 8.8). This includes all antipsychotic medications and not just Risperidone.

Around 55% or 7,600 of the people dispensed antipsychotic medications were women. The proportion of people within each age group who were prescribed scripts for antipsychotics decreased slightly with increasing age.

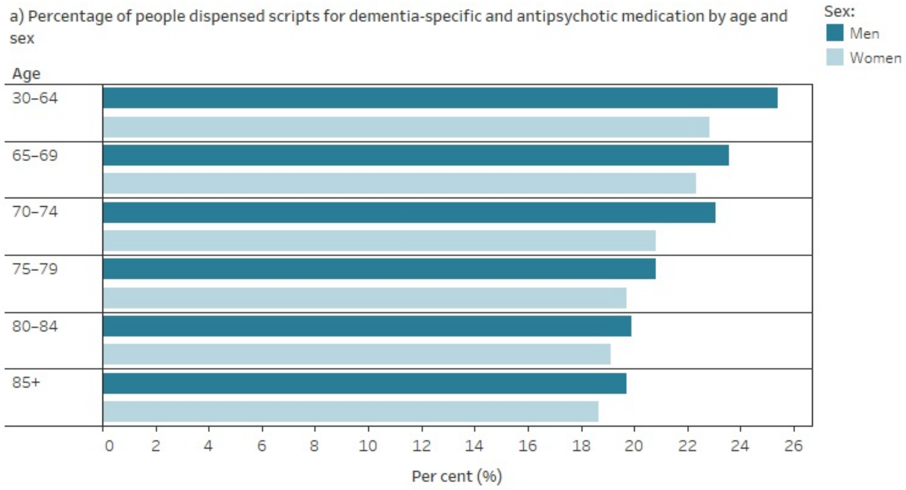
In each age group, men were relatively more likely to be dispensed scripts for antipsychotics at least once than women (Figure 8.8a). However, as more women have dementia, overall more women were dispensed antipsychotic medication than men.

Antipsychotics were more likely to be dispensed to people who were also taking Memantine (32% of people on Memantine) compared with other dementia-specific medicines (26% of people on Rivastigmine, 18% of people on Galantamine and 17% of people on Donepezil) (Figure 8.8b). This probably reflects the fact that Memantine is prescribed for moderately severe Alzheimer’s disease, whereas the other 3 dementia-specific medications are prescribed for mild to moderately severe Alzheimer’s disease.

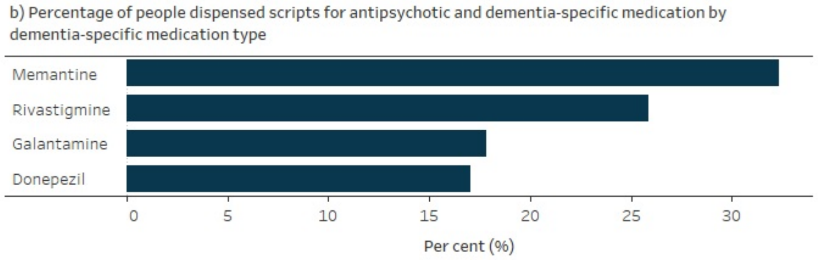
Although Risperidone is the only antipsychotic listed on the PBS for BPSD, scripts for other antipsychotic medications were dispensed to people with dementia. Around 36% of all antipsychotic scripts that were dispensed to people also on dementia-specific medication were for Risperidone, followed by Quetiapine (30%) and Olanzapine (25%) (Table S8.11).

Figure 8.8: People who were dispensed dementia-specific medications in 2021–22: percentage who were dispensed antipsychotic medication (a) by age and sex and (b) by dementia-specific medication

Figure 8.8 shows two bar graphs depicting breakdowns of the percentage of people who were dispensed prescriptions for dementia-specific medications and also dispensed prescriptions for antipsychotic medications at least once in 2021-22. The first graph shows the percentage by age and sex and the second graph shows the percentage by the type of dementia-specific medication they were dispensed. Overall, around one-fifth of people who were dispensed prescriptions for dementia-specific medications were also dispensed antipsychotic medications. The proportion within each age group who were prescribed scripts for antipsychotics decreased slightly with age. Men were relatively more likely to be dispensed scripts for antipsychotics than women in each age group. Antipsychotics were more likely to be dispensed to people who were also taking Memantine, which is the only dementia-specific medication prescribed for moderately severe to severe Alzheimer’s disease.



a) Percentage of people dispensed scripts for dementia-specific and antipsychotic medication by age and sex



b) Percentage of people dispensed scripts for antipsychotic and dementia-specific medication by dementia-specific medication type

Notes

1. Anti-psychotic medication is defined as ATC code N05A.
2. These figures refer to the percent of people who were dispensed both antipsychotic medication and dementia-specific medication out of all people who were dispensed a dementia-specific medication that year.

Source: AIHW analysis of PBS data maintained by the Australian Government Department of Health and Aged Care

http://www.aihw.gov.au

Box 8.2: Antipsychotic medications for people with dementia and inappropriate prescribing of antipsychotics

Antipsychotic medicines should only be prescribed to people with dementia following the unsuccessful attempt of managing symptoms of dementia using non-pharmacological treatments, as the combined use of dementia-specific and antipsychotic medicine increases the risk of serious adverse effects, including death. This risk increases over longer periods of use (Dementia Australia 2016; Dyer et al. 2016). Risperidone, which is a type of antipsychotic medicine, is the only antipsychotic currently listed on the PBS that may be prescribed to a person with dementia who displays persistent behavioural disturbances such as psychotic symptoms, restlessness and aggression (known as either ‘changed behaviours’ or ‘behavioural and psychological symptoms of dementia’ (BPSD)). However, inappropriate prescribing of antipsychotics to people living in residential aged care (where over half of people have dementia) is a major issue in Australia.

To reduce inappropriate prescribing of antipsychotic medicines to people with dementia, changes were made to the PBS for prescribing of Risperidone for managing changed behaviours. As of January 2020, prescribers will need to request authority approval from Services Australia to prescribe ‘continuing’ PBS-subsidised Risperidone treatment (beyond 12 weeks of initial use) to people with dementia (Department of Health 2019).

References

Dyer SM, Laver K, Pond CD, Cumming RG, Whitehead C and Crotty M (2016) 'Clinical practice guidelines and principles of care for people with dementia in Australia', *Australian Family Physician*, 45(12):884-889.

Dementia Australia (2016) *Drugs used to relieve behavioural and psychological symptoms of dementia*, Dementia Australia, accessed 10 July 2023.

Department of Health (2019) *Risperidone factsheet*, PBS website, accessed 10 July 2023.

Royal Commission (Royal Commission into Aged Care Quality and Safety) (2021) Final report: Care, Dignity and Respect. Volume 1 Summary and recommendations, Royal Commission, Australian Government, accessed 10 July 2023.

Health services used by people with dementia

Who prescribed scripts for dementia-specific medications?

In 2021–22, 8 in 10 people (83%) who were dispensed script/s for dementia-specific medications were prescribed at least 1 script by a general practitioner (GP). In addition, 37% were prescribed by other medical specialists and less than 1% were prescribed by nurse practitioners (Table S8.12).

The majority (79%) of people who were dispensed dementia-specific medications were prescribed these by 1 type of prescriber (Table S8.13). However, as people can receive prescriptions for multiple dementia-specific medications throughout the year, they could be prescribed these by different types of prescribers (for example, prescribed once by a GP and once by a geriatrician). Just over 21% of people who were dispensed scripts for dementia-specific medications received these scripts from 2 different types of prescribers and just 0.1% received prescriptions from 3 different types of prescribers. Of the people who were prescribed dementia-specific medications by at least 2 types of prescribers, the majority (97%) were prescribed by a GP and another medical specialist (Table S8.14).

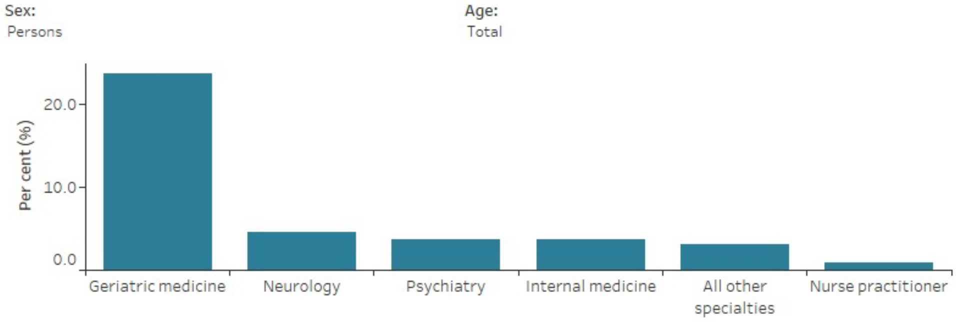
Types of medical specialists prescribing dementia-specific medications

Other than GPs, people were most commonly prescribed dementia-specific medications by specialists in geriatrics (24% of people who were dispensed a script for dementia-specific medications that year), followed by neurology (4.5%), psychiatry (3.7%) and internal medicine (3.6%) (Figure 8.9).

There was little difference in the prescribing patterns for men and women. However, patterns varied for people with younger onset dementia. As these people are younger and less likely to see a doctor with a specialisation in geriatric medicine, a greater proportion of dementia-specific medicines were prescribed by neurologists (15%) and psychiatrists (8.7%) than they were for people aged 65 and over (4.2% and 3.5%, respectively) (Table S8.15).

Figure 8.9: People who were dispensed dementia-specific medications in 2021-22: percentage by medical specialty of prescriber, age and sex

Figure 8.9 is a bar graph showing the percentage of people who were dispensed dementia-specific medications in 2021-22, by age and sex and by the prescribers' medical specialty (excluding GPs). Almost one-quarter were prescribed dementia-specific medications by geriatricians. A much smaller percentage were prescribed by neurologists (4.5%) and psychiatrists (3.7%). There was little difference between men and women but younger people were more likely to be prescribed dementia-specific medicines by neurologists (15%) and psychiatrists (8.7%) than people aged 65 years or more.



Notes
1. Dementia-specific medications prescribed by General Practitioners are excluded from this figure.
2. Prescriber specialty is derived by the Department of Health for a prescriber each quarter, and reflects both the registered specialty of the prescriber and the Medicare services claimed in the quarter.
Source: AIHW analysis of PBS data maintained by the Australian Government Department of Health and Aged Care
http://www.aihw.gov.au

Health services used by people with dementia

This section presents information on the number and characteristics of dementia-related episodes of admitted patient care (referred to as ‘hospitalisations’) between 2012–13 and 2021–22 from the National Hospital Morbidity Database. See the Technical notes for further information on hospitals data.

Each hospitalisation is assigned a principal diagnosis (the main reason for being admitted to hospital) and can also be assigned one or more additional diagnoses (conditions that impact the provision of care but are not the main reason for being admitted to hospital). Unless otherwise stated, this section focuses on hospitalisations with a principal diagnosis of dementia, or ‘hospitalisations *due* to dementia’. See Box 9.1 for key terms and considerations for hospitalisations for people with dementia.

Box 9.1: Data considerations for hospitalisations related to dementia

This section aims to provide a comprehensive picture of the impact of dementia on Australia’s hospital systems.

The following terms are used to distinguish dementia hospitalisations:

Hospitalisations due to dementia are hospitalisations where dementia was recorded as a principal diagnosis (the main reason for admission).

Hospitalisations with dementia are hospitalisations where dementia was recorded as a principal diagnosis and/or an additional diagnosis (where dementia impacted the hospitalisation but was not the main reason for admission), or where dementia was recorded as a ‘supplementary code’ (when dementia is identified as a chronic condition that is part of a patient’s current health status).

It is important to note that the statistics presented here cannot be considered a full count of hospitalisations among people with dementia for various reasons including:

- Hospital records only include conditions that were significant in terms of treatment, investigations needed and resources used during the ‘episode of care’, or when chronic conditions that are part of a patient’s current health status are identified but don’t meet the inclusion criteria as a principal or additional diagnosis. This means that hospitalisations among people with mild dementia may be under-recorded because the early stages of dementia are less likely to affect the care provided in hospitals, or dementia may not be identified as a chronic condition that is part of a patient’s current health status.

Further, specific dementia types may be misclassified or simply attributed to Unspecified dementia by medical professionals in the hospital setting (Crowther et al. 2017). As a result, the number of hospitalisations for a specific dementia type may not be accurate. The most reliable data are likely to be for the most common types of dementia. Caution should be taken when interpreting hospital statistics by dementia type.

References

Crowther GCE, Bennett MI and Holmes JD (2017) 'How well are the diagnosis and symptoms of dementia recorded in older patients admitted to hospital?', *Age and Ageing,* 46:1, doi:10.1093/ageing/afw169.

Health services used by people with dementia

On this page

- Hospitalisations due to dementia in 2021–22
- Length of hospitalisations due to dementia
- Hospitalisations due to dementia over time
- Dementia types that were hospitalised due to dementia
- How did hospitalisations due to dementia end?
- When Australians were hospitalised due to dementia, what other conditions did they have?
- Hospitalisations due to dementia involved palliative and other end-of-life care
- Hospitalisations due to dementia by geographic and socioeconomic areas

In 2021–22, there were just over 11.6 million hospitalisations in Australia. Of these, about 25,700 were hospitalisations *due* to dementia, which is equivalent to 2 out of every 1,000 hospitalisations in Australia.

Table 9.1 shows that of the hospitalisations *due* to dementia in 2021–22:

- there were more hospitalisations for men than women (13,300 hospitalisations compared to 12,300 hospitalisations)
- men also had a higher age-standardised rate of hospitalisations than women (49.7 hospitalisations for men and 36.2 hospitalisations for women, per 10,000 population aged 60 and over)
- the average length of stay was 14.8 days – this was 5 times higher than the average length of stay of 2.7 days for all hospitalisations (AIHW 2023a)
- the average length of stay was longer for men (15.9 days) than women (13.6 days).

Table 9.1: Overview of hospitalisations *due* to dementia in 2021–22 by sex

Measure	Men	Women	Persons
Number of hospitalisations	13,300	12,300	25,700
Age-standardised rate (number per 10,000)	49.7	36.2	42.3
Average length of stay, days per hospitalisation	15.9	13.6	14.8
Total number of bed days	212,000	168,000	380,000

Note: Age-standardised rates, which apply to people aged 60 and over, were standardised to the Australian population as at 30 June 2001 and are expressed per 10,000 population.

Source: AIHW analysis of National Hospital Morbidity Database.

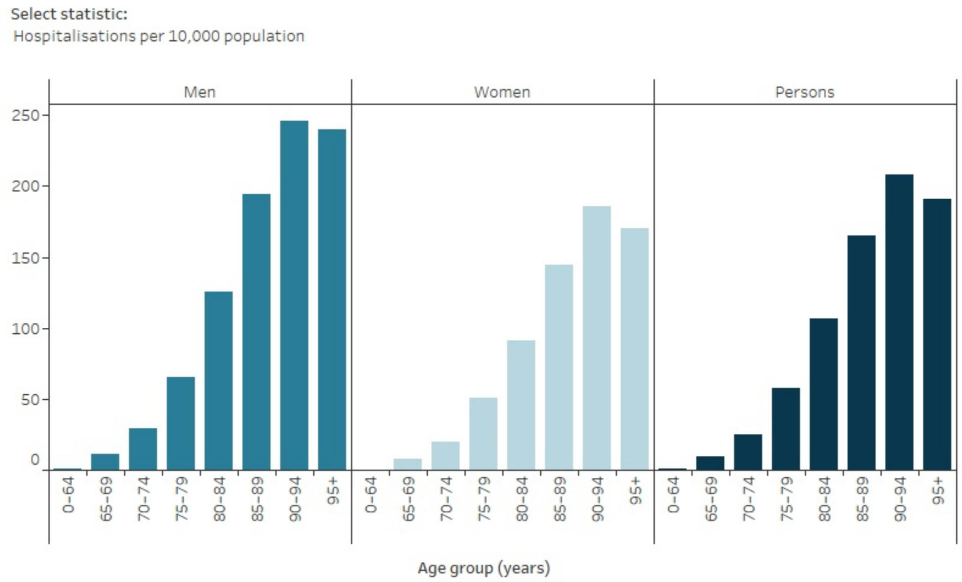
With increasing age, hospitalisations *due* to dementia increased in number but decreased in length

There were distinct patterns in hospitalisations *due* to dementia in 2021–22 by age and sex (Figure 9.1):

- the number of hospitalisations for both men and women increased with age up to 80–84 years, then decreased in the older age groups
- the rate of hospitalisations increased for both men and women up to age 90–94, before decreasing among those aged 95 and over
- people with younger onset dementia (aged under 65) had a greater average length of stay (31 days) than older people – the average length of stay decreased with increasing age, to 11 days for people hospitalised *due* to dementia aged 95 and over. This trend was observed among both men and women
- the trend of the total number of bed days was the same across all sexes, increasing to the 80–89 age group and decreasing with the 95+ age group having the least number of total bed days.

Figure 9.1: Overview of hospitalisations *due* to dementia in 2021-22, by age and sex

Figure 9.1 shows various measures of hospitalisations due to dementia in Australia by sex and age, including: the estimated number of hospitalisations due to dementia, rate of hospitalisations (per 10,000 population), bed days and average length of stay (days). Distinct patterns are explained in the previous paragraphs.



See the technical notes for further information, available at
https://www.aihw.gov.au/reports/dementia/dementia-in-aus/contents/technical-notes
Source: AIHW analysis of National Hospital Morbidity Database.
http://www.aihw.gov.au

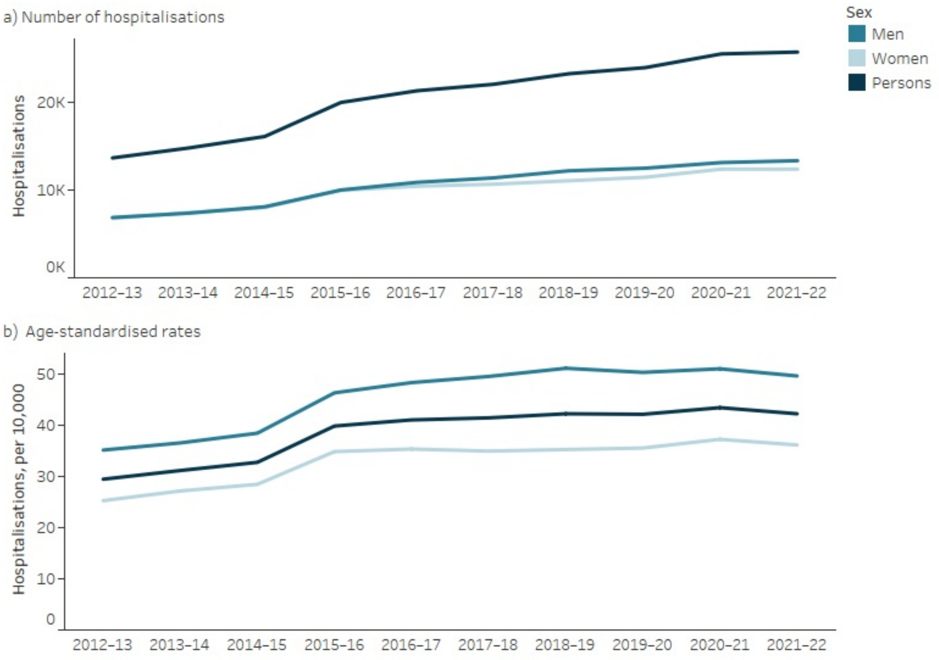
Hospitalisations due to dementia increased over time

All rates have been age-standardised to adjust for population differences, providing a more accurate reflection of changes over time. Figure 9.2 shows the number and age-standardised rate of hospitalisations due to dementia between 2012–13 and 2021–22:

- the rate of hospitalisations increased gradually each year from 2012–13 to 2014–15 (5.4% annual average increase) and from 2015–16 to 2021–22 (1.0% annual average increase)
- between 2014–15 and 2015–16 there was a large increase in both the number of hospitalisations (24% increase) and the age-standardised rate (22% increase). This increase is likely due to changes in coding for rehabilitation which came into effect in 2015–16 (see Box 9.2 for more information)
- although the numbers of hospitalisations were similar throughout the period, men consistently had higher rates of hospitalisations than women.

Figure 9.2: Hospitalisations *due* to dementia between 2012-13 and 2021-22: number and age-standardised rates

Figure 9.2 shows two line graphs showing the estimated number and age-standardised rates of hospitalisations due to dementia in Australia by sex between 2012–13 and 2021–22. Distinct patterns are explained in the previous paragraphs.



Notes
1. The age-standardised rates, which apply to people aged 60 and over, were standardised to the Australian population as at 30 June 2001 and are expressed per 10,000 population.
2. See the technical note for further information, available at https://www.aihw.gov.au/reports/dementia/dementia-in-aus/contents/technical-notes
Source: AIHW analysis of National Hospital Morbidity Database.
http://www.aihw.gov.au

Box 9.2: Coding changes impacting hospitalisations *due* to dementia over time

With many national health data collections, the primary purpose is to support the administrative objectives of the collecting organisation rather than to monitor disease. Factors such as changes in coding practices may affect how well conditions are recorded in the data.

The period 2014–15 to 2015–16 saw a substantial increase in hospitalisations *due* to dementia (where dementia was the principal diagnosis). In July 2015, a new coding standard *ACS2104 Rehabilitation* was introduced into the ICD-10-AM. Changes that may have led to an increase in admissions with dementia coded as the principal diagnosis include:

- prior to July 2015, patients who were admitted to hospital specifically for rehabilitation were assigned a principal diagnosis of *Z50.9 Care involving use of rehabilitation procedure, unspecified*, and the condition which led to the need for rehabilitation (such as dementia) was assigned as an additional diagnosis
- in July 2015, this coding standard was revised so that the principal diagnosis should be assigned to the condition which led to the need for rehabilitation, and *Z50.9 Care involving use of rehabilitation procedure, unspecified* should be assigned as an additional diagnosis.

When changes such as these are implemented in short time periods, distinct steps up or down in numbers and rates are expected to be observed in administrative data.

About a third of hospitalisations *due* to dementia were for Alzheimer's disease

In 2021–22, the most common dementia types recorded in hospitalisations *due* to dementia were:

- Alzheimer's disease (29%)
- Other dementia (20%)
- Unspecified dementia (16%)
- Vascular Dementia (12%) (Figure 9.3).

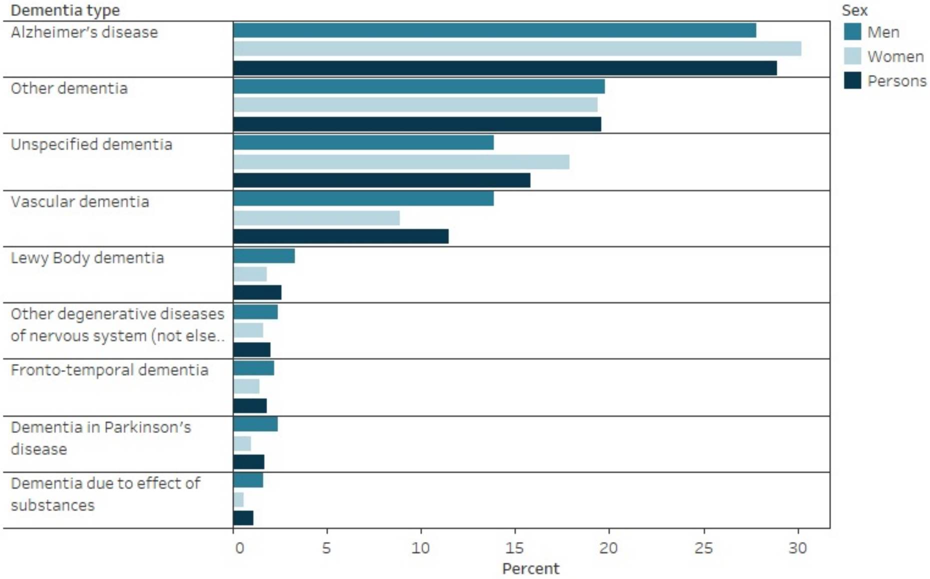
There were differences by sex in the dementia types recorded in hospitalisations *due* to dementia. Compared to men, there was a slightly higher proportion of hospitalisations among women due to *Alzheimer's disease* (30% of women compared with 28% of men) and *Unspecified dementia* (18% of women compared with 14% of men). There was a higher proportion of men with hospitalisations due to *Vascular dementia* than women (14% of men compared with 9.0% of women).

Although not a distinct type of dementia, *delirium superimposed on dementia* occurs when a person with pre-existing dementia experiences delirium, and is a common cause of hospitalisations among people with dementia. In 2021–22, 15% of hospitalisations *due* to dementia were for *Delirium superimposed on dementia* (Table S9.3).

As a person may have multiple types of dementia, it is possible to have more than one type of dementia recorded among hospitalisations with dementia. While the majority of dementia hospitalisations had only one type of dementia recorded, almost 10% (about 8,700 hospitalisations) had 2 or more types recorded.

Figure 9.3: Hospitalisations *due* to dementia in 2021–22: percentage, by type of dementia and sex

Figure 9.3 is a bar graph showing the percentage of hospitalisations due to dementia in Australia by type of dementia and sex in 2021–22. The most common dementia type recorded was *Alzheimer's disease*. Distinct patterns are explained in the previous paragraphs.



Notes

1. 'Other dementia' consists of Dementia in Creutzfeldt-Jakob disease, Dementia in Huntington's diseases, Dementia in human immunodeficiency virus (HIV) disease, rarer causes of dementia and delirium.
2. 'Other degenerative diseases of nervous system (not elsewhere classified)' was considered a hospitalisation due to dementia only when dementia was recorded as an additional diagnosis.
3. 'Delirium superimposed on dementia' was included in the total number of hospitalisations due to dementia, but is not shown in this figure as it is not a distinct type of dementia.
4. See the technical notes for further information, available at https://www.aihw.gov.au/reports/dementia/dementia-in-aus/contents/technical-notes

Source: AIHW analysis of National Hospital Morbidity Database.
http://www.aihw.gov.au

How did hospitalisations *due* to dementia end?

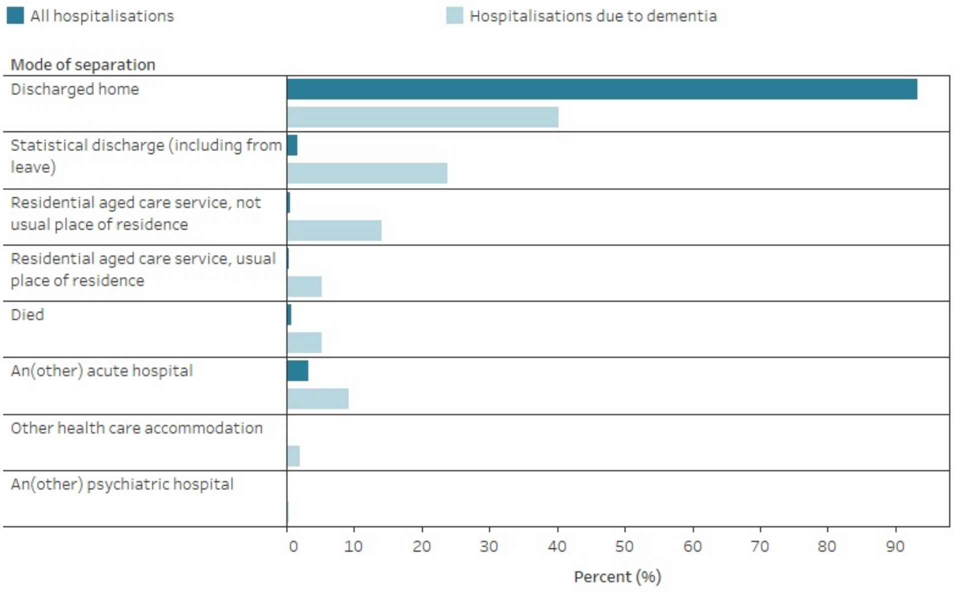
In 2021–22, 40% of all hospitalisations *due* to dementia ended in the patient being discharged home (Figure 9.4). This proportion was considerably less than seen for all hospitalisations in 2021–22, where 93% ended in the patient being discharged home (AIHW 2023c).

Of all dementia hospitalisations, 5.2% of hospitalisations were discharged to their usual place of residence which was a residential aged care facility. 14% were transferred to a residential aged care facility which was not their usual place of residence. Of those discharged or transferred to a residential aged care facility, 2 in 3 patients were aged over 80 (Table S9.9).

Around 24% of hospitalisations *due* to dementia ended with a 'Statistical discharge', which is when the intent of care changed during their stay in hospital (for example, from acute care to rehabilitation or palliative care). A further 9.2% ended with discharge or transfer to another acute hospital and 5.2% ended with the death of the patient.

Figure 9.4: All hospitalisations and hospitalisations *due* to dementia in 2021–22: percentage, by mode of separation

Figure 9.4 is a bar graph showing the percentage of all hospitalisations, and hospitalisations due to dementia in Australia by mode of separation. Distinct patterns are explained in the previous paragraphs.



See the technical notes for further information, available at
https://www.aihw.gov.au/reports/dementia/dementia-in-aus/contents/technical-notes
Source: AIHW analysis of National Hospital Morbidity Database.
http://aihw.gov.au

When Australians were hospitalised *due* to dementia, what other conditions did they have?

When Australians were admitted to hospital *due to* dementia, the most common other diagnoses (additional diagnosis and supplementary diagnosis), other than dementia were:

- hypertension
- arthritis and osteoarthritis primary
- constipation
- ischaemic heart disease, also known as coronary heart disease (AIHW 2023b)
- depression

Three of these diagnoses are closely related to the modifiable risk factors for dementia, hypertension, ischemic heart disease and depression. For further information on the top 10 other diagnoses, see Table S9.11.

6% of all hospitalisations *due* to dementia involved palliative and other end-of-life care

In 2021–22, there were over 900 palliative care-related hospitalisations due to dementia, accounting for 5.8% of all hospitalisations *due* to dementia (3.6% for palliative care and 2.2% for other end-of-life care) (Figure 9.5a). Palliative care-related hospitalisations include hospitalisations with a care type of *palliative care*, in which specialist palliative care is provided, as well as hospitalisations where a palliative care diagnosis was recorded, but care was not necessarily delivered by a palliative care specialist (referred to as *other end-of-life care*). See Palliative care services in Australia for more detail.

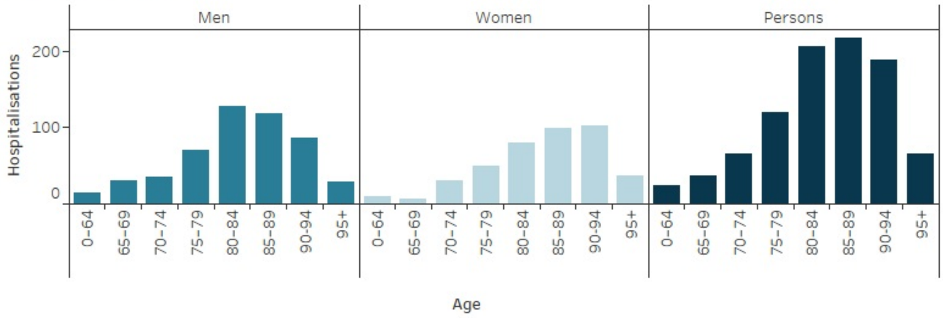
Compared to women, men tended to have higher rates of hospitalisations due to dementia involving palliative care or other end-of-life care, and this held across most age groups; for both men and women, the rate of hospitalisations increased with age (Figure 9.5b).

Figure 9.5: Palliative care and other end-of-life care hospitalisations *due* to dementia in 2021–22, by age and sex: (a) number and (b) age-specific rate

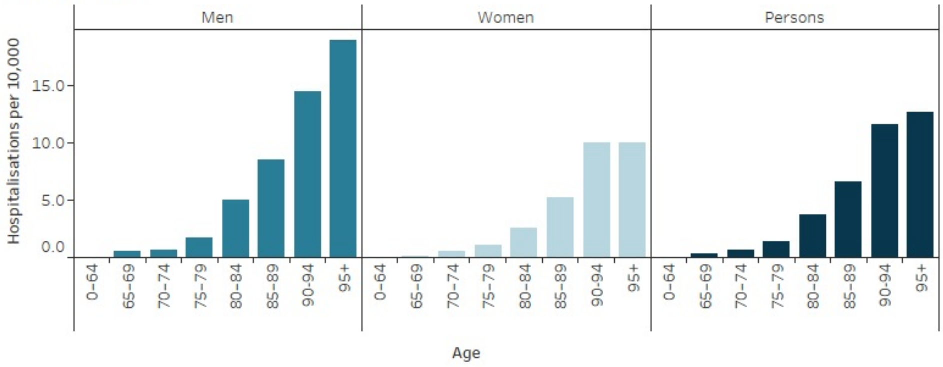
Figure 9.5 shows two bar graphs showing the estimated number and age-specific rates of palliative care and other end-of-life care hospitalisations due to dementia in Australia by sex and age in 2021–22. The trends across both palliative care and other end-of-life hospitalisations are similar. The number of hospitalisations increases to about the 85–89 age group and decreasing after. The age-specific rates increase as age increases.

Hospitalisation type:
Palliative care

a) Number of hospitalisations



b) Age-specific rate



Notes
1. Due to low counts, the rate of hospitalisations for palliative care and other end of life care is not reported for men, women and people aged 0–64 years.
2. See the technical notes for further information, available at https://www.aihw.gov.au/reports/dementia/dementia-in-aus/contents/technical-notes
Source: AIHW analysis of National Hospital Morbidity Database.
http://www.aihw.gov.au

How do hospitalisations *due* to dementia vary by geographic and socioeconomic areas?

Figure 9.6 shows the age-standardised rate of hospitalisations *due* to dementia by state and territory, remoteness areas and socioeconomic areas for 2021–22.

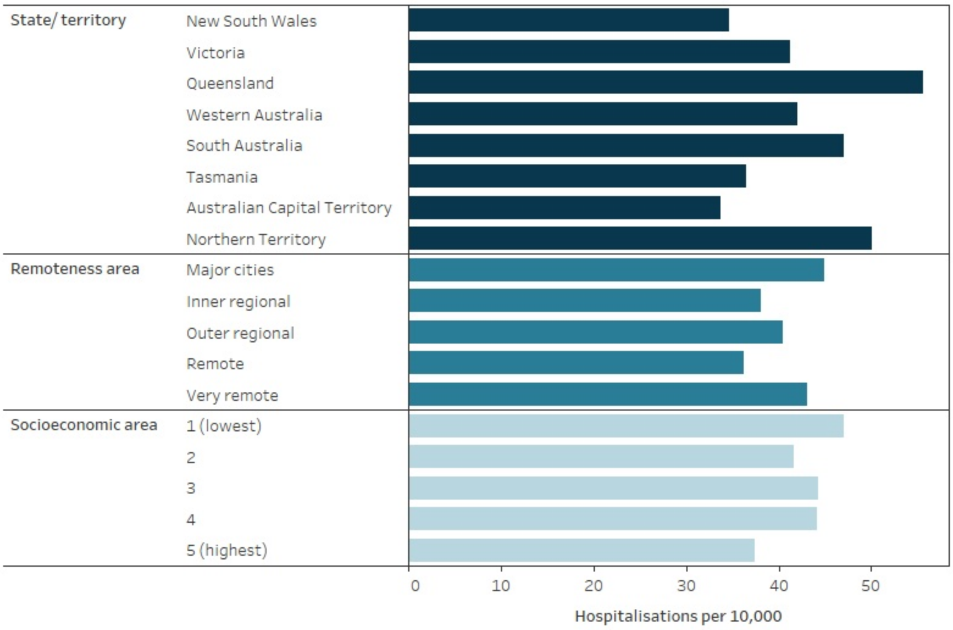
In 2021–22, after adjusting for population differences, the age-standardised rate of hospitalisations *due* to dementia for people aged 60 and over:

- varied across states and territories – ranging from 34 hospitalisations per 10,000 population in ACT to 56 hospitalisations per 10,000 population in Queensland
- varied by remoteness – the rate of hospitalisations due to dementia was highest in *Major cities* (45 hospitalisations per 10,000 population) and lowest in *Remote* areas (36 hospitalisations per 10,000 population)
- was lowest among people living in the highest socioeconomic areas (37 per 10,000 population) and highest among people living in the lowest socioeconomic areas (47 per 10,000 population). The other socioeconomic areas had similar rates of hospitalisation (ranging between 42 and 44 per 10,000 population).

Socioeconomic and demographic factors such as income, education, employment, geographic access to health and social support services, as well as identifying as a First Nations or culturally and linguistically diverse (CALD) person, may impact hospitalisations of people with dementia. For more information refer to Hospital care for First Nations people with dementia and Dementia in priority groups.

Figure 9.6: Hospitalisations due to dementia in 2021–22: age-standardised rate, by state and territory, remoteness area and socioeconomic area

Figure 9.6 shows a bar graph showing the age-standardised rates of hospitalisations due to dementia by state or territory, remoteness areas and socioeconomic areas in 2020–21. Distinct patterns are explained in the previous paragraph.



Notes
1. The age-standardised rates, which apply to people aged 60 and over, were standardised to the Australian population as at 30 June 2001 and are expressed per 10,000 population.
2. See the technical notes for further information, available at https://www.aihw.gov.au/reports/dementia/dementia-in-aus/contents/technical-notes
Source: AIHW analysis of National Hospital Morbidity Database.
http://www.aihw.gov.au

References

AIHW (Australian Institute of Health and Welfare) (2023a) *Admitted patient care 2021-22*, AIHW, Australian Government, accessed 19 June 2023.

AIHW (2023b) *Coronary heart disease*, AIHW, Australian Government, accessed 25 January 2023.

AIHW (2023c) *Palliative care services in Australia*, AIHW, Australian Government, accessed 20 June 2023.

Health services used by people with dementia

On this page

- Hospitalisations due to dementia versus hospitalisations with dementia
- What were the most common principal diagnoses when dementia was an additional diagnosis?

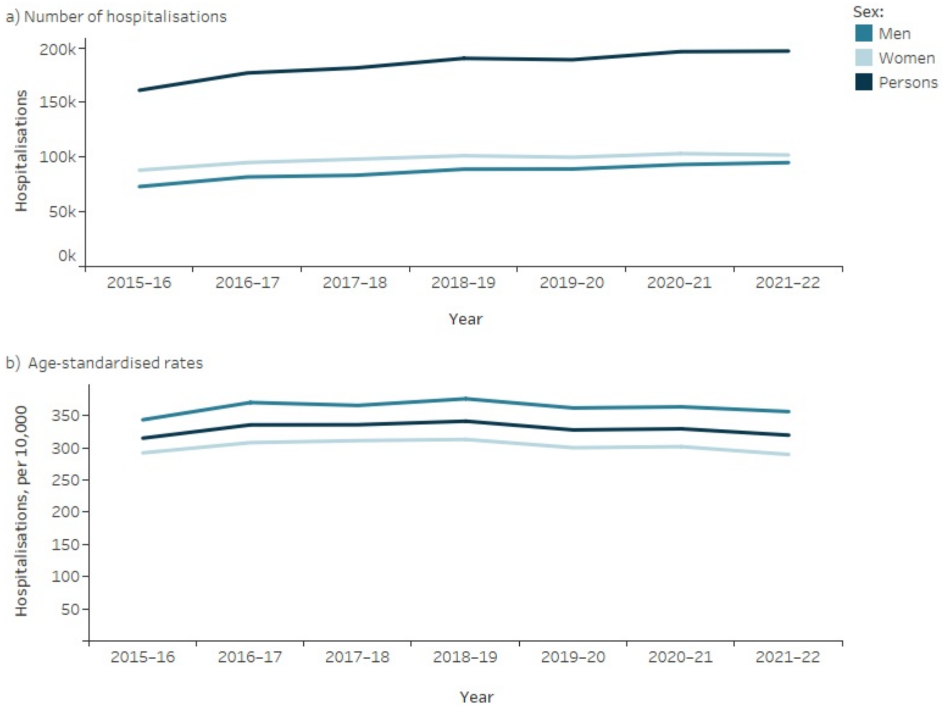
The previous page presented hospitalisations *due* to dementia (that is, when dementia was recorded as the principal diagnosis), but understanding hospitalisations *with* dementia provides important insights on the wide-ranging conditions that can lead people living with dementia to use hospital services. Hospitalisations with dementia are hospitalisations where dementia was recorded as a principal diagnosis and/or an additional diagnosis (where dementia impacted the hospitalisations but was not the main reason for admission), or where dementia was recorded as a ‘supplementary code’ (when dementia is identified as a chronic condition that is part of a patient’s current health status).

When accounting for all possible inclusions of dementia codes in a patient record, hospitalisations *with* dementia are just under 197,000 admissions (95,000 for men and 102,000 for women). This is equivalent to almost 2 out of every 100 hospitalisations in Australia.

Between 2015–16 and 2021–22, there was an increase in the number of hospitalisations (22.2% increase) while the age-standardised rate remained reasonably stable (Figure 9.7). Age-standardised rates are helpful for determining the trend independent of age structures changing over time (Australia’s ageing population) and population growth. The age-standardised rates increased slightly from 2015–16 to 2018–19, then decreased slightly to 2021–22. The age-standardised rate average annual increase was 0.2%.

Figure 9.7: Hospitalisations with dementia between 2015-16 and 2021-22 by sex: (a) number and (b) age-standardised rate

Figure 9.7 shows two line graphs showing the estimated number and age-standardised rates of hospitalisations with dementia in Australia by sex between 2015–16 and 2021–22. Distinct patterns are explained in the previous paragraph.



Notes
1. The age-standardised rates, which apply to people aged 60 and over, were standardised to the Australian population as at 30 June 2001 and are expressed per 10,000 population.
2. See the technical notes for further information, available at https://www.aihw.gov.au/reports/dementia/dementia-in-aus/contents/technical-notes
Source: AIHW analysis of National Hospital Morbidity Database.
http://www.aihw.gov.au

Box 9.3: Potential factors impacting hospitalisations *with* dementia over time

In July 2015, 29 supplementary codes for chronic conditions (including dementia) and a new Australian Coding Standard were implemented in existing classification systems and coding rules for assigning specific codes to diagnoses found in medical records (ACCD 2015). As a result, from July 2015 onwards dementia can be recorded in hospital data using a supplementary code when it does not meet the criteria to be recorded as a principal or additional diagnosis.

It is not yet understood whether the introduction of supplementary codes has impacted recording of chronic conditions as additional diagnoses in hospitals data. It may have resulted in less recording of dementia as an additional diagnosis, especially in cases where dementia did not directly impact the care provided to the patient. The exclusion of supplementary codes may explain the slightly declining rates from 2015–16 to 2021–22 (Figure 9.7).

What were the most common principal diagnoses when dementia was an additional diagnosis?

In 2021–22 there were almost 197,000 hospitalisations where dementia was recorded as an additional or supplementary diagnosis. Examining the most common principal diagnoses recorded for these hospitalisations provides insights on the diverse reasons why people with dementia require hospital services. The most common principal diagnoses were:

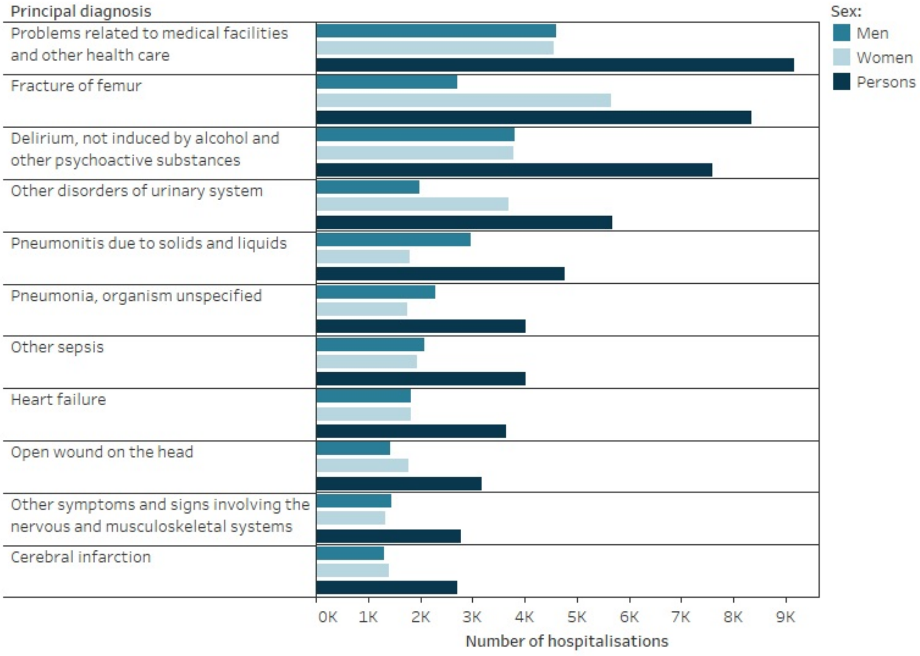
- *Problems related to medical facilities and other health care*, ICD-10-AM codes Z75.0–9 (9,200 hospitalisations or 5.1% of hospitalisations where dementia was an additional diagnosis).
    - these hospitalisations are where patients are required to stay in hospital longer to rehabilitate or are waiting 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)
- *Fracture of the femur*, ICD-10-AM codes S72.0–9 (8,400 hospitalisations or 4.6%)
- *Delirium, not induced by alcohol and other psychoactive substances*, ICD-10-AM codes F05.0–9 (7,600 hospitalisations or 4.2% of hospitalisations where dementia was an additional diagnosis)
- *Other disorders of urinary system*, ICD-10-AM code N39X (5,700 hospitalisations or 3.2%) (Figure 9.8).

Other common principal diagnoses recorded for these hospitalisations included respiratory diseases, cardiovascular diseases and sepsis.

Falls (ICD-10-AM codes W00–W19) accounted for 97% of all hospitalisations due to fractures of the femur, and 95% of hospitalisations due to fractures of the lumbar spine and pelvis, where dementia was an additional diagnosis. Women had twice as many hospitalisations than men for a fracture of the femur and fracture of the lumbar spine and pelvis, with an additional diagnosis of dementia (Table S9.10).

Figure 9.8: Most common principal diagnoses where dementia was an additional diagnosis in 2021-22, by sex

Figure 9.8 shows a bar graph showing the number of hospitalisations for the most common principal diagnoses when dementia was recorded as an additional diagnosis, by sex in 2021–22. Distinct patterns are explained in the previous paragraphs.



See the technical notes for further information, available at https://www.aihw.gov.au/reports/dementia/dementia-in-aus/contents/technical-notes

Source: AIHW analysis of National Hospital Morbidity Database.

http://www.aihw.gov.au

References

ACCD (The Australian Consortium for Classification Development) (2015) *Reference to Changes for ICD-10-AM/ACHI/ACS 9th edn*, Independent Hospital Pricing Authority, Australian Government, accessed 17 August 2022.

Aged care and support services used by people with dementia

While many people with dementia are able to live independently and rely on carers, family and friends for assistance, there are a range of aged care services, as well as dementia-specific services available for those in need of support, as well as for their carers, friends and family.

The following pages present statistics and information on:

- Overview of Australia's aged care system
- Aged care assessments
- Community-based aged care
- Residential aged care
- Overview of dementia support services and initiatives
- National Dementia Support Program and Dementia Friendly Communities
- Behaviour support programs
- What carer support services are available?

For the underlying data presented in these pages, refer to the Aged care data tables and the Dementia support services data tables.

For more information on aged care and support services used by people with dementia among different population groups, such as by First Nations people and people from culturally and linguistically diverse backgrounds, see Dementia in priority groups.

It is important to bear in mind that dementia is not able to be identified in all community-based aged care service data, which limits our ability to understand the use and need for these services by people with dementia.

Over **37,000** people with dementia completed a **comprehensive or home support assessment** in 2021–22

54% of people living in **permanent residential aged care** have dementia

Referrals to Dementia Support Australia services have **increased substantially** in recent years

Women with dementia were more likely to be living alone at the time of their aged care assessment than men

Aged care and support services used by people with dementia

Aged care services offer a variety of care in different settings to older Australians. Home support and home care services provide care for people living in the community and could include assistance with housework and property maintenance, cooking and providing assistive equipment (such as walking frames or installing handrails at home). Residential aged care services provide care and accommodation in residential facilities, both for permanent and short-term respite stays. At 30 June 2022, around 407,000 Australians were using residential aged care (permanent or respite), home care or transition care services. In 2021–22 nearly 818,000 people received assistance under the Commonwealth Home Support Programme (CHSP), and some of them may have also accessed residential aged care (AIHW 2023).

Australian Government-subsidised aged care services are generally provided on the basis of need – there are no age restrictions for eligibility (except for the CHSP). Aged care services are managed by government, not-for-profit and private organisations. At 30 June 2022 there were 811 organisations providing residential aged care through 2,671 services, 916 organisations delivering home care services through 2,427 services, and 1,452 organisations were providing home support during 2021–22 through 3,760 outlets in Australia (AIHW 2023). Note that some organisations may have been providing more than one type of care services and support. For more information on aged care in Australia, visit GEN Aged Care data.

In 2021–22 about 672 men and 627 women with younger onset dementia (that is, people with dementia aged under 65) were living in a residential aged care facility. For some young people with dementia, residential aged care may be their setting of choice. However, younger people are generally considered to be better served by other services (such as specialist disability accommodation provided through the NDIS) (see Box 10.1). The Australian Government has committed to minimising the need for younger people to live in aged care facilities, through the *Younger People in Residential Aged Care Strategy 2020–25* (NDIA 2022).

In addition to aged care services, people with dementia may access a range of health services, including: allied health services, medical specialists and specialised dementia services. See Overview of dementia support services and initiatives for information on dementia specific services available to Australians with dementia and their carers and GP and specialist services overview for information on the use of community-based GP and specialist health care services by people with dementia.

Refer to the Aged care data tables for the underlying data presented in these pages.

Box 10.1: Support services for people with younger onset dementia (aged under 65)

People with younger onset dementia may be eligible for support through the National Disability Insurance Scheme (NDIS) (NDIA 2019) and financial support through the Disability Support Pension (Services Australia 2023), in addition to aged care services. Data are not currently available on the number of people with younger-onset dementia accessing the NDIS or receiving the Disability Support Pension.

National Disability Insurance Scheme (NDIS)

The NDIS provides support for people aged under 65 who have a significant, ongoing disability. Through this scheme young people are provided with funding in order for them to access a range of support services and programs, including supports that assist people with daily personal activities (such as gardening, household chores and meal preparation), making home modifications to suit their needs, programs that enable and encourage participation in work or social activities, and funding towards therapeutic services.

Disability Support Pension

The Disability Support Pension provides financial help for people with an on-going physical, intellectual or psychiatric condition that prevents that person from working (such as people with younger-onset dementia). This pension is available to people aged 16 and over (who are less than pension age), with eligibility and payment amounts based on the person’s condition and level of impairment, and their assessable income and assets.

Dementia care workforce

Ensuring the aged care workforce is appropriately trained to care for people with dementia is essential to providing high quality care.

The *Aged Care Act 1997* does not mandate educational qualifications for those working in the aged care sector, however it does outline that approved residential aged care providers have a duty to ensure staff have the right qualifications and skills to provide care appropriate to the needs of people in care (Mond 2019).

The Royal Commission into Aged Care Quality and Safety (Royal Commission) has recommended implementing mandatory dementia care training for workers engaged in residential aged care and in care in the community, after finding that staff often lack skills and resources to appropriately care for people with dementia. This is especially relevant for people with dementia who experience behaviours and psychological symptoms, and require skilled staff to help them effectively manage symptoms (Royal Commission 2021).

The Australian Government is implementing reforms, including revising the Aged Care Quality Standards to strengthen requirements in relation to dementia care and increasing average care minutes per day to improve the quality of residential care for all older Australians, including people living with dementia. New requirements were introduced on 1 July 2023 for Registered Nurses to be on-site and on duty 24 hours a day, 7 days a week at residential aged care facilities. The Dementia Training Program provides specific training for the aged and health care sectors to improve the quality of care.

Due to a lack of national data, this page does not present statistics on the formal workforce caring for people with dementia. For information on unpaid carers, see Carers of people with dementia.

Need more information?

If you require more information about aged care services available for people with dementia, refer to:

- My Aged Care – for information on, and applying for access to government-subsidised aged care services
- GEN aged care data – for data, statistics and reports on aged care services in Australia
- Dementia Australia website
- National Dementia Helpline – 1800 100 500, a free and confidential service to discuss dementia and memory loss concerns for yourself or others.

References

AIHW (Australian Institute of Health and Welfare) (2023) *People using aged care*, AIHW, Australian Government, accessed 16 June 2023.

NDIA (National Disability Insurance Agency) (2022), *Younger People in Residential Aged Care Strategy 2020–25*. accessed 13 July 2023.

Mond J (2019) *EXHIBIT 3-79 - WIT.0144.0001.0001 - Statement of Josephine Mond*, Royal Commission into Aged Care Quality and Safety, accessed 20 January 2023.

NDIA (2019), *Access to the NDIS – The disability requirements*, accessed 13 May 2021.

Royal Commission (Royal Commission into Aged Care Quality and Safety) (2020) *Research Paper 4: What Australians Think of Ageing and Aged Care*, Royal Commission, Australian Government, accessed 10 October 2020.

Royal Commission (2021) *Final report: Care, Dignity and Respect*, Royal Commission, Australian Government, accessed 9 May 2021.

Services Australia (2023) *Disability Support Pension*, Services Australia, Australian Government, accessed 15 June 2023.

Aged care and support services used by people with dementia

The use of aged care services by a person with dementia will depend on numerous factors, including their health status and presence of other health conditions, the types of activities for which assistance is required and level of assistance needed, current carer status and availability, financial resources, accessibility, cultural influences and personal preferences.

Access to government-subsidised aged care services is co-ordinated through the My Aged Care system. After an initial screening to establish the person’s needs and types of services that could help, an appointment is organised with an assessor who will undertake an assessment. Data from the National Screening and Assessment Form (NSAF) captures information from both the initial screening and assessments.

There are two 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 community-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). By law, a Comprehensive Assessment is required before someone can receive residential, home, or transition care.

As part of a home support assessment or a comprehensive assessment, an assessor must record ‘at least one health condition (including mental health conditions or disabilities) which impact the person’s need for assistance with activities of daily living and social participation’ (Department of Health 2018). Therefore, people with dementia can be identified using assessment data where dementia is recorded as a health condition impacting their care needs. Dementia may already be diagnosed or Aged Care Assessment Teams may refer a person to be diagnosed for the first time during an assessment. See How is dementia diagnosed? for information on how people with dementia are diagnosed.

This page provides information on people with dementia who completed a comprehensive and/or home support assessment in 2021–22.

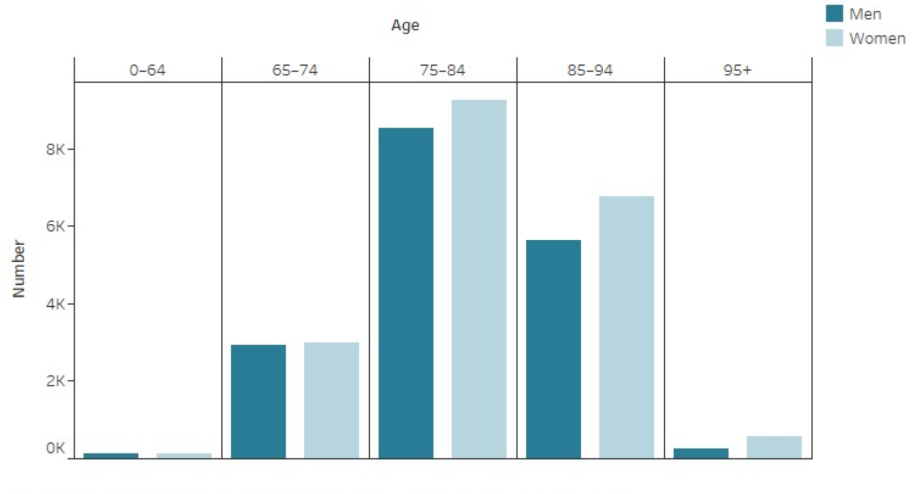
Around 37,100 people with dementia completed an aged care assessment in 2021–22

In 2021–22, just over 37,100 Australians who completed an aged care assessment (either a comprehensive or home support assessment) had dementia recorded as a health condition (Figure 10.1). This equates to 9.3% of people who completed an aged care assessment that year.

Among people with dementia who completed an aged care assessment, just over half were women (53% or 19,700 women, and 17,500 men).

Figure 10.1: People with dementia who completed an aged care assessment in 2021–22, by age and sex

Figure 10.1 is a bar graph showing the number of people with dementia who completed an aged care assessment in 2021–22, by age group and sex. Women and men in the 75–84 year age group accounted for the largest number of assessments (9,251 and 8,527 respectively), followed by women (6,766) and men (5,623) aged 85–94.



Note: Includes people who completed a home support assessment or comprehensive assessment.
Source: AIHW analysis of the National Aged Care Data Clearinghouse
http://www.aihw.gov.au

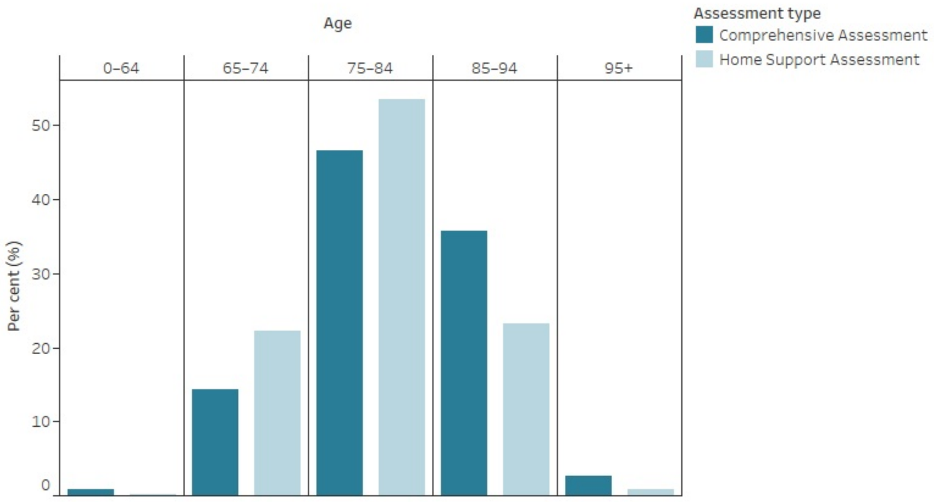
People with dementia were more likely to be seeking (or were more likely to be directed to seek) a higher level of aged care. Just over 4 in 5 (81%) aged care assessments undertaken by people with dementia in 2021–22 were comprehensive assessments (for people with more complex care needs) compared with 43% of people without dementia.

Almost half (47%) of people with dementia who completed a comprehensive assessment and 53% of people who completed a home support assessment were aged 75–84. People with dementia who completed a comprehensive assessment tended to be older (38% were aged 85 or over) than those who completed a home support assessment (24%) (Figure 10.2).

Among those who had a comprehensive assessment, just over 4 in 5 people with dementia had their dementia reported as the main condition impacting their need for assistance (82%) (Table S10.2).

Figure 10.2: People with dementia who completed an aged care assessment in 2021–22: percentage by age and assessment type

Figure 10.2 is a bar graph showing the percentage of people with dementia who completed an aged care assessment in 2021–22, by age group and assessment type. Around half of people who completed a home support assessment were aged 75–84, about 1 in 5 were aged 65-74 and another quarter were aged 84–94. People who completed a comprehensive assessment were more likely to be older: nearly half were aged 75–84 and just over one third were aged 84–94.



Source: AIHW analysis of the National Aged Care Data Clearinghouse
http://www.aihw.gov.au

An additional 19,300 people with cognitive impairment (but no record of dementia) completed an aged care assessment

This equates to 4.9% of people who completed an aged care assessment in 2021–22 (Table S10.3).

This group includes people with mild cognitive impairment – where they have significant memory loss but no other changes in cognitive function. Mild cognitive impairment increases the risk of Alzheimer's disease, but it does not mean that the development of dementia is certain. However, it is recognised that some people with cognitive impairment who complete an aged care assessment may be in the early stages of dementia and are yet to receive a formal diagnosis. Therefore, the number of people with dementia in this report may be an underestimate of the true number of Australians with dementia seeking entry into aged care services.

Women with dementia were more likely to be living alone at the time of their assessment than men with dementia

The majority (97%) of people with dementia who completed an aged care assessment in 2021–22 (both for comprehensive and home support assessments) were living in the community at the time of their assessment.

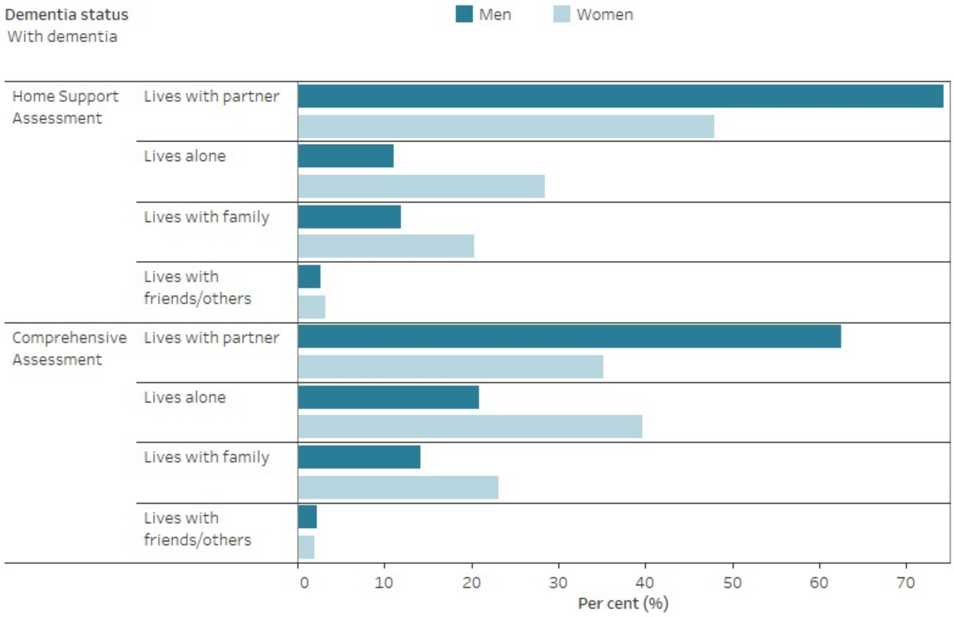
The living arrangements of people with dementia differed substantially by sex among those who completed home support assessments and comprehensive assessments (Figure 10.3). Men with dementia were more likely to be living with their partner than women with dementia—74% of men who completed a home support assessment compared with 48% of women, and 63% of men who completed a comprehensive assessment compared with 35% of women.

In contrast, women with dementia were much more likely to be living alone than men with dementia—11% of men who completed a home support assessment compared with 28% of women, and 21% of men who completed a comprehensive assessment compared with 40% of women. Women with dementia were also more likely to be living with family than men with dementia—12% of men who completed a home support assessment compared with 20% of women, and 14% of men who completed a comprehensive assessment compared with 23% of women.

Patterns in living arrangements for people with dementia were largely also reflected among those without dementia, likely due to women living longer on average.

Figure 10.3: Living arrangements of people who completed an aged care assessment in 2021–22: percent by dementia status, sex and assessment type

Figure 10.3 is a bar graph showing the living arrangements of people who completed an aged care assessment in 2021–22. The graph is disaggregated by assessment type (home support or comprehensive) and sex, and shows percentages for people with and without dementia. For people with dementia, the patterns were similar for both assessment types. At the time of their assessment, men were more likely to live with their partner than women and women were more likely than men to live alone or live with family.



Note: Includes people who were living in the community at the time of their assessment.
Source: AIHW analysis of the National Aged Care Data Clearinghouse
http://www.aihw.gov.au

The majority of people who completed a home support assessment (90% of people with dementia and 91% of people without dementia) and 3 in 5 people who completed a comprehensive assessment (61% of people with dementia and 65% without dementia) in 2021–22 completed the assessment in their own home. Comprehensive assessments can also take place in a hospital, and 25% of people with dementia had their comprehensive assessment performed in a hospital setting. This was similar to people without dementia who completed a comprehensive assessment that year (24%) (Table S10.5).

The majority of people with dementia (91%) were receiving assistance from a carer who was not associated with a service provider or paid service – this was much higher than for people without dementia (52%) (Table S10.6). Refer to Carers of people with dementia for detailed information on informal carers of people with dementia.

Triggers for doing an assessment

There are a number of triggers that indicate a potential need for aged care services and so prompt an aged care assessment to take place. These may be closely related to the individual's health and care needs, or related to other circumstances such as a change in care arrangements.

In 2021–22, 94% of people with dementia who completed a comprehensive assessment and 59% who completed a home support assessment had more than one trigger for needing an assessment. This was higher than for people without dementia; 91% who completed a comprehensive assessment and 41% who completed a home support assessment (Table S10.7).

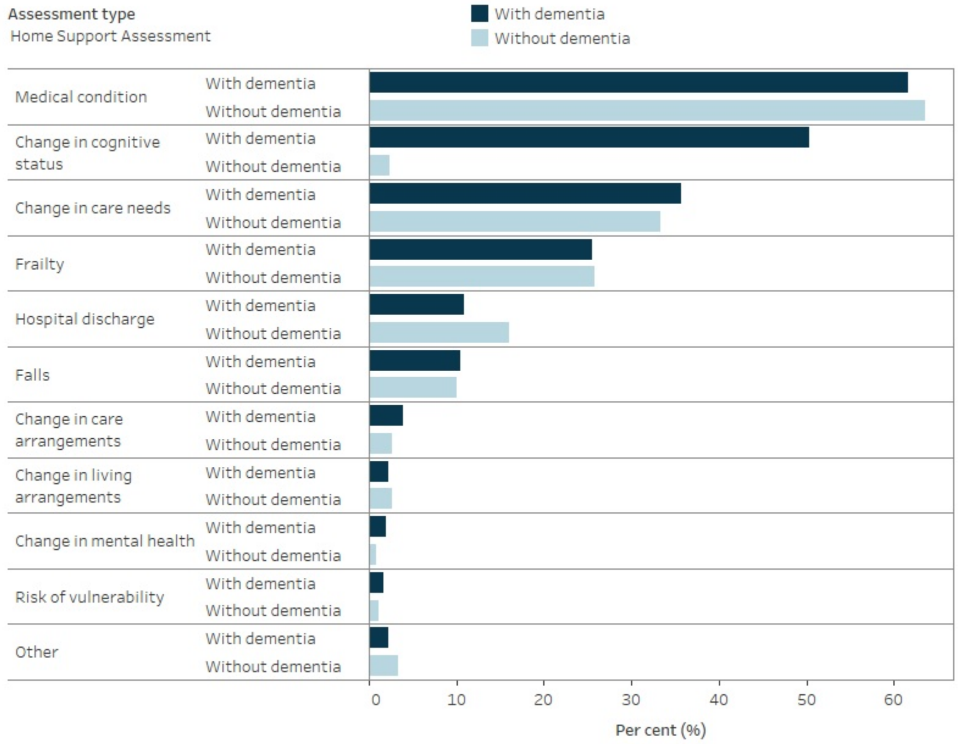
When looking at individual triggers, aged care assessments for people with dementia were most commonly triggered by:

- Change in cognitive status – 83% who completed a comprehensive assessment and 50% who completed a home support
- Change in care needs – 78% who completed a comprehensive assessment and 36% who completed a home support assessment
- Medical condition – 73% who completed a comprehensive assessment and 62% who completed a home support assessment
- Frailty – 54% who completed a comprehensive assessment and 26% who completed a home support assessment (Figure 10.4).

Understandably, aged care assessments for people with dementia were much more likely to be triggered by a change in cognitive status than for those without dementia (where a change in cognitive status triggered 21% of comprehensive assessments and 2.3% of home support assessments). Aged care assessments for people with dementia were also slightly more likely to be triggered by changes in care needs, care arrangements, mental health and risk of vulnerability than for people without dementia for both assessment types.

Figure 10.4: Triggers for aged care assessments among people who completed an aged care assessment in 2021–22: percent by dementia status and assessment type

Figure 10.4 is a bar graph showing the triggers for aged care assessments (home support or comprehensive assessments) among people who completed an aged care assessment in 2021–22. The graph depicts the proportion of assessments accounted for by each trigger for both people with and without dementia. An assessment could have more than one trigger recorded. Just over 2 in 5 people with dementia who had a comprehensive assessment were triggered to have the assessment by a change in their cognitive status. Other common comprehensive assessment triggers for people with dementia were a change in care needs, medical condition and frailty. The most common triggers for people with dementia to get a home support assessment were medical condition (almost 2 in 3 people) and a change in cognitive status (50%). The most common trigger for both types of assessment for people without dementia was a medical condition.



Note: People may have more than one trigger, therefore percentages do not sum to 100%.
Source: AIHW analysis of the National Aged Care Data Clearinghouse.
http://www.aihw.gov.au

Co-existing health conditions

Older people who require support and assistance provided by aged care services often have a number of co-existing health conditions. On average, people with dementia had 6.1 health conditions (including dementia) listed on their aged care assessment. This was similar to the average for people without dementia (5.5 health conditions). However, people with dementia who had a comprehensive assessment had more conditions recorded on average (6.5 health conditions) than those who had a home support assessment (4.6 health conditions) (Table S10.9). This reflects the fact that comprehensive assessments are generally undertaken for people with more complex care needs, who also tend to be older.

Figure 10.5 shows the 10 most common health conditions for people with dementia who completed an aged care assessment in 2021–22, and how this compared to people without dementia.

The most common conditions among people with dementia who completed an aged care assessment were:

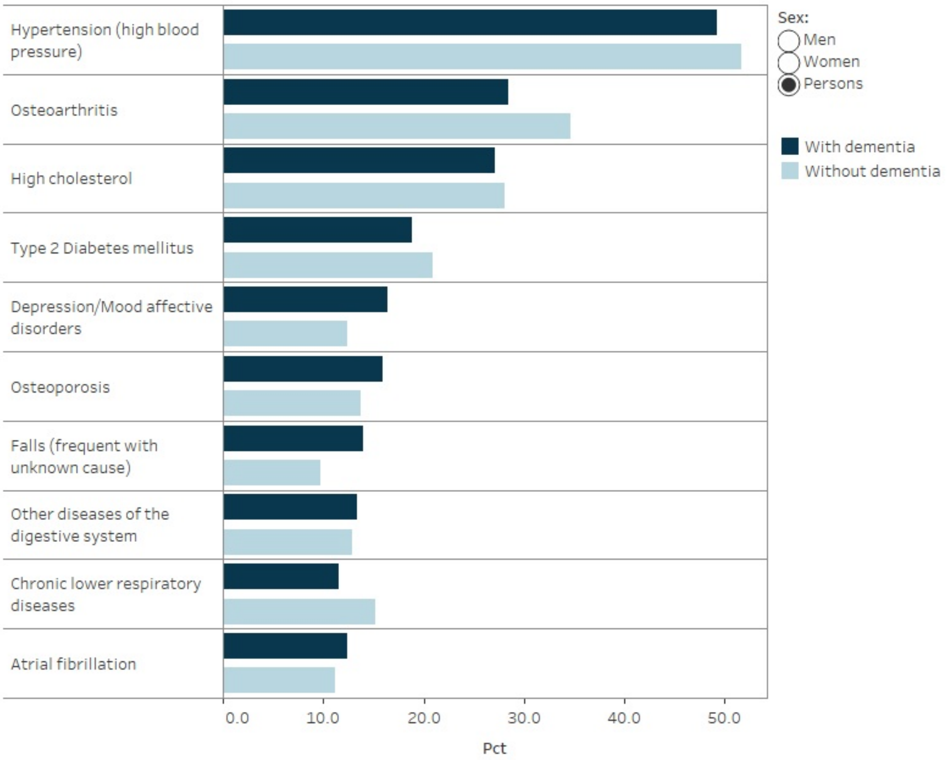
- high blood pressure (49% of all people with dementia)
- osteoarthritis (29%)
- high cholesterol (27%).

The 10 most common conditions for those with dementia were also frequently reported by people without dementia. The three most common conditions listed above, were recorded more frequently for those without dementia (52%, 35% and 28% respectively).

A number of cardiovascular conditions, such as heart disease and atrial fibrillation were among the 10 most common conditions recorded for men with dementia but not for women with dementia. In contrast, osteoporosis, anxiety, and thyroid-related disorders were reported among the leading 10 conditions for women but not men with dementia. Similar differences by sex were also observed among people without dementia.

Figure 10.5: Leading 10 health conditions impacting care needs of people who completed an aged care assessment in 2021–22: percent by dementia status and sex

Figure 10.5 is a bar graph showing the 10 most common health conditions impacting the care needs of people who completed an aged care assessment in 2021–22: the percentage for people with and without dementia by sex. Hypertension (high blood pressure) was the most common condition, affecting around half of men and women, both with and without dementia. Other common conditions were osteoarthritis and high cholesterol.



Notes
1. 'Other diseases of the digestive system' includes diseases of oral cavity, salivary glands and jaws, oesphagitis, gastitis and duodenitis, cholecystitis, other diseases of gallbladder, pancreatitis, coeliac disease and reflux.
2. 'Chronic lower respiratory diseases' includes emphysema, chronic obstructive airways disease, chronic obstructive pulmonary disease and asthma.
Source: AIHW analysis of the National Aged Care Data Clearinghouse
http://www.aihw.gov.au

The most common conditions shown in Figure 10.5 are similar to those reported by people with dementia in the ABS Survey of Disability, Ageing and Carers (SDAC) 2018. However, aged care assessment data and the SDAC capture different populations; in particular, the SDAC provides useful comparisons between people with dementia living in the community and those in cared accommodation (such as residential aged care), even if they did not undertake an aged care assessment. See How do care needs of people with dementia differ by place of residence? for more information on findings from the SDAC.

Geographic variations

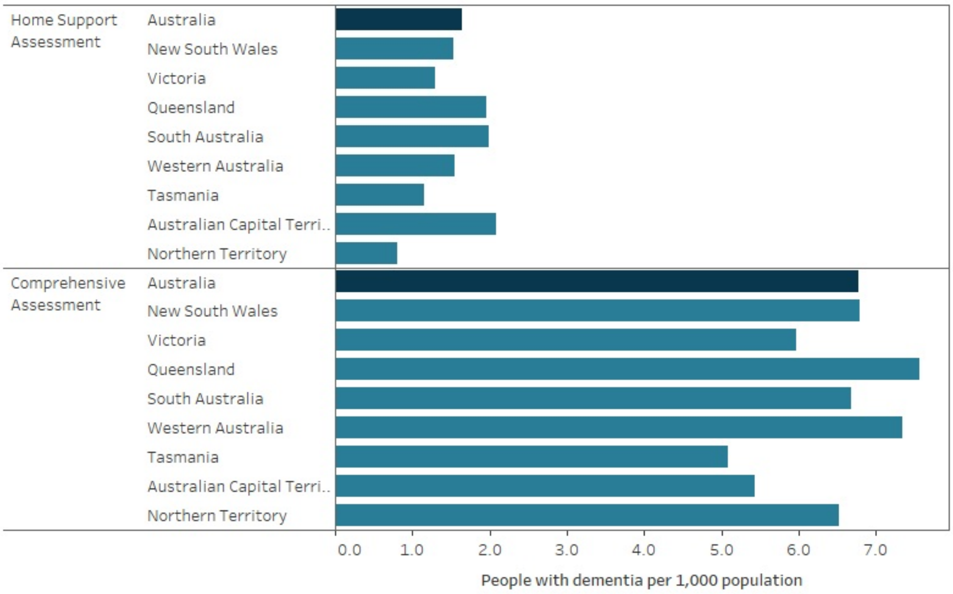
To assess variation in aged care assessments completed for people with dementia by state and territory, age-standardised rates were calculated for people aged 65 and over by the type of assessment they received. Age-standardised rates are used to account for population differences due to age. Crude rates for states and territories are available in Table S10.11.

The rate of older Australians (those aged 65 and over) who had dementia and completed an aged care assessment in 2021–22 varied by state and territory (Figure 10.6). For home support assessments, age-standardised rates were highest in the Australian Capital Territory (2.1 per 1,000 people) and lowest in the Northern Territory (0.8 per 1,000 people). For comprehensive assessments, rates were highest in Queensland (7.6 per 1,000 people) and lowest in Tasmania (5.1 per 1,000 people).

These variations may reflect differences in both the demand and utility of aged care services, as well as availability of other care and support for people with dementia across state and territories.

Figure 10.6: People with dementia who completed an aged care assessment in 2021–22: age-standardised rate by assessment type and state/ territory

Figure 10.6 is a bar graph showing age-standardised rates of people with dementia who completed an aged care assessment in 2021–22, by state or territory of residence. For every 1,000 people aged 65 and over living in Australia, 1.6 people with dementia completed a home support assessment. Home support assessment rates were highest in the ACT and lowest in the Northern Territory. For every 1,000 people aged 65 and over living in Australia, 6.8 people with dementia completed a comprehensive assessment. Comprehensive assessment rates were highest in Queensland and lowest in Tasmania.



Notes:
1. State and territory is based on the place of residence of the person with dementia at the time of their assessment.
2. The age-standardised rates, which apply to people aged 65 and over, were standardised to the Australian population as at 30 June 2001 and are expressed per 1,000 population.
Source: AIHW analysis of the National Aged Care Data Clearinghouse.
http://www.aihw.gov.au

Approvals for use of aged care services

Assessors recommend and approve people for entry into a range of aged care services based on a person's long-term care needs. Approvals are not only provided for immediate use of services but also for future use if a person's care needs are likely to change. This means that people can be approved for multiple services.

In 2021–22, the majority of people with dementia who completed a comprehensive assessment were approved for:

- residential respite care (72% of people with dementia who completed a comprehensive assessment, or 21,600 people)
- permanent residential aged care (66% or 19,900 people)
- community-based care under the Home Care Packages Program (63% or 19,000 people).

This highlights the current and anticipated need for a range of aged care services, particularly as a person's dementia progresses.

Information on the aged care service approvals for people with dementia who completed a home support assessment was not available in the NSAF data.

References

Department of Health and Aged Care (2023) *NSAF User Guide*, Department of Health and Aged Care, Australian Government, accessed 15 June 2023.

Aged care and support services used by people with dementia

Home based aged care services are a vital resource for supporting older Australians to remain living in their own home for as long as possible. Many older people express a desire to continue to live in a familiar setting in the community, with the Royal Commission into Aged Care Quality and Safety reporting that 80% of older Australians want to remain living in their current home and 62% want to receive community-based aged care services (Royal Commission 2020).

There are two types of community-based aged care services available:

- Commonwealth Home Support Programme (CHSP) – provides entry level care for people who require a low level of support to remain living independently
- Home Care Packages (HCP) program – provides community-based care to people with greater or more complex care needs.

More information on these services is available at: My Aged Care and information on the use of these services at: GEN Aged Care data.

Health conditions (such as dementia) are recorded in aged care assessments undertaken for people seeking access to aged care services, but they are not recorded directly for people using these services. However, there is some information on home care provided to people with dementia who receive the Dementia and Cognition Supplement. This supplement is available to people with moderate or severe cognitive impairment to acknowledge the additional costs of caring for this group. However, there are a number of factors to consider when using this information to describe the use of community-based aged care services by people with dementia (see Box 10.2).

As at 30 June 2022, over 17,200 people were receiving the Dementia and Cognition Supplement as part of their Home Care Package (10,900 women and 6,400 men). Around 80% of both men and women who were receiving the Dementia and Cognition Supplement were receiving high levels of care (Home Care Package Level 3 designed for those with intermediate care needs and Home Care Package Level 4 for those with high care needs) (Table S10.25).

Box 10.2: Home Care Dementia and Cognition Supplement

The Home Care Dementia and Cognition Supplement was introduced in 2013 to provide additional funding for people with moderate or severe cognitive impairment to acknowledge the additional costs associated with caring for this group. To receive the Dementia and Cognition Supplement, a person must meet specified criteria as part of a psychogeriatric assessment performed by a medical professional trained in the particular cognitive assessment tool.

It is acknowledged that this will not identify all people with dementia receiving Home Care services, for a number of reasons:

- A dementia diagnosis alone does not mean that a Home Care recipient is eligible for receipt of the supplement. People with lower levels of cognitive impairment do not attract the supplement and thus, people with less severe dementia may not be eligible for the supplement.
- Home Care recipients who are eligible for the Veterans' Supplement are not also paid the Dementia and Cognition Supplement.
- People with cognitive impairment associated with conditions other than dementia may also be found eligible for the supplement.

Therefore, the number of people using Home Care Packages who receive the Dementia and Cognition Supplement may not accurately describe the provision and need for community-based aged care services for people with dementia.

Respite care

Respite care is especially important for people caring for someone with dementia, where the demands of the caring role may involve providing substantial amounts of physical, psychological, cognitive and social support, while behaviour changes may add to the complexity of caring.

The Australian Government subsidises community-based and residential respite with the aim of providing a person and their carer with a break from their usual care arrangements, or during emergencies. However, due to a lack of national data, this page does not present any national statistics on the use of respite services by people with dementia.

Aged care assessments data records whether the person being assessed has received any respite services (informal, community or residential respite) in the past 12 months, but this information is not currently available for analysis in the first supply of the NSAF data. Although respite stays are usually short, many people also access respite care provided in residential aged care facilities. People who use residential respite care are not appraised using the Aged Care Funding Instrument (ACFI; see Box 10.3 in Residential aged care), so their dementia status cannot be determined using the currently available data, unless they go on to use permanent residential care and have an ACFI assessment.

For information on expenditure on respite care for people with dementia in 2018–19, see Expenditure on aged care services. Due to the lack of data on the use of respite care by people with dementia, expenditure was estimated using the proportion of approvals for respite care for people not currently living in residential care and were associated with a dementia diagnosis from the NSAF data.

Almost 1 in 4 (23%) primary carers of people with dementia in 2018 reported they needed more respite care. This was higher than what was reported by primary carers of people without dementia (13%). Refer to Carers unmet needs for more information.

References

(Royal Commission (Royal Commission into Aged Care Quality and Safety) (2020) *Research Paper 4: What Australians Think of Ageing and Aged Care*, Royal Commission, Australian Government, accessed 26 June 2023.

Aged care and support services used by people with dementia

Aged care services provided in residential aged care facilities are an important resource for older Australians, including those with dementia. Residential aged care services are particularly important for those in the advanced stages of dementia who need ongoing care, as well as accessible accommodation. People with dementia living in residential aged care have specific care needs that differ to the care needs of others living in residential aged care, such as wandering behaviours, cognition issues and difficulties in undertaking daily activities such as toileting, eating meals, and mobility.

This page uses Aged Care Funding Instrument (ACFI) data to present information on people with dementia who were living in permanent residential aged care in 2021–22, by:

- age and sex, and how age and sex patterns compare to people without dementia living in permanent residential aged care
- state/territory, remoteness and socioeconomic areas
- common co-existing conditions which also impact their care needs
- assistance needs
- time spent in care.

This page also presents how the number and age-standardised rate of people with dementia and people without dementia living in permanent residential aged care has changed between 2017–18 and 2021–22 (skip to this section).

A snapshot of people in permanent residential care on 30 June 2020 showed that ACFI data captures almost all people in permanent residential aged care (over 97% had a current ACFI appraisal) (AIHW 2020a). See Box 10.3 for more information on the ACFI.

Over half of people living in permanent residential aged care have dementia

In 2021–22 there were almost 242,000 people living in permanent residential aged care, and 54% of these people had dementia (about 131,000 people). In 2021–22, of those living in permanent residential aged care:

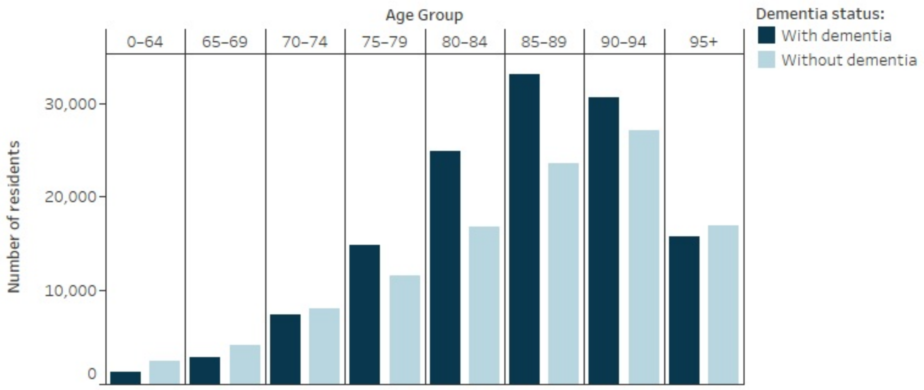
- over half of both women (54% or nearly 84,400) and men (54% or over 46,400) had dementia
- men tended to be younger than women, irrespective of whether or not they had dementia
- both men and women with dementia were similarly aged (84 and 87 on average, respectively) than those without dementia (average of 83 and 87 years)
- 1 in 3 people aged under 65 (35% or 1,300 people) had dementia (known as younger-onset dementia when aged under 65) (Figure 10.7).

The Royal Commission into Aged Care Quality and Safety in its final report made a high priority recommendation that all people under the age of 65 currently living in residential aged care facilities should be moved out of residential aged care and into other, more appropriate care types (Royal Commission, 2021). Through the *Younger People in Residential Aged Care Strategy 2020–25*, the Australian Government has committed to ensure that apart from exceptional circumstances, no person under the age of 65 lives in residential aged care. See Younger people in residential aged care for the most recent data available to track progress being made towards these targets.

Figure 10.7: People with and without dementia living in permanent residential care in 2021–22: number by age and sex

A bar graph showing the number of people by age, whether or not they had dementia and a drop-down option to change between sexes. For all sexes, with dementia the numbers increase gradually peaking at the age group of 85 to 89, decreasing slightly at age group 90 to 94 and then dropping off. For all sexes those without dementia follows a similar pattern, though less overall and, peaks at age group 90 to 94.

Sex:
Persons



Source: AIHW analysis of the National Aged Care Data Clearinghouse.
http://www.aihw.gov.au

Box 10.3: Residential aged care services and the Aged Care Funding Instrument

Residential aged care is primarily available to older Australians who can no longer live independently in the community, and includes accommodation in a 24-hour staffed facility along with health and nursing services (Department of Health 2020). For approved applicants, places in residential aged care facilities are subsidised by the Australian government, and the **Aged Care Funding Instrument (ACFI)** was used to allocate government funding to aged care providers based on the day-to-day needs of the people in their care up until the 30th of September 2022. From October 2022 onwards, the Australian National Aged Care Classification funding model (AN-ACC) will be used to determine the amount of funding that aged care providers receive.

The ACFI data did not capture people with dementia who accessed care through some specialised government programs. These include the Multi-Purpose Services Program, which provides integrated health and aged care services to regional and remote communities in areas that can't support both a separate aged care home and hospital, and the National Aboriginal and Torres Strait Islander Flexible Aged Care Program, which provides culturally appropriate aged care to older Aboriginal and Torres Strait Islander people, mainly in rural and remote areas.

Although the ACFI was a funding instrument and not a diagnosis or comprehensive service tool, it did provide information on assessed care needs of people in permanent residential aged care at the time of their appraisal; in some instances, not all services received were captured in the ACFI assessment. An ACFI reappraisal could be conducted for various reasons, such as when a person had a significant change in care needs or after 12 months from when their classification had taken effect. Therefore, the ACFI data provided information about people in permanent residential aged care and how their care needs changed over time.

As the care needs and health conditions reported in the ACFI were reported by providers for funding purposes, it is important to remember the ACFI was not a thorough diagnostic or comprehensive service tool, nor is the data collection independent and free from potential conflicts of interest. Furthermore, the ACFI form only allowed for up to 3 medical and 3 mental or behavioural conditions to be recorded, so it did not often provide a comprehensive list of a person's health conditions.

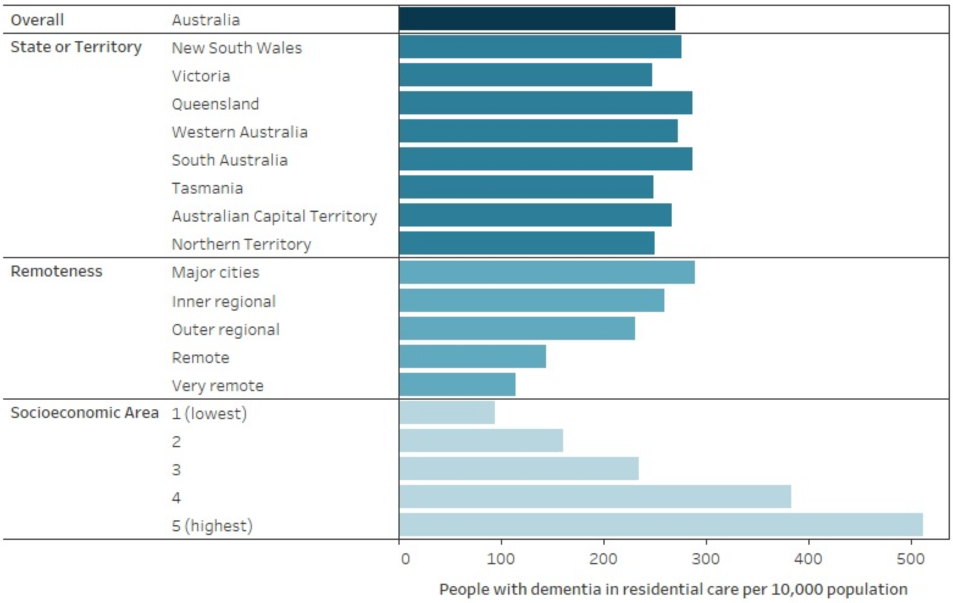
The proportion of people with dementia living in residential aged care varies across geographic and population groups

Figure 10.8 shows the rate of people living in permanent residential aged care with dementia in 2021–22, in Australia and by state and territory, remoteness area and socioeconomic area. Rates refer to the number of people with dementia living in permanent residential aged care as a proportion of the target population – that is, those aged 65 and over, in each area of interest. All rates have been age-standardised to adjust for population differences:

- In Australia the rate of people with dementia living in permanent residential aged care was 271 per 10,000 people.
- Across states and territories, there were slight variations in the proportion of people with dementia living in permanent residential aged care, ranging from 248 people per 10,000 people in Victoria to 287 people per 10,000 people in Queensland and South Australia.
- The rate of people with dementia living in permanent residential aged care increased as areas became less remote, from 115 per 10,000 people in *Very Remote* areas to 289 per 10,000 people in *Major Cities*.
- Rates of people with dementia living in permanent residential aged care fell as socioeconomic disadvantage decreased – ranging from 94 per 10,000 people in the lowest quintile to 512 per 10,000 people in the highest quintile.

Figure 10.8: People with dementia who were living in permanent residential aged care in 2021-22; age-standardised rate by state/territory, remoteness and socioeconomic area

A panel of bar graphs showing the age-standardised rates of people with dementia by state or territory, remoteness and socioeconomic areas. Between the states and territories, the bars are all similar. Remoteness categories the rate is highest in Major cities and decreases in each category with the lowest rate in very remote locations. Socioeconomic area rates increase from 1 (lowest) to 5 (highest).



Note: The age-standardised rates, which apply to people aged 65 and over, were standardised to the target population (the relevant geographic or socioeconomic area) as at 30 June 2001 and are expressed per 10,000 population.
Source: AIHW analysis of the National Aged Care Data Clearinghouse.
http://www.aihw.gov.au

The provision of aged care varies substantially in more remote areas; other government-subsidised aged care programs not captured in the ACFI, such as the Multi-Purpose Services Program and the National Aboriginal and Torres Strait Islander Flexible Aged Care Program, account for a substantial part of aged care provision in more remote areas. For example, Multi-Purpose Service facilities have been established in small remote communities where previously, community hospitals provided de facto residential aged care.

Depression and arthritis are common health conditions among people with dementia

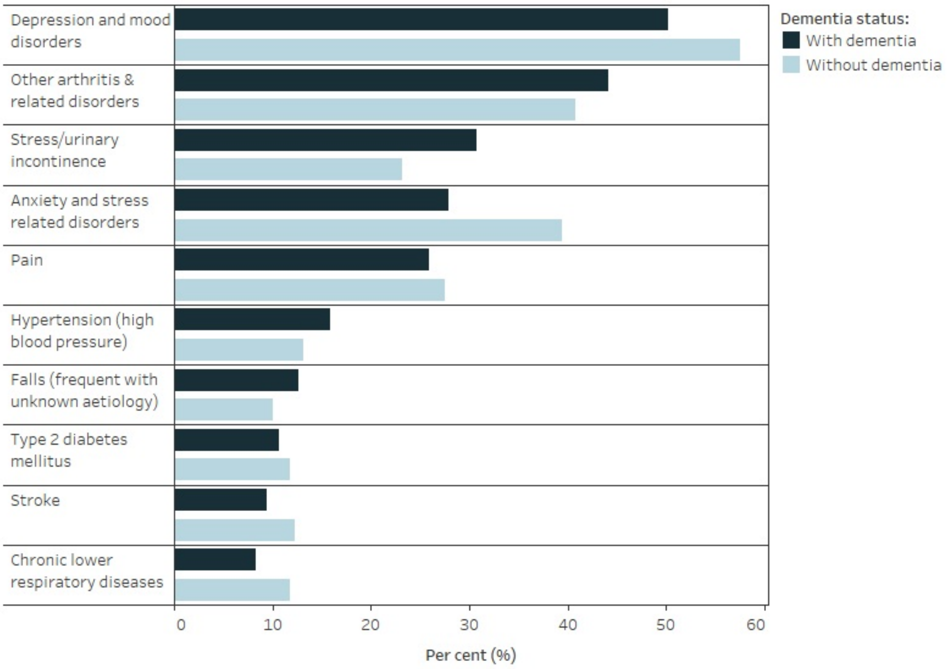
Depression and mood disorders (50%) and a range of arthritic disorders (44%) were the most common health conditions recorded on the ACFI among people with dementia living in permanent residential aged care (Figure 10.9).

Other conditions commonly recorded for people with dementia living in permanent residential aged care were: urinary incontinence (31%), anxiety and stress related disorders (28%), pain (26%), and hypertension (16%).

Compared to those without dementia, people with dementia were more likely to have arthritic disorders (44% compared with 41%), urinary incontinence (31% compared with 23%), hypertension (16% compared with 13%) and frequent falls with unknown aetiology (13% compared with 10%) recorded. Note that the ACFI allows aged care providers to record up to 3 medical conditions and 3 mental or behavioural conditions which impact the residents care needs. Therefore, health condition information from the ACFI will not accurately reflect all co-existing conditions among people living in permanent residential aged care. See Box 10.4 for more information on how health conditions are recorded in the ACFI.

Figure 10.9: Leading 10 health conditions of people with dementia living in permanent residential aged care in 2021-22: percent by dementia status

A bar graph showing the ten most common health conditions of people with and without dementia living in residential aged care.



Notes
1. The category 'Urinary incontinence' is made up of two possible recorded conditions: 'Stress/urinary incontinence' and 'Unspecified urinary incontinence'.
2. The category 'Other arthritis & related disorders' includes gout, arthrosis, osteoarthritis.
3. People may have more than one condition so the percentages will not add to 100%.
Source: AIHW analysis of the National Aged Care Data Clearinghouse.
http://www.aihw.gov.au

Assistance needs of people with dementia living in residential aged care

As the ACFI is used to allocate funding, it captures the day-to-day care needs that contribute the most to the cost of providing individual care. Care needs are categorised as 'nil', 'low', 'medium', or 'high' based on responses to 12 questions across 3 domains: *Activities of daily living*, *Cognition and behaviour*, and *Complex health care*. People with high care ratings in a domain have more severe needs and require extensive assistance and care in that domain, whereas those with a low care rating have less severe needs. See Box 10.4 for further information on how care needs are assessed for funding purposes using the ACFI tool.

In 2021–22, over half of people in permanent residential aged care with dementia were assessed as needing high levels of care in all ACFI domains. In 2 of the 3 ACFI domains, people with dementia tended to have higher care needs than those without dementia (Figure 10.10):

- over 4 in 5 people with dementia (84%) required high levels of care in the *Cognition and behaviour* domain (including cognitive skills, wandering, verbal behaviour, physical behaviour and depression) compared to 52% of people without dementia
- over 3 in 4 people with dementia (76%) required high levels of care in the *Activities of daily living* domain (including mobility, continence and nutrition), compared to 70% of people without dementia
- over 3 in 5 people with dementia (61%) needed high levels of care in the *Complex health care* domain (including management of chronic pain, chronic infectious conditions, ongoing tube feeding and oxygen therapy), slightly less than people without dementia (64%).

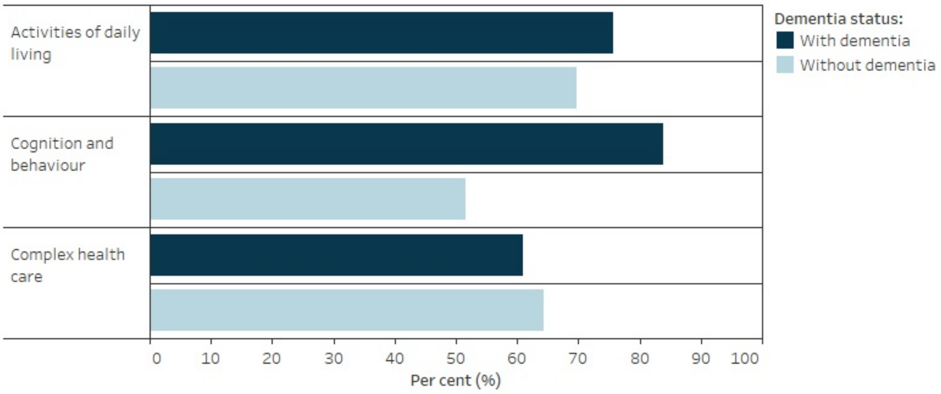
The ACFI also captures cognitive assessment information using the psychogeriatric assessment scale – cognitive impairment scale (PAS – CIS). There are four levels that rank a person's assessed usual cognitive skills: A (no or minimal impairment), B (mild impairment), C (moderate impairment) and D (severe impairment).

In 2021–22, there were an additional 98,700 people without dementia in residential aged care who were deemed to have mild, moderate or severe cognitive impairment, equivalent to 41% of all people living in residential aged care. There could be several reasons for this, including that diagnosed dementia merely wasn't captured in the ACFI as one of the three health conditions most impacting care. However, it may also indicate that there are more people in residential age care in the early stages of dementia who are yet to receive a formal diagnosis.

Overall, 47% of people with dementia living in residential aged care were considered to have severe cognitive impairment, compared to only 8.8% of people without dementia (61,800 and 9,750 people respectively). Additionally, only 10% of people with dementia had no/minimal or mild cognitive impairment, compared with 54% of people without dementia (13,500 and 60,100 people with and without dementia, respectively).

Figure 10.10: People living in permanent residential aged care in 2021–22: percent with the highest care needs in each ACFI domain by dementia status

A bar graph showing the percentage of people with and without dementia who needed help in three ACFI domains: activities of daily living, cognition and behaviour and complex health care.



Notes
1. The *Activities of daily living* domain includes needs related to mobility, continence and nutrition.
2. The *Cognition and behaviour* domain includes needs related to cognitive skills, wandering, verbal behaviour, physical behaviour and depression.
3. The *Complex health care* domain includes care needs related to management of chronic pain, chronic infectious conditions, ongoing tube feeding and oxygen therapy.
Source: AIHW analysis of the National Aged Care Data Clearinghouse.
http://www.aihw.gov.au

Box 10.4: How are care needs assessed using the Aged Care Funding Instrument?

The ACFI is a resource allocation tool designed to determine the amount of funding required for the ongoing care needs of people living in residential aged care facilities. The ACFI appraisal is centred on assessing an individual's care needs and consists of 12 care needs based questions, categorised into 3 domains:

- **Activities of Daily Living:** includes questions regarding nutrition, mobility, personal hygiene, toileting and continence
- **Cognition and Behaviour:** includes questions regarding cognitive skills, wandering, verbal behaviour, physical behaviour and depression
- **Complex Health Care**: includes questions regarding medication and complex health care procedures (such as daily blood glucose measurement, management of chronic infectious conditions, oxygen therapy or ongoing tube feeding and palliative care where ongoing care will involve intensive clinical care and/or complex pain management).

Ratings for each domain are used to determine the level of funding required and to assign care. Supporting documentation against each of the ratings, as well as documentation on up to 3 behavioural conditions and up to 3 medical conditions impacting care are also used to determine the funding required.

Low levels of care focus on personal care and support services and some allied health services such as physiotherapy. **High levels of care** are for those who need almost complete assistance with all tasks. This includes providing 24-hour care, either by or under the supervision of registered nurses, combined with support services, personal care services, and allied health services.

How do the assessed needs of people with dementia living in residential aged care differ by age?

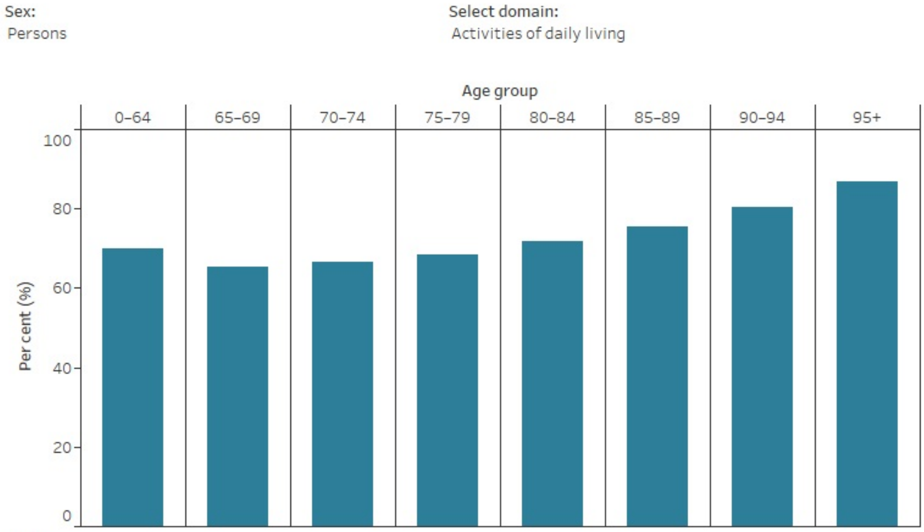
Figure 10.11 shows the proportion of people with dementia in residential aged care who were assessed as having the highest care needs in each of the ACFI domains, by different age groups and sex. For the:

- *Activities of daily living* domain – the proportion of people requiring high levels of care was greatest among older people with dementia. Proportions were similar by sex, with the exception of the younger age groups, where a higher proportion of women tended to require high levels of care.
- *Cognition and behaviour* domain – the proportion of people with dementia requiring high levels of care was greatest among people with younger-onset dementia, for both men and women. 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, such as frontotemporal dementia, alcohol-related dementia, and dementia with Lewy bodies (Sansoni et al. 2016; Jefferies & Agrawal 2009). Alternatively, this may reflect that younger people are more mobile and have less medical co-morbidities, and so providers may place more emphasis on cognitive needs when completing the ACFI form.
- *Complex health care* domain – the proportion of people requiring high levels of care increased steadily with age for both men and women.

Refer to Overview of dementia support services and initiatives for information on behavioural supports services for people with dementia.

Figure 10.11: People with dementia living in permanent residential aged care in 2021–22: percent with the highest care needs in each ACFI domain by sex and age

A bar graph showing the percentage of people with dementia living who were assessed as having the highest care needs in each of the three ACFI domains, by age group and sex. For all sexes the percentage of residents requiring a high level of care in activities of daily living and complex health care increases with increasing age. Percentage of residents with high level of care in cognition and behaviour decreases slightly with age, though mostly remains stable at 84%.



Notes
1. The *Activities of daily living* domain includes needs related to mobility, continence and nutrition.
2. The *Cognition and behaviour* domain includes needs related to cognitive skills, wandering, verbal behaviour, physical behaviour and depression.
3. The *Complex health care* domain includes care needs related to management of chronic pain, chronic infectious conditions, ongoing tube feeding and oxygen therapy.
Source: AIHW analysis of the National Aged Care Data Clearinghouse.
http://www.aihw.gov.au

How do the assessed care needs vary by geographic and population areas?

The assessed needs of people with dementia living in permanent residential aged care in 2021–22 varied by geographic and population groups (refer to Table S10.19):

- across all 3 ACFI domains, the largest variations were seen by remoteness area with the proportion of people with dementia requiring high levels of care decreasing with increasing remoteness
- Victoria had the highest proportion of people with dementia who required high levels of care in the *Activities of daily living* domain, whilst the Northern Territory had the highest proportion of people with dementia who required high levels of care in the *Cognition and behaviour* domain, and Victoria and South Australia had the highest proportion of people with dementia who required high levels of care in the *Complex health care* domain
- the Australian Capital Territory had the lowest proportion of people with dementia who required high levels of care in the *Activities of daily living* domain, South Australia had the lowest proportion of people with dementia who required high levels of care in the *Cognition and behaviour* domain, and Western Australia had the lowest proportion of people with dementia who required high levels of care in the *Complex health care* domain
- the proportion of people with dementia who required high levels of care were slightly lower for those in more disadvantaged areas, across all domains.

Note, these data should be interpreted with caution due to the smaller number of people living in permanent residential aged care in more remote areas, and because other government subsidised residential services are more commonly available in remote areas (like the Multi-Purpose Services Program and the National Aboriginal and Torres Strait Islander Flexible Aged Care Program) but are not captured in the ACFI data. Differences by remoteness area could also be due to some remote areas not having the facilities and resources to care for people with higher care needs. As a result, some people with dementia may be required to move to less remote locations to access appropriate care.

Case study: Chronic pain management and palliative care for people with dementia living in permanent residential aged care

The Royal Commission into Aged Care Quality and Safety (the 'Royal Commission') has exposed systemic issues related to inappropriate and substandard care in Australia's residential aged care setting and the negative impact this has on the mental and physical wellbeing of people in care. The Royal Commission has also documented the increasingly complex care needs of people living in residential aged care and that unmet needs (like untreated pain) are related to changed behaviours for people with dementia (Royal Commission 2019).

In this context, the needs for pain management and palliative care for people with dementia as recorded in the ACFI, is an important component of the services provided in residential care. As part of the *Complex health care* domain, the ACFI records information on ongoing pain management and palliative care services provided.

In 2021–22, among people with dementia living in permanent residential aged care, 83% required complex pain management at least weekly, and 57% required at least 4 long (80 minutes or longer) pain management sessions every week.

The ACFI also records whether a person is assessed as needing a palliative care program (involving end-of-life care) where ongoing care requires intensive clinical nursing and/ or complex pain management in the residential care setting. A small number of people with dementia in care in 2021–22 were assessed as needing palliative care (about 2,300 or 1.8%) at the time their ACFI appraisal was completed, which was slightly less than for the proportion of people without dementia (about 2,500 or 2.3%). These percentages likely underestimate the proportion of people needing palliative care as they only capture people assessed as needing palliative care at the time the ACFI assessment was conducted. In addition, because some people may receive end of life care in other settings such as hospitals, these care needs are not captured in ACFI data.

How long are people with dementia living in residential care?

When a person enters residential aged care, and how long they remain in care, is impacted by various factors like: a person's preferred living arrangements, wait times for residential places from point of assessed eligibility, the complexity of care needs and existing comorbidities, the availability of informal carer and alternative care settings; and the quality of care provided in residential care. The Government has been placing a strong focus on giving older Australians the support they need to remain living in the community as long as possible, and recent research shows the timely availability of high-level home care packages plays a big role in whether people with dementia can delay entry to residential care (Welberry et al. 2020).

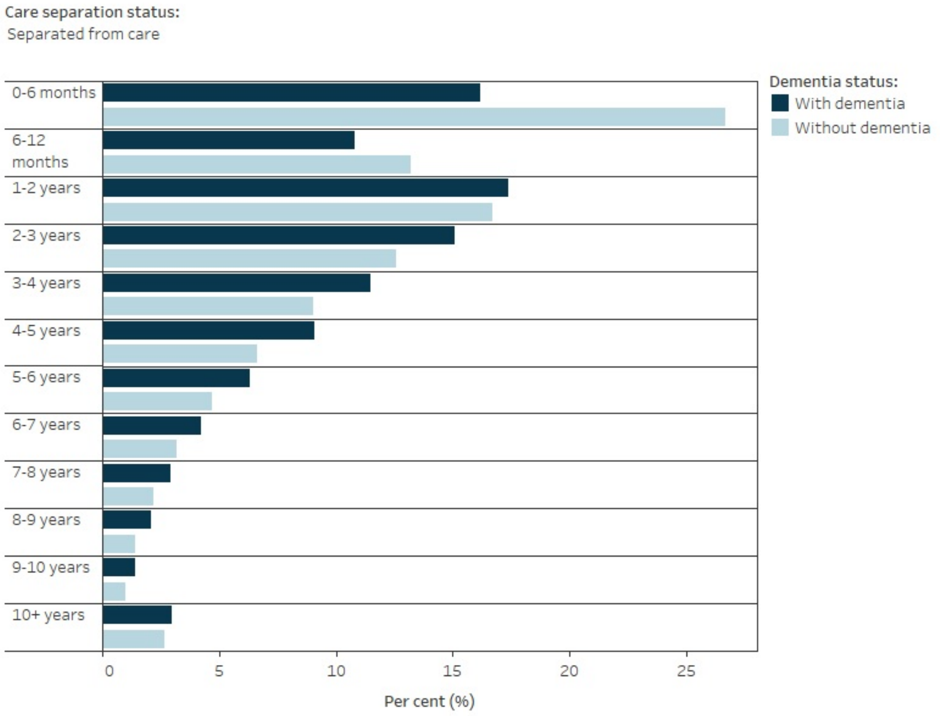
A person can have more than one 'episode of care' in a residential aged care facility in a given year if, for example, they moved from one facility to another. A separation from an 'episode of care' is most commonly due to: death, prolonged admission to hospital, movement to another residential aged care facility, or returning to the community. Of people with dementia who were receiving care in 2021–22, 1 in 3 people had separated from their latest episode of care that year. Most of these separations were due to death (96% of people with dementia and 93% of people without dementia who separated from their latest episode of care in 2021–22) (Table S10.22).

For people living in permanent residential aged care who did not separate from their latest episode of care during 2021–22, those with and without dementia had spent roughly the same length of time in care (median stay of 2.2 and 2.0 years, respectively). In contrast, for people who separated from their latest episode of care, there were larger differences by dementia status – people with dementia had spent a median of 2.3 years in care compared to 1.5 years for those without dementia (Figure 10.12).

These results may suggest that people without dementia may enter care closer to death as they may be able to live longer in the community, or perhaps that people with dementia separate to use other services less frequently (and may be more likely to die in residential aged care). Recent studies have found that towards the end of life, people with dementia tend to use hospital care at lower levels compared to people without dementia, and that dementia is a common cause of death for people who died in permanent residential aged care (AIHW 2020b; Dobson et al. 2020; AIHW 2021).

Figure 10.12: Time spent in care for people living in permanent residential aged care in 2021–22: percent by dementia status and whether the person separated from care or remained in care

A bar graph showing how long people with and without dementia had spent in permanent residential aged care, by whether they separated from care or not. Those that did separate from care, and those that did not separate had a similar pattern of length of stay.



Note: An episode of care is defined as a continuous service provided under the same program and care type for an individual. This figure is only referring to an individual's latest episode of care.
Source: AIHW analysis of the National Aged Care Data Clearinghouse.
http://www.aihw.gov.au

Trends in the use of residential care

The number of people living in permanent residential aged care was steadily increasing between 2017 and 2020 (from 241,000 people in 2017–18 to 244,000 people in 2019–20). Since then, there has been a small but steady decline in the number of people living in permanent residential aged care.

The Australian Government manages the supply of aged care places, aiming to increase the number of places available in government subsidised permanent residential care relative to the growth of Australia's older population (AIHW 2021). The number of men and women in permanent residential aged care between 2017–18 and 2021–22 differed slightly by dementia status – the number increased by 2.2% for men with dementia but decreased by 1.7% for men without dementia. For women, the number decreased by 2.3% and 2.7% for those with and without dementia, respectively. The proportion of people with dementia remained relatively stable at around 54–55%. The proportion of people in permanent residential aged care with dementia remained relatively stable between 2017–18 and 2021–22 at around 54–55%. (see Table S10.24).

Between 2017–18 and 2021–22 the crude and age-standardised rate of people living in permanent residential aged care aged 65 and over decreased overall, irrespective of if they had dementia or not, but the decrease was slightly greater among those with dementia. This might be linked to the preference of many older people to remain living in the community as long as possible, and correspondingly, an increased government focus on supporting alternatives to residential aged care (Royal Commission 2020).

References

AIHW (Australian Institute of Health and Welfare) (2020a) *People using aged care*, AIHW, Australian Government, accessed 8 July 2021.

AIHW (2020b) *Patterns of health service use by people with dementia in their last year of life: New South Wales and Victoria*, AIHW, Australian Government, accessed 26 June 2023.

AIHW (2021) *Providers, services and places in aged care*, AIHW, Australian Government, accessed 8 May 2021.

Department of Health and Aged Care (2023) *COVID-19 outbreaks in Australian residential aged care facilities – 14 April 2023*, Department of Health and Aged Care, Australian Government, accessed 17 June 2023.

Dobson AJ, Waller MJ, Hockey R, Dolja-Gore X, Forder PM and Byles JE (2020) 'Impact of Dementia on Health Service Use in the Last 2 Years of Life for Women with Other Chronic Conditions', *Journal of the American Medical Directors Association*, 21(11):1651-1657, doi:10.1016/j.jamda.2020.02.018.

Royal Commission (Royal Commission into Aged Care Quality and Safety) (2021) *Final report: Care, dignity and respect*, Royal Commission, Australian Government, accessed 26 June 2023.

Royal Commission (2020) *Research Paper 4: What Australians Think of Ageing and Aged Care*, Royal Commission, Australian Government, accessed 10 October 2020.

Welberry HJ, Brodaty H, Hsu B, Barbieri S and Jorm LR (2020) 'Impact of Prior Home Care on Length of Stay in Residential Care for Australians with Dementia', *Journal of the American Medical Directors Association*, 21(6):843-850, doi:10.1016/j.jamda.2019.11.023.

Aged care and support services used by people with dementia

While many people with dementia are able to live independently and rely on family and friends for assistance, there are a range of dementia-specific services available for those in need of support, as well as for their carers, friends and family. Support services and initiatives for dementia in Australia are provided by the Australian Government, state governments and non-governmental organisations. Services vary in scope and aim, and can address a range of challenges faced by people with dementia, and their friends, families and carers. Unless otherwise specified, data and program information on this page is sourced directly through personal correspondence with Dementia Australia and Dementia Support Australia.

For the underlying data presented in these pages refer to the Dementia support services data tables.

What dementia-specific support services are available?

The Australian Government provides funding for multiple dementia-related services and initiatives, which aim to improve awareness and understanding of dementia and support people experiencing changed behaviours due to their dementia, and support care-givers. These include:

- National Dementia Support Program – an Australian Government initiative delivered by Dementia Australia. The National Dementia Support Program provides information, education programs, services and resources that aim to improve awareness and understanding about dementia and empower people living with dementia and their carers and families to make informed decisions about the support services they access.
- Improving respite care for people with dementia and their carers Program – delivered by a range of organisations, the program will provide respite care that focuses on carer education and wellbeing, planning for future respite stays, and capability development for aged care providers to deliver quality dementia respite care and services.
- Dementia-Friendly Communities – a program delivered by Dementia Australia that builds understanding, awareness and acceptance of dementia in the community.
- Dementia Training Program – a national approach to accredited education, upskilling and professional development in dementia care delivered by Dementia Training Australia.
- Dementia Behaviour Management Advisory Service – helps staff and carers to support people living with dementia experiencing changes to their behaviour by providing assessment, clinical support, care planning, mentoring, linking to current research and a 24-hour help line, provided by Dementia Support Australia (DSA) (led by HammondCare).
- Severe Behaviour Response Teams – provide specialist clinical support and advice to organisations and aged care staff caring for people living with severe behaviours and psychological symptoms of dementia, provided by DSA (led by HammondCare).
- Specialist Dementia Care Program – funds specialist dementia care units in residential aged care homes for people with very severe behaviours and psychological symptoms of dementia to reduce or stabilise symptoms so that people can transition into less intensive care settings.

Need more information?

If you require more information about services and initiatives for people with dementia, their friends, family and carers refer to:

- Dementia Australia website
- The Dementia Guide by Dementia Australia
- National Dementia Helpline: 1800 100 500 (a free and confidential service to discuss dementia and memory loss concerns for yourself or others)
- Dementia Support Australia: 1800 699 799 (if needing help to manage behaviour associated with dementia)
- My Aged Care (for information on, and applying for access to, government-subsidised aged care services).

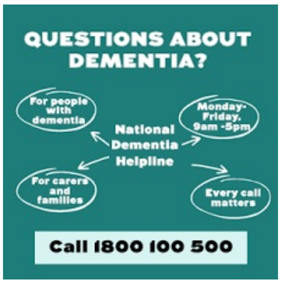
Aged care and support services used by people with dementia

National Dementia Support Program

Dementia Australia delivers a number of services and supports across Australia through the National Dementia Support Program (NDSP) including: education, information, counselling, and early-intervention support.

National Dementia Helpline

Dementia Australia provides support at every stage from pre-diagnosis onwards. This includes people with concerns about changes in memory and thinking. The first point of contact for most people engaging with Dementia Australia's NDSP-funded activities is the National Dementia Helpline (1800 100 500, via a helpline webchat or email).



The National Dementia Helpline operates 24 hours a day, seven days a week and is staffed by experienced professionals who provide support to people with dementia and their friends and family, carers of people with dementia, or anyone with concerns about changes to memory and cognitive function. The helpline provides education, counselling, early-intervention support and information about dementia and memory loss, risk reduction, government support services and emotional support to help manage the impact of dementia.

National Dementia Support Program services

Dementia Australia provides a number of other services and supports across Australia through the National Dementia Support Program, including:

- Post Diagnostic Support Program
- Living with Dementia program
- Memory Lane Cafes for people with dementia and their carer
- Peer Support Program offering one to one peer support
- Carer Support Groups
- Digital information kits
- Dementia expert webinars available on the Dementia Australia website
- Family carer education offered both in-person and online
- Brain Hubs (regional and remote outreach)
- Dementia Friendly In-home Design
- Outreach programs – CALD and First Nations partnerships.
- Younger Onset Dementia Hub

In 2022–23, there were just over 42,500 contacts to the National Dementia Helpline via phone, webchat and email. This accounted for nearly 50% of all contacts to the NDSP. Other contacts were via direct referrals.

Dementia Australia surveyed NDSP-funded program participants following their engagement with these services. After participating in an NDSP program in 2022–23:

- 95% of respondents reported an improvement in coping capacity among clients receiving **counselling/support**.
- 98% of respondents reported an improvement in coping capacity among clients receiving **early intervention**.
- 90% of respondents reported an improvement in coping capacity among clients receiving **education**.

Dementia-Friendly Communities

Another Australian Government-funded initiative undertaken by Dementia Australia is the Dementia-Friendly Communities program.

The aims of the Dementia-Friendly Communities program are to:

- increase understanding and public awareness of dementia across Australia
- increase training and opportunities for interested community members – to better foresee the signs and symptoms of dementia and effectively communicate with a person who has dementia

- improve levels of engagement with people living with dementia across the community
- enable communities to network and learn from other initiatives
- provide the latest evidence and information on best practice approaches to increasing community awareness
- better support people living with dementia.

See Box 11.1 for an example of a dementia-friendly community in Australia.

Between 2016 and 2019, Dementia Australia established the **National Dementia Friends Awareness Program** and developed the National Dementia-Friendly Communities Resource Hub to achieve the program's aims. The National Dementia Friends Awareness Program has now reached more than 20,000 people online and via face-to-face delivery formats in communities in every Australian state and territory. In addition, the program has engaged with 41 grant-funded projects through the Community Engagement Program (Dementia Australia 2021, pers. comm., 15 February). The resource hub also includes a list of businesses and organisations across Australia that are committed to supporting the needs for people with dementia to access their services.

Box 11.1: Dementia-friendly Kiama

A dementia-friendly community is a place where people living with dementia are supported to live a high quality of life with meaning, purpose and value (Dementia Australia 2021). This generally involves the formation of a dementia-friendly alliance in the community, and may also involve support from local businesses and organisations.

Located 120 kilometres out of Sydney, Kiama is a New South Wales township that was selected for a pilot project to create a dementia-friendly community. In 2015, the Kiama Dementia Action Plan was created by partners University of Wollongong, Dementia Australia (then Alzheimer's Australia), the Kiama Council and interested members of the community.

DEMENTIA FRIENDLY KIAMA
www.dementiais.com

This pilot project aimed to increase community awareness and understanding of dementia in Kiama; provide new opportunities for social participation and involvement in the community for people with dementia including volunteering, participation in clubs and groups; support organisations to become dementia-friendly and train staff to better communicate with people who have dementia; and improve the physical environment in the community, including improved signage (Dementia Illawarra Shoalhaven 2020).

Kiama has since adopted these aims with the support of their Local Dementia Alliance, and Dementia Advisory Group.

References

Dementia Australia (2021) *Dementia-friendly communities*, Dementia Australia, accessed 10 August 2021.

Dementia Illawarra Shoalhaven (2020) *Dementia Friendly Kiama*, Dementia Illawarra Shoalhaven, accessed 4 May 2020.

Aged care and support services used by people with dementia

The Dementia Behaviour Management Advisory Service (DBMAS), Severe Behaviour Response Teams (SBRT) and the Specialist Dementia Care Program (SDCP) form part of a three-tiered approach to behaviour support for people experiencing behaviours and psychological symptoms of dementia (BPSD). Each tier provides support for symptoms of increasing severity: DBMAS for mild to moderate symptoms; SBRT for more severe BPSD; and the SDCP transitional residential care for those with very severe BPSD.

Dementia Behaviour Management Advisory service (DBMAS)

Dementia Behaviour Management Advisory Service (DBMAS) is delivered by Dementia Support Australia. It is 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. DBMAS supports people with dementia and their carers living in community, residential care, and acute care settings.

Severe Behaviour Response Teams (SBRT)

The Severe Behaviour Response Teams (SBRT) are also delivered by Dementia Support Australia and 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. SBRT supports people with dementia and their carers residing in Commonwealth-funded residential aged care facilities, multi-purpose services, or flexibly funded services.

Specialist Dementia Care Program (SDCP)

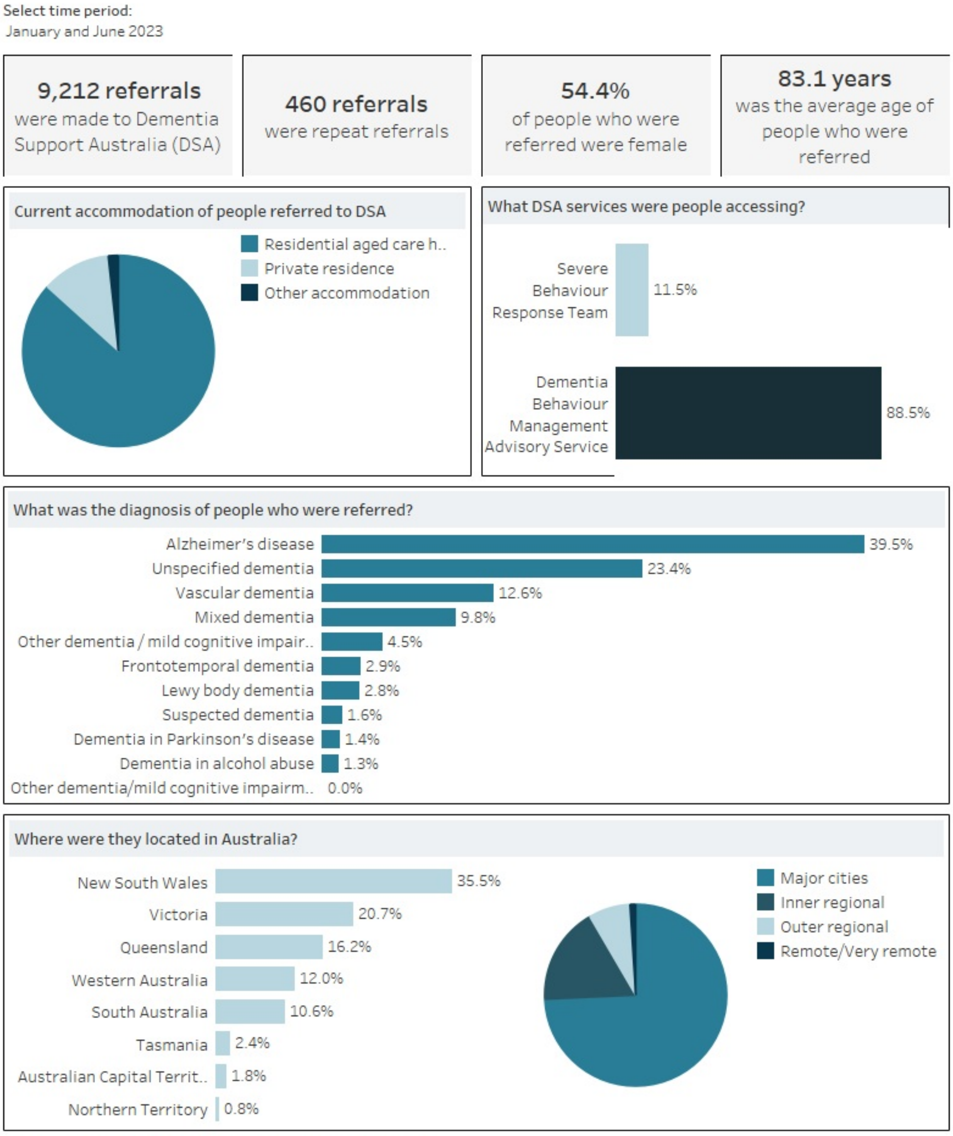
The Specialist Dementia Care Program (SDCP) provides a person-centred, multidisciplinary approach to care for people experiencing very severe BPSD, whose behaviours may put them or others at risk, or otherwise mean they are unable to be appropriately cared for by mainstream aged care services. The SDCP offers specialised, transitional residential support in a small dementia friendly unit, focusing on reducing or stabilising symptoms over time, with the aim of enabling people to move to less intensive care settings.

Between January to June 2018 and January to June 2023 there was a 161% increase in the total number of referrals that were supported by DSA (DBMAS, SBRT) – a 153% increase for the DBMAS and 235% increase for SBRTs. This increase is likely due to increased awareness of DSA, combined with a growing awareness of the importance of supporting people experiencing behaviours and psychological symptoms of dementia in Australia. Inadequate care for this group was highlighted in the Royal Commission into Aged Care, Quality and Safety.

Select a 6-month time period (between 1 January to 30 June 2018 and 1 January to 30 June 2023) in Figure 11.1 to explore the profile of referrals supported by DSA (DBMAS, SBRT) during this time.

Figure 11.1: Profile of referrals supported by Dementia Support Australia (DSA)

A panel of figures including bar graphs and pie charts showing demographic characteristics and service use information of referrals to Dementia Support Australia in 6 month periods between January to June 2018, and January to June 2023. The majority of referrals were for people living in residential aged care, and those living in Major cities from the most populous states (New South Wales, Victoria and Queensland). The majority of referrals were for accessing the Dementia Behaviour Management Advisory Service rather than Severe Behaviour Response Teams. The most common type of dementia recorded was Alzheimer’s disease, closely followed by Unspecified dementia.



Select time period:
January and June 2023

9,212 referrals were made to Dementia Support Australia (DSA)

460 referrals were repeat referrals

54.4% of people who were referred were female

83.1 years was the average age of people who were referred

Source: Data supplied to AIHW by Dementia Support Australia.
http://www.aihw.gov.au

Between January and June 2023, there were just over 9,200 referrals to DSA (DBMAS, SBRT). This had slightly decreased by 1.8% (from nearly 9,400 referrals) from the number of referrals in the previous 6 months (July to December 2022).

From January 2020 onwards, DSA were able to continue to deliver services when there were changes in public health policy as a result of the COVID-19 pandemic. This was achieved by adhering to social distancing and infection control requirements, as well as providing video conferencing services. DSA also released a resource for aged care services with tips for managing a person living with dementia whose behaviour may be impacting their care.

Aged care and support services used by people with dementia

Carers of people with dementia may require additional support for the emotional and financial challenges they may face in their role.

The Australian Government has established a Carers Gateway to disseminate information, resources and support services available to carers.

Carers Australia is the national peak body representing Australia's unpaid carers, advocating on their behalf to influence policies and services at a national level. The organisation provides support for carers through advocacy, advice and information.

Carers Australia also provides support for young carers through the Young Carers Network, where members can learn about support services, access resources and share their stories and opinions. In addition, the organisation has collaborated with SANE Australia to offer a free and anonymous forum which allows users to share stories and information to help find positive pathways through their experiences caring for people with mental health issues.

Dementia in priority groups

Australians living with dementia come from diverse backgrounds and have unique and variable needs for services and support. As the prevalence of dementia continues to increase, the rising proportion of care users with special needs and preferences have become a stronger focus of the aged care sector (Australian Government 2019).

The following pages present statistics and information on:

- Understanding dementia among First Nations people
- Population health impacts of dementia among First Nations people
- Burden of disease due to dementia among First Nations people
- Hospital care for First Nations people with dementia
- Aged care service use by First Nations people with dementia
- First Nations-specific health and aged care programs and caring roles among First Nations people
- Dementia among people from culturally and linguistically diverse backgrounds
- Cultural and linguistic diversity among Australians who died with dementia
- Dementia among people with intellectual disabilities
- Dementia among veterans
- Dementia in the LGBTIQ+ community

For more information on the data sources and methods used to examine dementia in priority population groups, refer to the Technical notes.

For the underlying data presented on these pages, refer to the First Nations people data tables and Priority populations data tables.

Key statistics

In 2018, **28%** of people with dementia in Australia were born in a **non-English speaking** country

In 2018, people with dementia from non-English speaking countries were **more likely to rely on informal carers only**

During 2019-2021, dementia was the **fifth leading cause of death among First Nations people** aged 65 and over

In 2021, **Down syndrome** was the **leading cause of death** in people aged under 65 with dementia as an associated cause of death

References

Department of Health and Aged Care (2019) *Australian Government Diversity Action Plan*, Department of Health and Aged Care, Australian Government, accessed 24 August 2021.

Dementia in priority groups

Dementia has a deep impact on Aboriginal and Torres Strait Islander people (respectfully referred to as First Nations people) and communities. The following pages present the impact of dementia among First Nations people in relation to:

- Population health impacts (incidence, prevalence and deaths)
- Burden of disease
- Hospital care
- Aged care service use
- First Nations-specific health and aged care programs and caring roles.

The pages also discuss what is being done to address the impact of dementia and the availability of services to meet the needs of First Nations people.

It is essential to understand how dementia is understood and managed among First Nations people in order to devise culturally appropriate and effective policies and services. However, there are important data gaps in relation to dementia in First Nations people, which limit the robustness of analyses and the generalisability of findings for First Nations people. These gaps include the lack of First Nations representation in key survey data, and that data on available services and uptake are not necessarily available outside the organisation providing them (AIHW 2020). As such, results presented here should be interpreted carefully.

First Nations people: key demographics

The term ‘First Nations people’ refers to hundreds of different groups of people with distinct cultures, traditions and languages.

The Australian Bureau of Statistics (ABS) estimates that in 2022, there were over 896,300 First Nations people, making up 3.5% of the total Australian population. According to the ABS (2022), among First Nations people in 2021:

- 91% identified as Aboriginal people, 4.2% as Torres Strait Islander people, and 4.4% as Aboriginal and Torres Strait Islander people.
- 5.9% were aged 65 years and over, compared with 18% of non-Indigenous Australians. However, the First Nations population has been ageing and it is expected to continue to do so in the future (Temple et al. 2020).
- 37% lived in capital city areas, compared with 35% in 2016.

Perceptions of dementia and enablers for living well with dementia

Experiences of dementia and awareness of risk factors for developing dementia vary greatly among First Nations people, as with non-Indigenous Australians (Flicker and Holdsworth 2014). However, as long as dementia doesn’t affect connection to family, community, and culture, many First Nations people perceive the condition as a natural part of life and not necessarily a medical problem that needs to be fixed (Alzheimer's Australia 2006).

> The causes of Aboriginal dementia in Gugu Yimithurr culture is part of a natural process. The body, mind and spirit naturally get older including the brain... It may not need to get fixed as long as the individual is safe and the family and the community is safe there may not be any need to do anything at all.
>
> Mr. Eric Deeral
>
> Chairperson, Elders Justice Group, Hopevale Community, Queensland

There are also known enablers that tend to support First Nations people with dementia, to live well. These include policies and services that: incorporate First Nations cultural perspectives of dementia; support family and communities to care for loved ones with dementia on Country; and are controlled by the community and delivered in a culturally safe manner (see Table 12.1 for more details).

Table 12.1: Common enablers among First Nations people for living well with dementia

Cultural security	• Availability of culturally safe and Aboriginal and Torres Strait Islander community-controlled health and aged care services, especially community-controlled aged care • Growing the First Nations workforce in all areas of aged care • Appropriate transport options to access preferred services • Use of culturally appropriate and co-designed screening tools for dementia and quality of life, and creating culturally safe care plans
Caring for family and friends with dementia	• Availability of culturally safe and community-controlled aged care support services, so families and communities can care for people with dementia on Country • Integrated care models with well-coordinated health and aged care service provision

Ongoing culture	• Many First Nations people view dementia as a natural part of the life cycle rather than an illness, as long as the person with dementia, their family and community, are safe. That is, as long as it doesn't affect the connection to family, community and culture.

Source: Information is summarised from: Alzheimer's Australia 2006; Arkles et al. 2010; Lindeman et al. 2017; LoGiudice et al. 2020; Smith et al. 2007; Smith 2008; Smith et al. 2020; Warburton and Chambers 2007; Western Australian Centre for Health and Ageing 2010.

Need more information?

If you require more information about dementia in First Nations people, or if you are an Aboriginal and/or Torres Strait Islander person and want to know where to seek help if dementia is suspected or want to find out about available support services refer to:

- Dementia Australia (for resources for First Nations communities)
- 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)
- My Aged Care (for information on supporting First Nations people accessing aged care).

References

ABS (Australian Bureau of Statistics) (2022) *Aboriginal and Torres Strait Islander people: Census, 2021* , ABS, Australian Government, accessed 1 August 2022.

AIHW (2020) *Dementia data gaps and opportunities*, AIHW, Australian Government, accessed 17 August 2021.

Alzheimer's Australia (2006) *Beginning the conversation: addressing dementia in Aboriginal and Torres Strait Islander communities*, Alzheimer's Australia, accessed 14 July 2023.

Arkles R, Jackson Pulver L, Robertson H, Draper B, Chalkley S and Broe A (2010) 'Ageing, cognition and dementia in Australian Aboriginal and Torres Strait Islander peoples: a life cycle approach', *University of New South Wales.*

Flicker L and Holdsworth K (2014) *Aboriginal and Torres Strait islander people and dementia: a review of the research*, Dementia Australia website, accessed 17 August 2022.

Lindeman MA, Smith K, LoGiudice D and Elliott M (2017) 'Community care for Indigenous older people: an update', *Australasian Journal on Ageing,* 36(2):124–127, doi:10.1111/ajag.12316.

LoGiudice D, Josif CM, Malay R, Hyde Z, Haswell M, Lindeman MA et al. (2020) 'The well-being of carers of older Aboriginal people living in the Kimberley Region of remote Western Australia: empowerment, depression, and carer burden', *Journal of Applied Gerontology,* doi:10.1177/0733464819898667.

Smith K, Flicker L, Lautenschlager NT, Almeida OP, Atkinson D, Dwyer A et al. (2008) 'High prevalence of dementia and cognitive impairment in Indigenous Australians', *Neurology,* 71(19):1470–1473, doi:10.1212/01.wnl.0000320508.11013.4f.

Smith K, Gilchrist L, Taylor K, Clinch C, LoGiudice D, Edgill P et al. (2020) 'Good Spirit, Good Life: a quality of life tool and framework for older Aboriginal peoples', The Gerontologist, doi:10.1093/geront/gnz185.

Temple J, Wilson T, Taylor A, Kelaher M and Eades S (2020) 'Ageing of the Aboriginal and Torres Strait Islander population: numerical, structural, timing and spatial aspects', *Australian and New Zealand Journal of Public Health,* 44(4):271–278, doi:10.1111/1753-6405.13001.

Warburton J and Chambers B (2007) 'Older Indigenous Australians: their integral role in culture and community'. *Australasian Journal on Ageing,* 26(1):3–7, doi:10.1111/j.1741-6612.2007.00213.x

Western Australian Centre for Health and Ageing (2010). *Indigenous services study: Lungurra Ngoora community care final report*.Western Australian Centre for Health and Ageing, accessed 6 July 2023.

Dementia in priority groups

This page presents the latest data showing the population health impacts of dementia among First Nations people including:

- prevalence and incidence of dementia
- deaths due to dementia
- deaths *due to* dementia versus deaths *with* dementia.

Prevalence and incidence of dementia

Although there are no national-level estimates of the number of First Nations people with dementia, studies examining different communities of First Nations people have consistently found that dementia prevalence rates are about 3–5 times as high as rates for Australia overall.

High dementia prevalence (that is, all dementia cases in a given period) and incidence (that is, new dementia cases in a given period) have been documented recently for very different groups of First Nations people:

- Rates of dementia for First Nations people in remote and rural communities are among the highest in the world. For First Nations people aged 45 and over living in the remote Kimberley region of Western Australia, dementia prevalence was 12.4% (Smith et al. 2008), and when followed up 7 years later for those aged 60 and over, dementia incidence was 21 per 1,000 person years (LoGiudice et al. 2016).
- Across the Northern Territory, the age-adjusted prevalence of dementia diagnoses recorded in electronic health data systems for First Nations people aged 45 and over was 6.5%, compared with 2.6% among the non-Indigenous Australians (Li et al. 2014).
- First Nations people also had a younger age of onset of dementia, with a median age of 72 years compared with a median age of 79 years among non-Indigenous Australians. The age-adjusted incidence rate of dementia among First Nations people aged 45 and over was about 2.5 times as high as the rate among non-Indigenous Australians (27 and 11 per 1,000 person years, respectively) (Li et al. 2014).
- Among urban and regional dwelling First Nations people aged 60 and over, the prevalence of dementia was about 3 times as high as the overall Australian prevalence for the same age group (21% and 6.8%, respectively), with Alzheimer's disease being the most common type of dementia present. Dementia prevalence rates among urban and regional dwelling First Nations people were slightly lower compared to rates among First Nations people living in remote areas (Radford et al. 2017).
- A study by Russell et al. (2020), estimated a dementia prevalence of 14.2% among Torres Strait Islanders aged between 45 and 93 years.
- The ARC Centre for Excellence in Population Ageing Research projected that by 2051, the relative growth in the number of First Nations people aged 50 years and over with dementia will be 4.5 to 5.5 times the 2016 estimated prevalence (Temple et al. 2022). The study attributes this to the Aboriginal and Torres Strait Islander population ageing, where age is a known risk factor for dementia.

Evidence of high prevalence, younger onset, and high incidence of dementia, suggests that without interventions to help moderate the impact of dementia, its burden among First Nations people will continue to grow in coming years.

Preventing dementia in First Nations people requires an understanding of the underlying medical and social risk factors for developing dementia. Some important risk factors that present at higher levels among First Nations people include: head injury, stroke, diabetes, high blood pressure, renal disease, cardiovascular disease, obesity, hearing loss, childhood stress and trauma, and lower socioeconomic status (Flicker and Holdsworth 2014; Goldberg et al. 2018; Radford et al. 2019). A key national research priority is to develop and evaluate culturally responsive programs, interventions and policies to reduce dementia risk factors across the life course and prevent or delay the onset of cognitive decline and dementia (including by targeting social determinants of health) (NHMRC 2020).

Continuing the improvement and quality of First Nations identifiers in administrative data sets would support better dementia prevalence estimates for First Nations people across Australia (AIHW 2020; Griffiths et al. 2019). Similarly, ensuring the availability and uptake of culturally sensitive and validated assessment tools to diagnose cognitive decline and dementia would lead to improved estimates of dementia prevalence as well as better diagnosis of dementia among First Nations people. The Kimberley Indigenous Cognitive Assessment (KICA) tool is an example of such a tool, which allows for the cognitive screening of older First Nations people living in urban, rural (KICA urban regional) and remote (KICA remote) areas of Australia, as well as the assessment of possible dementia. The complete resource package includes patient and carer assessments, family reports, pictures, and an instruction booklet and video. These are available from Aboriginal Ageing Well Research.

Deaths due to dementia among First Nations people

This section reports on deaths where dementia was recorded as the underlying cause of death, referred to as deaths *due to* dementia. It also presents death statistics aggregated over several years as a result of the small number of deaths due to dementia among First Nations people in any given year. Except for data reported by remoteness area, dementia-related deaths for First Nations people exclude data from Tasmania, Victoria and Australian Capital Territory, as these jurisdictions are considered to have inadequate levels of Indigenous identification in mortality data. Refer to Deaths due to dementia for more information on dementia-related deaths for all Australians. See the Technical notes for more information about deaths data, such as known issues with under-identification of First Nations people.

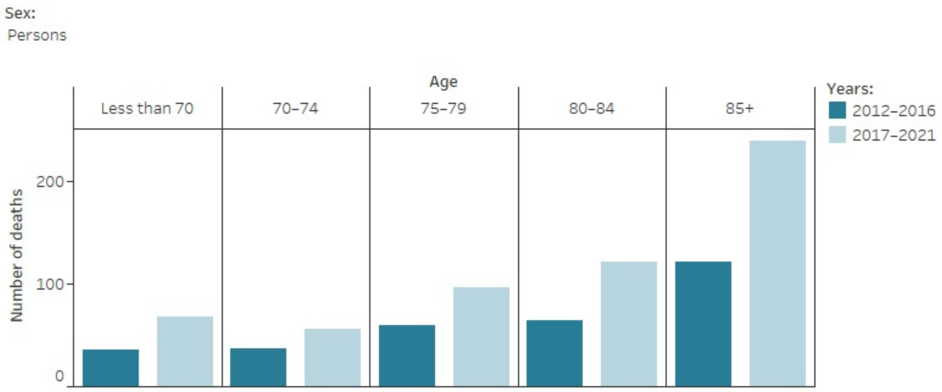
During 2019–21, about 370 First Nations people died due to dementia (230 women and 130 men). During this period, dementia was the fifth leading cause of death among First Nations people aged 65 and over (about 350 deaths, after coronary heart disease, chronic obstructive pulmonary disease, diabetes, and lung cancer), accounting for 8% of all deaths among First Nations people aged 65 and over.

To assess trends in deaths due to dementia over the past 10 years, the number of deaths due to dementia for 2012–2016 were compared to the number of deaths in the most recent 5-year period (2017–21). The number of deaths due to dementia among First Nations people increased in the most recent 5-year period (2017–21) for men and women across all ages (Figure 12.1). During 2012–2016, there were around 320 deaths due to dementia among First Nations people, while there were 580 deaths due to dementia during 2017–21. This is equivalent to an 83% increase in deaths due to dementia among First Nations people during this period, with the highest increase among people who died aged 85 and over (98% increase).

Between 2017 and 2021, most deaths due to dementia among First Nations men and women occurred among those aged 85 and over, but a larger proportion of First Nations men (70%) were aged less than 85 compared to First Nations women (52%). With an ageing First Nations population, it is expected that the number of deaths due to dementia will continue to rise in the future.

Figure 12.1: Deaths due to dementia among First Nations people during 2012–2016 and 2017–2021, by age and sex

This figure shows that the number of deaths among First Nations men and women increased by age and recency.



Notes
1. This analysis is only based on the underlying cause of death and not on associated causes of death.
2. Data are reported for 5 jurisdictions combined—New South Wales, Queensland, Western Australia, South Australia and the Northern Territory. These jurisdictions are considered to have adequate levels of Indigenous identification in mortality data.
3. See the technical notes for further information, available at https://www.aihw.gov.au/reports/dementia/dementia-in-aus/contents/technical-notes
Source: AIHW analysis of the National Mortality Database.
https://www.aihw.gov.au

The majority of deaths among First Nations people due to dementia in 2019–21, were recorded as due to *Unspecified dementia* (around 220 or 62% of deaths due to dementia), followed by *Alzheimer's disease* (23%) and *Vascular dementia* (10%) (Table S12.4). These dementia types were also the most common types recorded overall among Australians who died due to dementia in 2021 (see the Deaths due to dementia).

A nationwide study of mortality data between 2006–2014 showed that deaths with dementia were 57% higher among First Nations people compared to non-Indigenous Australians, with the biggest difference occurring among men and those aged less than 75 years. First Nations people were also more likely to have dementia coded as *Unspecified dementia*, compared to non-Indigenous Australians (Waller et al. 2021).

Due to the low number of deaths among First Nations people for particular types of dementia, and because there are known limitations with the accuracy and consistency of dementia coding on death certificates, the breakdowns by dementia subtypes presented here can only be considered indicative of the distribution of dementia types among First Nations people. For more information on these limitations, see Deaths due to dementia and Technical notes.

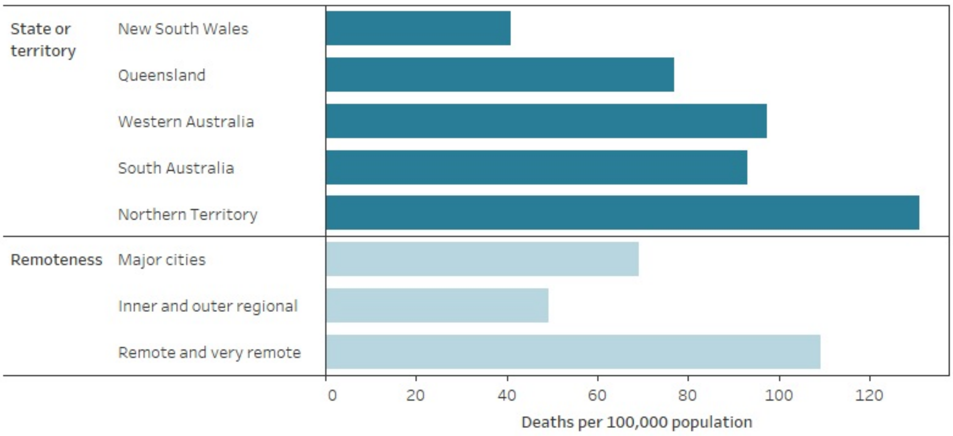
Geographic variation

After accounting for population differences in different geographic areas in Australia, there are notable geographic variations in deaths due to dementia during 2019–21 (Figure 12.2). Age-standardised rates of deaths due to dementia among First Nations people were:

- lowest in New South Wales (41 per 100,000 First Nations people) and highest in the Northern Territory (131 per 100,000 First Nations people)
- lowest in *Inner* and *Outer regional areas* (49 per 100,000 First Nations people) and highest in *Remote* and *Very remote areas* (109 per 100,000 First Nations people).

Figure 12.2: Deaths due to dementia among First Nations people during 2019–21: age standardised rate by geographic area

This figure shows that dementia death rates of First Nations people varied by state or territory, as well as by remoteness areas.



Notes
1. Death rates due to dementia for the various categories, have been standardised to the 2001 Australian Standard Population. This means they have been adjusted to have the same age distribution.
2. This analysis is only based on the underlying cause of death and not on associated causes of death.
Source: AIHW analysis of the National Mortality Database.
http://aihw.gov.au

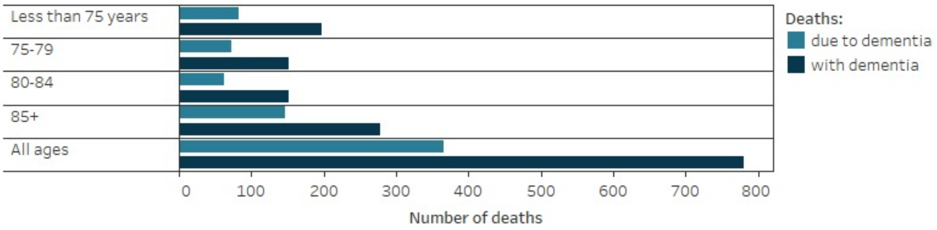
Deaths *due to* dementia versus deaths *with* dementia

The discussion about dementia deaths among First Nations people has so far been restricted to deaths *due to* dementia, that is, where dementia was recorded as the underlying cause of death (UCOD). In addition to the underlying cause of death, the National Mortality Database contains information on up to 19 associated causes of death (ACOD) – that is, other causes that were instrumental or significantly contributed to the death. Given people with dementia often have other health conditions and there can only be one underlying cause of death recorded, it is important to also account for all other cases where First Nations people died *with* dementia (where dementia was recorded as the underlying or an associated cause of death).

During 2019–21, about 370 First Nations people died *due to* dementia. In comparison, just over 780 First Nations people died *with* dementia (Figure 12.3). Around half (47%) of the deaths *with* dementia among First Nations people in 2021 were deaths *due* to dementia (that is, dementia was the underlying cause of death). This proportion increased by age at death, from 41% of deaths *with* dementia among First Nations people who died aged under 75, to 53% among First Nations people who died aged 85 or over. Across all age groups, the number of deaths involving dementia were much higher when associated cause of death information on dementia was included.

Figure 12.3: Deaths related to dementia among First Nations people during 2019–21, by age

This figure shows that in all age groups, the number of deaths among First Nations people was higher when deaths with dementia were included along with deaths due to dementia.



Note: Data are reported for 5 jurisdictions combined — New South Wales, Queensland, Western Australia, South Australia and the Northern Territory. These jurisdictions are considered to have adequate levels of Indigenous identification in mortality data.
Source: AIHW analysis of the National Mortality Database.
https://www.aihw.gov.au

When dementia was an associated cause of death, common underlying causes of death included: diabetes, coronary heart disease and cerebrovascular disease (Table S12.7). These conditions were also common underlying causes of death among Australians generally when dementia was an associated cause of death (Table S3.8).

References

Australian Institute of Health and Welfare (2020) *Dementia data gaps and opportunities*, AIHW, Australian Government, accessed 17 August 2022.

Flicker L and Holdsworth K (2014) *Aboriginal and Torres Strait islander people and dementia: a review of the research*, Dementia Australia website, accessed 17 August 2022.

Goldberg LR, Cox T, Hoang H and Baldock D (2018) 'Addressing dementia with Indigenous peoples: a contributing initiative from the Circular Head Aboriginal community', *Australian and New Zealand Journal of Public Health*, 42(5):424–426, doi:10.1111/1753-6405.12798

Griffiths K, Coleman C, Al-Yaman F, Cunningham J, Garvey G, Whop L et al (2019) 'The identification of Aboriginal and Torres Strait Islander people in official statistics and other data: critical issues of international significance', *Statistical Journal of the IAOS*, 35(1):91–106, doi:10.3233/SJI-180491

Li SQ, Guthridge SL, Aratchlge PE, Wang Z, Zhao Y and Krause V (2014) 'Dementia prevalence and incidence among the Indigenous and non-Indigenous populations of the Northern Territory', *Medical Journal of Australia*, 200(8):465–469, doi:10.5694/mja13.11052.

LoGiudice D, Smith K, Fenner S, Hyde Z, Atkinson D, Skeaf L et al. (2016) 'Incidence and predictors of cognitive impairment and dementia in Aboriginal Australians: a follow-up study of 5 years', *Alzheimer's & Dementia*, 12(3):252–261, doi:10.1016/j.jalz.2015.01.009.

NHMRC (National Health and Medical Research Council) (2020) *Aboriginal and Torres Strait Islander roadmap for dementia research and translation*, NHMRC, Australian Government, accessed 17 August 2022.

Radford K, Delbaere K, Draper B, Mack HA, Daylight G, Cumming R et al. (2017) 'Childhood stress and adversity is associated with late-life dementia in Aboriginal Australians', *The American Journal of Geriatric Psychiatry*, 25(10):1097–1106, doi:10.1016/j.jagp.2017.05.008.

Radford K, Lavrencic LM, Delbaere K, Draper B, Cumming R, Daylight G et al. (2019) 'Factors associated with the high prevalence of dementia in older Aboriginal Australians', *Journal of Alzheimer's Disease*, 70(s1):S75–S85, doi:10.3233/JAD-180573.

Russell SG, Quigley R, Thompson F, Sagigi B, LoGiudice D, Smith K et al. (2020) 'Prevalence of dementia in the Torres Strait', *Australasian Journal on Ageing* 40(2):e125–e132, doi:10.1111/ajag.12878.

Smith K, Flicker L, Lautenschlager NT, Almeida OP, Atkinson D, Dwyer A et al. (2008) 'High prevalence of dementia and cognitive impairment in Indigenous Australians', *Neurology*, 71(19):1470–1473, doi:10.1212/01.wnl.0000320508.11013.4f.

Temple J, Wilson T, Radford K, LoGiudice D, Utomo A, Anstey KJ and Eades S (2022) 'Demographic drivers of the growth of the number of Aboriginal and Torres Strait Islander people living with dementia, 2016–2051', *Australasian Journal on Ageing,* 41(4):e320-e327, doi:10.1111/ajag.13116.

Waller M, Buckley RF, Masters CL, Nona FR, Eades SJ and Dobson AJ (2021) 'Deaths with dementia in Indigenous and Non-Indigenous Australians: a nationwide study', *Journal of Alzheimer's Disease*, 81(4):1589–1599, doi:10.3233/JAD-201175.

Dementia in priority groups

Burden of disease is a measure of the combined impact of living with illness and injury (non-fatal burden) and dying prematurely (fatal burden). Combined, this is referred to as the total burden, measured using disability-adjusted life years (DALY) – one DALY is equivalent to one year of healthy life lost. Burden of disease analysis allows for comparisons of all diseases, illnesses and injuries, by considering not only the number of people affected, but also the severity and duration of illness, and the age at death for fatal conditions.

The Australian Burden of Disease Study: impact and causes of illness and death in Aboriginal and Torres Strait Islander people 2018 provides the most recent estimates of disease burden among First Nations people.

Dementia was the 19th leading cause of disease burden among First Nations people in 2018

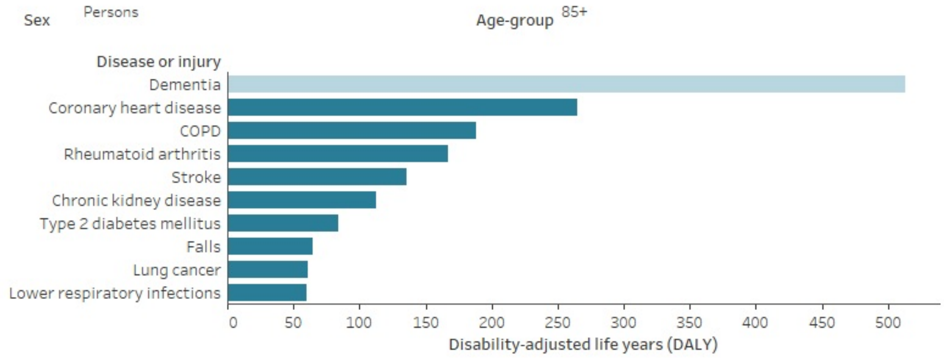
In 2018, dementia was the 19th overall leading cause of burden of disease among First Nations people. Dementia was responsible for just under 3,300 healthy years of life lost (DALY), 1.4% of the total burden experienced by First Nations people in 2018 (AIHW 2022). Women experienced over half (56%) of the total burden due to dementia among First Nations people.

The rate of burden due to dementia among First Nations people was over twice as high as the rate among non-Indigenous Australians (age-standardised rates of 13.0 and 6.1 DALY per 1,000 people, respectively).

Age is the biggest risk factor for dementia, and dementia's ranking as a leading contributor to disease burden increased with age. Dementia was the leading cause of disease burden for First Nations people aged 75 and over. This was partially due to the high disease burden among women in older ages. For First Nations men aged 75–79, dementia was the third leading cause of disease burden, whereas among First Nations women aged 75–79, dementia was the leading cause (Figure 12.4).

Figure 12.4: Leading 10 causes of disease burden (DALY) among First Nations people in 2018, by sex and age

Figure 12.4 is a bar graph showing the leading 10 causes of disease burden (by number of disability-adjusted life years, DALY) among Indigenous Australians, by sex and age in 2018. Dementia was a higher ranked cause of disease burden with increasing age; it was the leading cause of disease burden among all Indigenous Australians aged 80 and over, and the leading cause of disease burden among Indigenous women aged 75 and over.



Notes
1. DALY represents the total burden and is the sum of all disability-adjusted life years.
2. COPD refers to chronic obstructive pulmonary disease.
3. Lower respiratory infections include influenza and pneumonia.
4. Conditions which were not grouped into residual categories in the Australian Burden of Disease Study 2018 (such as 'Other musculoskeletal conditions') are not included in the rankings.
Source: AIHW Australian Burden of Disease Study 2018.
http://www.aihw.gov.au

YLL, YLD and DALY

The fatal burden, or years of life lost (YLL), is measured against an ideal life expectancy (AIHW 2022). Fatal burden for dementia was calculated based on deaths where dementia was recorded as the underlying cause of death. It does not include deaths where dementia was an associated cause of death (see Dying due to dementia compared to dying with dementia for more information).

Years lived with disability (YLD) is measured as years living in poor health and is weighted by severity of disease to consider different impacts of different diseases. The total DALY is equal to YLL plus YLD.

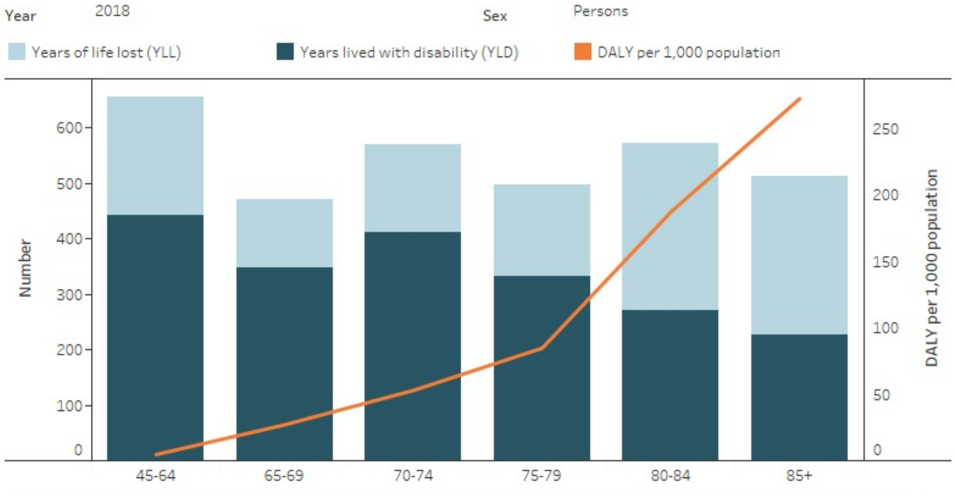
In 2018, 62% of the burden due to dementia among First Nations people was due to years lived with disability (YLD) and 38% was from dying prematurely (YLL). This was similar for both men (64% YLD, 36% YLL) and women (61% YLD, 39% YLL) (Table S12.10).

This differs to the burden of disease due to dementia among non-Indigenous Australians which was mostly due to years of life lost (56% of DALY). There was also greater variation between men (YLL accounted for 62% of DALY) and women (YLL accounted for 53% of DALY).

Among First Nations people, the rate of burden of disease due to dementia (DALY per 1,000 people) increased gradually with age until 75–79 years, and then sharply increased in the 80–84 and 85 and over groups, mainly due to higher numbers of years of life lost (YLL) in those older age groups (Figure 12.5).

Figure 12.5: Dementia burden among First Nations people in 2011 and 2018: number (YLL, YLD) and age-specific rate (DALY per 1,000 people), by sex and age

Figure 12.5 is a stacked bar graph showing the number of years of life lost and years lived with disability due to dementia by age (which added together equal to disability-adjusted life years, or DALY) and a line graph showing the age-specific dementia DALY rate, amongst Indigenous Australians, by sex and year (2011 and 2018). It shows that the number of years of life lost and years lived with disability due to dementia were highest by number in Indigenous Australians aged 45-64. Years of life lost due to dementia became an increasing cause of the disease burden due to dementia with increasing age. The rate of DALY due to dementia increased with increasing age and was highest among people aged 85 and over. Overall patterns were similar for each year presented.



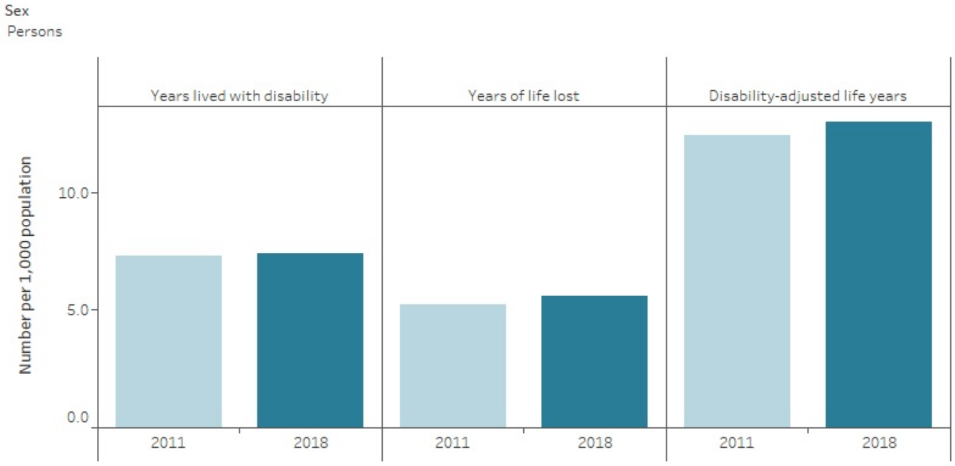
Note: DALY represents the total burden and is the sum of all disability-adjusted life years, expressed as age-specific rates per 1,000 population.
Source: AIHW Australian Burden of Disease Study 2018.
http://www.aihw.gov.au

Burden due to dementia among First Nations people increased between 2011 and 2018

There was a slight increase in the age-standardised rate of burden due to dementia among First Nations people between 2011 and 2018, from 12.4 to 13.0 DALY per 1,000 people. This was due to an increase in the rate of fatal burden (from 5.2 to 5.6 YLL per 1,000 people), while the rate of non-fatal burden remained relatively stable between 2011 and 2018 (7.3 and 7.4 YLD per 1,000 people, respectively) (Figure 12.6).

Figure 12.6 : Dementia burden among First Nations people in 2011 and 2018: age-standardised YLL, YLD and DALY per 1,000 people, by sex

Figure 12.6 is a bar graph showing the age-standardised rate of years of life lost, years lived with disability and disability-adjusted life years due to dementia among Indigenous Australians in 2011 and 2018 by sex. There was a slight increase in the rate of disability-adjusted life years due to dementia between 2011 and 2018, mainly due to an increase in the rate of years of life lost due to dementia.



Note: Age-standardised rates are standardised to the 2001 Australian Standard Population and expressed as per 1,000 population.
Source: AIHW Australian Burden of Disease Study 2018.
https://www.aihw.gov.au

Dementia burden among First Nations people attributable to risk factors

Disease burden due to risk factors is known as the attributable burden. It is measured as the number of healthy years of life lost that could have been avoided if exposure to the risk factor had been reduced or completely avoided.

The Australian Burden of Disease Study (ABDS) 2018 estimated the dementia burden attributable to 6 modifiable risk factors, including:

- tobacco use
- overweight (including obesity)
- physical inactivity
- high blood pressure
- high blood plasma glucose
- impaired kidney function.

Note, this is not an exhaustive list of risk factors linked to dementia (for example, low education levels – an established risk factor for dementia – is not included) and only includes risk factors measured in the ABDS 2018. The list of risk factors and measures of additional risk (relative risks) were based on those used in recent Global Burden of Disease studies and a number of epidemiological studies. Refer to What puts someone at risk of developing dementia? for more information on the complete list of established risk factors for dementia.

53% of the dementia burden among First Nations people was attributable to 6 risk factors combined

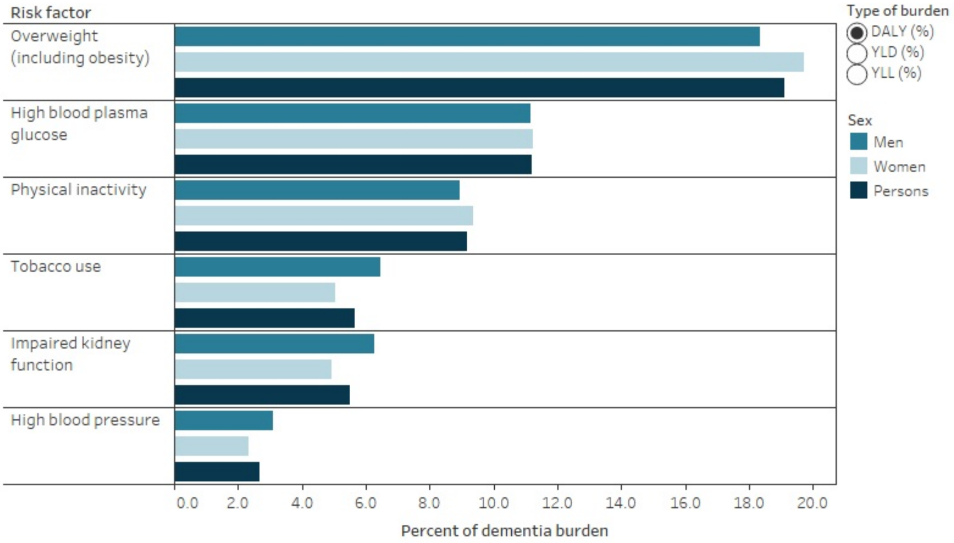
Overall, 53% of the dementia burden in 2018 was attributable to the 6 risk factors combined (Table S12.12). This estimate takes into account the complex pathways and interactions between risk factors, such as the relationship between physical inactivity, overweight (including obesity) and high blood pressure. However, this work does not incorporate the impact of age as a separate risk factor for dementia. Age is the main risk factor for dementia but because it is not a modifiable risk factor, it is not included in burden of disease studies.

Of the 6 risk factors, overweight (including obesity) contributed the most to dementia burden among First Nations people (19%), followed by high blood plasma glucose (11%) and physical inactivity (9%). These leading 3 risk factors were consistent across men and women.

The proportions of burden attributable to overweight (including obesity) and physical inactivity were higher among women compared to men. While the proportions of burden attributable to tobacco use, impaired kidney function and high blood pressure were higher among men compared to women (Figure 12.7).

Figure 12.7: Joint effect of risk factors contributing to dementia burden among First Nations people in 2018: DALY, YLD and YLL (proportion of total dementia burden), by sex

Figure 12.7 is a bar graph showing the percentage of years of life lost, years lived with disability and disability-adjusted life years (DALY) due to dementia that were attributable to specific risk factors among Indigenous Australians by sex in 2018. Risk factors include tobacco use, overweight (including obesity), physical inactivity, high blood pressure, high blood plasma glucose and impaired kidney function. Overall, overweight (including obesity) was the greatest contributor to disability-adjusted life years due to dementia, followed by high blood plasma glucose and physical inactivity. The proportion of dementia DALY attributable to overweight (including obesity) and physical inactivity were higher in women compared to men, while the proportion of dementia DALY attributable to tobacco use, impaired kidney function and high blood pressure were higher in men compared to women.



Notes
1. The 'joint effect' estimate takes into account the inter-relationships between factors and their combined risk contributing to dementia burden.
2. Percent YLL/YLD/DALY refers to the proportion of the total burden (YLL, YLD or DALY, respectively) due to dementia, attributable to that risk factor.
Source: AIHW Australian Burden of Disease Study 2018.
https://www.aihw.gov.au

How do risk factors impact dementia burden among First Nations people by age?

The amount of dementia burden attributable to each of the 6 linked risk factors varied by age. This is due to age differences in both exposure to the risk factor, as well as the burden of dementia by age. The attributable dementia burden was greatest in First Nations people aged 75 and over (Figure 12.8).

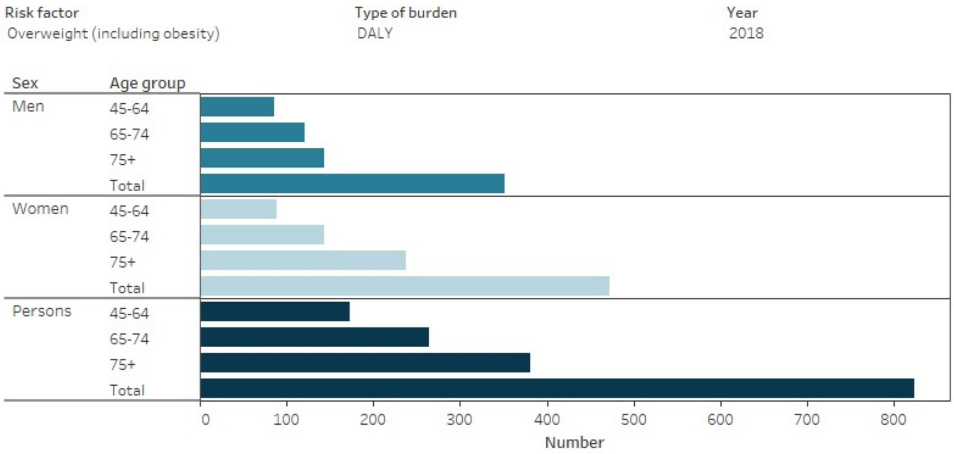
In 2018, dementia burden attributable to tobacco use was slightly higher in First Nations people aged 45–64 (78 DALY) compared to those aged 65–74 (75 DALY). Dementia burden attributable to tobacco use was highest in First Nations people aged 75 and over (88 DALY).

For the other 5 risk factors – overweight (including obesity), high blood plasma glucose, physical inactivity, impaired kidney function and high blood pressure – dementia burden attributable to each factor increased with age.

Between 2011 and 2018, there was little difference across age groups in changes to the proportion of dementia burden attributable to overweight (including obesity), physical inactivity, high blood pressure and high blood plasma glucose. However, the proportion of burden due to tobacco use decreased in First Nations people aged 65-74 and 75 and over between 2011 and 2018, and the proportion of burden attributable to impaired kidney function increased for First Nations people aged 75 and over.

Figure 12.8: Dementia burden among First Nations people attributable to specific risk factors in 2011 and 2018: YLL, YLD and DALY, by sex and age

Figure 12.8 is a bar graph showing the number of years of life lost, years lived with disability and disability-adjusted life years (DALY) due to dementia that were attributable to specific risk factors among Indigenous Australians by sex and age in 2011 and 2018. Risk factors include tobacco use, overweight (including obesity), physical inactivity, high blood pressure, high blood plasma glucose and impaired kidney function. The dementia DALY attributable to each risk factor increased with increasing age and was greatest among those aged 75 or over.



Notes
1. Attributable burden is the number of dementia burden attributed to by the specific risk factor.
2. Not all risk factors had attributable burden estimated for all age groups. For more information on age group exclusions by risk factor see the ABDS 2018 methods paper.
Source: AIHW Australian Burden of Disease Study 2018.
http://www.aihw.gov.au

References

AIHW (Australian Institute of Health and Welfare) (2022) *The Australian Burden of Disease Study: impact and causes of illness and death in Aboriginal and Torres Strait Islander people 2018*, AIHW, Australian Government, accessed 3 May 2022.

Dementia in priority groups

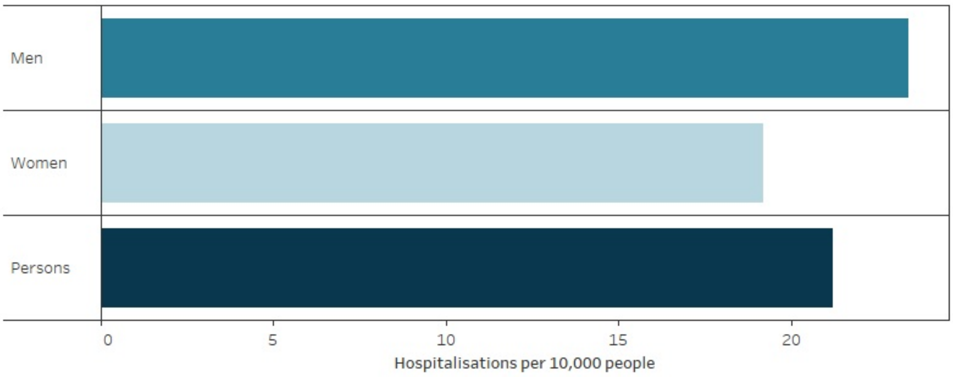
In 2021–22, there were 382 hospitalisations *due* to dementia (where dementia was the principal diagnosis or the main reason for the hospital admission) where the patient identified as a First Nations person.

First Nations men were more likely to be hospitalised due to dementia (23 hospitalisations per 10,000 First Nations men) than First Nations women (19 hospitalisations per 10,000 First Nations women) (Figure 12.9).

Refer to Hospital care for more information on overall hospitalisations for dementia in Australia and see the Technical notes for further information on hospitals data. For information about the quality of First Nations identification in hospitals data, see Indigenous identification in hospital separations data: quality report.

Figure 12.9: Hospitalisations for First Nations people *due* to dementia in 2021–22: age-standardised rate, by sex

A bar graph showing the age standardised rate of hospitalisations due to dementia for male and female First Nations people in 2021–22.



Notes
1. The age-standardised rates, which apply to people aged 40 and over, were standardised to the Australian population as at 30 June 2001 and are expressed per 10,000 population.
2. See the technical notes for further information, available at https://www.aihw.gov.au/reports/dementia/dementia-in-aus/contents/technical-notes
Source: AIHW analysis of National Hospital Morbidity Database.
http://www.aihw.gov.au

The average length of stay among First Nations people for hospitalisations due to dementia was 15.5 days, slightly longer than the average length of stay for all hospitalisations due to dementia in 2021–22 for non-Indigenous Australians (14.8 days).

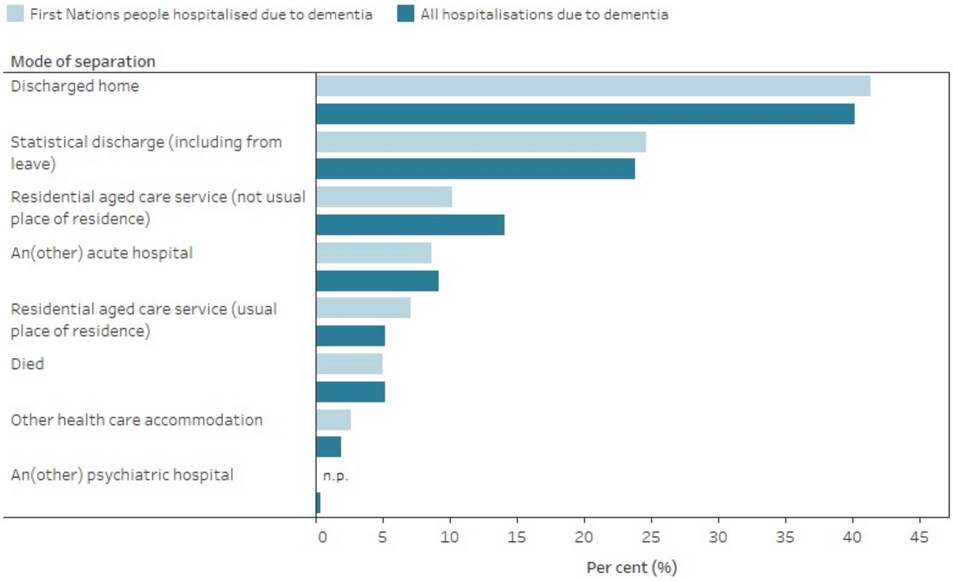
There are many reasons why First Nations people may not want to use hospital services, such as: competing family and cultural obligations; distrust in the health system due to negative past and present experiences; a lack of culturally safe care options; communication barriers with medical staff, including barriers for First Nations people for whom English is a second language; limited access to health services in regional and remote locations requiring patients to receive care away from their community; high travel and other out-of-pocket costs, especially for people living in regional and remote locations (AHMAC 2017; Shaw 2016).

How did hospitalisations *due* to dementia end for First Nations people?

In 2021–22 about 40% of hospitalisations of First Nations people due to dementia ended with the patient being discharged home, 7% were discharged to residential aged care which was their usual place of residence and 10% discharged to residential aged care that was not their usual place of residence (Figure 12.10). This trend is similar across all hospitalisations due to dementia.

Figure 12.10 First Nations hospitalisations *due* to dementia in 2021–22: percentage by mode of separation

Figure shows a bar chart comparing the method of discharge between First Nations hospitalisations due to dementia with all hospitalisations due to dementia. First Nations hospitalisations due to dementia and all hospitalisations due to dementia follow similar trends with hospitalisation most likely to end due to being discharged home (41%), then statistical discharge (25%) entering residential aged care, not the usual place of residence (10%).



Note: Values may not add up due to rounding.
Source: AIHW analysis of National Hospital Morbidity Database.
http://aihw.gov.au
See the technical notes for further information, available at
https://www.aihw.gov.au/reports/dementia/dementia-in-aus/contents/technical-notes

When First Nations people were hospitalised *due* to dementia, what other conditions did they have?

When First Nations people were admitted to hospital *due to* dementia, the most common diagnoses (additional and supplementary diagnoses), other than dementia were:

- hypertension
- ischaemic heart disease (also known as coronary heart disease)
- type 2 diabetes without complications
- constipation
- arthritis and osteoarthritis

Three of these diagnoses are closely related to the modifiable risk factors for dementia, hypertension, ischaemic heart disease and type 2 diabetes. For further information on the top 10 other diagnoses, see table S12.20.

How did hospitalisations *due* to dementia for First Nations people vary by geographic area?

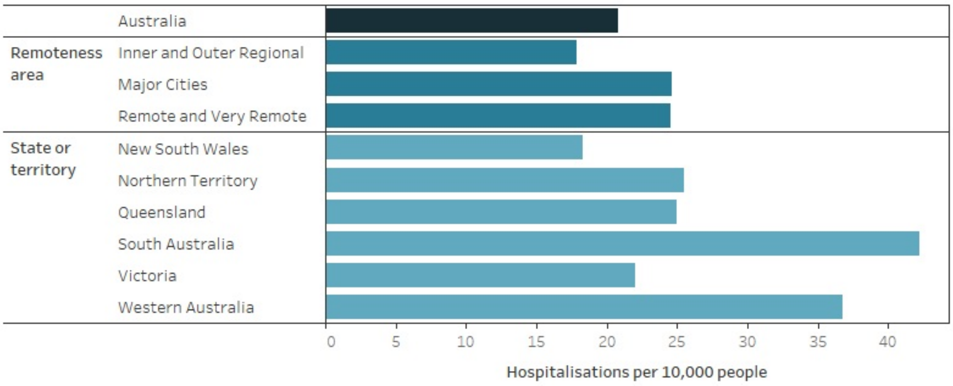
Given the small number of hospitalisations due to dementia for First Nations people in a given year, the rates of hospitalisations due to dementia presented in this analysis were aggregated over a 3-year period (2019-20, 2020-21 and 2021-22).

After adjusting for population differences, between 2019–20 and 2021–22, the age-standardised rate of hospitalisations due to dementia for First Nations people aged 40 years and over, was:

- highest in South Australia (42 hospitalisations per 10,000 First Nations people) followed by Western Australia (37 hospitalisations per 10,000) and was lowest in New South Wales (18 hospitalisations per 10,000)
- highest in *Remote and Very Remote areas* and *Major Cities* (25 hospitalisations per 10,000 First Nations people) and was lowest in *Inner and Outer Regional areas* (18 hospitalisations per 10,000) (Figure 12.11).

Figure 12.11: Hospitalisations for First Nations people due to dementia between 2019–20 and 2021–22: age-standardised rate, by state and territory and remoteness area

A bar graph showing the age standardised rate of hospitalisations due to dementia among First Nations people between 2019-20 and 2021-22 by remoteness area and state or territory.



Notes
1. The age-standardised rates, which apply to people aged 40 and over, were standardised to the Australian population as at 30 June 2001 and are expressed per 10,000 population.
2. Estimates for the Australian Capital Territory and Tasmania are not published due to small numbers.
3. See the technical notes for further information, available at https://www.aihw.gov.au/reports/dementia/dementia-in-aus/contents/technical-notes
Source: AIHW analysis of National Hospital Morbidity Database.
http://www.aihw.gov.au

First Nations hospitalisations *with* dementia

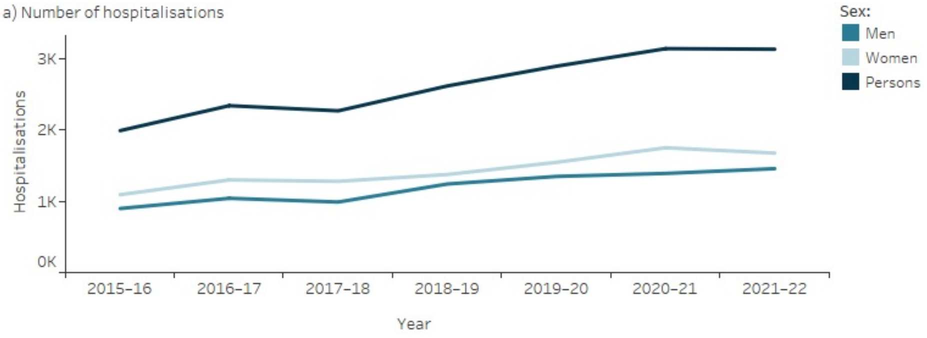
Previous sections have presented hospitalisations *due* to dementia (that is, when dementia was recorded as the principal diagnosis), but understanding hospitalisations *with* dementia (that is all hospitalisations with a record of dementia, whether as the principal and/or an additional diagnosis and/or a supplementary diagnosis) provides important insights on the wide-ranging conditions that can lead people living with dementia to use hospital services.

There were just over 3,100 First Nations people hospitalised in 2021–22 with dementia, a 57% rise from 2015–16. The age-standardised rate also rose during this time from about 155 to 170 per 10,000 First Nations people. This rise shows that this is a genuine increase in hospitalisations and not simply due to Australia having a growing and ageing population.

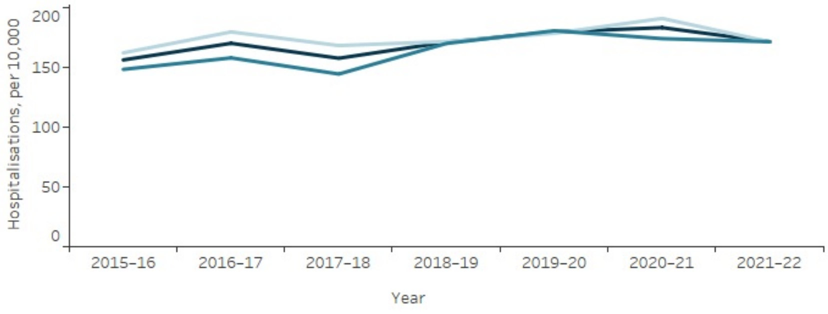
Figure 12.12 First Nations hospitalisations *with* dementia between 2015–16 and 2021–22 by sex: (a) number and (b) age-standardised rate

Figure shows two line graphs. The first showing the number of hospitalisations of First Nations people with dementia over time, increasing steadily from 2015–16 (1,990 hospitalisations) to 2021–22 (3,132 hospitalisations). The second graph shows the age-standardised rates of hospitalisations of First Nations people with dementia over time slightly increasing over time from 156 hospitalisations per 10,000 First Nations people to 171 hospitalisations per 10,000 First Nations people.

a) Number of hospitalisations



b) Age-standardised rates



Notes
1. The age-standardised rates, which apply to people aged 40 and over, were standardised to the Australian population as at 30 June 2001 and are expressed per 10,000 population.
2. See the technical notes for further information, available at https://www.aihw.gov.au/reports/dementia/dementia-in-aus/contents/technical-notes
Source: AIHW analysis of National Hospital Morbidity Database.
http://www.aihw.gov.au

What were the most common principal diagnoses for First Nations people when dementia was an additional diagnosis?

In 2021–22 there were about 3,100 hospitalisations of First Nations people with dementia.

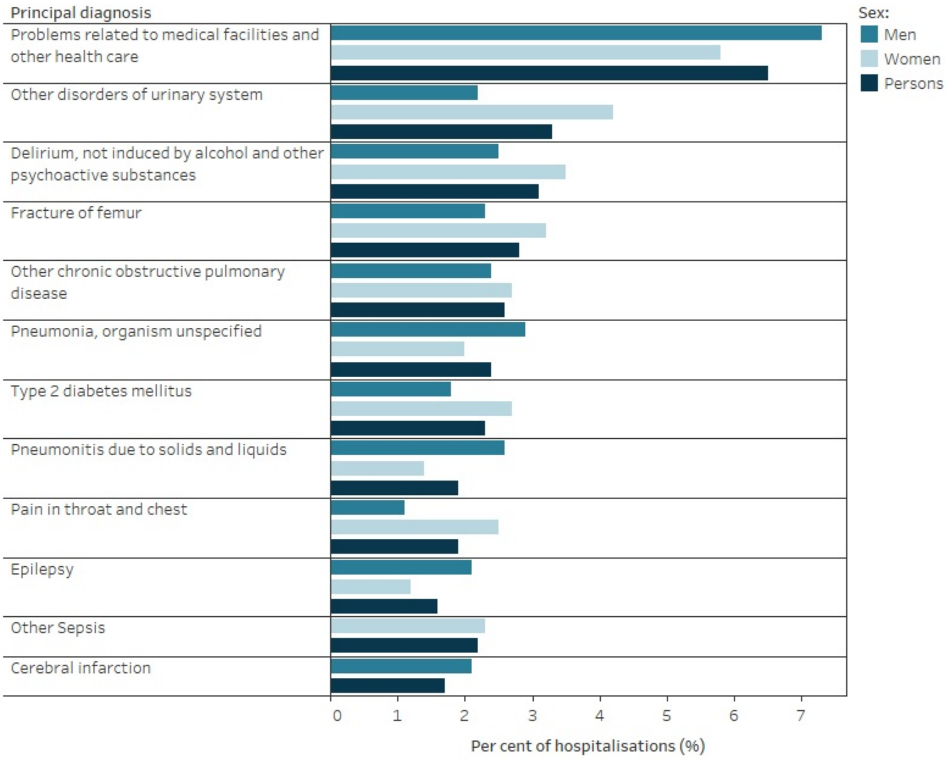
The most common principal diagnoses among hospitalisations for First Nations people aged 40 years and over, where dementia was an additional diagnosis, were:

- Problems related to medical facilities and other health care (6.5%)
- Other disorders of urinary system (3.3%)
- Delirium, not induced by alcohol and other psychoactive substances (3.1%)

Other common principal diagnoses recorded for these hospitalisations included pneumonia, sepsis, femur fractures and a number of chronic conditions such as chronic obstructive pulmonary disease, cardiovascular diseases, and diabetes (Figure 12.13).

Figure 12.13: **Common principal diagnoses for hospitalisations of First Nations people where dementia was an additional diagnosis in 2021–22: percent of hospitalisations, by sex**

A bar chart showing the age standardised rates of hospitalisations by common principal diagnoses and sex for First Nations people where dementia was an additional diagnosis in 2021–22.



Notes
1. Hospitalisations include First Nations people aged 40 and over, hospitalised with dementia as an additional diagnosis.
2. Values for Cerebral infarction for women, and Other Sepsis for men are not published due to small numbers.
3. Refer to the technical notes for information on the ICD-10-AM codes for these principal diagnoses, available at https://www.aihw.gov.au/reports/dementia/dementia-in-aus/contents/technical-notes

Source: AIHW analysis of National Hospital Morbidity Database.
http://www.aihw.gov.au

References

AIHW (Australian Institute of Health and Welfare) (2023) *Coronary heart disease*, AIHW, Australian Government, accessed 25 January 2023.

Australian Health Ministers' Advisory Council (2017) *Aboriginal and Torres Strait Islander Health Performance Framework 2017 report*, Australian Health Ministers' Advisory Council, Australian Government, accessed 17 August 2022.

Shaw C (2016) *An evidence-based approach to reducing discharge against medical advice amongst Aboriginal and Torres Strait Islander patients*, The Deeble Institute for Health Policy Research, Australian Healthcare and Hospitals Association, accessed 17 August 2022.

Dementia in priority groups

First Nations people accessing government-subsidised aged care services tend to be younger and use these services at higher rates as a proportion of the population than non-Indigenous Australians (AIHW 2021). Differences in use are due to various factors, including (but not limited to):

- **government policies:** First Nations people are identified as 1 of 10 'special needs groups' under the *Aged Care Act 1997*. As a result of the specific needs of First Nations people, planning for aged care services focuses on First Nations people aged 50 and over rather than age 65 and over for non-Indigenous Australians. However, ultimately, access to aged care services is based on the care needs of each individual. In 2019, the Australian Government published an action plan to support the Aged Care Diversity Framework and address barriers faced by older First Nations people when accessing aged care. For a brief overview of Australia's aged care system, see Overview of Australia's aged care system.
- **preferred care types and availability of services**: Eligible older Australians have access to a variety of government-subsidised services. However, First Nations people may face challenges with accessing services that provide culturally appropriate care. Older First Nations people generally wish to remain in their communities and on Country for as long as possible, and to have access to culturally safe health and aged care services in their own communities, as well as away from their communities when needed. While all government-subsided aged care services are available to First Nations people and should be designed to provide them with appropriate care, there are First Nations-specific services available (and often preferred) such as the National Aboriginal and Torres Strait Islander Flexible Aged Care Program (NATSIFACP). The aim of this program is to provide quality, flexible aged care for older First Nations people, in a culturally safe environment. Associated NATSIFACP providers work mainly in regional, remote, and very remote areas, and help First Nations people with home care, emergency or planned respite, short-term care and permanent residential care. At 30 June, 2020, NATSIFACP offered almost 1,300 places. It is also important to note that Stolen Generations survivors were all aged 50 and over and eligible for aged care services by the year 2022 – refer to Box 12.1 for more information on this group and how their life experiences could impact their care needs.
- **population age structures:** both First Nations people and non-Indigenous Australians are experiencing population ageing, but First Nations people have a younger age structure compared to non-Indigenous Australians.
- **health status:** health conditions associated with ageing and with an increased risk of developing dementia are often more common and begin at younger ages among First Nations people. Rates of aged care use are also generally higher for First Nations people than for non-Indigenous Australians.

This page presents information on how First Nations people use aged care services based on data on comprehensive assessments undertaken for people wanting to access government-subsidised aged care services and for those receiving government-subsidised permanent residential aged care. These data have limitations that should be kept in mind when interpreting the information presented, including that there is incomplete information on First Nations-specific aged care services. For example, data from the National Aboriginal and Torres Strait Islander Flexible Aged Care Program are not included.

Box 12.1: Providing effective health and aged care to Stolen Generations survivors

There were about 33,600 survivors of the Stolen Generations in 2018–19, all are now aged 50 and over and eligible for aged care services (AIHW 2021).

Under racially motivated policies, between 1910 and the 1970s, as many as 1 in 3 Aboriginal and Torres Strait Islander children were forcibly removed from their families and placed in institutions or adopted by non-Indigenous Australian families, where they often experienced trauma and human rights violations (AIHW 2021). These children have become known as the 'Stolen Generations'.

Stolen Generations survivors are more likely to experience a range of health, cultural and socioeconomic adverse outcomes compared to other First Nations people and non-Indigenous Australians. Childhood stress and trauma has also been linked as a risk factor for developing dementia in later life among First Nations people (Radford et al. 2019).

While Stolen Generations survivors often prefer health and aged care services tailored to First Nations people and to receive care in their own homes and communities, these options are not always available. Leading advocacy and expert organisations have called for urgent government action to provide culturally appropriate support and aged care options to survivors (Healing Foundation and Aboriginal and Torres Strait Islander Ageing Advisory Group of the Australian Association of Gerontology 2019). Residential aged care and clinical settings that resemble childhood institutions where removed children were placed can re-trigger trauma (Smith and Gilchrist 2017), so it is essential that health and aged care providers understand the effects of trauma and that care is culturally appropriate and safe (Healing Foundation 2019).

In its final report, the Royal Commission into Aged Care Quality and Safety echoed the importance of providing Stolen Generations survivors with appropriate aged care options and further highlighted the importance of '… accessible pathways linking Aboriginal and Torres Strait Islanders to the care that they need. To deliver culturally safe pathways to aged care … the Australian Government should ensure that care finders serving Aboriginal and Torres Strait Islander communities are local Aboriginal and Torres Strait Islander people' (Royal Commission 2021).

Assessment for use of aged care services

Access to government-subsidised aged care services is co-ordinated through the My Aged Care system, in which, after an initial screening to determine eligibility, a person's needs and types of services are assessed using the National Screening and Assessment Form (NSAF). There are 2 main types of aged care assessments 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). Dementia is a condition commonly prompting a comprehensive assessment (Ng and Ward 2019).

See Aged care assessments for more information on aged care assessments and the types of services available.

Information on people with dementia who completed a comprehensive and/or home support assessment in 2021–22 is available from NSAF data as part of the National Aged Care Data Clearinghouse.

Aged care assessments

In 2021–22, just over 8,500 people, or 2.4% of all people who completed an aged care assessment (either a comprehensive or home support assessment) identified as being a First Nations person. Dementia was recorded as a condition contributing to the care needs of 480 First Nations people, or 5.6% of all First Nations people who completed an aged care assessment in 2021–22.

Among First Nations people who completed an aged care assessment in 2021–22, those with dementia were older than those without dementia. Over half (54%) of First Nations people with dementia were aged 75 and over compared with 25% of First Nations people without dementia (Figure 12.14).

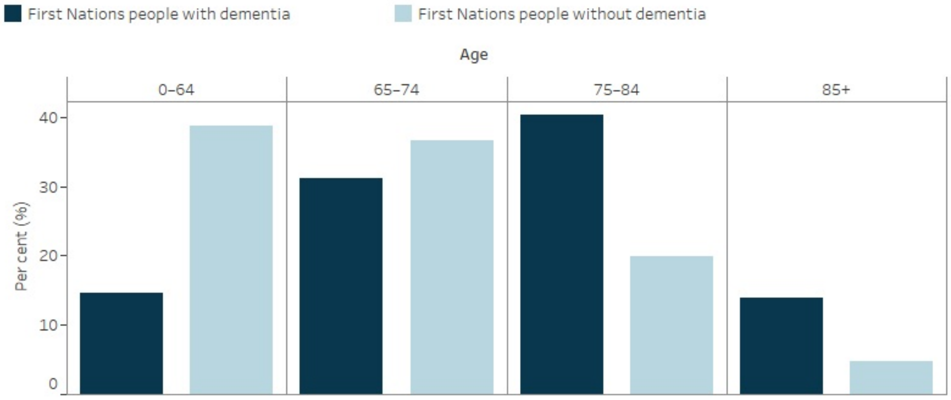
An additional 300 First Nations people with cognitive impairment (but no record of dementia) completed an aged care assessment

This equates to 3.5% of First Nations people who completed an aged care assessment in 2021–22.

This group includes people with mild cognitive impairment – where they have significant memory loss but no other changes in cognitive function. Mild cognitive impairment increases the risk of Alzheimer's disease, but it does not mean that the development of dementia is certain. However, it is recognised that some people with cognitive impairment who complete an aged care assessment may be in the early stages of dementia and are yet to receive a formal diagnosis. Therefore, the number of First Nations people with dementia in this report may be an underestimate of the true number of First Nations people with dementia seeking entry into aged care services.

Figure 12.14: First Nations people with and without dementia who completed an aged care assessment in 2021–22: percentage, by age

This figure shows the age profile of First Nations people with and without dementia who completed an aged care assessment.



Source: AIHW analysis of the National Aged Care Data Clearinghouse
http://www.aihw.gov.au

The majority of First Nations people with dementia (94%) who completed an aged care assessment were living in the community at the time of their assessment. First Nations people with dementia were more likely to be living with family (40% of First Nations people with dementia living in the community) than non-Indigenous Australians with dementia (18%) (Table S12.24).

Assessment type and setting

Dementia is a common reason for needing a comprehensive assessment. Around 4 in 5 First Nations people with dementia who completed an assessment in 2021–22 (79% or 378 people) completed a comprehensive assessment rather than a home support assessment (21% or 99 people).

Over half (56%) of First Nations people with dementia who completed a comprehensive assessment and 88% who completed a home support assessment, completed the assessment in their own home. Comprehensive assessments can also take place in a hospital, and 1 in 4 First Nations people with dementia (26%) completed their comprehensive assessment while in a hospital setting.

Co-existing health conditions

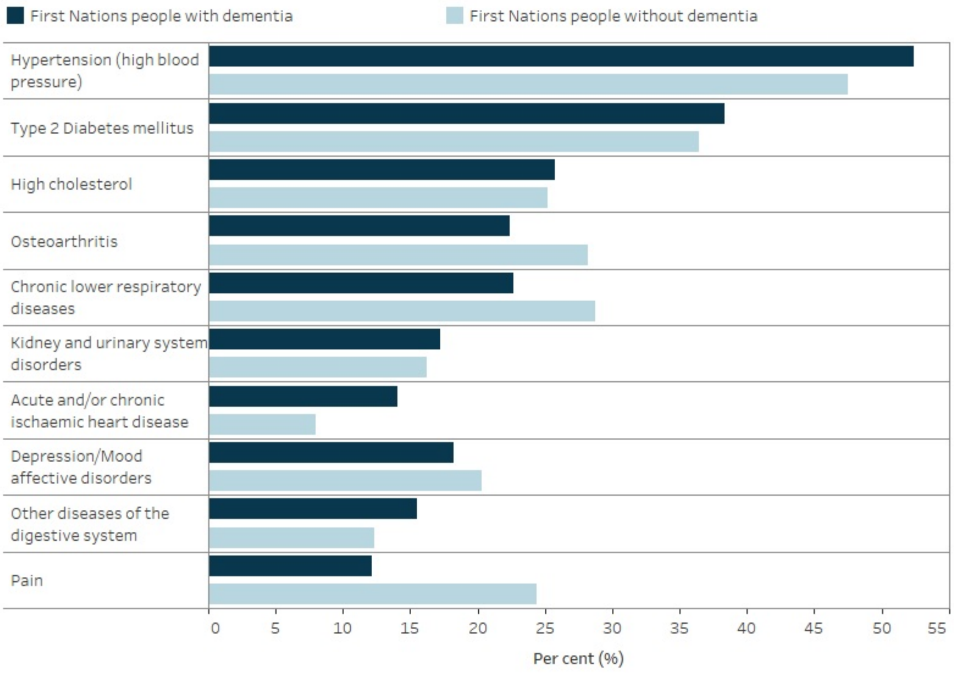
People with dementia typically have other co-existing conditions that impact care needs.

The most common conditions among First Nations people with dementia who completed an aged care assessment in 2021–22 were:

- high blood pressure (52% of all First Nations people with dementia)
- type 2 diabetes mellitus (38%)
- high cholesterol (26%)
- chronic lower respiratory diseases (23%)
- osteoarthritis (22%) (Figure 12.15).

Figure 12.15: Leading 10 health conditions among First Nations people who completed an aged care assessment in 2021-22: percentage, by dementia status

This bar chart shows the top 10 comorbidities of First Nations Australians with and without dementia who completed an aged care assessment in 2021–22.



Notes:
1. 'Chronic lower respiratory diseases' includes emphysema, chronic obstructive airways disease, chronic obstructive pulmonary disease and asthma.
2. 'Other diseases of the digestive system' includes diseases of the oral cavity, salivary glands and jaws, oesophagitis, gastritis and duodenitis, cholecystitis, other diseases of the gallbladder, pancreatitis, coeliac disease and reflux.
3. 'Kidney and urinary system disorders' includes nephritis, renal failure and cystitis. It excludes urinary tract infection and incontinence.

Source: AIHW analysis of the National Aged Care Data Clearinghouse.
http://www.aihw.gov.au

Approvals for use of aged care services

Assessors recommend and approve people for entry into a range of government-subsidised aged care services based on a person's long-term care needs. Approvals are not only provided for immediate use of services but also for future use if a person's care needs are likely to change. This means that people can be approved for multiple services.

Of the First Nations people with dementia who completed a comprehensive assessment in 2021–22:

- 66% or 249 people were approved for residential respite care
- 62% or 235 people were approved for community-based care under the Home Care Packages Program
- 58% or 220 people were approved for permanent residential aged care.

Approvals for people with dementia who completed a home support assessment were not readily available in the NSAF data.

Use of permanent residential aged care

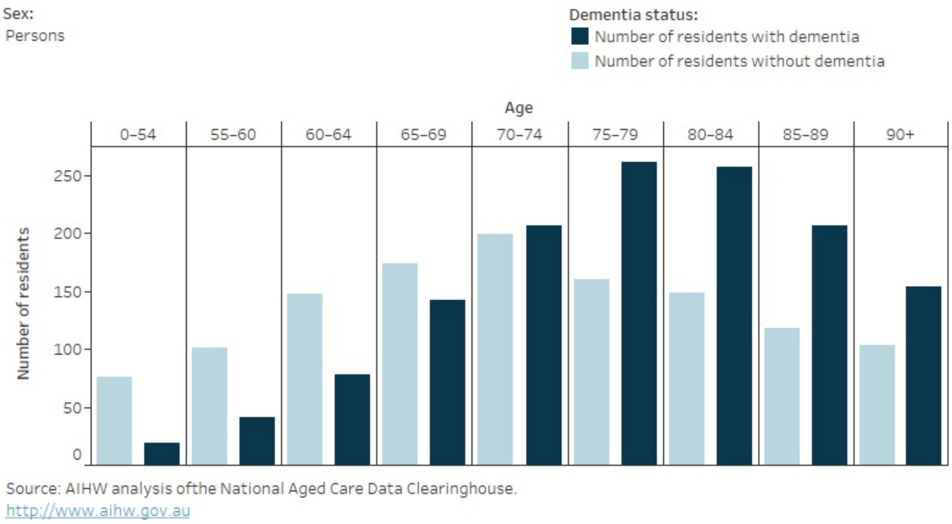
This section presents data from Aged Care Funding Instrument (ACFI) appraisals to describe the characteristics of First Nations People with dementia living in permanent residential aged care. The ACFI is a funding tool used by the Australian Government to allocate funding to providers based on the ongoing care needs of people living in residential aged care. See Residential aged care for more details on the ACFI and residential aged care provision in Australia.

During 2020-21, about 241,000 people were living in permanent residential aged care services across Australia. Of these, just under 2,600 (1%) identified as being First Nations. About half (53% or 1,370) of the First Nations people living in permanent residential aged care had dementia.

Figure 12.16 shows the age profile of First Nations people living in permanent residential aged care by dementia status. First Nations men and women with dementia were older than First Nations people without dementia.

Figure 12.16: First Nations people living in permanent residential aged care 2021–22: number, by dementia status, age and sex

A bar chart showing the number of First Nations people living in permanent residential aged care in 2021–22 by age and sex. The number of First Nations people with dementia living in residential aged care increases with age until 75 to 79. Both First Nations men and women with dementia were older than First Nations men and women without dementia living in residential aged care.



Source: AIHW analysis ofthe National Aged Care Data Clearinghouse.
http://www.aihw.gov.au

The number of First Nations people with dementia living in permanent residential aged care has increased in recent years from just under 1,100 in 2014–15 to just under 1,370 in 2021–22. Consistently, just over 50% of First Nations people living in permanent residential aged care were living with dementia during this 7-year period.

Time spent living in permanent residential care

A person can have more than one episode of care in a residential aged care facility in a given year if, for example, they moved from one facility to another. A separation from an 'episode of care' is most commonly due to: death, prolonged admission to hospital, movement to another residential aged care facility, or returning to the community. First Nations people with dementia who separated from their latest episode of care during 2021–22 had a median stay of 2.2 years, with the majority of separations due to death (87%).

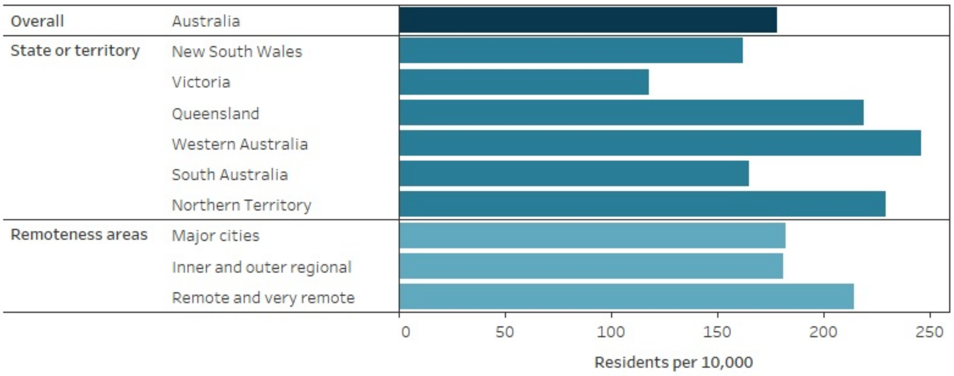
Use of residential aged care services by state/territory and remoteness area

Figure 12.17 shows how the age-standardised rate of permanent residential aged care use among First Nations people varied by dementia status and across geographic areas in 2021–22. After accounting for population differences:

- across states and territories, the rate of permanent residential aged care use for First Nations people with dementia was highest in Western Australia (246 people with dementia per 10,000 First Nations people) and lowest in New South Wales and Victoria (162 and 119 people with dementia per 10,000 First Nations people, respectively). Due to data limitations, rates for Tasmania and the Australian Capital Territory are not included
- First Nations people with dementia tended to use permanent residential aged care services at higher rates in more remote areas – 214 people with dementia per 10,000 First Nations people in *Remote and very remote areas* compared with 181 and 182 people with dementia per 10,000 First Nations people in *Inner and outer regional areas* and *Major cities*, respectively.

Figure 12.17: First Nations people with dementia living in permanent residential aged care 2021-22: age standardised rate, by state/territory and remoteness

A bar graph showing the age standardised rate of First Nations people with dementia living in permanent residential aged care in 2021–22 by state and territory and remoteness area.



Notes
1. The age-standardised rates, which apply to people aged 50 and over, were standardised to the Australian population as at 30 June 2001 and are expressed per 10,000 population.
2. Due to data limitations, rates are not presented for Tasmania or the Australian Capital Territory.
Source: AIHW analysis of the National Aged Care Data Clearinghouse.
http://www.aihw.gov.au

Co-existing health conditions

The ACFI collects information on health conditions that impact on a person's care needs. This includes up to 3 mental and behavioural disorders (including dementia), as well as three medical conditions impacting care needs.

During 2021–22, depression and mood disorders (40%), arthritis and related disorders (36%), and urinary incontinence (28%) were the 3 most common health conditions among First Nations people with dementia living in permanent residential aged care (Table S12.32). Other common conditions included: type 2 diabetes mellitus (23%), hypertension (17%), pain (16%), anxiety and stress related disorders (16%), chronic lower respiratory diseases (16%), stroke (12%), falls (9.2%), kidney and urinary system disorders (8.7%) and other mental and behavioural disorders (8.1%).

Care needs

The ACFI determines the funding allocation for a resident based on the level of care they require in three domains: *Activities of daily living*, *Cognition and behaviour* and *Complex health care*.

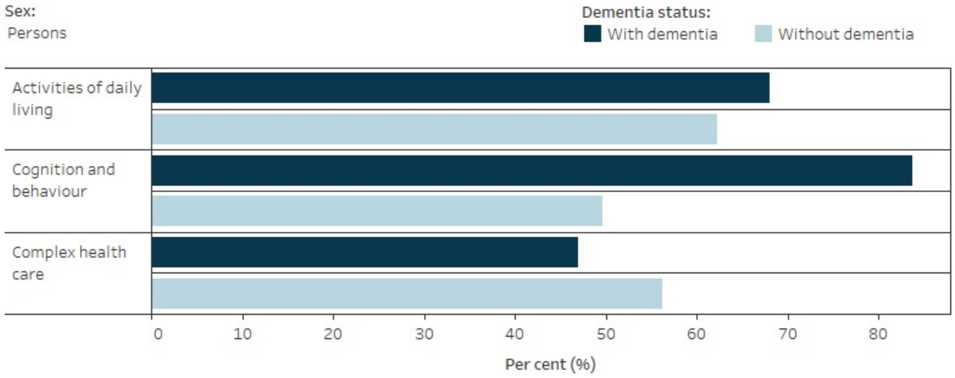
Among First Nations people with dementia who were living in permanent residential aged care in 2021–22:

- 68% required high levels of care related to *Activities of daily living* (such as nutrition, mobility, personal hygiene, toileting and continence needs) – this was slightly higher than for First Nations people without dementia (62%)
- 84% required high levels of care related to their *Cognition and behaviour*, which includes cognitive skills, wandering, verbal behaviour, physical behaviour and depression – this was higher than for First Nations people without dementia (50%)
- 47% required high levels of care related to *Complex health care*, which includes ongoing medication needs and complex health-care procedures – this was lower than for First Nations people without dementia (56%)

For each ACFI domain, there was little difference in percentage of men and women with dementia with the highest care needs. It is important to remember that many First Nations people access comprehensive care outside their home that is not captured in the ACFI data, such as through the National Aboriginal and Torres Strait Islander Flexible Aged Care Program, so information presented in this report does not comprehensively capture the care needs of all First Nations people accessing residential aged care services.

Figure 12.18: First Nations people living in permanent residential aged care with the highest care needs in each ACFI domain 2021–22: percentage, by sex and dementia status

A bar chart showing the percentage of First Nations people living in residential aged care with and without dementia who required high levels of care in each ACFI domain in 2021–22 by sex.



Notes
1. The *Activities of daily living* domain includes needs related to mobility, continence and nutrition.
2. The *Cognition and behaviour* domain includes needs related to cognitive skills, wandering, verbal behaviour, physical behaviour and depression.
3. The *Complex health care* domain includes needs related to management of chronic pain, chronic infectious conditions, ongoing tube feeding and oxygen therapy.
Source: AIHW analysis of Aged Care Funding Instrument.
http://www.aihw.gov.au

References

AIHW (Australian institute of Health and Welfare) (2019) *Aged care for Indigenous Australians*, AIHW, Australian Government, accessed 20 June 2023.

AIHW (2021) *Aboriginal and Torres Strait Islander Stolen Generations aged 50 and over: updated analyses for 2018–19*, AIHW, Australian Government, accessed 20 June 2023.

Healing Foundation (2019) *Working with the Stolen Generations: understanding trauma. Providing effective aged care services to Stolen Generations survivors*, Healing Foundation website, accessed 26 June 2023.

Healing Foundation and Aboriginal and Torres Strait Islander Ageing Advisory Group of the Australian Association of Gerontology (2019) *Stolen Generations aged care forum report August 2019*, Royal Commission in Aged Care Quality and Safety website, accessed 26 June 2023.

Ng NSQ and Ward SA (2019) 'Diagnosis of dementia in Australia: a narrative review of services and models of care', *Australian Health Review*, 43(4):415–424, doi:10.1071/AH17167.

Radford K, Lavrencic LM, Delbaere K, Draper B, Cumming R, Daylight G, Mack HA, Chalkley S, Bennett, H, Garvey G, Hill TY, Lasschuit D and Broe GA (2019) 'Factors associated with the high prevalence of dementia in older Aboriginal Australians', *Journal of Alzheimer's Disease*, 70(s1):S75–S85, doi:10.3233/JAD-180573.

Royal Commission (Royal Commission into Aged Care Quality and Safety) (2021) *Final report: Care, dignity and respect*, Royal Commission, Australian government, accessed 26 June 2023.

Dementia in priority groups

First Nations-specific health and aged care programs

There is uncertainty regarding how First Nations people use government-subsidised health and aged care services due to issues related to: health and aged care workers preferring not to ask about First Nation status; under-disclosure of First Nation status when asked; inadequate data collection; and small First Nations samples in surveys limiting meaningful extrapolations.

There is however robust evidence that First Nations people prefer First Nations-specific services. Studies have also shown that First Nations people prefer services that allow people with dementia to remain in their homes and communities, and which are locally designed in partnership with communities (Lindeman et al. 2017). Other factors enabling First Nations people to access dementia services and support include: availability of affordable dementia support services on Country; accessible transport options to reach service providers; and reasonable waiting times for health and aged care services (Alzheimer's Australia 2007; Flicker and Holdsworth 2014).

Good Spirit, Good Life, a quality of life framework assessment and package of resources, has recently been developed and validated with Aboriginal elders and could be used to inform national aged care assessment tools. This validated package enables the cultural wellbeing priorities and unmet needs of older First Nations people with and without dementia to be identified, to inform culturally safe care plans, and for elder-informed strategies to be implemented and evaluated (Smith et al. 2020). It also outlines a culturally based and designed framework for supporting the healing and strengthening of the spirit of older First Nations people and thus health and wellbeing outcomes. The Good Spirit, Good Life package is available to be downloaded from Improving the Health and Wellbeing of older Aboriginal and Torres Strait Islander people.

First Nations-specific health and aged care services are essential for providing appropriate care that takes into account the challenges faced by people with dementia, as well as by their carers and communities. Aboriginal Community Controlled Health Services (ACCHS) deliver holistic and culturally appropriate health services to communities, and are often a first point of contact for First Nations people with dementia. ACCHS can also act as a referral point to other available services like specialist care, and can help First Nations people navigate the aged care system. In its final report, the Royal Commission recommended prioritising assistance to Aboriginal and Torres Strait Islander organisations to expand into aged care service delivery, including in partnerships with existing Aboriginal Community Controlled Organisations (Royal Commission 2021). First Nations people health services and other primary health-care providers are also integral for managing risk factors for developing dementia, including providing services such as subsidised First Nations-specific health checks and follow-up care, as well as pharmaceutical subsidies for First Nations people with (or at risk of developing) a chronic disease (Department of Health and Aged Care 2022).

The National Health and Medical Research Council (NHMRC) has recently developed a roadmap for driving strengths-based, high-priority research on dementia among First Nations people (NHMRC 2020). The NHMRC has also funded a number of targeted research projects that collaborate with Aboriginal Community Controlled Health Services and First Nations communities to improve the prevention, detection and management of cognitive impairment and dementia (NHMRC 2018).

While First Nations-specific services are important providers of high-quality dementia care for First Nations people, it is important that all government-subsidised health and aged care services provide a culturally safe and accessible environment. In its final report, the Royal Commission made several recommendations to move towards an aged care system that provides culturally safe and flexible care for First Nations people, including in services that are not First Nations-specific (Royal Commission 2021).

Caring for others with dementia

Family and other community members tend to play a strong caring role in First Nations communities, and caring roles are often shared across the community. Elders play a key role in many First Nations communities and there tends to be a strong preference for people with dementia to age and die on Country.

The ABS Survey of Disability, Ageing and Carers is the only national data source providing information on unpaid carers in Australia. However, due to sampling issues, data on First Nations carers of people with dementia and/or carers of people with First Nations people with dementia are not available. While there is limited information available on First Nations people caring for someone with dementia specifically, previous work has highlighted challenges faced by First Nations carers more broadly (Hill et al. 2012). These include:

- limited options for culturally safe respite care, which places more burden on carers. In some remote areas, there may be no available respite services
- greater financial costs incurred by carers in regional and remote areas, where carer payments and allowances are insufficient to cover the higher costs of transport, medications, and special equipment required to assist with care
- difficulties with navigating government systems and processes to claim carer-related payments
- high costs of respite and community services in regional and remote areas, when these are available
- higher rates of informal caregiving among First Nations people than among non-Indigenous Australians. First Nations carers are more likely to be younger and female, and to face challenges related to their own health and financial resources.

A recent study by LoGiudice et al. (2020) showed that carers of older First Nations people living in remote Western Australia tended to be young and female (mostly children and grandchildren), and that carers who attended high school and felt empowered, had a lower sense of carer burden.

References

Alzheimer’s Australia (2007) *Support Needs of People living with Dementia in Rural and Remote Australia: Report of Findings*, Dementia Australia website, accessed 14 July 2023.

Department of Health and Aged Care (2022) *Annual health checks for Aboriginal and Torres Strait Islander people*, Department of Health and Aged Care, Australian Government, accessed 14 July 2023.

Flicker L and Holdsworth K (2014) *Aboriginal and Torres Strait islander people and dementia: a review of the research*, Alzheimer's Australia, accessed 14 July 2023.

Hill T, Cass B, Newton BJ and Valentine K (2012) *Indigenous carers*, Royal Commission into Aged Care website, accessed 14 July 2023.

Lindeman MA, Smith K, LoGiudice D and Elliott M (2017) 'Community care for Indigenous older people: an update', *Australasian Journal on Ageing*, 36(2):124–127, doi:10.1111/ajag.12316.

LoGiudice D, Josif CM, Malay R, Hyde Z, Haswell M, Lindeman MA, Etherton-Beer C, Atkinson D, Bessarab D, Flicker L and Smith K (2020) 'The well-being of carers of older Aboriginal people living in the Kimberley Region of remote Western Australia: empowerment, depression, and carer burden', *Journal of Applied Gerontology*, 40(7):693-702, doi:10.1177/0733464819898667.

NHMRC (National Health and Medical Research Council) (2018) *Let's CHAT (Community Health Approaches To) - dementia in Indigenous communities*, Research Data Australia website, accessed 14 July 2023.

NHMRC (2020) *Aboriginal and Torres Strait Islander roadmap for dementia research and translation*, NHMRC website, accessed 2 August 2021.

Royal Commission (Royal Commission into Aged Care Quality and Safety) (2021) *Final report: Care, dignity and respect*, Royal Commission, Australian Government, accessed 14 July 2023.

Dementia in priority groups

Australia has a long and rich history of immigration, and as a result, the Australian population includes a large number of people who were born overseas, have a parent born overseas and/or who speak a variety of languages. These groups of people are generally referred to as culturally and linguistically diverse (CALD) populations. However, it is not always easy to identify CALD people or populations in data because the relevant information is not always systematically recorded. As a result of these limitations, this section mainly uses both country of birth and main language spoken at home to identify CALD populations.

Understanding dementia with respect to people of CALD backgrounds is essential for health and aged care policy and planning, as research suggests that the CALD community, or specific cultural subgroups may experience different patterns of disease, health risk factors and access to and utilisation of services (AIHW 2018). Widespread use of appropriate dementia diagnostic tools (such as the Rowland Universal Dementia Assessment Scale (RUDAS)) are needed to ensure diagnosis is not further delayed due to communication and cultural differences. Further, as people with dementia who can speak multiple languages will often revert to their first language or mix languages as their dementia progresses, this can lead to communication barriers that can cause feelings of isolation, loneliness, and anxiety and depression in those with dementia and result in their needs not being met.

Until more information is available, this page aims to explore dementia in CALD communities in Australia, using the currently available national data, by:

- examining patterns of cultural and linguistic diversity in people living with dementia
- assessing the use of permanent residential aged care services by people with dementia from CALD backgrounds and how this compares with people from English speaking backgrounds (skip to this section)
- examining the source of assistance for people with dementia from CALD backgrounds and how this compares with people from English speaking backgrounds (skip to this section)
- exploring CALD among primary carers of people with dementia (skip to this section).

See Cultural linguistic diversity among Australians who died with dementia for patterns of CALD among people who died with dementia, using linked Census and mortality data. For more information on this priority population group, see culturally and linguistically diverse Australians.

Expand the sections below for more information on what data are available to report on dementia in Australia's CALD communities, limitations of these data and what is being done to improve them.

What national data are available to report on dementia in Australia's CALD communities

According to the 2021 Census of Population and Housing, 7 million people residing in Australia at the time of being surveyed were born overseas (ABS 2022). The birthplace composition of Australia's older population, 65 years and over, is largely reflective of the waves of migration that have occurred since World War Two (Wilson et al. 2020). The oldest Australians today who were born overseas primarily come from the British Isles and New Zealand, followed by Western and Eastern Europe. This migration wave was followed by Southern Europe, particularly Italy, Malta and Greece. A recent study by the University of Melbourne projects an increase in the population of overseas born Australians, which will shift from European-born dominance to Asia-born dominance (Wilson et al. 2020). As age is one of the most prominent risk factors for dementia, the birthplace composition of older age groups in Australia gives insight into the communities that may be impacted by dementia. In addition, changes in migration patterns also need to be considered with respect to the aged care workforce, particularly differences in languages other than English spoken among aged care workers compared with their older care recipients.

Due to the limited national data on dementia that includes identifiers of culturally and linguistically diverse communities in Australia, data in this report are limited to:

- ABS Survey of Disability, Ageing and Carers (SDAC) – is a national survey which collects information about 3 target populations: people with disability (that is, those who have a limitation, restriction or impairment, which has lasted, or is likely to last, for at least six months and restricts every-day activities), people aged 65 or over, and people who care for individuals with disability, or older people. These data identify Australians with dementia and record country of birth, main language spoken and English language proficiency.
- The Aged Care Funding Instrument (ACFI) data set (a data holding within the National Aged Care Data Clearinghouse (NACDC)) – these data identify people with dementia who are living in permanent residential aged care, as well as recipient demographic data (including country of birth and main language spoken) that can be linked to the ACFI.
- Multi-Agency Data Integration Project (MADIP) – a partnership among Australian Government agencies to develop a secure and enduring approach for combining information on healthcare, education, government payments, personal income tax, and population demographics (including the Census) to create a comprehensive picture of Australia over time. For this report, people who died with dementia were identified using mortality data and their country of birth, ancestry, year of arrival, language spoken at home, religion and English language proficiency were derived from the 2016 Census.

Note, these data sources draw from different population groups and do not represent all Australians with dementia. For example, dementia is only recorded if it contributes to a persons' limitation, restriction or impairment in the SDAC; if it is a main condition impacting care needs in the ACFI; and if it is on a persons' death certificate as an underlying or associated cause of death in MADIP. Not all people with dementia are captured by these data.

Limitations in data on dementia in CALD communities and what is being done to improve this?

Unfortunately, there are few national data sources that provide insight on the CALD community living with dementia in Australia. The Federation of Ethnic Communities' Councils of Australia (FECCA) (2015) concluded that while there is a substantial body of research available evaluating the culturally sensitive tools for dementia diagnosis, there is little known about the experience of older CALD Australians with dementia, including diagnostic rates, age of onset, their experiences and interactions with medical professionals as well as broader health, aged care and social support services.

More high-quality data on CALD among people with dementia are required for service planning and development. To highlight and address these gaps, the then National Health and Medical Research Councils National Institute of Dementia Research (NNIDR) and the National Ageing Research Institute (NARI) published a CALD Dementia Research Action Plan. The plan aims to increase CALD inclusion in dementia research (NNIDR and NARI 2020).

The Australian Clinical Trials Alliance (2020a) has also published a position statement with guiding principles on recognising underrepresentation of people from CALD backgrounds and how to increase and enhance diversity in clinical trials. A review of national and international initiatives was also undertaken that have aimed to increase participation in clinical trials by ethnic minority groups. This aims to understand how to improve and develop clinical trial awareness, involvement and access for the CALD populations of Australia, and if successful, could offer a greater insight into Australia's CALD population living with dementia (Australian Clinical Trials Alliance 2020b).

There are a number of risk factors for dementia which people born in certain countries may experience at different rates compared to people who were born and live in Australia. This includes increased mortality and hospitalisations rates from type 2 diabetes mellitus and self-reported mental health conditions (AIHW 2005; Jatrana et al. 2017). However, people from CALD backgrounds are less likely to report drinking alcohol at harmful levels and are more likely to report that they have never smoked than English speakers (AIHW 2020). More research is needed on the current prevalence of risk factors for dementia among people in Australia from CALD backgrounds, including sub-populations in the CALD community and how these are changing over time.

New health condition question in the 2021 Census

For the first time, the 2021 ABS Census of Population and Housing collected information from respondents on selected health conditions. This new question enables examination of self-reported dementia by a wide range of demographic information, including for CALD communities.

Some key findings for dementia include:

- Those born in Italy had the highest rate of dementia after controlling for age differences.
- The rate of dementia increased as proficiency in English decreased.
- The longer that migrants have been in Australia, the higher the rate of dementia.

For further information on dementia and other chronic health conditions among CALD communities, see the following web report: Chronic health conditions among culturally and linguistically diverse Australians, 2021.

CALD among Australians with dementia

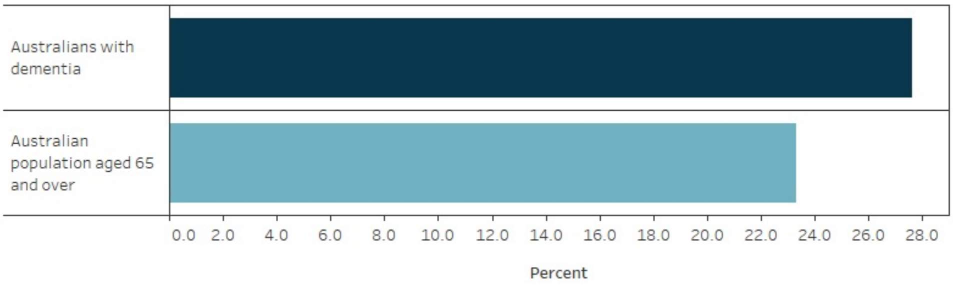
According to the SDAC, in 2018, 28% of people with dementia in Australia were born in a non-English speaking country (Figure 13.1). This proportion is slightly greater than what is reported for all Australians aged 65 and over in 2018 according to the ABS Estimated Resident Population (23% of Australians aged 65 and over were born in a non-English speaking country).

Italy was the most common non-English speaking country of birth among those with dementia, accounting for 3.5% of all people with dementia in 2018. This is largely reflective of the post-World War II migration of Italians to Australia (ABS 2020). Greece and China were the next most common non-English speaking countries of birth among those with dementia (3.0% and 2.2%, respectively) (Table S13.2).

The SDAC also collected information on English proficiency for those whose main language spoken at home was not English. Around 62% of people with dementia whose main language was not English, reported that they either did not speak English or if they spoke English they did not speak it well (Table S13.3).

Figure 13.1: Cultural and linguistic diversity among people with dementia and Australians aged 65 and over in 2018: percentage who were born in non-English speaking countries

Figure 13.1 is a bar graph showing the percentage of people who were born in a non-English speaking country among Australians with dementia and all Australians aged 65 and over, in 2018. It shows that a slightly higher proportion of Australians with dementia were born in a non-English country (28%), compared with all Australians aged 65 and over (23%).



Notes:
1. People who were born in non-English speaking countries excludes people who were born in Australia, Canada, Ireland, New Zealand, South Africa, United Kingdom and United States of America.
2. 'Australians with dementia' includes all people who reported having dementia in 2018 from the ABS Survey of Disabilty Ageing and Carers 2018.
3. 'Australian population aged 65 and over' is based on the 2018 ABS Estimated Residential Population.

Source: AIHW analysis of ABS 2018 Survey of Disability, Ageing and Carers confidentialised unit record file; ABS Estimated Residential Population.
http://www.aihw.gov.au

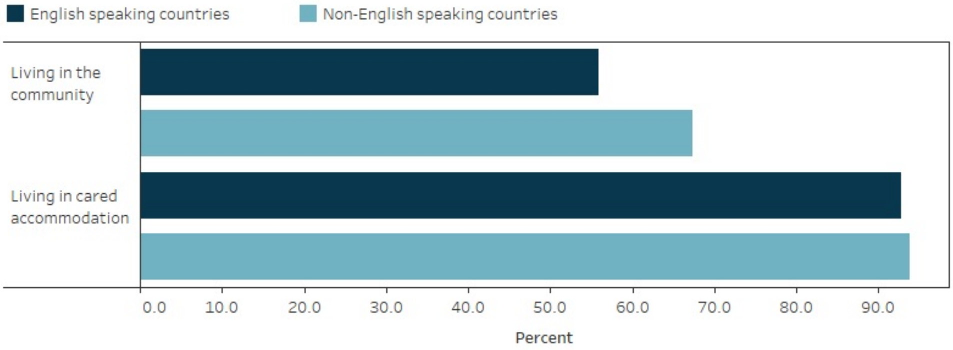
It is important to note that there are a number of issues with using the SDAC to report on people with dementia, and further for those with dementia from CALD backgrounds. The SDAC may underestimate the number of people with dementia living in the community as it relies on people in the community self-reporting their health condition rather than a medical assessment. Issues of stigma associated with dementia may affect the likelihood that a person reports their condition in this survey, and this may vary depending on cultural background. In addition, language barriers and cultural practices may affect when people are diagnosed with dementia, meaning that people from CALD backgrounds may have greater levels of undiagnosed dementia than other Australians, especially among those who are not living in residential aged care. However, the use of proxy interviews for SDAC respondents who experience language barriers would minimise this issue. Despite this, the proportion of people with dementia from CALD backgrounds may still be underestimated by the SDAC data.

Level of disability

According to the SDAC, in 2018, 67% of people with dementia who were born in non-English speaking countries and were living in the community had profound limitations. That is, they are unable to do, or always need help with self-care, communication and/or mobility (Figure 13.2). By comparison, 56% of people with dementia who were born in English speaking countries had profound limitations. However, this difference was not statistically significant. There was also no statistically significant difference in the percentage of people with dementia who had profound limitations by region of birth among those living in cared accommodation.

Figure 13.2: People with dementia with profound limitations in 2018: percentage by region of birth and place of residence

Figure 13.2 is a bar graph that shows the percentage of people with dementia who had profound limitations in 2018, by whether they were living in the community or cared accommodation and whether they were born in an English or non-English speaking country. In comparison to people with dementia living in cared accommodation, lower proportions of people with dementia living in the community had profound limitations. Among those living in the community, people born in English speaking countries were less likely to have profound limitations compared with those born in non-English speaking countries (56% versus 67% respectively had profound limitations). Among people living in cared accommodation there was little difference between those who were, and were not, born in English speaking countries.



Note: People who were born in Non-English speaking countries excludes people who were born in Australia, Canada, Ireland, New Zealand, South Africa, United Kingdom and United States of America.
Source: AIHW analysis of ABS 2018 Survey of Disability, Ageing and Carers confidentialised unit record file.
http://www.aihw.gov.au

Co-existing health conditions

Based on the SDAC, in 2018, there were some distinct differences in the most common co-existing health conditions of people with dementia between people born in English speaking countries compared with those born in non-English speaking countries (Figure 13.3). These differences were mainly evident among those living in the community.

Among people with dementia living in the community, the following co-existing health conditions were most commonly reported among those who were born in non-English speaking countries:

- hypertension – reported in 42% of people born in non-English speaking countries
- diabetes – 33%
- high cholesterol– 31%
- back problems – 20%
- other deafness/ hearing loss – 19%
- depression – 14%.

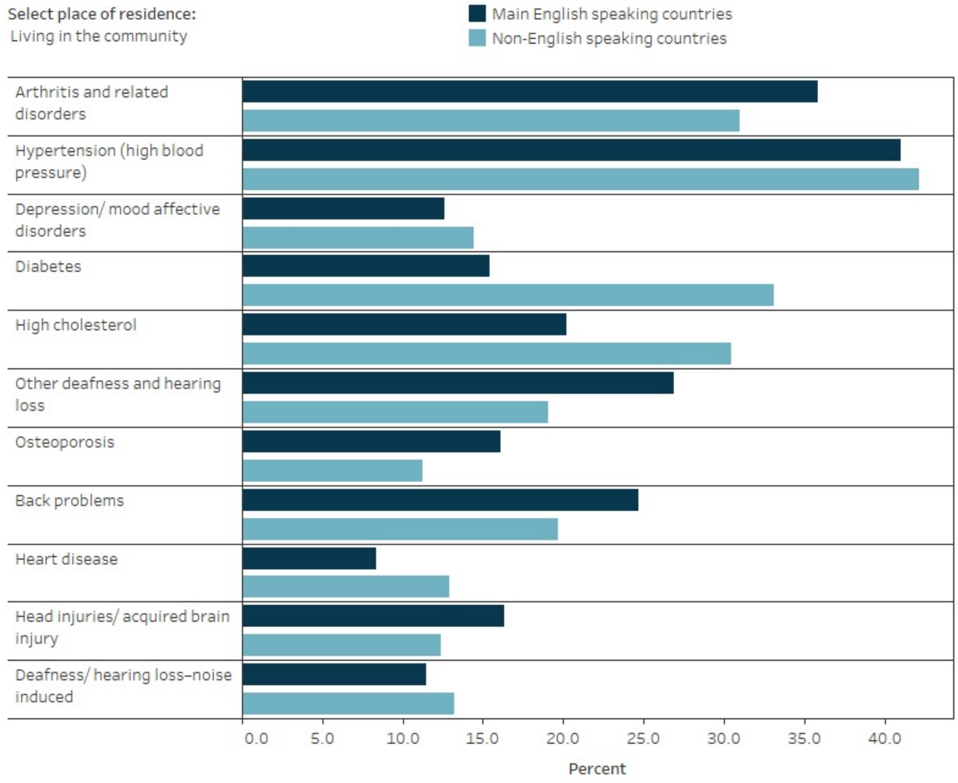
Diabetes was reported significantly more among people with dementia born in non-English speaking countries than those born in English speaking countries (15%). There was no significant difference between common co-existing conditions reported by people with dementia born in non-English speaking countries to those born in English speaking countries.

Among people with dementia who were living in cared accommodation, diabetes was reported in 25% of people with dementia from non-English speaking countries compared with 16% of those with dementia born in English speaking countries. For all other health conditions, there were similar patterns between people born in non-English speaking countries and people born in English speaking countries.

The conditions shown in Figure 13.3 (besides back problems, arthritis and osteoporosis) are also known risk factors for dementia. See the What puts someone at risk of developing dementia? for more information.

Figure 13.3: Common co-existing conditions among people with dementia in 2018: percentage by region of birth and place of residence

Figure 13.3 is a bar graph that shows the percentage of people with dementia who had each of the 10 most common health conditions in 2018, by whether the person was born in an English speaking country and place of residence. *Arthritis and related disorders, Hypertension (high blood pressure)* and *Depression/mood affective disorders* were the most common conditions among those living in cared accommodation, regardless of whether they were born in a main English speaking country. Among those living in the community *Hypertension (high blood pressure)* and *Arthritis and related disorders* were the most common health conditions. Diabetes was more common for those born in non-English speaking countries than for those born in English speaking countries, regardless of place of residence.



Notes:
1. As a person may have more than one health condition, percentages will sum to more than 100%.
2. People who were born in Non-English speaking countries exclude people who were born in Australia, Canada, Ireland, New Zealand, South Africa, United Kingdom and United States of America.
3. Health conditions were based on the International Classification of Diseases and Related Health Problems, 10th Revision (ICD-10). Refer to the Technical notes for more information on health conditions in the SDAC.
4. 'Other deafness/ hearing loss' includes the ICD-10 codes H910-912 and H918-919.
5. 'Diabetes' includes the ICD-10 codes E10-14.
6. Estimates for people with dementia living in cared accommodation born in English speaking countries who also had heart disease has a relative standard error between 25% and 50% and should be used with caution.
7. Estimates for people with dementia living in cared accommodation born in non-English speaking countries who also had depression/ mood affective disorders, other deafness and hearing loss, back problems, head injuries/ acquired brain injury and deafness/ hearing loss- noise induced have a relative standard error between 25% and 50% and should be used with caution.

Source: AIHW analysis of ABS 2018 Survey of Disability, Ageing and Carers confidentialised unit record file.
http://www.aihw.gov.au

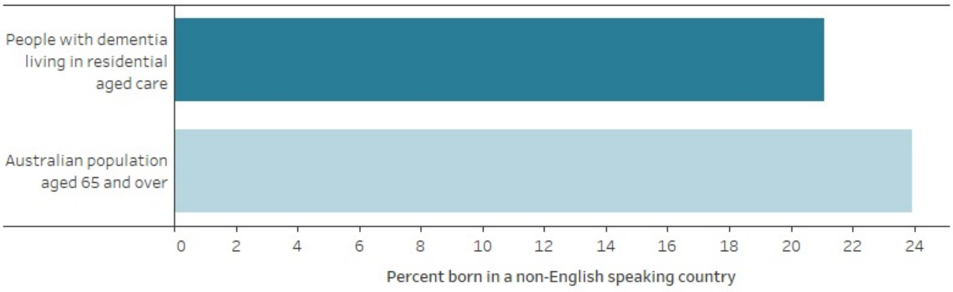
CALD among Australians with dementia living in permanent residential aged care facilities

According to Aged Care Funding Instrument data, 21% of people with dementia living in permanent residential aged care facilities in 2021–22 were born in a non-English speaking country (Figure 13.4, see Residential aged care for more detail on this data). This is lower than the proportion of all people with dementia in 2018 as estimated by SDAC (28%). Italy was the most common non-English speaking country of birth among people with dementia living in permanent residential aged care (3.9%). This was followed by mostly European countries, including Greece (2%), Germany (1.4%), and the Netherlands (1.2%).

The smaller proportion of people from CALD backgrounds in permanent residential aged care may reflect differences in how aged care services are used by people from CALD backgrounds. Use of residential aged care is likely to be affected by cultural attitudes to formal aged care services and family obligations or cultural norms for providing care, as well as variation in the availability of culture-specific residential aged care services. For some cultures, the responsibility of caring for the elderly population falls upon kin, and choosing residential care over a family member's home may be taboo (Rees & McCallum 2018). For people of CALD backgrounds, it can sometimes also be difficult to access and utilise services, if services are not designed with CALD communities in mind and if there are language barriers between service providers and people from non-English speaking backgrounds. Considerations when designing a service accessible to members of the CALD community may include providing information in a number of languages and ensuring the availability of interpreters, food choices, access and respect of cultural practices and family, and general independence (Aged Care Quality and Safety Commission 2020).

Figure 13.4: People with dementia living in permanent residential aged care and the Australian population aged 65 and over in 2021–22: percentage who were born in non-English speaking countries

Figure 13.4 is a bar graph that shows the percentage of people who were born in a non-English speaking country among Australians with dementia living in residential aged care compared with all Australians aged 65 and over, in 2021–22. It shows that a slightly lower proportion of Australians with dementia living in residential aged care were born in a non-English country (21%), compared with all Australians aged 65 and over (24%).



Notes
1. People who were born in a non-English speaking country does not include people who were born in Australia, Canada, Ireland, New Zealand, South Africa, United Kingdom and United States of America.
2. People with missing sex and age were included in this analysis and so totals do not match other counts of people living in permanent residential aged care in this report.
Source: AIHW analysis of the National Aged Care Clearinghouse and the ABS Estimated Residential Population.
http://www.aihw.gov.au

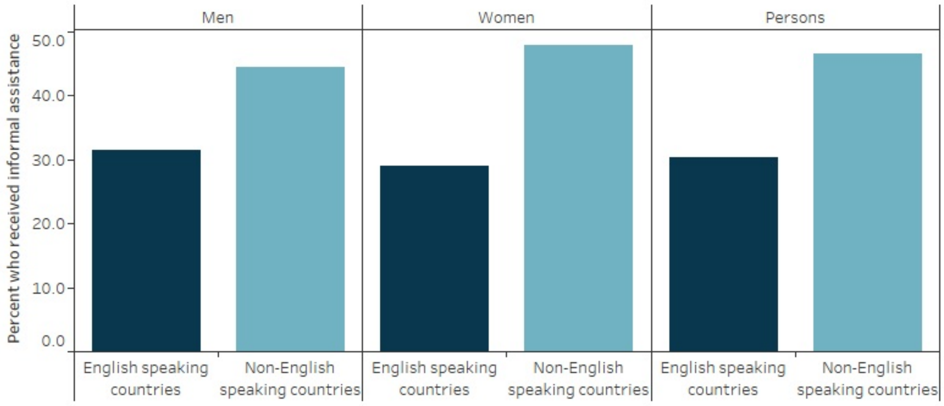
People with dementia from non-English speaking countries are more likely to rely on informal carers only

Based on the SDAC, in 2018 just under half (47%) of people with dementia who were living in the community and were born in non-English speaking countries and 30% who were born in English speaking countries relied on informal assistance only, as opposed to using formal services or a combination of formal services and informal assistance (Figure 13.5).

Among people with dementia, there were only slight differences by sex – 45% of men and 48% of women with dementia who were born in non-English speaking countries relied on informal assistance only. Whereas, 31% of men and 29% of women who were born in English speaking countries relied on informal assistance only.

Figure 13.5: People with dementia who lived in the community and received informal assistance only in 2018: percentages by region of birth and sex

Figure 13.5 is a bar graph that shows the proportion of people with dementia who relied on informal assistance only in 2018 by sex and whether they were born in non-English speaking countries. People born in non-English speaking countries were more likely to rely on informal assistance only—47%, compared with 30% of those born in English speaking countries.



Notes:
1. People who were born in Non-English speaking countries excludes people who were born in Australia, Canada, Ireland, New Zealand, South Africa, United Kingdom and United States of America.
2. 'Other assistance' includes people who relied on formal services only, a combination of informal and formal services and people who had no assistance. These data were too low to be presented individually. The proportion who had no assistance was minimal.
3. Men from non-English speaking countries who relied on informal assistance only has a relative standard error between 25% and 50% and should be used with caution.
Source: AIHW analysis of ABS 2018 Survey of Disability, Ageing and Carers confidentialised unit record file.
http://www.aihw.gov.au

Diversity among primary carers of people with dementia

It is not only the diversity of the people with dementia who need to be considered, but also their support systems (family and friends).

According to the SDAC in 2018:

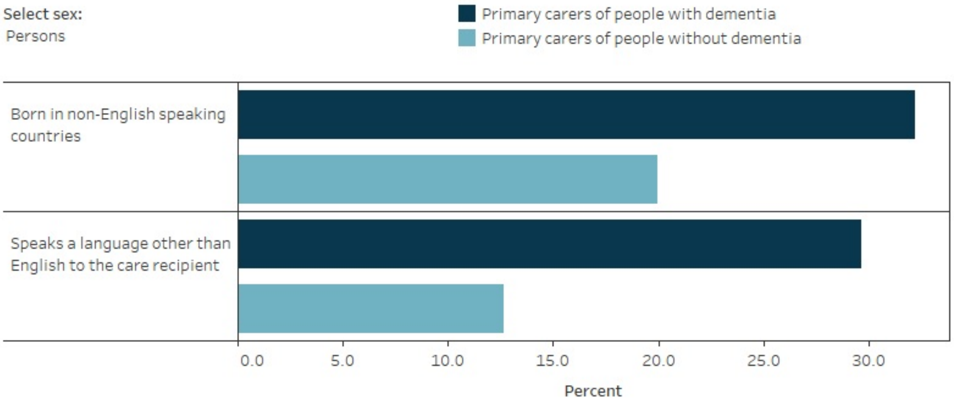
- 32% of primary carers of people with dementia were born in a non-English speaking country – this was significantly greater than among primary carers of people without dementia (20%).
- 30% of primary carers of people with dementia usually spoke a language other than English to their care recipient – this was also greater than among primary carers of people without dementia (13%) (Figure 13.6).

There was no statistical difference in the proportion of male carers who usually spoke a language other than English to their care recipient with dementia than female carers (36% and 27%, respectively).

Refer to Carers of people with dementia for more information on carers of people with dementia including the relationship of carers to their care recipients.

Figure 13.6: Primary carers of people with dementia and people without dementia in 2018: percentage by sex and CALD characteristics

Figure 13.6 is a bar graph that shows, among primary carers in 2018, the percentage who were born in non-English speaking countries and the percentage who spoke a language other than English to the care recipient. Results are disaggregated by sex and whether the person cared for someone with or without dementia. Overall, nearly 32% of primary carers of people with dementia were born in non-English speaking countries and 27% spoke a language other than English to their care recipient. In comparison, 20% of carers of people without dementia were born in a non-English speaking country and 13% spoke a language other than English to their care recipient.



Notes:
1. People who were born in non-English speaking countries exclude people who were born in Australia, Canada, Ireland, New Zealan, South Africa, United Kingdom and United States of America.
2. Estimates for male primary carers of people with dementia have a relative standard error of 25% to 50% and should be used with caution.
Source: AIHW analysis of ABS 2018 Survey of Disability, Ageing and Carers confidentialised unit record file.
http://www.aihw.gov.au

References

ABS (Australian Bureau of Statistics) (2022) *Cultural diversity of Australia*, ABS, Australian Government, accessed 26 June 2023.

AIHW (Australian Institute of Health and Welfare) (2005) *Diabetes in culturally and linguistically diverse Australians*, AIHW, Australian Government, accessed 26 June 2023.

AIHW (2020) *Alcohol, tobacco & other drugs in Australia*, AIHW, Australian Government, accessed 18 September 2020.

AIHW (2021) *Older Australia at a glance*, AIHW, Australian Government, accessed 26 June 2023.

Aged Care Quality and Safety Commission (2020) *Working with aged care consumers – Resource*, Aged Care Quality and Safety Commission, Australian Government, accessed 28 August 2020.

ACTA (Australian Clinical Trials Alliance) (2020a) *Advancing clinical trial awareness, involvement and access for people from CALD backgrounds: position statement*, ACTA website, accessed 24 August 2021.

ACTA (Australian Clinical Trials Alliance) (2020b) *ACTA Clinical trial awareness and access amongst culturally and linguistically diverse (CALD) populations: environmental scan*, ACTA website, accessed 28 August 2020.

FECCA (Federation of Ethnic Communities' Councils of Australia) (2015) *Review of Australian Research on Older People from Culturally and Linguistically Diverse Backgrounds*, FECCA website, accessed 4 July 2023.

Jatrana S, Richardson K and Samba SRA (2017) 'Investigating the dynamics of migration and health in Australia: a longitudinal study', *European Journal of Population*, 34: 519 – 565, doi:10.1007/s10680-017-9439-z.

NHMRC (National Health and Medical Research Council), NNIDR (National Institute for Dementia Research) and NARI (National Ageing Research Institute) (2020) *Culturally and Linguistically Diverse (CALD) Dementia Research Action Plan*, NHMRC website, accessed 4 July 2023.

Rees K and McCallum J (2018) *Dealing with Diversity: Aged care services for new and emerging communities*, National Seniors Australia website, accessed 4 July 2023.

Wilson T, McDonald P, Temple J, Brijnath B and Utomo A (2020) 'Past and projected growth of Australia's older migrant populations', *Genus* 76(20), doi:10.1186/s41118-020-00091-6.

Dementia in priority groups

This page presents data on nearly 27,800 Australians who had dementia recorded on their death certificate between September 2016 and December 2017, and had a linked 2016 Census record in the Multi-Agency Data Integration Project (MADIP). This includes information and statistics on CALD patterns by:

- region of birth
- place of residence
- year of arrival and country of birth
- ancestry, language spoken at home and English proficiency
- religious affiliation
- education.

It should be noted that the rate of "not stated" responses to questions in the Census are often relatively high for people with dementia, particularly for people living in residential aged care. When this is the case, the results should be interpreted with caution.

Region of birth

In the MADIP, country of birth information was available for 99% of people who died with dementia.

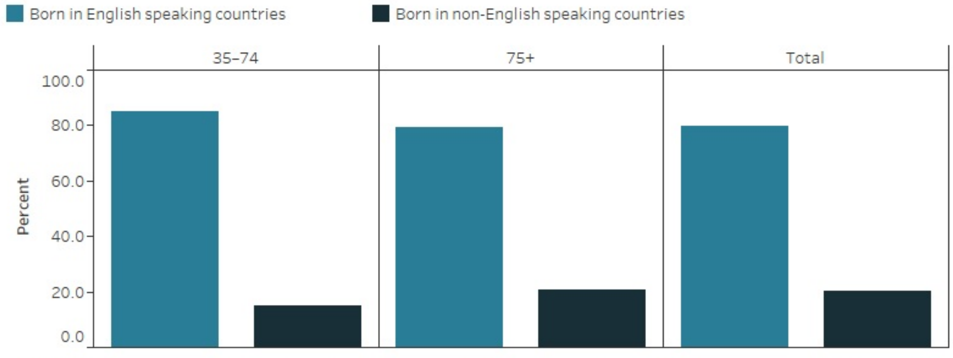
Of the people who died with dementia:

- 2 in 3 people were born in Australia and 1 in 3 were born overseas.
- 1 in 5 people (20%) were born in a non-English speaking country, most commonly European countries such as Italy, Greece and Germany (Table S13.11).

A smaller proportion of younger people who died with dementia (aged 35–74) were born in non-English speaking countries (15%) compared with people aged 75 and over (21%) (Figure 13.7).

Figure 13.7: People who died with dementia between September 2016 and December 2017: percentage by region of birth for each age group

Figure 13.7 is a bar graph that shows the proportion of people who died with dementia between September 2016 and December 2017 who were born in English-speaking countries or non-English speaking countries. These result are disaggregated by age. Around 80% of people who died with dementia were born in English speaking countries. This proportion was slightly higher for those who died aged 35–74 (85%) compared with those aged 75 and over (79%).



Note: People who were born in non-English speaking countries exclude people who were born in Australia, Canada, Ireland, New Zealand, South Africa, United Kingdom and United States of America.
Source: AIHW analysis of data in the ABS Multi-Agency Data Integration Project.
https://www.aihw.gov.au

A higher proportion of the overseas-born population who died with dementia were men (43%), when compared to the Australian-born population (38%), while the proportion of women was lower (57% of the overseas-born population, compared to 62% of those born in Australia) (Table S13.12). This difference could be influenced by the prioritization of male migration from some countries after World War II (Wilson et al. 2020).

The median age at death was similar for Australian-born and overseas-born people who died with dementia (88 years and 87 years, respectively). The median age at death for women (89 years) was higher than that for men (86 years) for both overseas- and Australian-born people (Table S13.12).

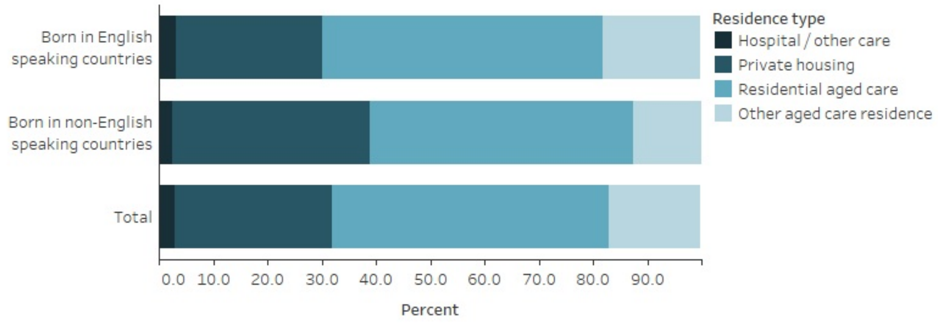
Place of residence

Of the people who died with dementia, when they completed the 2016 Census:

- Over half (51%) lived in a residential aged care facility.
    - This was only slightly lower among people born in non-English speaking countries (48%) than those born in English speaking countries (52%).
- 29% lived in a private dwelling.
    - This was higher among people born in non-English speaking countries (36%) than those born in English speaking countries (27%).
- 17% lived in accommodation for the retired or aged (other than a residential aged care facility).
    - This was lower among people born in non-English speaking countries (13%) than those born in English speaking countries (18%) (Figure 13.8).

Figure 13.8: People who died with dementia between September 2016 and December 2017: percentage by place of residence and region of birth

Figure 13.8 is a bar graph that shows the proportion of people who died with dementia between September 2016 and December 2017 who lived in each residence type, by whether they were born in an English speaking country. People who died with dementia were primarily living in residential aged care, followed by private housing. 36% of those born in non-English speaking countries who died between September 2016 and December 2017 were living in private housing in August 2016. This compares to27% of people born in English speaking countries.



Notes:
1. People who were born in Non-English speaking countries excludes people who were born in Australia, Canada, Ireland, New Zealand, South Africa, United Kingdom and United States of America.
2. 'Other aged care residence' excludes people who live in a self-contained residence. 'Hospital/ other care' includes people living in private hospitals, public hospitals, psychiatriv hospitals or hostels for the disabled.
3. Data exclude people whose country of birth was not stated or who were born at sea.
4. Residence is sourced from census data collected in August 2016.

Source: AIHW analysis of data in the ABS Multi-Agency Data Integration Project.
https://www.aihw.gov.au

Year of Arrival and Country of Birth

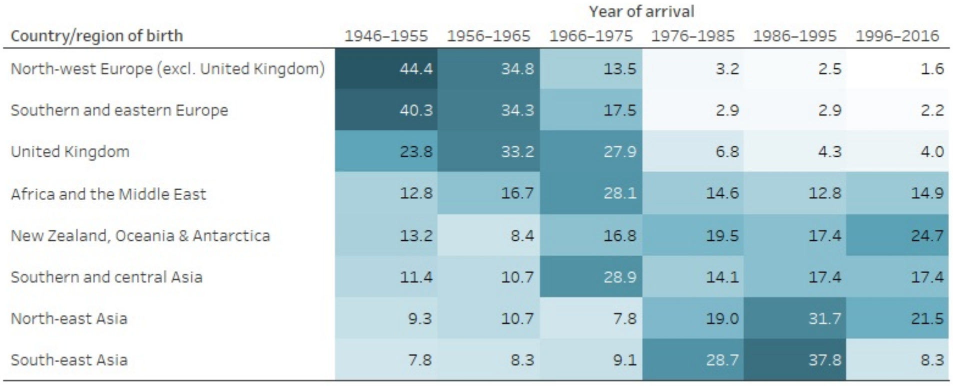
The different waves of migration to Australia (Wilson et al. 2020) are evident in the reported country of birth and year of arrival in Australia of people who died with dementia between September 2016 and December 2017 (Figure 13.9):

- Those born in Southern and Eastern Europe and North–West Europe predominantly immigrated to Australia between the late 1940s and the 1960s. For example, 75% of people born in Southern and Eastern Europe (including Italy and Greece) who died with dementia arrived in Australia between 1946 and 1965.
- 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.

Consideration of these migration patterns will be important in assessing and planning for the cultural needs of the dementia population as the population overall ages. Similarly, such patterns may be considered in assessing the needs of people with younger onset dementia, which may differ from older people with dementia. Importantly, the cultural diversity of Australia's older population may continue to change, as younger migrants from Asian countries support the migration of older relatives to Australia (Wilson et al. 2020).

Figure 13.9: People who died with dementia between September 2016 and December 2017: percentage by year of arrival and region of birth

Figure 13.9 is a table that shows the proportion of people who died with dementia between September 2016 and December 2017, by the world region in which they were born and their decade of arrival in Australia. Among those who died with dementia, those born in Southern and Eastern Europe and North-west 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.



Country/region of birth	Year of arrival 1946–1955	1956–1965	1966–1975	1976–1985	1986–1995	1996–2016
North-west Europe (excl. United Kingdom)	44.4	34.8	13.5	3.2	2.5	1.6
Southern and eastern Europe	40.3	34.3	17.5	2.9	2.9	2.2
United Kingdom	23.8	33.2	27.9	6.8	4.3	4.0
Africa and the Middle East	12.8	16.7	28.1	14.6	12.8	14.9
New Zealand, Oceania & Antarctica	13.2	8.4	16.8	19.5	17.4	24.7
Southern and central Asia	11.4	10.7	28.9	14.1	17.4	17.4
North-east Asia	9.3	10.7	7.8	19.0	31.7	21.5
South-east Asia	7.8	8.3	9.1	28.7	37.8	8.3

Note: Excludes people born in Australia and people who did not state their year of arrival in Australia.
Source: AIHW analysis of data in the ABS Multi-Agency Data Integration Project.
https://www.aihw.gov.au

Ancestry, language spoken at home and English proficiency

Ancestry reporting provides additional detail about a person's cultural affiliations. Respondents were able to report up to two ancestries in the 2016 Census, although 26% of people who died with dementia did not state any ancestry. Where ancestry information was reported, the most commonly reported ancestries of people who died with dementia were British (38%), Australian (30%), Irish, (7.3%), Southern and Eastern European (excluding Italian and Greek) (5.5%), Italian (5.1%) and German (4.0%) (Table S13.15).

In 2016, 83% of Australian-born people who died with dementia reported speaking only English at home and 1% reported speaking a different language. In comparison, 46% of the overseas-born population (includes English and non-English speaking countries) who died with dementia spoke a language other than English at home, and 41% reported speaking only English (Table S13.16).

These proportions differed for people who were born in non-English speaking countries: 16% spoke only English at home, and 73% spoke a language other than English. The most common of these languages were:

- Italian (19%)
- Eastern European languages (15%)
- Northern European languages (10%)
- Greek (10%)
- Chinese languages (5.1%)
- Southern European languages, excluding Italian and Greek (5.1%) (Table S13.17).

Of those born overseas, 31% reported that they did not speak English well, or not at all. Patterns of English proficiency varied depending on the year of arrival of migrants who died with dementia (Table S13.18–20).

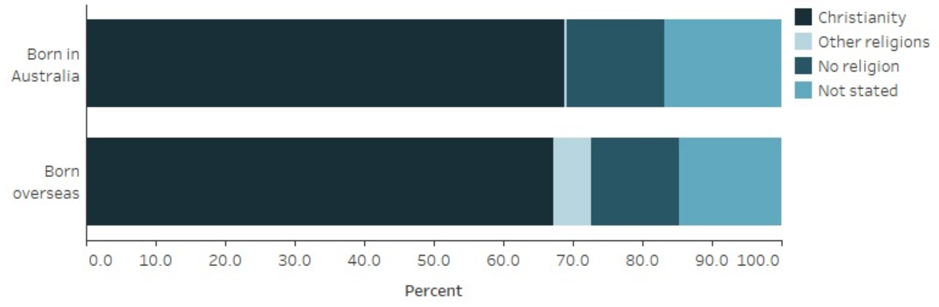
- 45% of relatively recent migrants (arrived since 1996), either did not speak English well, or not at all. The most common regions of birth for this group were Southern and Eastern Europe (including Italy and Greece) (29%), North-East Asia (including China) (29%), and North Africa and the Middle East (15%).
- 30% of earlier migrants (arrived before 1996) did not speak English well, or not at all, with Italy (30%), Southern and Eastern Europe (excluding Italy and Greece) (24%) and Greece (16%) the most common regions of birth in this group.

Religious affiliation

Christianity was the most commonly reported religion for Australian-born (69%) and overseas-born (67%) people who died with dementia (Figure 13.10). People born overseas were more likely to report a religion other than Christianity (5.5%), compared to people born in Australia (0.3%). A similar proportion reported they had no religious affiliation (13% of overseas-born and 14% of Australian-born people).

Figure 13.10: People who died with dementia between September 2016 and December 2017: percentage by region of birth and religion

Figure 13.10 is a bar graph that shows the proportion of people who died with dementia between September 2016 and December 2017, by whether they were born overseas and broad religious affiliation (if any). The majority of people who died with dementia had reported in the August 2016 census that they were Christian, for both those born overseas and those born in Australia. People born overseas were more likely to report that they belonged to religions other than Christianity.



Notes:
1. Religious affiliation is sourced from census data collected in August 2016.
2. 'No religion' includes secular and other spiritual beliefs.
3. 'Not stated' includes responses which were inadequately described.

Source: AIHW analysis of data in the ABS Multi-Agency Data Integration Project.
https://www.aihw.gov.au

Education

Lower levels of education are a modifiable risk factor for dementia (Livingston et al. 2020), and in Australia, dementia mortality rates are higher in people with lower levels of education (Welsh et al. 2021).

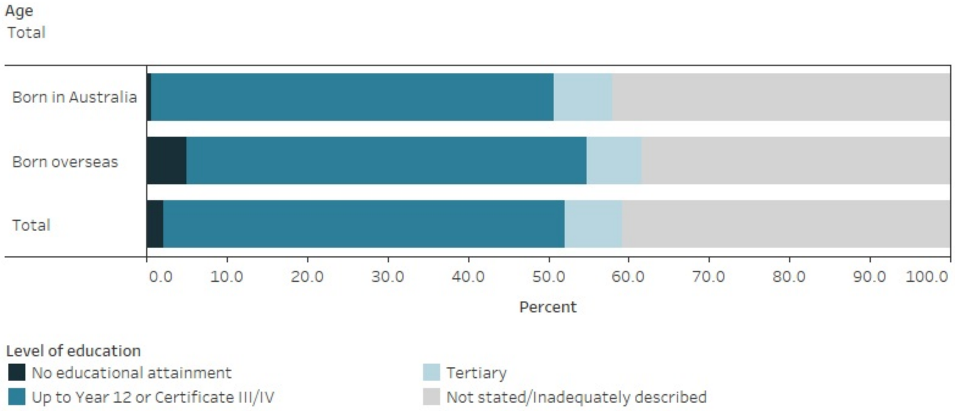
Among people who died with dementia, rates of no educational attainment were:

- higher among older people (aged 75 or over at the 2016 Census) born overseas (5.2%) compared with those born in Australia (0.5%)
- similar among younger people (aged 35–74 at the 2016 Census) in the overseas-born and Australian-born populations (2.5% and 2.4%, respectively) (Figure 13.11).

In the 2016 Census, questions about education were either not answered or inadequately described for 41% of respondents who subsequently died with dementia, compared to 24% of older Australians overall. For people who died with dementia, missing fields were more common for those living in residential aged care and other care facilities (51%) compared to those living in the community (17%). People living in residential aged care and other care facilities may have the census form completed for them by another person, which can lead to higher rates of not stated responses for some questions. Therefore, the following results do not represent all people who died with dementia and should be interpreted with caution.

Figure 13.11: People who died with dementia between September 2016 and December 2017: percentage by educational attainment, age and region of birth

Figure 13.11 is a bar graph that shows the proportion of people who died with dementia between September 2016 and December 2017 who had completed different levels of education, by whether or not they were born overseas and age. Among older people (75+), 5.2% of those born overseas had no educational attainment recorded and this compared with 0.5% of those born in Australia. Rates of no educational attainment were similar among younger people regardless of whether they were born in Australia. Overall, around half of people who died with dementia had completed education up to Year 12 or Certificate III/IV. Note that a high proportion (41%) did not state, or inadequately described, their level of education.



Notes:
1. Education is sourced from census data collected in August 2016.
2. 'Up to Year 12 or Certificate III/IV' includes: 'Years 9 and below', 'Certificate I and II', 'Years 10 and above' and 'Certificate III and IV'.
3. 'Tertiary' includes: 'Advanced Diploma and Diploma', 'Bachelor level', 'Graduate Diploma and Graduate Certificate' and 'Postgraduate'.

Source: AIHW analysis of data in the ABS Multi-Agency Data Integration Project.
https://www.aihw.gov.au

References

Welsh J, Joshy G, Moran L, Soga K, Law HD, Butler D, Bishop K, Gourley M, Eynstone-Hinkins J, Booth H, Moon L, Biddle N, Blakely A, Banks E and Korda RJ (2021) 'Education-related inequalities in cause-specific mortality: First estimates for Australia using individual-level linked census and mortality data', *International Journal of Epidemiology*, 50:1981-1994, doi:10.1093/ije/dyab080.

Wilson T, McDonald P, Temple J, Brijnath B and Utomo A (2020) 'Past and projected growth of Australia’s older migrant populations', *Genus* 76(20), doi:10.1186/s41118-020-00091-6.

Dementia in priority groups

People with intellectual disability are at a higher risk of developing dementia than the general Australian population (Evans and Troller 2018). Down syndrome in particular carries a higher risk of dementia, specifically for Alzheimer's disease (Evans and Troller 2018; see Box 13.2 for more information). Less research has been undertaken on dementia in Australians with other intellectual and physical disabilities, but the findings show the onset of dementia in people with intellectual disabilities (other than Down syndrome) is on average 10 years younger than the general population (Evans and Troller 2018).

Box 13.2: Down syndrome and Alzheimer's disease

Down syndrome, or trisomy 21, is a congenital condition where a person is born with extra genetic material – an additional copy of chromosome 21 (Dementia Australia 2021). Usually people are born with 46 chromosomes (23 pairs) in most of their cells, but people with Down syndrome are born with 47 chromosomes. The additional genetic material causes developmental and health issues in individuals, presenting as Down syndrome.

As advances in health care and knowledge have increased the average life span of individuals with Down syndrome, a relationship between Down syndrome and Alzheimer's disease has become increasingly apparent. Autopsy studies have shown that by the age of 40, almost all individuals with Down syndrome have the physiological hallmarking of Alzheimer's disease (this includes significant levels of beta-amyloid plaques and tau tangles) (Alzheimer's Association 2021). However, it is important to note that not all individuals who present with the physiological markers of Alzheimer's disease will display symptoms.

There are limited national statistics on people with both dementia and Down syndrome. However, some information is available for this population group within permanent residential aged care and mortality data:

- In 2021–22, 66% of people with Down syndrome living in permanent residential aged care also had dementia recorded as a condition contributing to their care needs (Table S13.23). In contrast, dementia was recorded among 54% of residents who did not have Down syndrome.
- In 2021, for those under the age of 65 years who had dementia listed as an associated cause of death, Down syndrome was the leading underlying cause of death (Table S13.24), accounting for 33% of these deaths.

Note, there are limitations with these data. The ACFI (see Box 10.3 in Residential aged care for information on this tool) only collects up to 3 behavioural conditions and 3 medical conditions that impact a persons' care needs. Therefore, people with multiple health conditions may not have all of their conditions listed. Furthermore, dementia may not be recorded as an associated cause of death among people with Down syndrome who also had dementia. This is because as associated cause of death is only recorded if it directly contributes to the underlying cause of death. This may mean early stages of dementia in people with Down syndrome are not noted.

Further explorative studies are needed to accurately quantify the relationship between the two conditions. Developments in data linkage studies that capture both dementia diagnosis and a person's detailed health history may contribute towards furthering our understanding of the relationship between Down syndrome and dementia.

While the strongest risk factor for dementia in people with intellectual disabilities is having Down syndrome, other factors found to increase the risk of dementia include:

- poor physical and mental health, in particular depression and epilepsy
- poor cardiovascular health, which can be common in this group
- a high rate of sensory impairments, including vision and hearing loss, and undiagnosed impairments (Evans and Troller 2018; Prasher et al. 2016).

There are also many factors known to increase the risk of dementia in the general population that are common in people with intellectual disability, such as poor diet and exercise, poorer social, employment and education engagement and head injury (Evans and Troller 2018).

While this section focuses on the relationship between intellectual disability and dementia, it should be noted that dementia may impact anyone who is managing a pre-existing health condition. The additional needs of those living with disability, be it intellectual, physical or a pre-existing medical condition, and dementia are not well understood. The Royal Commission into Aged Care Quality and Safety (Royal Commission) discussed findings regarding the unsuitability of residential aged care for younger people with disability. The Royal Commission called for 'personalised care from well-trained staff', and noted that 'there is not one correct model of care for those with dementia', highlighting the need for further insight to tailor support services for these individuals (Royal Commission 2021).

References

Alzheimer's Association (2021) *Down Syndrome and Alzheimer's Disease*, Alzheimer's Association website, accessed 24 August 2021.

Dementia Australia (2021) *Down syndrome and Alzheimer's disease*, Dementia Australia website, accessed 24 August 2021.

Evans E and Troller J (2018) '*Dementia in people with Intellectual Disability: Guidelines for Australian GPs*', University of New South Wales website, accessed 5 July 2023.

Prasher VP, Mahmood H and Mitra M (2016) 'Challenges faced in managing dementia in Alzheimer's disease in patients with Down syndrome', *Degenerative and Neurological and Neuromuscular Disease,* 6:85-94, doi:10.2147/DNND.S91754.

Royal Commission (Royal Commission into Aged Care Quality and Safety) (2021) *Final report: Care, Dignity and Respect*, Royal Commission, Australian Government, accessed 17 August 2022.

Dementia in priority groups

As of 30 June 2021, the Department of Veterans' Affairs (DVA) estimated that there were 613,000 living Australian veterans who have ever served in the Australian Defence Force, either full time or in the reserves (AIHW 2022).

International studies suggest an increased prevalence of dementia among veterans compared to the general population, with veterans having an increased prevalence of risk factors for dementia including traumatic brain injury sustained through active duty, post-traumatic stress disorder (PTSD) and major depressive disorder (Rafferty 2018; Singer 2015).

Although there is limited dementia research specifically for Australian veterans, studies suggest that:

- Behavioural and psychological symptoms of dementia (BPSD) differ among veterans compared with non-veterans, and veterans with dementia who experienced PTSD had more severe BPSD than veterans with dementia who had not experienced PTSD (Dunt et al. 2012).
- PTSD may not increase dementia risk among veterans, but antipsychotic use may be a contributor to dementia risk among veterans with and without PTSD (Roughead et al. 2017).

Further research is needed to better understand the relationship between dementia risk factors and prevalence of dementia among Australian veterans.

There are various aged care services available to veterans in Australia, including those with dementia. Other than the mainstream aged care services available to all Australians, eligible veterans are able to access DVA's care and support programs - the Veterans Home Care and Community Nursing Programs for medical and personal care services to support clients to remain living independently. See Jim's story for how DVA services are currently helping Jim (who has Alzheimer's disease) to remain living at home on his own.

For more information on the expenditure from these programs for people with dementia, see Health and aged care expenditure on dementia.

References

AIHW (Australian Institute of Health and Welfare) (2022) *Health of veterans*, AIHW, Australian Government, accessed 17 August 2022.

Dunt D, Doyle C, MacFarlane A, Morris P, Hunter C and Day S (2012) *The Impact of War Experiences on Dementia in Veterans*, Department of Veterans' Affairs website, accessed 17 September 2020.

Rafferty LA, Cawkill PE, Setvelink SAM, Greenberg K and Greenberg N (2018) 'Dementia, post-traumatic stress disorder and major depressive disorder: a review of the mental health risk factors for dementia in the military veteran population', *Psychological Medicine,* 48: 1400-1409, doi:10.1017/S0033291717001386.

Roughead EE, Pratt NL, Kalisch Ellett LM, Ramsay EN, Barratt JD, Morris P and Killer G (2017) 'Posttraumatic stress disorder, antipsychotic use and risk of dementia in veterans', *Journal of the American Geriatrics Society,* 65(7): 1521-1526, doi:10.1111/jgs.14837.

Singer CM (2015) Dementia risk factors in veterans, *Journal of Aging Life Care*, Spring 2015 (3), accessed 29 June 2020.

Dementia in priority groups

Inclusive reporting

The acronym LGBTIQ+ is used here to refer to a diverse population of people who identify as lesbian, gay, bisexual, trans/transgender, intersex, queer, and other sexuality (including asexual), gender, and bodily diverse people. There is no single LGBTIQ+ community, rather a range of identities and experiences which may change over time. Other variations of this acronym exist and may vary depending on the groups or issues being discussed and the available evidence. In much of the research included on this page people with innate variations of sex characteristics (often referred to as intersex) were excluded due to small sample sizes. As such the acronyms used in this resource reflect the research conducted.

LGBT people with dementia may experience unique challenges to living with memory problems directly related to their sexual orientation and/or gender identity. This can include forgetting who knows about their sexual orientation and gender identity and being unsure about who to trust with this disclosure (Cousins et al. 2021). They are less likely to have children, or be married, and more likely to live alone. Due to this, and potential isolation from their family of origin, LGBT people are more likely to have chosen family who may not be recognised within the context of healthcare decisions (Department of Health and Aged Care 2019; Fredriksen-Goldsen et al. 2013b).

While there is limited research and data available on LGBTIQ+ Australians living with dementia, international research has begun to explore the rate of dementia prevalence and look more closely at dementia risk factors that are higher among LGBTIQ+ communities; recognising that ageing in these communities has a separate set of challenges not experienced by all Australians. For more information on LGBTIQ+ communities see AIHW’s LGBTIQ+ topic page.

Why are LGBTIQ+ communities more at risk?

Multiple studies, largely international, have looked at potential risk factors for dementia in LGBTIQ+ communities, by using the modifiable risk factors (health behaviours that can increase or decrease the risk of developing dementia) for dementia as a guide. LGBTIQ+ communities may be more likely to have:

- poorer mental health and physical health
- elevated stress
- social isolation
- subjective cognitive decline defined as self-reported cognitive problems (Fredriksen-Goldsen et al. 2016; Lambrou et al. 2020; Saunders et al. 2021).

Some communities may be at even more risk due to higher rates of risk factors including bisexual people (La Roi et al. 2019; Rosenberg et al. 2021b; Saunders et al. 2021) who may experience more discrimination from members of their own community (Chan and Leung 2023; Rosenberg et al. 2021b) and transgender and gender diverse people who may experience increased:

- drug and alcohol use
- smoking
- unemployment/ underemployment
- verbal, physical and sexual violence (Brady et al. 2023; Hill et al. 2020; Rosenberg et al. 2021a).

Subjective cognitive decline may be the first sign of a future dementia diagnosis. Some studies have shown people that report subjective cognitive decline are more likely to receive a dementia diagnosis compared with people that do not report subjective cognitive decline (Lee et al. 2020). Connection and belonging has been shown to reduce risk factors for dementia including depression and poor physical health (Fredriksen-Goldsen et al. 2013a). Maintaining an active social life in itself is a protective factor against dementia.

A fear of accessing healthcare may impact the diagnosis of dementia among LGBTIQ+ communities (LHA 2022). The *We are still gay report* details past experiences as common concerns for the interviewees and highlights the struggles faced by many participants to secure service providers and carers that the interviewees felt safe with (Crameri et al. 2015). The report draws on research by two studies conducted by the Australian Research Centre in Sex, Health and Society (ARCSHS) at La Trobe University.

The *LGBTI Dementia* project documented the experiences and needs of LGBTI people living with dementia and the *Trans Ageing and Aged Care* project documented trans people’s experiences of ageing and aged care, including their experiences of dementia. The findings of these projects reinforce that gender diverse people often fear accessing healthcare due to prejudicial treatment and refusal of care altogether (Latham and Barrett 2015). See Sandra’s story of their experience.

Care and support services

A range of frameworks, programs and resources have been developed in Australia recognising the LGBTIQ+ population as a priority group among those with dementia and more broadly in the ageing population. More information is available on the government's commitments through the Aged Care Diversity Framework (Department of Health and Aged Care 2017) and other complementary frameworks on the

Department's website. The National policy response to dementia explores more of the policy changes to Aged Care as they relate to dementia in Australia following the Royal Commission into Aged Care.

In July 2022, the Department of Health and Aged Care released the Specialisation Verification Framework to support aged care consumers to find services that meet their specific needs. The framework sets out the criteria for specialised care delivery. Aged care providers who deliver specific services that meet diverse needs may apply for specialisation verification including LGBTI specialisation.

LGBTIQ+ specific resources for dementia

- The *LGBTI and dementia* guide is a free resource from Dementia Australia for people living with dementia who are LGBTI, their partners, family and friends, with information on dementia, support services and finding inclusive service providers, legal rights and advanced care planning.
- The Actions to Support LGBTI Elders: a Guide for Consumers and Actions to Support LGBTI Elders: a Guide for Aged Care providers details specific actions which can be adopted, in order to ensure inclusivity and respect for older LGBTI people.
- LGBTIQ+ Health Australia in partnership with Dementia Support Australia developed *LGBTI and Dementia: Understanding changes in behaviour* for aged care staff who are caring for LGBTI people. It aims to provide an understanding of some of the issues LGBTI people may have faced at different times in their lives and how this may impact on changes in behaviour if the person develops dementia.
- The Aged Care Volunteer Visitors Scheme (ACVVS) identifies LGBTI people as a priority group and funds community organisations to support volunteers to visit socially isolated older LGBTI people and provide connection and friendship.

Sandra's story

Born in the UK and recorded male at birth, Sandra was married with three children. The family immigrated to Australia over fifty years ago. As the breadwinner, Sandra worked in engineering whilst their wife kept the home and raised their children. In their early sixties, after the death of their wife eight years prior, Sandra affirmed their gender as female. Finally living their authentic self as a transgender woman, Sandra was diagnosed with dementia several years later.

After living at home with dementia successfully for some time, there came a time when the police found Sandra after she got lost on a walk. Sandra was returned home to her son, prompting a call to Dementia Support Australia (DSA). Sandra's cognitive ability had declined substantially. Their love for singing and dancing had been impacted by experiences of disinhibition, hallucinations, suicidal thoughts, as well as poor personal hygiene. Sandra was becoming a different person. Some days they would refer to themselves as a man when distressed and would become abusive and argumentative. Sandra's son was desperate for support, but Sandra refused care from anyone else.

The DSA Consultant visited Sandra and their son at their home and provided a very practical and detailed approach to supporting them both when agitation and aggression become a concern. The DSA Consultant also assisted with access to further medical assessment and treatment, as well as information about home care or residential support options. Sandra's son was relieved to have a plan moving forward. He felt supported.

Fast forward a year and a half, and DSA received another call requesting support. Sandra had moved from community to residential care (after twenty years living at home). Sandra continued to experience increasing agitation and aggression; they had been disturbing other residents, and on several occasions had been physically aggressive towards them. With a formal pain assessment suggesting Sandra was experiencing mild pain, the DSA Consultant recommended pain management for Sandra's chronic and acute conditions. A DSA Medical Specialist also provided a new medication plan, following a detailed review. To help Sandra's mood and engagement, activities that affirm their gender and engage them in their previous interests were suggested, along with an interactive plush dog, brokered by DSA, to address Sandra's love for dogs.

With new strategies in place, care staff reported Sandra making great progress, despite a couple of incidents, possibly triggered by changes to her environment. The DSA Consultant continued to contact the care home for updates and provide further support. Several months on, Sandra was much more settled, with no further aggressive behaviours directed at others, and care staff were comfortable with supporting Sandra through various engagement strategies. Sandra's quality of life had significantly improved; they found joy and fulfilment once again, living their authentic self.

Story provided by Dementia Support Australia. Client name has been changed for confidentiality.

A new way to collect information

In 2021 the Australian Bureau of Statistics (ABS) released the Standard for sex, gender, variations of sex characteristics and sexual orientation variables 2020. The 2020 Standard replaces the previous version (ABS 2016) with updated sex and gender variables, and introduces new variables for variations of sex characteristics and sexual orientation. The four variables included in the 2020 Standard, when cross-classified with other variables, can provide comprehensive data on a particular topic, issue or population group. The new Standard can be used by other government, academic and private sector organisations in their own statistical collections to improve the comparability and quality of data. The Standard will begin to be used in a small number of ABS household-based surveys and this will increase over time (ABS 2021).

References

ABS (Australian Bureau of Statistics) (2016) *Standard for Sex and Gender Variables*, ABS website, accessed 13 February 2024.

ABS (2021) *Standard for sex, gender, variations of sex characteristics and sexual orientation variables*, ABS website, accessed 25 August 2023.

Brady B, Zheng L, Kootar S and Antsey KJ (2023) 'Sex and gender differences in risk scores for dementia and Alzheimer's disease among cisgender, transgender, and non-binary adults', *Alzheimer's & Dementia*, doi:10.1002/alz.13317.

Carman M, Farrugia C, Bourne A, Power J and Rosenberg S (2022) 'Research Matters: How many people are LGBTIQ?', *La Trobe*, Educational resource, doi:10.26181/20304708.v1.

Chan RCH and Leung JSY (2023) 'Monosexism as an Additional Dimension of Minority Stress Affecting Mental Health among Bisexual and Pansexual Individuals in Hong Kong: The Role of Gender and Sexual Identity Integration', *The Journal of Sex Research*, 60(5):704-777, doi:10.1080/00224499.2022.2119546.

Crameri P, Barrett C, Lambourne S and Latham JR (2015) 'We are still gay … An evidence based resource exploring the experiences and needs of lesbian, gay, bisexual and trans Australians living with dementia', *La Trobe University*, doi:10.26181/20304561.v1.

Cousins E, De Vries K and Harrison Dening K (2021) 'LGBTQ+ people living with dementia: an under-served population', *British Journal of Healthcare Assistants*, 15(1), doi:10.12968/bjha.2021.15.1.26.

Dementia Australia (2022) *HIV associated dementia*, Dementia Australia website, accessed 7 August 2023.

Department of Health and Aged Care (2017) *Aged Care Diversity Framework*, Department of Health and Aged Care, Australian Government, accessed 25 August 2023.

Department of Health and Aged Care (2019) *Actions to support Lesbian, Gay, Bisexual, Trans and Gender Diverse and Intersex elders*, Department of Health and Aged Care, Australian Government, accessed 21 August 2023.

Fredriksen-Goldsen KI, Emlet CA, Kim H-J, Muraco A, Erosheva EA, Goldsen J and Hoy-Ellis CP (2013a) 'The Physical and Mental Health of Lesbian, Gay Male, and Bisexual (LGB) Older Adults: The Role of Key Health Indicators and Risk and Protective Factors', *The Gerontologist*, 53(4): 664–675, doi:10.1093/geront/gns123.

Fredriksen-Goldsen KI, Kim H-J, Barkan SE, Muraco A, Hoy-Ellis CP (2013b) 'Health disparities among lesbian, gay, and bisexual older adults: Results from a population-based study', *American Journal of Public Health*, 103(10):1802-9, doi:10.2105/AJPH.2012.301110.

Fredriksen-Goldsen KI, Jen S, Bryan AEB and Goldsen J (2016) 'Cognitive Impairment, Alzheimer's Disease, and Other Dementias in the Lives of Lesbian, Gay, Bisexual and Transgender (LGBT) Older Adults and Their Caregivers: Needs and Competencies', *Journal of Applied Gerontology*, 37(5):545–569, doi:10.1177/0733464816672047.

Hill AO, Bourne A, McNair R, Carman M and Lyons A (2020) 'Private Lives 3: The health and wellbeing of LGBTIQ people in Australia', *Australian Research Centre in Sex, Health and Society*, La Trobe University, ARCSHS Monograph Series No. 122.

Jones TW, Brown A, Carnie L, Fletcher G and Leonard W (2018) *Preventing Harm, Promoting Justice: Responding to LGBT conversion therapy in Australia*, GLHV@ARCSHS and the Human Rights Law Centre, accessed 22 August 2023.

Kim H-J, Fredriksen-Goldsen K and Jung HH (2022) 'Determinants of Physical Functioning and Health-Related Quality of Life among Sexual and Gender Minority Older Adults with Cognitive Impairment', *Journal of Aging and Health*, 35(1-2):138-150, doi:10.1177/08982643221108658.

La Roi C, Meyer IH and Frost DM (2019) 'Differences in sexual identity dimensions between bisexual and other sexual minority individuals: Implications for minority stress and mental health', *American Journal of Orthopsychiatry,* 89(1):40–51, doi:10.1037/ort0000369.

Lam JO, Hou CE, Hojilla JC, Anderson AN, Gilsanz P, Alexeeff SE, Levine-Hall T, Hood, N, Lee C, Satre DD and Silverberg MJ (2021) 'Comparison of dementia risk after age 50 between individuals with and without HIV infection', *AIDS*, 35(5):821-828, doi:10.1097/QAD.0000000000002806.

Lambrou NH, Gleason CE, Cicero E and Flatt JD (2020) 'Prevalence of subjective cognitive decline higher among transgender and gender nonbinary adults in the U.S., 2016–2018', *Alzheimer's & Dementia*, 16(S10):e044298, doi:10.1002/alz.044298.

Latham JR and Barrett C (2015) *We're people first: Trans Health and Ageing-An evidence-based guide to inclusive services*, Australian Research Centre in Sex, Health and Society, La Trobe University, accessed 25 August 2023.

Lee YC, Kang JM, Lee H, Kim K, Kim S, Yu TY, Lee E, Kim CT, Kim DK, Lewis M, Won H, Jessen F and Myung W (2020) 'Subjective cognitive decline and subsequent dementia: a nationwide cohort study of 579,710 people aged 66 years in South Korea', Alzheimer's research therapy, 12:52, doi:10.1186/s13195-020-00618-1.

LHA (LGBTIQ+ Health Australia) (2022) *Factsheet: LGBTI People and dementia, LHA website*, LHA, accessed 7 August 2023.

LHA (2023) *Silver Rainbow: Ageing and aged care*, LHA website, accessed 7 August 2023.

Rosenberg S, Carman M, Bourne A, Starlady and Cook T (2021a) *Research Matters: Trans and gender diverse health and wellbeing*, Rainbow Health Victoria website, accessed 30 August 2023.

Rosenberg S, Carman M, Power J and Taylor J (2021b) *Research Matters: Bisexuality, health and wellbeing*, Rainbow Health Victoria website, accessed 30 August 2023.

Saunders CL, MacCarthy S, Meads C, Massou E, Mant J, Saunders AM and Elliott MN (2021) 'Long-term conditions among sexual minority adults in England: evidence from a cross-sectional analysis of responses to the English GP Patient Survey', *BJGP Open*, 5(5), doi:10.3399/BJGPO.2021.0067.

Dementia in priority groups

Although dementia is a disease more commonly seen in people aged 65 or over, it can occur at any age. This section presents information collated from across the Dementia in Australia report relevant to people with dementia under the age of 65 (referred to as younger onset dementia). Note that younger onset dementia is distinct from childhood dementias.

For younger people, the impact of dementia as well as the services and needs required can differ compared to older people. This can be attributed to the significant stage of life differences in people with dementia under the age of 65, who may be working and/or caring for a family at the time of diagnosis. This can greatly affect the social and psychological impact of dementia on the individual, their family, and community (Draper and Withall 2016).

The following pages present statistics and information on:

- Population health impacts of younger onset dementia
- Health services used by people with younger onset dementia
- Aged care and support services available to people with younger onset dementia

For further information on people with younger onset dementia including social characteristics from the 2016 Census, patterns of Centrelink payments, patterns of health service use, residential aged care service use and causes of death see Younger onset dementia: new insights using linked data.

For more information about the types of younger onset dementia, risk factors, diagnosis and support, see the Dementia Australia YOD hub.

References

Draper B and Withall A (2016) ‘Young onset dementia’, *Intern Med J*, 46(7):779-786, doi:10.1111/imj.13099.

Dementia in priority groups

How many people have younger onset dementia in Australia?

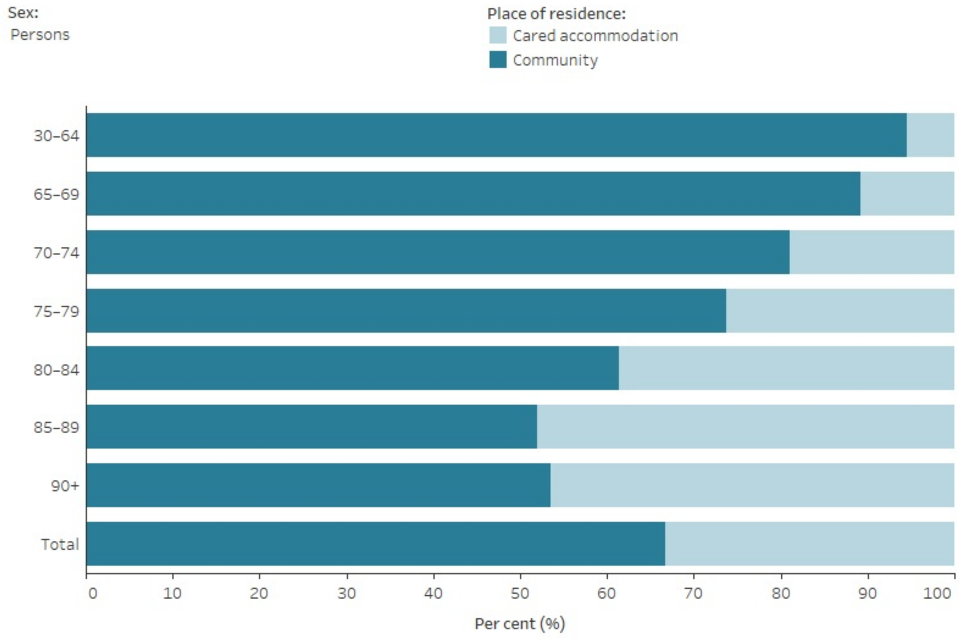
The exact number of people with younger onset dementia is currently not known. However, the AIHW estimates that in 2023 there were about 28,900 people aged 30–64 living with dementia in Australia (13,300 men and 15,600 women). People with younger onset dementia accounted for 7% of the total estimated number of people living with dementia in Australia (about 411,100 people in 2023). For more information on the available data sources and methodologies used to estimate dementia prevalence, see Prevalence of dementia.

Most young people with dementia live in the community

Based on AIHW estimates, in 2022, most people with younger onset dementia lived in the community (95% or 26,900 people) (Figure 2.2). People were more likely to move to cared accommodation as they got older: just over half (54%) of people with dementia aged 90 or over lived in the community in 2022.

Figure 2.2: Australians living with dementia in 2022: estimated percentage by age, sex and place of residence

Stacked bar graph showing that younger people with dementia are more likely to live in the community, while older people with dementia are more likely to live in cared accommodation.



Note: Cared accommodation includes people in hospitals, residential aged care facilities, aged care hostels, cared components of retirement villages and other 'homes', such as a group home for people with disability.
Source: The AIHW estimates were derived using prevalence rates from the 2015 World Alzheimer report and Withall et al. 2014, and AIHW analysis of 2021–22 Aged Care Funding Instrument data and the ABS 2018 Survey of Disability, Ageing and Carers confidentialised unit record file.
http://www.aihw.gov.au

Deaths *due* to dementia or *with* dementia in people under the age of 65

Dementia is a progressive condition that leads to reduced life expectancy. The mortality statistics presented here are derived from the National Mortality Database. In 2021, 124 people under the age of 65 died in Australia due to dementia.

Deaths due to dementia refers to cases where dementia was recorded as the underlying cause of death. Given people with dementia often have other health conditions and there can only be one underlying cause of death recorded, it is important to also account for all other cases where Australians died with dementia (where dementia was recorded as either the underlying cause or an associated cause of death).

In 2021, 139 people under the age of 65 died with dementia as an associated cause of death. Of these, Down syndrome was the leading underlying cause of death (33% of deaths), followed by unspecified fall (5%), motor neuron disease (4%) and Parkinson's disease (3%) (Table S13.24).

For more information see Deaths due to dementia.

Dementia in priority groups

Services provided by health professionals, including primary health care providers (such as general practitioners, or GPs), other medical specialists (such as geriatricians and psychiatrists) and allied health professionals (such as physiotherapists and speech pathologists), as well as prescribed medications, play a crucial role in the diagnosis, treatment and/or management of dementia.

The following sections present statistics and information on:

- Primary health care services used by people with younger onset dementia
- Medications dispensed to people with younger onset dementia
- Hospitalisations of people with younger onset dementia

For more information on health service use by people with dementia of all ages, see Health services used by people with dementia.

Primary health care services used by people with younger onset dementia

The following section presents data that are currently available on the use of primary health care services by people with dementia through services provided under the Medicare Benefits Scheme (MBS).

Key data considerations

Dementia diagnostic information is not available in the MBS, so it is not possible to distinguish between dementia-specific services and services for the management of other health issues. These data are sourced from linked health and aged care services data in the National Health Data Hub (AIHW NHDH 2020–21), previously referred to as the National Integration Health Services Information (NIHSI) analytical asset. Identification of people with dementia depends on their use of other health and aged care services (for example, through admission to hospital or entry to permanent residential aged care), so the information below will not include all younger people with dementia in Australia.

Results of this analysis should be interpreted with caution due to data limitations. For more information on data considerations of this analysis, refer to the Technical notes.

In 2020–21, there were nearly 11,700 people aged 30–64 who were identified as having dementia in the linked data (Table S7.2). Of these, just over 2,000 (17%) lived in permanent residential aged care for all or part of the year (this is a higher proportion than the estimate in the prevalence section because people in the later stages of dementia are more likely to be identified in the linked data than people in the early to moderate stages).

Among people with younger onset dementia (aged 30–64), those living in the community used an average of 36 MBS services and those living in permanent residential aged care used an average of 46 MBS services (Table S7.2). This was similar for those aged 65 years and older, with an average of 38 MBS services used by those living in the community and an average of 45 MBS services used by those in permanent residential aged care.

Measures of service use

- Percentage of people who used a service: ‘Percentage’ is the proportion of people with at least one service recorded in the linked data in 2020–21. This is also referred to as a rate of service use.
- Average number of services per person: The average number of services per person was calculated for people who used the service at least once in 2020–21, referred to in figure as ‘Mean (service user)’.

These measures reflect different aspects of access to services. For example, for people living in the community, more people living with dementia had one or more GP chronic disease management attendances than those without dementia in the age groups 30–80 years. However, among people who used the service, there was little difference in the average number of attendances.

Health service attendances for people living in the community

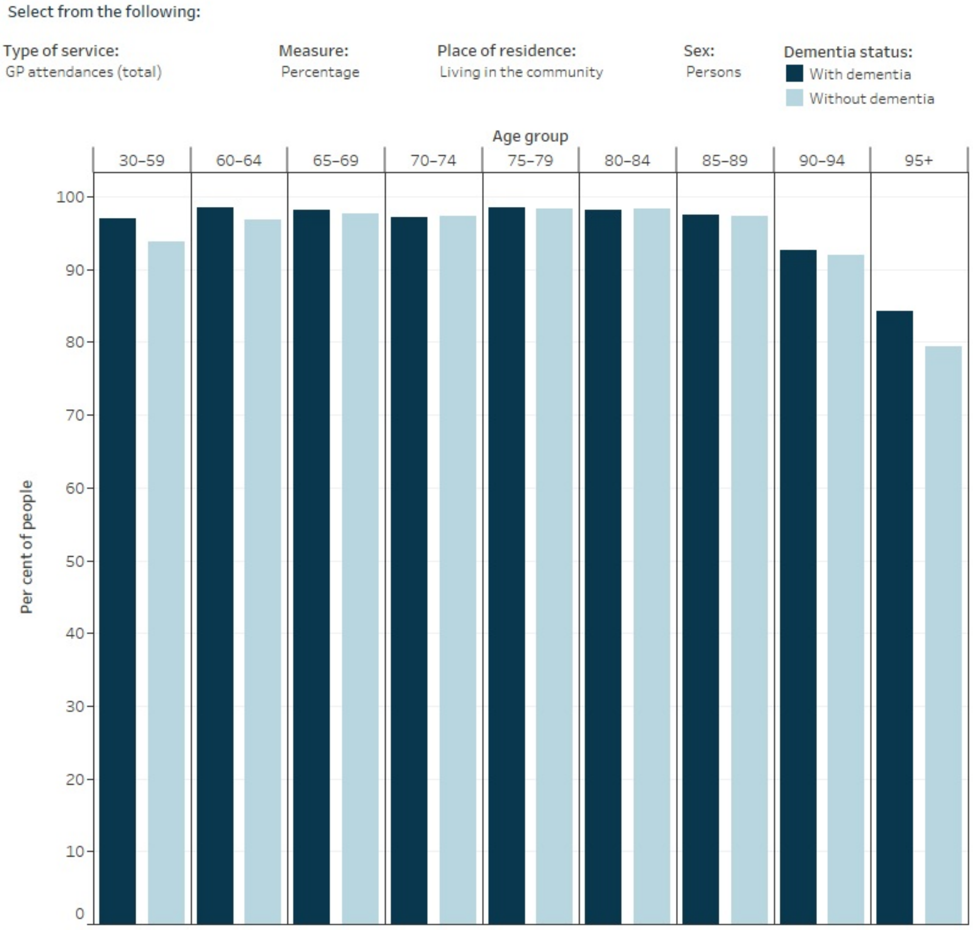
Among people aged 30–59, living in the community and who had used a particular MBS service at least once, the average number of attendances for certain services was greater for people with dementia than for those without dementia, and this difference tended to decrease in the older age groups (Figure 7.2). The MBS services where people aged 30–59 with dementia had a greater number of attendances than those without dementia were:

- GP attendances (17 attendances for people with dementia compared to 7.3 for those without dementia).
- Specialist attendances (4.8 for people with dementia compared to 3.0 for those without dementia). This difference was largely driven by differences in the number of geriatric medicine, neurology, and general medicine attendances.
- Allied health attendances (3.4 for people with dementia compared to 2.5 for those without dementia). Within allied health attendances, podiatry and optometry followed a similar pattern.
- Pathology services (14 for people with dementia compared to 9.1 for those without dementia).

- Diagnostic imaging (3.4 for people with dementia compared to 2.7 for those without dementia).
- Nurse attendances (2.4 nurse attendances per person), this was higher than those without dementia (1.8) of the same age, and all other age groups with or without dementia.

Figure 7.2: MBS service use by type of service, place of residence, sex and age

Bar graph showing that younger people with dementia had a greater average number of attendances for certain services compared to those without dementia, such as GP services for those living in the community, and psychiatry attendances for those living in PRAC.



Source: AIHW NHDH 2020–21, analysis of NHDH.

Health service attendances while living in permanent residential aged care

In 2020–21, people with dementia aged 30–59 years living in permanent residential aged care had a greater average number of nurse attendances per person (6.0) than those without dementia of the same age (4.6). This age group had the largest difference in average nurse attendances between those with or without dementia, although older age groups tended to follow this pattern as well.

Those aged 30–59 with dementia had the highest average number of general medicine attendances per person (4.0) compared to those of the same age without dementia (1.8), and all other age-groups. Aside from people aged 95 years or older, people aged 30–59 were the only age group to have a greater average number of psychiatry attendances per person (4.4) than those without dementia (3.8).

For more information on MBS services used by people with dementia see Primary health care services.

Medications dispensed to people with younger onset dementia

While there is currently no known cure for dementia, there are four medications available under the Pharmaceutical Benefits Scheme (PBS) and Repatriation Pharmaceutical Benefits Scheme (RPBS) that may assist in managing dementia symptoms and slow dementia progression. In Australia, these medications are currently only subsidised for people with a diagnosis of Alzheimer's disease. This section focuses on dispensing patterns of dementia-specific medications supplied to people aged 30–64, under the PBS and RPBS.

Considerations of PBS and RPBS data

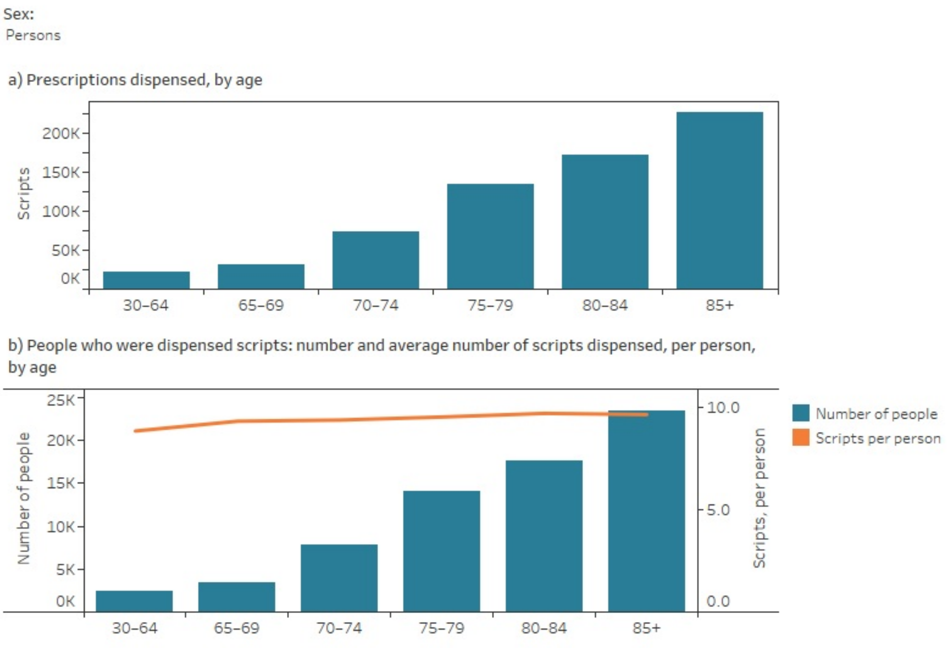
It is important to note that information on medication intake and adherence to medication plans is not available. The data presented here relate only to prescriptions dispensed. In addition, the PBS and RPBS do not contain data on dispensing of privately prescribed medications (prescriptions that are not eligible for subsidy under the PBS or RPBS), medications to public hospital in-patients and over-the-counter medications. For more information on dementia-specific medications see Prescriptions for dementia-specific medications.

Prescriptions for dementia-specific medications varied with age

In 2021–22, nearly 2,500 people aged 30–64 were dispensed nearly 21,800 dementia-specific medications (Figure 8.1a). The average number of scripts dispensed per person was lower for people aged 30–64 (8.9 per person) than for people aged 85 and over (9.7 per person) (Figure 8.1b).

Figure 8.1: Dementia-specific medications by age and sex in 2021-22: (a) numbers of prescriptions dispensed and (b) number of people who were dispensed scripts and average number of scripts dispensed per person

Two graphs on prescriptions dispensed for dementia-specific medications to people aged 30 and over by age and sex in 2021-22. The first is a bar graph showing the number of scripts dispensed by age group. The second is a bar and line graph, with the bar graph showing the number of people who were dispensed scripts for dementia-specific medications and the line graph showing the average number of scripts dispensed per person, both broken down by age groups. The number of prescriptions dispensed, the number of people dispensed scripts and the average number of scripts dispensed per person all increased with age. A greater number of women were dispensed a greater number of scripts than men.

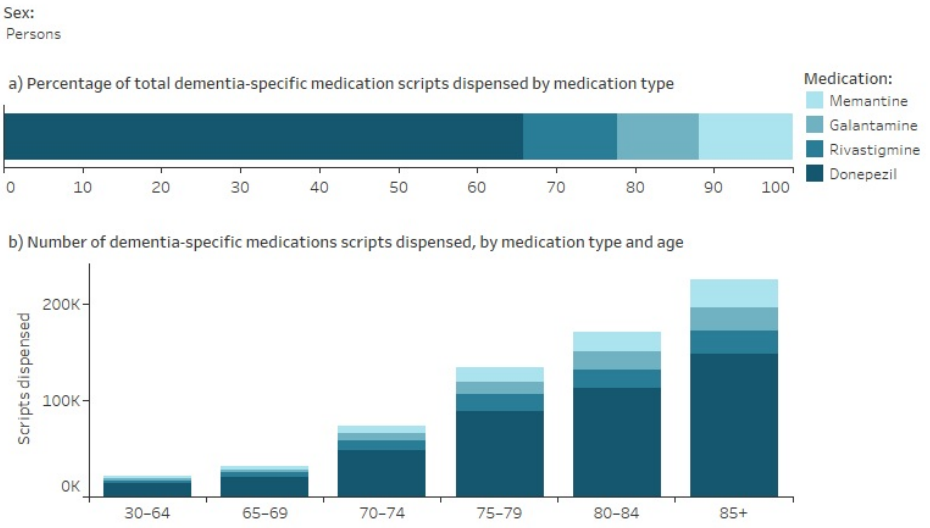


Source: AIHW analysis of PBS data maintained by the Australian Government Department of Health and Aged Care
http://www.aihw.gov.au

Donepezil was the most dispensed dementia-specific medication in 2021–22 for people aged 30–64, accounting for about 14,000 prescriptions or 64% of all dementia-specific scripts dispensed (Figure 8.3). Memantine, usually prescribed for moderately severe to severe Alzheimer's disease, accounted for 14.2%.

Figure 8.3: Dementia-specific medications, by medication type and sex in 2021-22: (a) percentage of all scripts dispensed by medication type and (b) number of scripts dispensed by medication type and age

Two graphs on the prescriptions dispensed for dementia-specific medications, by the four types of dementia-specific medications and sex in 2021-22. The first graph is a stacked bar graph showing the percentage of all scripts dispensed by medication type. The second graph is a stacked bar graph showing the number of scripts dispensed by medication type and age. Around two-thirds of prescriptions dispensed for dementia-specific medications were for Donepezil, and this was the most commonly dispensed medication in each age group in both men and women. Women were dispensed a greater number of scripts than men for each of dementia-specific medication.



Source: AIHW analysis of PBS data maintained by the Australian Government Department of Health and Aged Care
http://www.aihw.gov.au

In 2021–22, the proportion of people who were dispensed scripts for dementia-specific medications for the first time varied by age: 1 in 3 people (34%) aged 30-64 were dispensed scripts for the first time (Table S8.5). This decreased to almost 1 in 5 people (18%) among those aged 85 and over.

As people with dementia often have other co-existing conditions, they are likely to be prescribed a range of other medications. For people who were dispensed scripts for dementia-specific medications in 2021–22, psychoanaleptics (medications used to treat depression and other neurological and mental disorders) were dispensed to a larger proportion of people aged 30–64 (61%) compared with people aged 85 and over (48%) (Table S8.8). However, most other medications were dispensed to a greater proportion of people aged 85 and over.

People with younger onset dementia were more likely to be dispensed antipsychotic medications

People with dementia may experience changed behaviours, such as aggression, agitation and delusions, commonly known as behavioural and psychological symptoms of dementia (BPSD). To manage these symptoms, non-pharmacological interventions are recommended, but medical professionals may prescribe antipsychotic medications to people with dementia with BPSD as a last resort.

In 2021–22, among people dispensed scripts for dementia-specific medication, people aged 30–64 were more likely to also be dispensed antipsychotic medications (which are part of the psycholeptics group): 23% of women and 25% of men aged 30–64, compared with 20% of men and 19% of women aged 85 and over (Table S8.9).

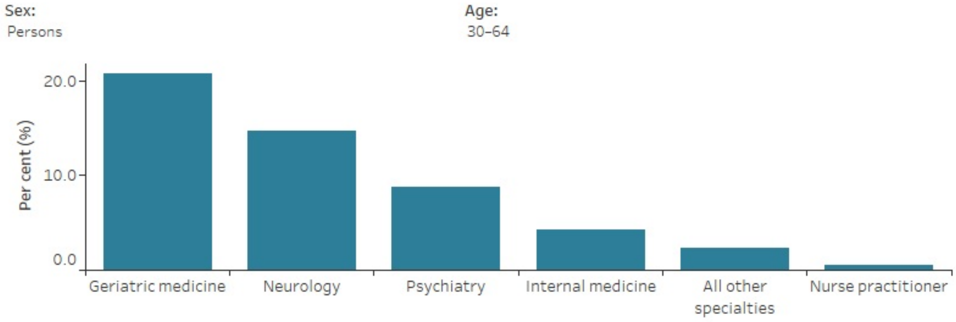
Prescribers of dementia-specific medications to people with younger onset dementia

In 2021–22, 3 in 4 people (74%) aged 30–64 who were dispensed scripts for dementia-specific medications were prescribed at least one script by a general practitioner (GP), compared with 84% of people aged 65 and over (Table S8.15).

As younger people aged 30–64 are less likely to see a doctor with a specialisation in geriatric medicine, a greater proportion of dementia-specific medications were prescribed by neurologists (15%) and psychiatrists (8.7%) than they were for people aged 65 and over (4.2% and 3.5%, respectively) (see Figure 8.9).

Figure 8.9: People who were dispensed dementia-specific medications in 2021-22: percentage by medical speciality of prescriber, age and sex

Bar graph showing that younger people were more likely to be prescribed dementia-specific medicines by neurologists and psychiatrists than people aged 65 years or more.



Notes
1. Dementia-specific medications prescribed by General Practitioners are excluded from this figure.
2. Prescriber specialty is derived by the Department of Health for a prescriber each quarter, and reflects both the registered specialty of the prescriber and the Medicare services claimed in the quarter.
Source: AIHW analysis of PBS data maintained by the Australian Government Department of Health and Aged Care
http://www.aihw.gov.au

Hospitalisations of people with younger onset dementia

This section includes information on the number and characteristics of dementia-related episodes of admitted patient care (referred to as 'hospitalisations') from the National Hospital Morbidity Database, including hospitalisations due to dementia in 2021–22. Hospitalisations due to dementia refer to hospitalisations where dementia was the main reason for the admission to hospital. For more information see Hospital care.

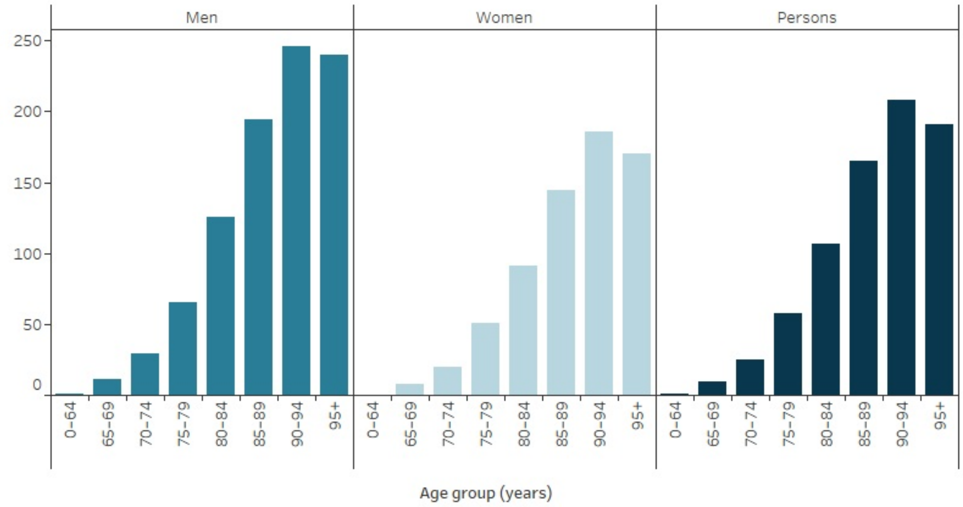
With increasing age, hospitalisations due to dementia increased in number but decreased in length

In 2021–22, people aged 0–64 had the lowest number of hospitalisations due to dementia (just over 1,000) compared to all other age groups except those aged 95 and over (995 hospitalisations). While having fewer hospitalisations, people aged 0–64 had the longest average length of stay in hospital (31 days) than all other age groups, decreasing to an average of 11 days among people aged 95 and over (see Figure 9.1).

Figure 9.1: Overview of hospitalisation *due* to dementia in 2021–22, by age and sex

Bar graph showing that younger people with dementia tend to have fewer hospitalisations but a longer average length of stay in hospital than older people with dementia.

Select statistic:
Hospitalisations per 10,000 population



See the technical notes for further information, available at
https://www.aihw.gov.au/reports/dementia/dementia-in-aus/contents/technical-notes
Source: AIHW analysis of National Hospital Morbidity Database.
http://www.aihw.gov.au

References

AIHW (2020–21) National Health Data System, aihw.gov.au, accessed 10 February 2024.

Draper B and Withall A (2016) ‘Young onset dementia’, *Intern Med J*, 46(7):779-786, doi:10.1111/imj.13099.

Dementia in priority groups

While there are a range of aged care services, as well as dementia-specific services, available for those in need of support, they may not be suitable for people living with younger onset dementia. For further information about aged care see Overview of Australia's aged care system. While living in a residential aged care facility may be their setting of choice, younger people are generally considered to be better served by other services (such as specialist disability accommodation provided through the National Disability Insurance Scheme (NDIS) or financial support through the Disability Support Pension) (see Box 10.1).

The Royal Commission into Aged Care Quality and Safety in its final report made a high priority recommendation that all people under the age of 65 currently living in residential aged care facilities should be moved out of residential aged care and into other, more appropriate care types (Royal Commission 2021). Through the *Younger People in Residential Aged Care Strategy 2020–25*, the Australian Government has committed to ensure that apart from exceptional circumstances, no person under the age of 65 lives in residential aged care. For the most recent data available to track progress being made towards these targets, see Younger people in residential aged care.

Box 10.1: Support services for people with younger onset dementia (aged under 65)

People with younger onset dementia may be eligible for support through the NDIS (NDIA 2019) and financial support through the Disability Support Pension (Services Australia 2023), in addition to aged care services. For further information about the use of the Disability support Pension see *Income support recipients* in Younger onset dementia: new insights using linked data. NDIS data is publicly accessible on their website via the Participant datasets page.

National Disability Insurance Scheme (NDIS)

The NDIS provides support for people aged under 65 who have a significant, ongoing disability. Through this scheme young people are provided with funding in order for them to access a range of support services and programs, including supports that assist people with daily personal activities (such as gardening, household chores and meal preparation), making home modifications to suit their needs, programs that enable and encourage participation in work or social activities, and funding towards therapeutic services.

Disability Support Pension

The Disability Support Pension provides financial help for people with an on-going physical, intellectual or psychiatric condition that prevents that person from working (such as people with younger-onset dementia). This pension is available to people aged 16 and over (who are less than pension age), with eligibility and payment amounts based on the person's condition and level of impairment, and their assessable income and assets.

People with younger onset dementia in residential aged care

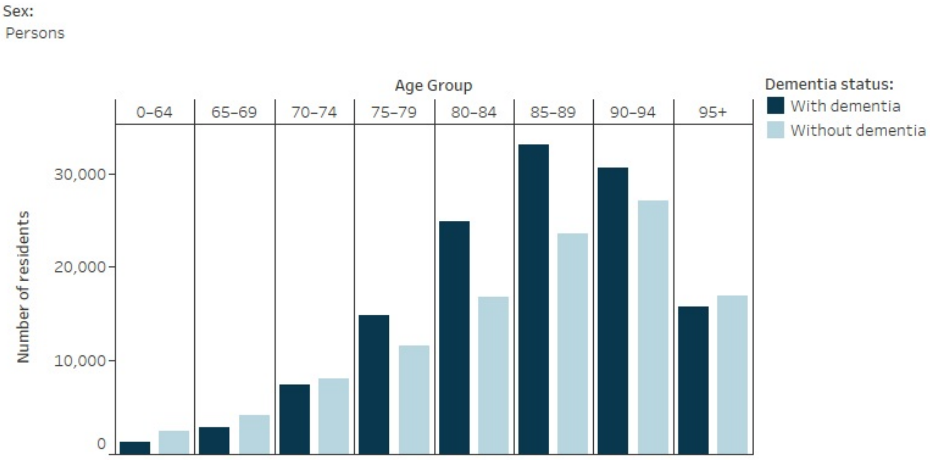
This page uses Aged Care Funding Instrument (ACFI) data to present information on people with younger onset dementia who were living in permanent residential aged care. The ACFI captures the day-to-day care needs that contribute the most to the cost of providing individual care. The ACFI appraisal is centred on assessing an individual's care needs and consists of 12 needs-based questions, categorised into 3 domains; Activities of daily living, cognition and behaviour, and complex health care.

Ratings for each domain are used to determine the level of funding required and to assign care. High levels of care are indicated for those who need almost complete assistance with all tasks. This includes providing 24-hour care, either by or under the supervision of registered nurses, combined with support services, personal care services, and allied health services. For more information about this data source, see the Residential aged care section.

In 2021–22, around 1,300 people (672 men and 627 women) with dementia aged under 65 were living in permanent residential aged care (Figure 10.7), representing 35% of all younger people living in residential aged care. People with younger onset dementia aged under 65 were most likely to require high levels of care in the cognition and behaviour domain (88%) and the activities of daily living domain (70%), with a lower proportion requiring high levels of care in the complex health care domain (51%).

Figure 10.7: People with and without dementia living in permanent residential care in 2021–22: number by age and sex

A bar graph showing that for people with dementia, the number of people living in permanent residential care increases gradually with age, peaking at the age group of 85–89, decreasing slightly at age group 90–94 and then dropping off in the 95 and over age group.



Source: AIHW analysis of the National Aged Care Data Clearinghouse.
http://www.aihw.gov.au

References

NDIA (National Disability Insurance Agency) (2023), *Younger People in residential Aged Care Strategy 2020–25*, accessed 13 July 2023.

Royal Commission (2021) *Final report: Care, Dignity and Respect*, Royal Commission, Australian Government, accessed 10 October 2020.

Services Australia (2023) *Disability Support Pension*, Services Australia, Australian Government, accessed 15 June 2023.

Health and aged care expenditure on dementia

Key statistics

$3.7 billion of the total direct health and aged care system expenditure in 2020–21 was spent directly on dementia

$1.8 billion was spent on **residential aged care services**

$741 million was spent on **community-based aged care services**

$662 million was spent on **hospital services**

Australia's response to dementia requires economic investment across the health, aged care and welfare sectors. This investment includes expenditure associated with: diagnosis, treatment and care of people with dementia (including supporting a workforce of trained professionals); and support services for people with dementia and their informal carers.

The following pages present direct expenditure estimates for caring for people with dementia across the health and aged care sectors in 2020–21. It includes the estimated expenditure on:

- aged care and support services – including aged care assessments, community-based and residential aged care services and other dementia support services.
- total health expenditure – including hospital services and out-of-hospital services.
    - Hospital services include admitted patient care, outpatient clinics and emergency department care.
    - Out-of-hospital services include general practitioner (GP) and other medical specialist services, diagnostic services, allied health services and dementia-specific medications.

For the underlying data presented in these pages, refer to the Expenditure data tables.

This report focuses on health and aged care expenditure estimates that:

- are **directly attributable to dementia** (rather than all costs for people with dementia), to avoid including expenditure related to other conditions
- have been adjusted to **reflect the contribution of comorbidities** to the costs for treatment and care of people with dementia
- **exclude indirect expenditure**, such as costs arising from the social and economic burden on carers and family, or from lost wages and productivity.

More information on the methodology and data sources used to estimate expenditure directly attributable to dementia can be found in the Technical notes.

Total estimated expenditure on dementia

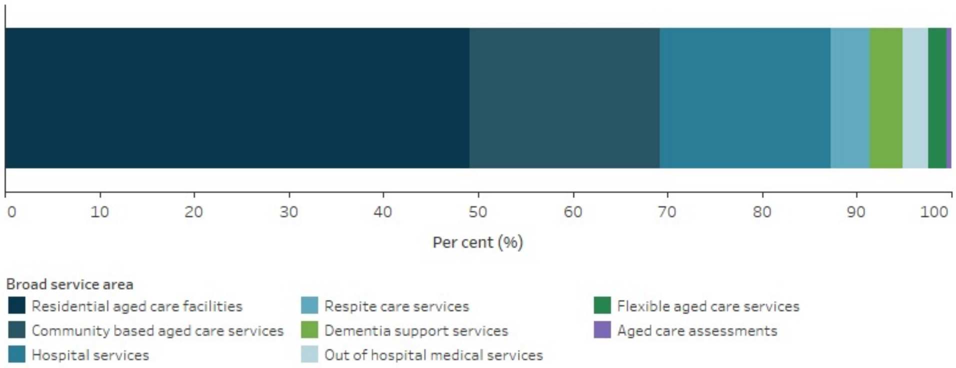
It is estimated that almost $3.7 billion of the total direct health and aged care system expenditure in 2020–21 was directly attributable to the diagnosis, treatment and care of people with dementia.

The health and aged care system expenditure directly attributable to dementia was mainly for:

- residential aged care services – $1.8 billion or 49% of the total direct health and aged care system expenditure for dementia
- community-based aged care services – just over $741 million or 20%
    - Home Care Packages, Commonwealth Home Support Programme (excluding respite care), Veterans' Home Care Program and DVA Community Nursing program.
- hospital services – almost $662 million or 18%
    - public and private admitted patient hospital care, public hospital outpatient clinics and public hospital emergency department care (Figure 14.1).

Figure 14.1: Health and aged care system expenditure attributable to dementia in 2020–21: percentage by broad area

Bar graph showing the distribution of dementia expenditure between broad service areas. It shows that the majority of spending was on residential aged care services, with most of the remainder consisting of community based aged care services and hospital services.



Note: See technical notes for sources and methods used to derive estimates for each of the service areas/programs.
http://www.aihw.gov.au

Health and aged care expenditure on dementia

This page presents the total expenditure on aged care services as well as expenditure on dementia support services in 2020–21.

Total aged care expenditure

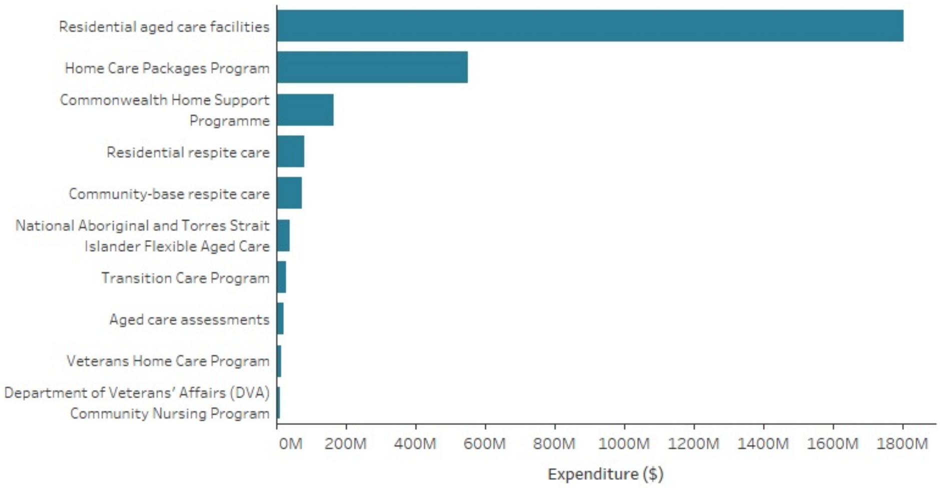
There are a range of government-funded aged care services available to provide care and assistance to those who need it, including: home-based care and support, short-term care and respite, and residential aged care services. In 2020–21, $23.6 billion was spent on aged care services and $2.8 billion of this was directly for dementia.

Aged care accounted for most (76%) of the total direct health and aged care system expenditure on dementia. Aged care expenditure for dementia included:

- $1.8 billion for people with dementia in permanent residential aged care facilities
- $550 million for people with dementia receiving Home Care Packages – services that provide support for people with complex care needs to live independently in their own homes. Of this, 45% was for Level 4 packages, which are designed for people with high care needs
- $166 million for people with dementia under the Commonwealth Home Support Programme – a program that provides entry level care for people who require a low level of support to remain living independently and safely at home
- $156 million for community-based and residential respite care services (Figure 14.2).

Figure 14.2: Estimated Australian Government expenditure on aged care programs that was attributable to dementia in 2020–21

Bar graph showing Australian Government expenditure on different aged care programs in 2020–21 that was directly attributable to dementia. The largest area of spending was residential aged care services (with spending of $1.8 billion) followed by Home Care Packages ($550 million), the Commonwealth Home Support Programme ($166 million) and community-case and residential respite care services ($156 million).



Note: Expenditure for residential aged care services is for permanent residents only.
Source: AIHW Analysis of National Aged Care Data Clearinghouse.
http://www.aihw.gov.au

For more information on aged care services for people with dementia, refer to Aged care assessments, Community-based aged care, and Residential aged care.

Expenditure on dementia support services

There are a number of dementia support programs and initiatives funded by the Australian Government and delivered by individual organisations. These programs are designed to assist people with dementia and their carers, as well as the dementia care workforce.

In 2020–21, the Australian Government provided almost $126 million to fund dementia support programs and initiatives under the Dementia and Aged Care Services Fund. This was equivalent to 3.4% of the total direct health and aged care system expenditure on dementia and included:

- $56.6 million for the Specialist Dementia Care Program
- $22.5 million for Severe Behaviour Response Teams
- $20.7 million for the Dementia Behavioural Management Advisory Service
- $13.8 million for the National Dementia Support Program
- $12.4 million for the National Dementia Training Program – a national approach to accredited education, upskilling and professional development in dementia care delivered by Dementia Training Australia.

For further information on the Dementia and Aged Care Services Fund and provision of dementia support services in recent years, refer to Overview of dementia support services and initiatives, National policy response to dementia and Behaviour Support Programs.

Health and aged care expenditure on dementia

Key statistics

In 2020–21, almost $763 million was spent on health services directly for dementia

$481 million was spent on public hospital admitted patient care and $31 million for private hospital admitted patient care

Almost $141 million was spent on outpatient clinic services in public hospitals

For common principal diagnoses, the average cost per hospitalisation was higher for patients with dementia than those without

This page presents the total health expenditure directly attributable to dementia in 2020–21, as well expenditure on hospital services, including:

- Total health expenditure
- Hospital services expenditure
- Public hospital outpatient clinics and emergency department care expenditure
- Expenditure on out-of-hospital services
- Expenditure on medications for dementia

Total health expenditure

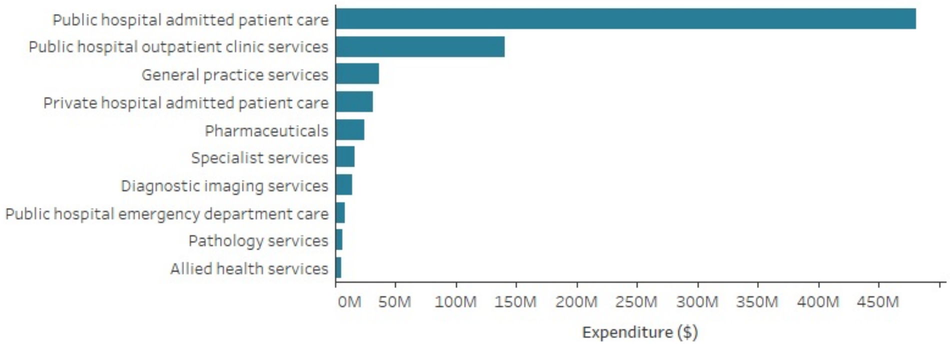
In 2020–21, it was estimated that almost $763 million (or 21% of the total direct health and aged care system expenditure on dementia) was for health expenditure alone. The majority of this expenditure was for:

- hospital-related services – almost $662 million, which included:
  - $481 million for public hospital admitted patient care and $31 million for private hospital admitted patient care
  - $141 million for outpatient clinics in public hospitals
  - $8.6 million for emergency department care in public hospitals.
- GP services – almost $37 million
- pharmaceuticals – just over $24 million (Figure 14.3).

Note that, as with other expenditure estimates in this report, expenditure for public hospital admitted patient care only includes dementia-specific costs of hospital separations (referred to as ‘hospitalisations’) where dementia was a principal or additional diagnosis. It does not include expenditure for the management of conditions other than dementia in estimates for that episode of care, which was 47% of the total cost of hospitalisations with a principal diagnosis of dementia.

Figure 14.3: Estimated health-care system expenditure attributable to dementia in 2020-21: by health-care area

Bar graph showing Australian Government health-care system expenditure attributable to dementia in 2020–21, by health-care area. The graph shows that the majority of expenditure was on public hospital admitted patient care (nearly $481 million) and public hospital outpatient clinic services (nearly $141 million). This was followed by spending on general practice services, private hospital admitted patient care and pharmaceuticals.



Note: Pharmaceuticals include all prescriptions dispensed under the Pharmaceutical Benefits Scheme.
Sources: AIHW analysis of Bettering the Evaluation and Care of Health data; AIHW disease expenditure database; AIHW National Hospital Morbidity Database; National Hospital Cost Data Collection; Pharmaceutical Benefits Scheme and Repatriation Pharmaceutical Benefits Scheme data.
http://www.aihw.gov.au

Hospital services expenditure

Admitted patient care in public hospitals

In 2020–21, $481 million was spent on public hospital admitted patient care for dementia. Of this, $224 million (or 47%) was for hospitalisations where dementia was the principal diagnosis - or the main reason for admission. The remaining $257 million (or 53%) was for hospitalisations where dementia was an additional diagnosis – where dementia impacted care but was not the main reason for being admitted to hospital. These estimates are for expenditure directly related to dementia and not for the management of other conditions in the same hospitalisation.

How does dementia affect the cost of hospitalisations in public hospitals for common principal diagnoses?

A diagnosis of dementia will influence the cost of a hospitalisation even when it is not the main reason for being admitted to hospital. To understand the costs related to dementia patients in hospital, the average costs of hospitalisations in a public hospital with an additional diagnosis of dementia were compared to those without dementia for 5 common principal diagnoses seen among older people.

The average cost per hospitalisation was greater among people with dementia than people without dementia for each principal diagnosis (Table 14.1).

Table 14.1: Average cost per hospitalisation in a public hospital for patients with dementia compared to patients without dementia in 2020–21: by select principal diagnoses

Principal diagnosis (ICD-10 code)	**Average cost, per hospitalisation ($)** **With dementia**	Average cost, per hospitalisation ($) Without dementia	Average cost difference ($)	Rate ratio
Urinary tract infection, site not specified (N390)	11,830	5,699	6,130	2.1
Pneumonia, organism unspecified (J18)	14,031	9,611	4,420	1.5
Fracture of femur (S72)	29,879	25,023	4,856	1.2
Delirium, not induced by alcohol and other psychoactive substances (F05)	16,050	15,741	309	1.0
Pneumonitis due to solids and liquids (J69)	13,068	12,274	793	1.1

Notes
1. ICD-10-AM refers to the International Classification of Diseases 11th revision Australian Modification.
2. Average cost difference is the average cost per separation with dementia minus the average cost per separation without dementia.
3. Rate ratio is the average cost per separation with dementia divided by the average cost per separation without dementia.
4. Delirium, not induced by alcohol and other psychoactive substances (F05) does not include delirium superimposed on dementia (F051) as this is included in the costs for dementia.

Source: AIHW analysis of National Hospital Morbidity Database and National Hospital Cost Data Collection.

Public hospital outpatient clinics and emergency department care expenditure

In 2020–21, $141 million was spent on non-admitted patient care for dementia in public hospital outpatient clinics, equivalent to 3.8% of the direct health and aged care expenditure attributable to dementia. Services provided in outpatient clinics include; consultations with specialist medical practitioners; allied health and specialist nursing care; diagnostic and other procedures; dispensing of medicines; and some community health services provided by hospitals (AIHW 2023).

A further $8.6 million was spent on emergency department (ED) care in public hospitals, equivalent to 0.2% of the total direct health expenditure on dementia. It is acknowledged that the ED expenditure will be an underestimate, as it relates only to presentations where dementia was recorded as the principal diagnosis. For more information on health condition coding in ED data, refer to the Technical notes.

Expenditure on out-of-hospital services

In 2020–21, over $101 million was estimated to have been spent on out-of-hospital services for dementia, such as GP and specialist services, allied health services, pharmaceuticals, and tests involved in the diagnosis and management of dementia. The expenditure on out-of-hospital services is equivalent to 13% of the total direct health expenditure on dementia and 2.7% of the total health and aged care expenditure on dementia. These estimates are for services where dementia was directly managed and do not include services for patients with dementia where management and treatment related only to their other co-existing health conditions.

Services contributing to the out-of-hospital medical expenditure for dementia were:

- general practice services – almost $37 million
- pharmaceuticals dispensed under the Pharmaceutical Benefits Scheme (PBS) – $24 million
- this includes dementia specific medicines and a range of other medications prescribed for the management of dementia symptoms
- diagnostic imaging – $14 million
- specialist services – over $16 million.

The estimates of expenditure on out-of-hospital medical services include Australian Government costs (under the Medicare Benefits Schedule (MBS) and the PBS), as well as out-of-pocket costs by individuals. The majority of out-of-hospital medical expenditure for dementia (89%, or just under $90 million) was from Australian Government benefits.

Expenditure on medications for dementia

There are 4 dementia-specific medications – Donepezil, Galantamine, Rivastigmine and Memantine – currently subsidised by the Australian Government through the Pharmaceutical Benefits Scheme (PBS) and the Repatriation Pharmaceutical Benefits Scheme (RPBS) for treatment of Alzheimer's disease. For information on the dispensing of scripts for these medications in Australia in recent years, see Prescriptions for dementia-specific medications.

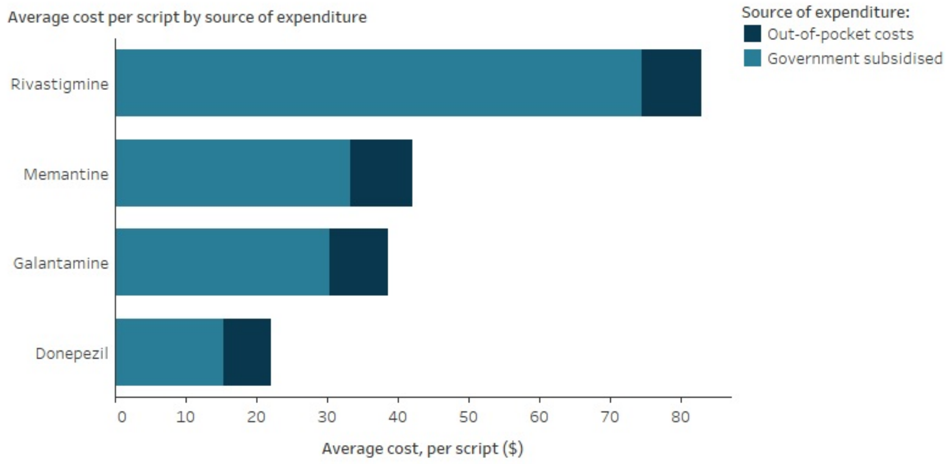
In 2020–21, the total expenditure on dementia-specific medications was just over $21 million. This included Australian Government expenditure ($17 million, or 78% of expenditure on dementia-specific medications) and out-of-pocket expenses by patients ($4.7 million or 22%). Note, these estimates may include a small amount of expenditure for off-label prescribing of these medications which aren't captured in the PBS/RPBS.

Of the total expenditure for dementia-specific medications, nearly half was on Donepezil (43% or $9.3 million), followed by Rivastigmine (30% or $6.4 million), Galantamine (13% or $2.8 million) and Memantine (14% or $3.0 million).

The Australian Government subsidised most of the expenditure on each type of dementia-specific medication (Figure 14.4). For patients, the average out-of-pocket cost for a single prescription for a dementia-specific medication was between $7 and $9. The average government subsidised amount per prescription varied substantially - from $15 for Donepezil to $74 for Rivastigmine.

Figure 14.4: Dementia-specific medication expenditure by medication type in 2020–21: average price per script by source of expenditure

Bar graph showing expenditure on four dementia-specific medications (Memantine, Galantamine, Rivastigmine and Donepezil) in 2020–21. The graph shows average cost per script for each medication, by source of expenditure. At $83 per script, Rivastagmine cost approximately twice as much as Memantine and Galantamine and four times as much as Donepezil ($22). The majority of the cost per script was covered by government subsidies for all four medications.



Source: AIHW analysis of Disease Expenditure database.
http://www.aihw.gov.au

References

AIHW (Australian Institute of Health and Welfare) (2023) *Non-admitted patient activity*, AIHW, Australian Government, accessed on 21 February 2024.

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. BPSD can have a significant impact on quality of life, health outcomes and caring needs of people with dementia. Information on BPSD in Australia enables better policy and service planning for supporting people with BPSD and their carers.

The following pages present statistics and information on:

- What are behaviours and psychological symptoms of dementia?
- National dementia behaviour support programs
- Behaviours captured in aged care assessments
- Data gaps and limitations in understanding BPSD

These pages also present the current data landscape for reporting on BPSD in Australia and ways this may be improved in the future.

Data are presented on people with BPSD who accessed behaviour support programs delivered by Dementia Support Australia, as well as data from completed comprehensive assessments for people accessing government subsidised aged care services. For the underlying data presented in these pages, refer to the Behaviours and psychological symptoms of dementia data tables.

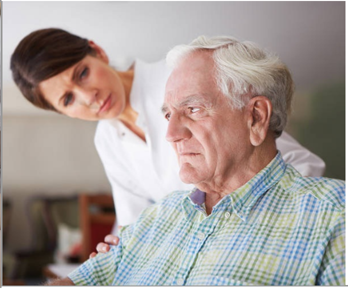
For more information on available support services, including aged care assessments and Dementia Support Australia, see Aged care and support services used by people with dementia.

Key statistics

291 referrals were assessed under the Needs Based Assessment program for very severe BPSD care between **July 2022 and June 2023**

Agitation was the most commonly referred behaviour (primary behaviour) among Dementia Support Australia assessments completed between **2022 and 2023**

Insomnia was the most frequently reported symptom among people with dementia who completed a comprehensive aged care assessment in 2021–22



People with dementia were **over twice as likely** to report **3 or more behaviours** in their comprehensive aged care assessments than people without dementia

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. The majority of people with dementia will experience at least one type of BPSD as their dementia progresses (Tible et al. 2017). Symptoms may vary in type and severity on a day-by-day basis and as a person's dementia progresses. BPSD can have a significant impact on people with dementia, their carers and family, and has been associated with premature admission to residential care, increased hospitalisation, distress for carers and reduced functional ability for the person with dementia (Cunningham, Macfarlane and Brodaty 2019).

Language surrounding behaviours and psychological symptoms of dementia (BPSD)

In this report, the term 'behaviours and psychological symptoms of dementia (BPSD)' is used to describe non-cognitive symptoms common among people with dementia. While there is concern that use of this term can lead to the underlying causes or needs of a person's behaviour being ignored, it remains the preferred term in a clinical context (Cunningham, Macfarlane and Brodaty 2019).

This report presents information on the prevalence of select symptoms using available data. However, understanding the causes of BPSD is a key information gap. There are a range of underlying causes, from physiological changes due to dementia to unmet needs or physical ailments. These underlying causes can differ between individuals, and management of symptoms requires person-centred care. BPSD support advocates for a focus on understanding why behaviours are occurring, rather than a focus on symptoms themselves.

Measuring BPSD

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
- 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).

The NPI is administered to caregivers of people with dementia. A screening question is asked about each sub-domain, and if a response indicates there is an issue in a particular sub-domain, the caregiver is then asked further questions about that sub-domain. Further questions include a rating of severity, frequency and distress the symptoms causes on a 4-point, 3-point and 5-point scale respectively (APA 2011). The Neuropsychiatric Inventory – Questionnaire (NPI-Q), Neuropsychiatric Inventory – Nursing Home (NPI-NH) and Neuropsychiatric Inventory – Clinician (NPI-C) are all validated against the NPI but vary in their administration.

To comprehensively plan for dementia and aged care-related service delivery, greater understanding of BPSD is needed. BPSD is associated with poorer prognosis, greater caregiver and nursing-home staff stress and earlier institutionalisation (Brodaty, Draper and Low 2003). As such, the complex care needs involved in managing BPSD are crucial to understand when designing dementia support services and residential care needs.

For more information on the support services available, see Dementia Support Australia.

References

APA (American Psychology Association) (2011) *Neuropsychiatric Inventory*, APA website, accessed 17 January 2022.

Brodaty H, Draper B and Low LF (2003) 'Behavioural and psychological symptoms of dementia: a seven-tiered model of service delivery', *The Medical Journal of Australia* ,178(5): 231-234, doi:10.5694/j.1326-5377.2003.tb05169.x.

Cunningham C, Macfarlane S and Brodaty H (2019) 'Language paradigms when behaviour changes with dementia: #BanBPSD' *Geriatric Psychiatry, 34(8): 1109-1113,* doi:10.1002/gps.5122.

Tible OP, Riese F, Savaskan E and von Gunten A (2017) ‘Best practice in the management of behavioural and psychological symptoms of dementia’, *Therapeutic Advances in Neurological Disorders*, 10(8): 297-309, doi:10.1177/1756285617712979.

Behaviours and psychological symptoms of dementia

Behaviours and psychological symptoms of dementia (BPSD) are often associated with complex care needs, with those affected requiring support from a number of health teams and professionals. BPSD is associated with carer stress, increased duration of hospitalisation and greater likelihood of placement in a residential care facility (NSW Health 2013). In Australia, there are a range of services available to support people experiencing BPSD, including programs supported by funding from the Australian Government.

This page provides information and statistics on:

- Services offered by Dementia Support Australia
- Trends in primary behaviours by age and sex
- Trends in primary behaviours by support program
- Neuropsychiatric Inventory (NPI) scores following program engagement

Dementia Support Australia

Dementia Support Australia (DSA) is a service led by HammondCare's Dementia Centre and funded by the Australian Government. Learn more about DSA's aims and services in Overview of dementia support services and initiatives.

DSA provides key national support services that can be accessed independently and provide tiered levels of support for people with dementia, their carers and aged care providers. These include:

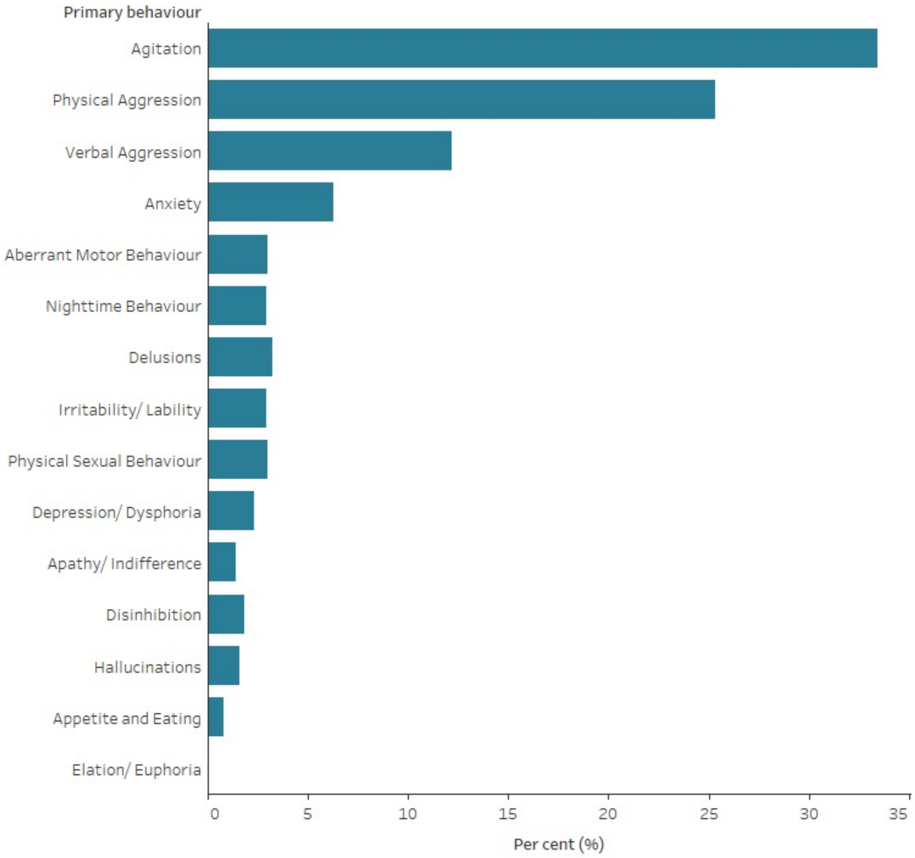
- Dementia Behaviour Management Advisory Service (DBMAS)
- Severe Behaviour Response Teams (SBRT)
- Needs Based Assessment program, which determines eligibility for the Specialist Dementia Care Program.

Currently DSA are the only national data source that collect Neuropsychiatric Inventory (NPI) information about people who experience BPSD, however this only captures people accessing their services. As such, DSA data are not representative of all people living with dementia or BPSD in Australia.

At intake and case closure, DSA routinely administers the Neuropsychiatric Inventory – Questionnaire (NPI-Q) and Neuropsychiatric Inventory – Nursing Home (NPI-NH) for DBMAS and SBRT clients respectively. Both instruments assess BPSD across three shared metrics: the total number of behaviours exhibited by the client, the total severity of these behaviours, and the total distress these behaviours cause formal and informal caregivers. In addition, the primary behaviour (indicating the main reason for referral) of the person with dementia is recorded during the referral process. Among assessments completed between July 2022 and June 2023, agitation was the most commonly recorded primary behaviour, accounting for one third (33%) of referrals. This was followed by physical aggression (25%), verbal aggression (12%) and anxiety (6.3%) (Figure 15.1a).

Figure 15.1a: Dementia Support Australia referrals between July 2022–June 2023, percentage by primary behaviours

Horizontal bar graph showing that agitation was the most recorded primary behaviour among assessments completed between July 2022 and June 2023, followed by physical aggression and verbal aggression.



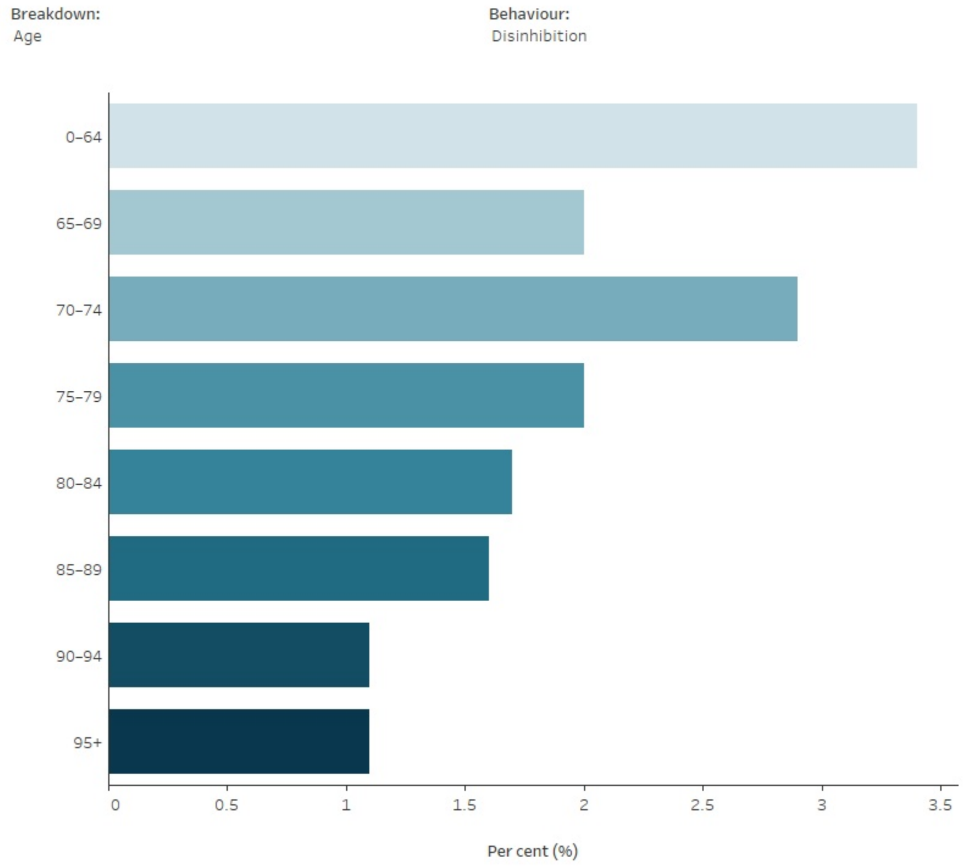
Source: DBMAS and SBRT program data supplied to AIHW by Dementia Support Australia.
http://www.aihw.gov.au

Primary behaviours varied by age and sex

Primary behaviours varied by age and sex. While there were no clear trends by age group, some primary behaviours were more common by sex. Male clients were more likely to be referred for physical aggression, disinhibition or physical sexual behaviour than female clients. While most other primary behaviours, including anxiety, delusions and depression/dysphoria appeared more commonly in referrals of female clients compared to male clients (Figure 15.1b).

Figure 15.1b: Dementia Support Australia referrals between July 2022–June 2023, percentage of primary behaviours by age and sex

Horizontal bar graph displaying percentage of symptoms by symptom type, age, and sex. Most primary behaviours occurred more commonly in referrals of female clients compared to male clients.



Source: DBMAS and SBRT program data supplied to AIHW by Dementia Support Australia.
http://www.aihw.gov.au

Primary behaviours varied between Dementia Support Australia’s behaviour support programs

The DBMAS is a program designed to provide proactive support early on, where there is less risk related to behaviour. For people living with dementia who are experiencing severe behaviour and psychological symptoms, the SBRT is recommended.

Between July 2022 and June 2023, clients assessed for DBMAS and SBRT varied in primary behaviour. The majority of referrals resulting in an SBRT assessment recorded physical aggression (63%) or agitation (20%) as a primary behaviour. While physical aggression and agitation were also the leading recorded primary behaviours at referral of a DBMAS assessment, they accounted for a lower proportion (combined 55%) of primary behaviours recorded at referral, compared to the same behaviours in SBRT.

Table 15.1: Dementia Support Australia referrals between July 2021–June 2022, percentage of primary behaviours by program

Primary behaviour	DBMAS	SBRT
Agitation	35.3	19.9
Physical Aggression	19.8	63.0
Verbal Aggression	13.1	5.5
Anxiety	7.1	1.2
Aberrant Motor Behaviour	3.2	1.5
Delusions	3.5	1.2
Nighttime Behaviour	3.2	1.1
Irritability/ Lability	3.2	1.1
Physical Sexual Behaviour	2.9	3.8
Depression/ Dysphoria	2.5	0.6
Disinhibition	1.9	0.8
Apathy/ Indifference	1.5	0.2
Hallucinations	1.8	0.3

Appetite and Eating	0.9	0.0
Elation/ Euphoria	0.0	n.p.

Note: n.p. – Not available for publication. Estimate is considered to be unreliable.

Source: DBMAS and SBRT program data supplied to AIHW by Dementia Support Australia.

Severe BPSD requires specialist care

Although rare, BPSD can be severe enough that highly specialised care is needed above that provided by SBRT. For clients requiring specialist accommodation, care and support, the Needs Based Assessment Service (NBA) is recommended to assess eligibility for Specialist Dementia Care Program (SDCP) placement. As the prevalence of people experiencing BPSD decreases as severity of the symptoms increase, there is a much smaller number of NBA referrals when compared with the SBRT and DBMAS programs. Between July 2022 and June 2023, a total of 291 NBA referrals were assessed.

The NBA program assesses eligibility with three key principles:

- Behaviours and psychological symptoms are primarily the result of dementia.
- Symptoms are severe or very severe.
- Symptoms have remained non-responsive to adequate trials of treatment, including non-pharmacological interventions and other specialist programs.

Assessments may be rated ineligible for a number of reasons, including severity not being evaluated as high enough. Conversely, assessments may be rated as ineligible due to behaviours being too severe for Specialist Dementia Care Program (SDCP) placement. Of the referrals between July 2022 and June 2023, 1 in 3 (33%) were rated ineligible. Of these, around a quarter (26%) were rated ineligible due to extreme behaviours.

Overall Neuropsychiatric Inventory (NPI) scores improved following engagement with programs

While the information presented above focuses on the primary behaviour clients present with, clients can experience multiple behaviours at once. Between January 2023 and June 2023 DSA clients presented with behaviour symptoms in an average of 5.1 domains out of the 12 NPI domains upon program intake, and 2.7 upon program exit (an overall reduction of 47%) (Table 15.1). This decrease demonstrates the effectiveness of tailored services for BPSD management, and supports findings from a 2021 evaluation on the clinical impact of these programs on neuropsychiatric outcomes (Macfarlane et al. 2021).

Other measures included in the NPI are total severity of behaviours and total distress/disruptiveness of behaviours to formal and informal carers. The average total severity score decreased between clients who were referred to a program compared to clients who were discharged from a program within the six-month period (10.5 compared with 3.9, respectively) (Table 15.2). Similarly, the average total distress score among carers at intake between January 2023 and June 2023 was 14.4, dropping to 4.7 among carers at exit from the program.

Table 15.2: Dementia Support Australia referrals between January–June 2023, total severity, total distress, and average number of NPI domains

	Intake	**Discharge**
Number of domains	5.1	2.7
Total distress	14.4	4.7
Total severity	10.5	3.9

Source: DBMAS and SBRT program data supplied to AIHW by Dementia Support Australia.

While DSA aims to provide support for people with dementia and their carers, programs also aim to support residential aged care facilities in their support of people experiencing behavioural symptoms. Between January 2023 and June 2023, DSA had an average of 6.5 client referrals per residential aged care facility in Australia and provided support to 2,260 (85%) residential aged care homes in Australia.

References

Macfarlane S, Atee M, Morris T, Whiting D, Healy M, Alford M and Cunningham C (2021) 'Evaluating the Clinical Impact of National Dementia Behaviour Support Programs on Neuropsychiatric Outcomes in Australia', *Frontiers in Psychiatry*, doi: doi.org/10.3389/fpsyt.2021.652254.

NSW Health (NSW Ministry of Health) & RANZCP (Royal Australian and New Zealand College of Psychiatrists) (2013) *Assessment and Management of People with Behavioural and Psychological Symptoms of Dementia (BPSD)*, NSW Health, accessed 29 March 2022.

Behaviours and psychological symptoms of dementia

To access government-subsidised aged care services, a person will undertake an initial screening to establish their needs and the types of services that could help them. Only the most comprehensive type of assessment captures behaviour and psychological symptoms. For more information on aged care assessments, please visit Aged care assessments.

Behaviours recorded in comprehensive aged care assessments compared to the Neuropsychiatric Inventory (NPI)

As discussed in the previous section, the NPI is the gold-standard assessment for identifying BPSD. However, the NPI is not undertaken for people accessing government funded aged care services. Instead, select behaviours are recorded in comprehensive aged care assessments that align with descriptions of some BPSD domains in the NPI.

While the information presented below provide useful insight on the symptoms experienced by people accessing aged care services, ‘symptoms’ recorded in a comprehensive aged care assessment do not reflect the preferred clinical terms. For example, the description of NPI domain *disinhibition* overlaps with the recorded symptom, *risky behaviours*, in a comprehensive aged care assessment. While we present information on people experiencing *risky behaviours* below as recorded in the comprehensive aged care assessment data, *disinhibition* remains the preferred clinical term. Further, while *wandering* is not listed in the NPI, it is frequently cited as an example of BPSD in literature (RACGP 2019; Burley et al. 2021) and is listed as an example behaviour under the *Sleep and Nighttime Behaviours* NPI domain. As such, *wandering* information collected in the comprehensive assessments have been included in this section.

In 2021–22, nearly 199,400 Australians completed a comprehensive aged care assessment and 16% (32,600) of people were recorded as having dementia. Among all people who completed a comprehensive aged care assessment, 41% reported experiencing one or more behaviours or psychological symptoms ‘regularly’ or ‘always.’

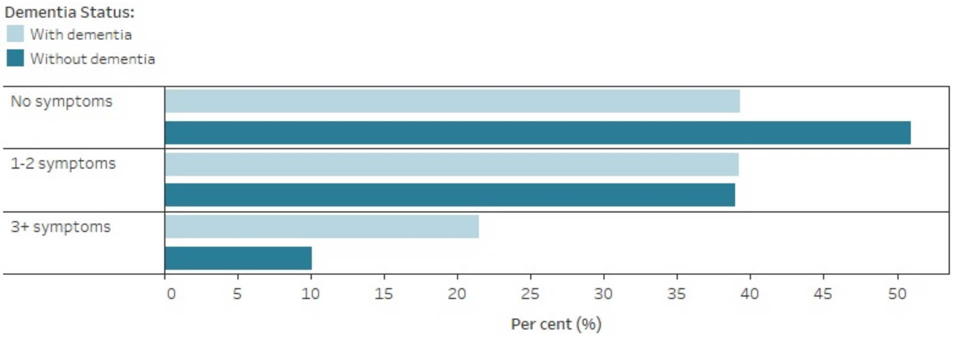
A higher proportion of people with dementia reported experiencing one or more symptoms compared with people without dementia (61% compared with 49%, respectively). In addition, the proportion of people with dementia who reported experiencing three or more symptoms always or regularly was more than twice as high as the proportion of people without dementia (22% compared with 10%, respectively) (Figure 15.2).

Symptoms recorded in comprehensive aged care assessments

- Agitation – described as extreme emotional disturbance.
- Anxiety – described as an unpleasant state of inner turmoil, often accompanied by nervous behaviours such as pacing back and forth, somatic complaints and rumination.
- Apathy – described as the absence or suppression of passion, emotion, or excitement.
- Depression – described as depressive symptoms, including physical symptoms, long periods of feeling lonely, overwhelming feelings of being unable to keep going or regular tears.
- Hallucinations or delusions – delusions are described as false or erroneous beliefs that usually involve a misinterpretation of perceptions or experiences. Hallucinations can occur in any sensory modality, including auditory, visual, olfactory (smell), gustatory (taste) and tactile (touch).
- Insomnia – described as persistent difficulty in initiating or maintaining sleep.
- Risky behaviour – described as behaviours that put the person or others at risk of harm.
- Resistive behaviour – described as a person resisting, opposing or withstanding help or caregiving tasks such as taking medication, eating or self-feeding.
- Verbal aggression – described as a person yelling, screaming and/or threatening.
- Wandering – described as moving without definite destination or purpose.

Figure 15.2: Proportion of people who completed a comprehensive aged care assessment in 2021-22, by number of behaviours and psychological symptoms and dementia status

Horizontal bar graph showing that a greater proportion of people without dementia recorded zero symptoms, while a greater proportion of people with dementia recorded three or more symptoms.



Note: Symptoms group included people who reported experiencing the assessed symptom types 'always' or 'regularly'. Responses of 'occasionally', 'rarely' , 'never' and 'not stated' were categorised as no symptoms. Aged care assessments with 'not stated' recorded across all symptoms were excluded from analysis.

Source: AIHW analysis of the National Aged Care Data Clearinghouse.

Symptom types

Insomnia was the most frequently reported symptom among people who completed a comprehensive aged care assessment in 2021–22 and rates were similar among people with dementia and people without dementia (30% and 34%, respectively). This was followed by anxiety (21% and 19%, respectively) and resistive behaviours (16% and 3.4%, respectively).

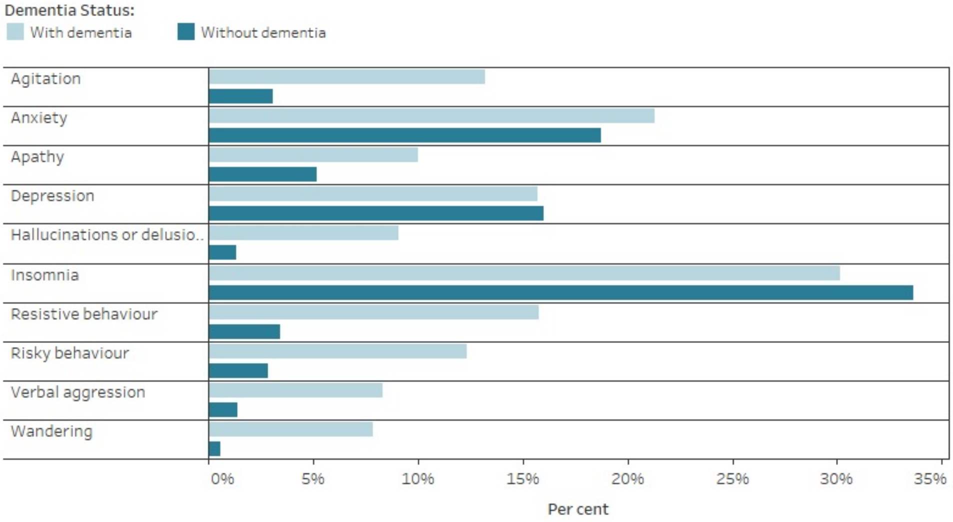
When comparing symptom frequency by dementia status, the following symptoms had the greatest percentage point difference:

- Resistive behaviours – (16% of people with dementia compared with 3.4% of people without dementia).
- Agitation – (13% of people with dementia compared with 3.1% of people without dementia).
- Risky behaviours – (12% of people with dementia compared with 2.9% of people without dementia) (Figure 15.3a).

It is important to note that while frequency of symptoms is captured within the comprehensive aged care assessment data, there is no indication of symptom severity or carer distress. Data in this section are based on an individual reporting their experience of a particular symptom to be 'always' or 'regularly,' however it is difficult to estimate the full extent of symptom impact without further severity and distress information.

Figure 15.3a: Proportion of people who reported experiencing behaviours and psychological symptoms 'always' or 'regularly' in comprehensive aged care assessment in 2021–22, by symptom type

Horizontal bar graph showing that insomnia was the most recorded symptom among people with and without dementia.



Source: AIHW analysis of the National Aged Care Data Clearinghouse.

Symptoms decreased with age and varied by sex

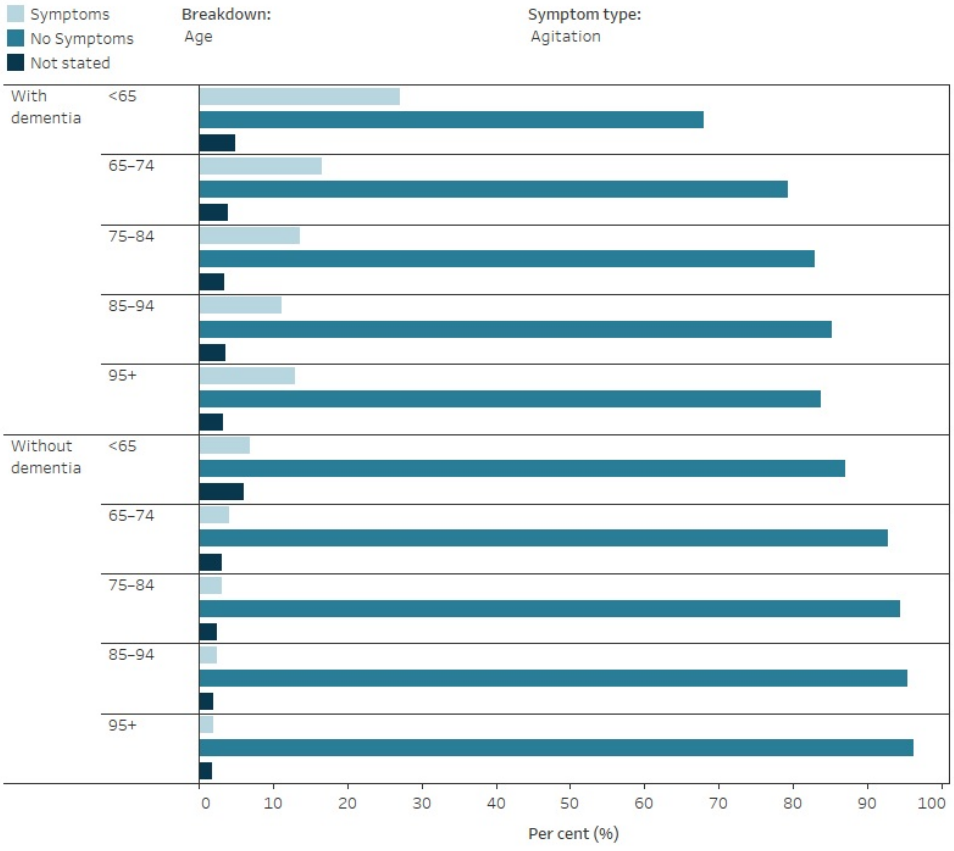
Among people who completed a comprehensive aged care assessment and had dementia recorded as a health condition:

- A higher proportion of men reported experiencing symptoms of agitation, apathy, insomnia, risky behaviour, verbal aggression and wandering 'always' or 'regularly' compared with women. A higher proportion of women reported experiencing symptoms of anxiety, depression and resistive behaviours 'always' or 'regularly' compared with men.
- Symptoms of resistive behaviour, agitation, apathy and insomnia decreased with age until ages 85–94, followed by a slight increase in the 95+ age group. Symptoms of hallucinations or delusions varied over the age groups. Across all remaining symptom types, rates decreased with age, except for depression, which increased in the 65–74 age group and then decreased (Figure 15.3b).

Within Figure 15.3b, the proportion of the 'not stated' responses are presented for each symptom. Across all symptom types, there were a greater proportion of 'not stated' responses for people who recorded dementia as a health condition compared to people who did not. As such, it is likely that these estimates disproportionately undercount the frequency of symptoms experienced among people with dementia who completed a comprehensive aged care assessment.

Figure 15.3b: Reported symptoms among people who completed a comprehensive aged care assessment in 2021–22, by symptom type, age and sex

Horizontal bar graph showing that reported symptoms from people with or without dementia decreased with age. Overall, except for insomnia and depression, people with dementia were more likely to report symptoms than people without dementia.



Note: Symptoms group included people who reported experiencing symptom type 'always' or 'regularly'. Responses of 'occasionally', 'rarely' and 'never' were categorised as no symptoms.

Source: AIHW analysis of the National Aged Care Data Clearinghouse.

Triggers for assessment

Comprehensive aged care assessments record the triggers that indicate the need for an individual's assessment to take place. These triggers may be closely related to an individual's health and care needs, or related to other circumstances such as a change in care arrangements. An individual may also have more than one trigger for assessment recorded.

Comprehensive aged care assessments for people with dementia who reported behaviours or psychological symptoms were most commonly triggered by a change in cognitive status (85%), change in care needs (79%), and change in medical condition (74%). These triggers were similarly common among people with dementia who did not report symptoms (79%, 75% and 72% respectively). Across every trigger, there was a higher proportion of people with symptoms recorded compared with people without symptoms (Table S15.10).

References

Burley C, Casey AN, Chenoweth L and Brodaty H (2021) 'Reconceptualising Behavioural and Psychological Symptoms of Dementia: Views of People Living With Dementia and Families/Care Partners', *Frontiers in Psychiatry,* doi: doi.org/10.3389/fpsyt.2021.710703.

RACGP (Royal Australian College of General Practitioner) (2019) *RACGP aged care clinical guide (Silver Book)*, RACGP, accessed 11 November 2022.

Behaviours and psychological symptoms of dementia

Despite the high impact of BPSD on quality of life and care needs, there are no current national prevalence estimates of BPSD among people with dementia in Australia. While the primary Australian service planning model adopted in 2003 estimates that approximately 60% of people with dementia experience BPSD, estimates across the literature fluctuate depending on sample characteristics (community-based sample compared with residential aged care or hospital based) and measurement methodology (Brodaty, Draper and Low 2003). The estimates most recently reported by Australian studies range from 61–88% of people with dementia in the community setting, 29–90% of residents in Australian nursing homes and 95% of hospitalised patients in long term acute care (APH 2014). However, these estimates of BPSD prevalence are based on studies with smaller samples conducted between 1996 and 2001, highlighting the need for studies with more robust and representative samples and up-to-date prevalence estimates. In addition, while prevalence estimates indicate an increase in dementia over the next decade, there has been no research that confirms whether rates of BPSD will similarly rise (NSW Health 2021).

Despite its importance and impact, there are key gaps in our understanding of BPSD in Australia. Firstly, there is no singular cause of BPSD. Causes and influences vary between individuals, ranging from physiological changes in the brain due to dementia, to unmet needs or physical co-morbidities. There are also significant difficulties in untangling separate mental health conditions from BPSD and dementia during disease progression. Similarly, there is no diagnostic code for BPSD in available administrative data and often behaviour concerns are not distinguished from a dementia diagnosis in data. Understanding the drivers and influences of BPSD is key in developing targeted treatment and support services.

Further, while there are a range of management and support services available for people experiencing BPSD, synthesising data and patterns from service use and management techniques is a key challenge. Pharmacological treatments are difficult to estimate due to the range of medications that can be used to manage BPSD, including off-label prescriptions. Similarly, non-pharmacological treatment services range from BPSD-specific programs to broader exercise and counselling services. Greater identification of BPSD is needed in administrative datasets to understand the health and aged care service use patterns among people experiencing BPSD in Australia. There is a potential opportunity through future data linkages to provide a more comprehensive picture across all tiers of BPSD in Australia, including geographical and residential location, demographic background and utilisation of support services.

References

APH (Australian Parliament House) (2014) *Care and management of younger and older Australians living with dementia and behavioural and psychiatric symptoms of dementia (BPSD)*, Canberra: APH, accessed 9 December 2021.

Brodaty H, Draper B and Low LF (2003) 'Behavioural and psychological symptoms of dementia: a seven-tiered model of service delivery', *The Medical Journal of Australia* 178(5): 231-234, doi:10.5694/j.1326-5377.2003.tb05169.x.

NSW Health (New South Wales Ministry of Health) (2021) *Extreme Behavioural and Psychological Symptoms of Dementia (BPSD)*, NSW Health, accessed 17 January 2022.

National policy response to dementia

Australia was one of the first countries to design comprehensive dementia-specific policy initiatives at a national level, in response to the rising challenges of an expanding and ageing population and advocacy from groups, such as the then Alzheimer's Association of Australia (Hunter and Doyle 2014).

The first federal dementia policy initiative was launched in 1992 (the National Plan for Dementia Care 1992–1997) and succeeding policy initiatives have cemented dementia as a key priority in the national aged care agenda. Dementia has also been increasingly recognised as a national health priority requiring a focus on preventive strategies, high-quality health and social care, and investments in medical research (Hunter and Doyle 2014; Department of Health 2015). In 2017, the World Health Organization developed The Global action plan on the public health response to dementia 2017-2025 to encourage a concerted international effort to address the global impacts of dementia. The global action plan was adopted by Australia and other Member States (WHO 2017).

This webpage focuses on:

- the Royal Commission into Aged Care Quality and Safety (see Box 16.1), including dementia-focused recommendations and the Australian Government's response to these recommendations.
- the National Dementia Action Plan
- the Aged Care Diversity Framework
- government-funded dementia research.

While this page focuses on the national policy response to dementia by the federal government, it is acknowledged that governments at all levels develop and deliver dementia-specific policies and services. State and territory governments also fund (in full or part) essential services such as: memory clinics; geriatric evaluations and aged care visiting services; older adult mental health services; hospital to residential aged care transition services; and support for people experiencing behaviours and psychological symptoms of dementia (Mond 2019). Some of these essential services also receive federal government funding, for example through the Medicare Benefits Scheme or through specific programs and initiatives (for example, Dementia Behaviour Management Advisory Service, Severe Behaviour Response Teams and the Specialist Dementia Care Program).

Box 16.1: The Royal Commission into Aged Care Quality and Safety

The Royal Commission into Aged Care Quality and Safety (Royal Commission) was set up in 2018 to look into issues related to the quality of residential and in-home aged care. The Royal Commission's final report, Care, Dignity and Respect, was tabled in the Australian Parliament on 1 March 2021. This report included 148 wide-ranging recommendations for fundamental reform of the aged care system.

The Royal Commission identified four areas in need of immediate attention: food and nutrition; care and support for people living with dementia; elimination and reduction of restrictive practices; and palliative care (Royal Commission 2021).

Other recommendations specific to dementia from the final report, are:

- **Recommendation 15:** establishing a comprehensive, clear and **accessible post-diagnosis support pathway** for people living with dementia, their carers and families.
- **Recommendation 16:** reviewing and publicly reporting on whether the number of **Specialist Dementia Care Units** established or planned to be established is sufficient to address need within the areas and populations they are designed to cover.
- **Recommendation 19:** reviewing of the Aged Care Quality Standards, including **dementia care standards**.
- **Recommendation 45:** improving the design of aged care accommodation, including **dementia-friendly design**.
- **Recommendation 80:** implementing **mandatory dementia care training** for workers engaged in residential aged care and in care at home (Royal Commission 2021).

The Australian Government's response to the Royal Commission into Aged Care Quality and Safety

A range of changes are being made to aged care in response to the final report of the Royal Commission into Aged Care Quality and Safety. These changes are expected to deliver significant reform in aged care, providing care, dignity and respect to senior Australians.

Dementia-specific changes will support people living with dementia and their carers at every stage from diagnosis through to residential aged care. Together this will ensure people living with dementia are connected with the support they need post-diagnosis, are enabled to remain in their home for longer, and able to access high quality, dementia informed aged care services.

Key initiatives include:

- improved early intervention assistance
- more help to navigate the aged care system
- more staff trained in dementia care
- improved respite experience for people living with dementia

- improvements in capacity and quality of dementia care
- more support for carers to maintain their caring role.

For more information on any of the above points see Our work related to dementia | Australian Government Department of Health and Aged Care.

The reforms also include funding to improve dementia data collection and understanding, and to develop new National Design Standards for residential aged care, incorporating dementia-friendly design. A more detailed description on the Australian Government's response to the final report can be found on the Australian Government Department of Health website.

The National Dementia Action Plan

The Australian Government commenced development of the new National Dementia Action Plan ('the Plan') in 2021 with state and territory governments, informed by the 2019 review of the National Framework for Action on Dementia 2015-19. The Plan will span 10 years and include specific actions that promote a collaborative national approach to drive improvements for people living with dementia, their carers and families throughout Australia.

This Plan is a collaborative effort between the Commonwealth, States and Territories, and is occurring in consultation with key stakeholders, including people living with dementia and their carers and families, Dementia Australia, health professionals, aged care providers and researchers. The Plan forms part of the Commonwealth Government's response to the Royal Commission and contributes to Australia's international obligations as a member state to the World Health Organization's Global action plan on the public health response to dementia 2017–2025.

Governments are working to release the plan in 2024.

The Aged Care Diversity Framework

In 2017 the Australian Government launched the Aged Care Diversity Framework and associated action plans to address the needs of older Australians from diverse backgrounds, including those with cognitive impairment and dementia. The Diversity Framework provides a mechanism for government, aged care providers, peak bodies and representative groups, service users, and their families and carers, to ensure diversity is embedded in the design and delivery of aged care services.

The delivery of safe and inclusive services to people with diverse needs and life experiences is built into the Aged Care Quality Standards (Quality Standards). Diversity is embedded throughout the standards and underpinned by Standard 1 to value the identity, culture and diversity of each aged care recipient and to deliver culturally safe care and services.

While the Quality Standards are a powerful tool to maintain and improve quality of care, in response to Royal Commission recommendations a review of the Quality Standards was conducted and has now been completed. This was to make the Quality Standards more comprehensive, measurable and easy to understand to better support quality care. The review included a focus on key areas including dementia, diversity, governance, clinical care and food and nutrition. Following significant consultations since December 2021 and a pilot by the Aged Care Quality and Safety Commission in 2023, the final draft of the strengthened Quality Standards has been published to support sector readiness.

The draft of the strengthened Quality Standards embeds dementia and diversity and significantly enhances expectations for the delivery of safe and quality care. The final draft of the strengthened Quality Standards will be written into legislation under the new Aged Care Act (Act) and will be implemented at the same time as the Act.

In February 2019, four Action Plans designed to address the specific needs and challenges faced by diverse groups in the community were launched under the Aged Care Diversity Framework for:

- First Nations people
- older people from Culturally and Linguistically Diverse Communities
- people who identify as Lesbian, Gay, Bisexual, Trans and Gender Diverse, Intersex, Queer or other (LGBTIQ+)
- actions common to all diverse older people, in recognition of the many commonalities within and between diverse groups.

These plans assist aged care providers to identify actions they could take to deliver more inclusive and culturally appropriate services for their residents and clients. They acknowledge that there is no 'one-size-fits-all' approach to diversity, and that each aged care provider will be starting from a different place and operating in a different context.

Dementia research

Australian dementia researchers funded by the Australian Government through the National Health and Medical Research Council (NHMRC) have a renowned reputation for producing international-leading work. Australian research has high potential to positively impact Australians with dementia, particularly when research is collaborative and conducted on a large-scale (Moira Clay Consulting 2021).

Starting in 2014, the government funded a 5-year $200 million dementia research expansion coordinated by the then NHMRC National Institute for Dementia Research (NNIDR) (Mond 2019). While allocation of the funding for the NNIDR concluded in 2019, the NHMRC still offers dedicated dementia-specific research funding opportunities (NHMRC 2021).

The NHMRC awarded funding to establish the Australian Dementia Network (ADNeT) in 2018 – a network of scientists, clinicians, and researchers across multiple institutions. ADNeT has established Australia's first dementia clinical quality registry to monitor, report and improve clinical care for people with dementia; establish a collaborative network of memory clinics and develop best practice guidelines for dementia diagnosis treatment and management; and progressed screening sites for people with dementia who are suitable for participation in clinical trials. The government also funds a broad range of research and innovation projects on emerging priorities in dementia:

- The Medical Research Future Fund (MRFF) is a $20 billion long-term investment by the government that aims to support health and medical research and innovation. The Dementia, Ageing and Aged Care Mission will invest $185 million over 10 years under the MRFF to improve outcomes for people living with dementia and older Australians. The Mission will support older people to maintain their health and quality of life as they age, live independently for longer, and access quality care when they need it.
- Aged Care Research and Industry Innovation Australia is designed to address long-standing barriers to the development, evaluation and uptake of aged care workforce research. They focus on the development of innovation to improve workforce capability and the development of assistive technologies to enable care recipients to maintain independence for longer. Funding of $34m was announced over 4 years, starting in 2021–22.

There are still persistent gaps in national data that limit monitoring and reporting on dementia in Australia and planning for dementia programs and services. The National Centre for Monitoring Dementia (NCMD), located at the Australian Institute for Health and Welfare (AIHW) was established in 2021 and is undertaking routine monitoring of dementia in Australia, addressing existing data gaps and informing specific Government policy on the needs for Australians living with dementia. The NCMD currently undertakes activities in two main streams:

- Analysis and reporting: including routine monitoring of dementia via the Dementia in Australia report (this report) and special interest or thematic projects that utilise currently available data to address specific policy and research information priorities and dementia data gaps.
- Improving dementia data: including projects to address dementia data gaps or data quality issues.

For more information on current dementia data gaps, and ways in which these gaps can be systematically and strategically addressed, see the 2023 AIHW report: National Dementia Data Improvement Plan 2023–2033.

References

Department of Health (2015) *National Framework for Action on Dementia 2015–2019*, Department of Health, Australian Government, accessed 3 January 2023.

Department of Health (2017) *Aged Care Diversity Framework*, Department of Health, Australian Government, accessed 5 January 2023.

Hunter C and Doyle C (2014) ‘Dementia policy in Australia and the 'Social Construction' of infirm old age’, *Health & History: Journal of the Australian & New Zealand Society for the History of Medicine*, 16(2):44–62, doi:10.5401/healthhist.16.2.0044.

Moira Clay Consulting (2020) *A Snapshot of High Potential Impact Research on Dementia in Australia*, NHMRC, accessed 18 January 2023.

Mond J (2019) *EXHIBIT 3-79 - WIT.0144.0001.0001 - Statement of Josephine Mond*, Royal Commission into Aged Care and Safety, accessed 20 January 2023.

NHMRC (National Health and Medical Research Council) (2020) *NHMRC Dementia Research News*, NHMRC, accessed 18 January 2023.

Royal Commission (2021) *Final report: Care, Dignity and Respect*, Royal Commission, Australian Government, accessed 18 January 2023.

WHO (World Health Organization) (2017) *Global action plan on the public health response to dementia 2017-2025*, WHO, accessed 20 January 2023.

Technical notes

In order to provide a more complete picture of dementia in Australia, data presented in this report are sourced from a range of data collections from several organisations, including:

- Australian Institute of Health and Welfare (AIHW)
- Australian Bureau of Statistics (ABS)
- Australian Government Department of Health and Aged Care
- Dementia Australia
- Dementia Support Australia.

The latest data have been used wherever possible. Data are subject to change due to: the nature and timing of the data collection; a regular program of updates and maintenance; and newly discovered errors or anomalies. Revisions and changes in coverage should be considered when interpreting changes over time.

A summary of the main data sources used in this report are included in Table 1 below. For more detailed information, see Data sources.

For information on the methodologies used to derive estimates (for example, dementia prevalence or health and aged care expenditure) and other statistics presented in this report, see Methods. It is important to note that differences between data collections and methodological approaches may influence the comparability of estimates across data sources within this report, as well as with other published information not estimated by AIHW. Where relevant these considerations have been noted within the report.

In this report, numbers are generally rounded to the nearest 10, 100 or 1,000 in text. Percentages and rates are generally rounded to whole numbers, except for numbers less than 10 which are rounded to 1 decimal place. For unrounded numbers, refer to the Supplementary data tables.

For definitions of technical concepts used throughout this report, see Glossary.

Table 1: Summary of the main data sources used in *Dementia in Australia*

Source	Data source	Main source year	Frequency of updates	Description	Section/s where data was used
Australian Institute of Health and Welfare	Australian Burden of Disease Study	2023 (national estimates) 2018 (small area and First Nations people estimates)	Ad hoc	Data on the fatal, non-fatal and total burden of disease in Australia.	Burden of disease due to dementia Burden of disease due to dementia among First Nations people
	Disease Expenditure Database	2020–21	Ad hoc	Data on government expenditure on disease estimated using multiple data sources.	Health and aged care expenditure on dementia

	National Aged Care Data Clearinghouse	Various	Various	A central repository of national aged care data from various sources, mostly related to government-subsidised aged care programs operating under the *Aged Care Act 1997*. In this report data on the National Screening and Assessment Form and the Aged Care Funding Instrument are presented.	Aged care and support services used by people with dementia Behaviours and psychological symptoms of dementia Dementia among people from culturally and linguistically diverse backgrounds Aged care and support services available to people with younger onset dementia
	National Hospital Morbidity Database	2021–22	Annual	Episode-level records from admitted patient morbidity data collection systems in Australian hospitals (public and private). The data set for the reference period 2021–22 includes records for admitted patient separations between 1 July 2021 and 30 June 2022.	Hospital care Hospitalisations due to dementia Hospitalisations with dementia Hospital care for First Nations people with dementia
	National Health Data Hub (NHDH) (previously referred to as the National Integrated Health Services Information (NIHSI) analytical asset)	2020–21	Version 3.0	NIHSI version 3.0 contains linked data from 2010–11 to 2020–21 on: • admitted patient care services (in all public and, where available, private hospitals), emergency department services and outpatient services in public hospitals for New South Wales, Victoria, South Australia and Tasmania • Pharmaceutical Benefits Scheme and Repatriation Pharmaceutical Benefits Scheme national data • Medicare Benefits Schedule national data • Residential aged care data from National Aged Care Clearinghouse (person level assessments, episodes in care, and leave from care and information on facilities) national data • National Mortality Database data.	Primary health care services Health services used by people with younger onset dementia

	National Mortality Database	2021	Annual	Data on records for deaths in Australia from 1964.	Deaths due to dementia Population health impacts of dementia among First Nations people Population health impacts of younger onset dementia
	Pharmaceutical Benefits Scheme/ Repatriation Pharmaceutical Benefits Scheme	2021–22	Daily	Data on medications prescribed and prescriptions dispensed under the Pharmaceutical Benefits Scheme and Repatriation Pharmaceutical Benefits Scheme.	Prescriptions for dementia-specific medications Health services used by people with younger onset dementia
Australian Bureau of Statistics	Estimated Resident Population	Various	Yearly	ABS estimates of the usual resident population of Australia.	Prevalence of dementia
	Multi-Agency Data Integration Partnership data asset	Various	Ad hoc	Linked national survey and administrative data from a range of Commonwealth agencies, including healthcare, Census, social security payments, personal income tax, and mortality to create a comprehensive picture of Australia over time.	Cultural and linguistic diversity among Australians who died with dementia
	Survey of Disability Ageing and Carers	2018	Every 3–4 years	Detailed information on a sample of people who either; have a disability that restricts every-day activities, are aged 65 or over or are people who care for individuals with a disability, long-term health condition(s) (including dementia) or older people.	Carers and care needs of people with dementia Aged care assessments Dementia among people from culturally and linguistically diverse backgrounds
Dementia Australia	National Dementia Helpline administrative data	2022–23	Ad hoc	Data on contacts to the National Dementia Helpline. Further information on these data is not available.	National Dementia Support Program and Dementia Friendly Communities
Dementia Support Australia	Dementia Behaviour Management Advisory Service and Severe Behaviour Response Teams administrative data	2023	Ad hoc	Data on cases supported by the Dementia Behaviour Management Advisory Service and Severe Behaviour Response Teams.	Behaviour Support Programs Behaviours and psychological symptoms of dementia

Technical notes

Australian Burden of Disease Study 2018 and 2023

The Australian Burden of Disease Study (ABDS) 2023 provides projected estimates of burden of disease for 220 diseases and injuries for the total population for 2023. The study used trend analysis techniques to project increases in sex- and age-specific rates in disease burden. Full analysis techniques can be found in the ABDS technical notes.

The Australian Burden of Disease Study (ABDS) 2018 provides First Nations-specific burden of disease estimates for the total population for 2018, 2015, 2011 and 2003 and for the First Nations population for 2018, 2011 and 2003, as well as estimates of the disease burden attributable to specific risk factors. The study utilised and adapted methods developed as part of the previous ABDS 2015 and 2011 (AIHW 2019; AIHW 2016). The ABDS uses Australian data sources and adapts the methods from global studies to produce estimates that are relevant to the Australian context (AIHW 2016).

The fatal burden estimates for dementia were derived from the AIHW National Mortality Database and are considered to be of high quality. National non-fatal burden estimates for dementia were based on prevalence rates published in this online report applied to the relevant Australian estimated resident populations. The severity distribution was based on estimates published by Barendregt and Bonneux (1998) for those aged under 80 and from a study by Lucca et al. (2015) for those aged 80 and over. The quality of the non-fatal burden estimates could be improved if more recent and more generalisable data on dementia prevalence and severity in Australia becomes available.

A comparative risk assessment method was used to quantify the impact of each risk factor on the disease burden for associated diseases, referred to as the ‘attributable burden’. Diseases that were found to have a causal association with dementia and their associated relative risks (the amount of additional risk of developing dementia if exposed to the risk factor) were based on those used in recent Global Burden of Disease studies and a number of epidemiological studies. The prevalence of exposure to each risk factor was derived from a variety of Australian-specific data sources.

References

AIHW (Australian Institute of Health and Welfare) (2016). *Australian Burden of Disease Study: impact and causes of illness and death in Aboriginal and Torres Strait Islander people 2011*, catalogue number BOD 7, AIHW, Australian Government, accessed 12 December 2022.

AIHW (2019) *Australian Burden of Disease Study: methods and supplementary material 2015*, catalogue number BOD 23, AIHW, Australian Government, accessed 15 December 2022.

AIHW (2023) *Australian burden of disease study 2023: technical notes*, AIHW, Australian Government, accessed 20 December 2023.

Barendregt JJM and Bonneux LGA (1998) *Degenerative disease in an ageing population models and conjecture*, Erasmus University, Rotterdam.

Lucca U, Tettamanti M, Logroscino G, Tiraboschi P, Landi C, Sacco L, Garrì M, Ammesso S, Bertinotti C, Biotti A, Gargantini E, Piedicorcia A, Nobili A, Pasina L, Franchi C, Djignefa Djade C, Riva E and Recchia A (2015) ‘Prevalence of dementia in the oldest old: the Monzino 80-plus population based study’, *Alzheimer's & dementia*, 11(3):258-70.e3, doi:10.1016/j.jalz.2014.05.1750.

Estimated Resident Population

The Estimated Resident Population (ERP) is the official measure of the Australian population and contains estimates of the usual resident population of Australia. The ERP includes all people, regardless of nationality or citizenship, who usually live in Australia (except for foreign diplomatic personnel and their families).

Throughout this report, ERP data were used to derive rates of, for example, dementia prevalence and mortality in the Australian population. The ERP data were sourced from the ABS using the most up-to-date estimates available at the time of analysis.

To derive its estimates of the resident populations, the ABS uses the 5-yearly Census of Population and Housing data and adjusts them as described here:

- All respondents in the Census are placed in their state or territory, Statistical Local Area and postcode of usual residence; overseas visitors are excluded.
- An adjustment is made for persons missed in the Census.
- Australians temporarily overseas on Census night are added to the usual residence Census count.

Estimated resident populations are then updated each year from the Census data, using indicators of population change, such as births, deaths and net migration.

Projections of the Australian population past 2023 are formulated on the basis of past demographic trends projected into the future.

More information is available from the ABS website.

Multi-Agency Data Integration Project data asset

The Multi-Agency Data Integration Project (MADIP) data asset contains linked national survey and administrative data from a range of Commonwealth Agencies, including healthcare, Census, social security payments, personal income tax, and mortality to create a comprehensive picture of Australia over time. The MADIP is managed under the custodianship of the Australian Bureau of Statistics. Information on specific datasets and linkage is available from the ABS website.

The MADIP datasets used in this report include:

- 2016 Census of Population and Housing
- National Death Index, 2011–2017.

Classification of dementia

The analysis presented in this report examines Census information on cultural and linguistic diversity among people with a dementia diagnosis recorded on their record in the National Death Index. Deaths registration data uses the International Statistical Classification of Diseases and Related Health Problems 10th Revision (ICD-10) to code cause of death information (see Table 2).

Table 2: Codes used to identify dementia in deaths registrations data

Cause of death field	Dementia-specific codes (ICD-10 codes)
Underlying cause of death	F01, F03, G30, G31.0, G31.8, F051, F107, F137, F187
Associated cause of death	F00, F01, F02, F03, G30, G31.0, G31.8, F051, F107, F137, F187

Exclusion criteria

The MADIP analysis was restricted to people identified in the linked data who:

- died with a dementia diagnosis after the 2016 Census period (September 2016 to December 2017)
- had a linked 2016 Census record
- were not recorded as an overseas visitor at the 2016 Census
- were aged 35 or over at the 2016 Census and
- were not missing country of birth information in the linked data.

Country of birth

Classification of country of birth in the analysis of MADIP in this report is obtained from the MADIP demography file and the 2016 census. Classification is based on the Standard Australian Classification of Countries 2016. More information on this classification is available from the ABS website.

In this analysis, people who died with dementia born in ‘English speaking’ countries include people born in Australia, New Zealand, United Kingdom, Ireland, United States of America, Canada and South Africa.

National Aged Care Data Clearinghouse

The National Aged Care Data Clearinghouse (NACDC) is an independent and central repository of national aged care data, mostly related to government-subsidised aged care programs operating under the *Aged Care Act 1997*.

The holdings include activity data for residential aged care programs, community-based aged care packages, aged care assessments and a number of other aged care programs and packages. The holdings also include recipient details, payment subsidies, and service (facility/provider) details. These data are refreshed annually (including a full replacement of historical data) by the Department of Health and Aged Care and are sourced from the Human Services payment systems, centralised client record systems and minimum datasets.

This report presents information from two key datasets as part of the NACDC – data from the National Screening and Assessment Form (NSAF) and from the Aged Care Funding Instrument (ACFI).

National Screening and Assessment Form data – aged care assessments

Following an initial screening through the My Aged Care system – the starting point for accessing aged care services subsidised by the Government – people are directed to either a home support assessment (conducted by the Regional Assessment Service) or a comprehensive assessment (conducted by an Aged Care Assessment Team). These processes assess people’s circumstances and care needs and, where relevant, approve them for aged care services. The National Screening and Assessment Form (NSAF) captures the information from these assessments.

The following should be considered when interpreting NSAF data presented in this report:

- While the information is reflective of people who completed a home support or comprehensive assessment, this does not equate to the number of people who were approved to use aged care services, or the number of people who were using aged care services that year.
- A small number of individuals were associated with the same assessment record. In these instances, assessment information was assumed to be identical for all individuals associated with the same assessment.

- A person was considered to have dementia if dementia was recorded as a health condition impacting their care needs (primary condition or otherwise, see Table 3 for a full list of codes used). This may not capture everyone with dementia because not all people with dementia will have the condition impact their care needs.
- Individuals with missing date of birth or sex information were excluded.
- Due to small counts and confidentiality issues, intersex individuals were excluded from the analysis.
- Individuals with missing First Nations status were not included in counts of First Nations people and non-Indigenous Australians.

Table 3: Health condition codes used to identify dementia and cognitive impairment in NSAF

NSAF code	Description
0500, 0501, 0502, 0503, 0504	Alzheimer's disease
0510, 0511, 0512, 0513, 0514, 0515, 0516	Vascular dementia
0521	Fronto-temporal dementia
0584	Lewy Body dementia
0532	Unspecified dementia (includes presenile & senile dementia)
0542	Delirium superimposed on dementia
0520, 0522, 0523, 0524, 0525, 0526	Dementia in other diseases classified elsewhere (such as Creutzfeldt-Jakob, Huntington's disease, Parkinson's disease)
0530, 0531	Other dementias
0585	Cognitive impairment not otherwise specified[(a)]

a. People who had cognitive impairment recorded and no record of dementia were not counted as having dementia but were reported separately.

Aged Care Funding Instrument (ACFI) data – permanent residential aged care

Up until September 2022 the Aged Care Funding Instrument (ACFI) was used to allocate government funding to aged care providers based on the day-to-day needs of the people in their care. A snapshot of people in permanent residential aged care on 30 June 2020 showed that ACFI data captures almost all people living in permanent residential aged care (97%). The ACFI ceased from 1 October 2022 onwards and was replaced with the Australian National Aged Care Classification (AN-ACC).

Although the ACFI was a funding instrument and not a diagnosis or comprehensive assessment tool, it collected information on the assessed care needs of people entering permanent residential aged care at the time of their appraisal. It is important to bear in mind that in some instances, not all services received were captured in the ACFI assessment.

People using respite care in a residential aged care facility did not have an ACFI assessment unless they also received permanent care at some point. Therefore, information on residential respite care using the ACFI data is not presented. Further, the ACFI data did not capture people who are in certain specialised residential aged care programs, such as the Multi-Purpose Services Program and the National Aboriginal and Torres Strait Islander Flexible Aged Care Program.

Unless otherwise stated, all analyses using ACFI data excluded individuals with missing age and sex information. Individuals with missing information on their geographic location were only excluded from analysis by state/territory, remoteness, or socioeconomic areas.

Analyses on a person's time in care are based only on the length of their latest episode of care. An episode of care is defined as a continuous service provided under the same program and care type for an individual. An episode of care ends when a person has a long admission to hospital, a change in care providers, returns to the community or dies.

Identifying dementia and other health conditions

The ACFI data captured up to 3 behavioural or mental conditions, and up to 3 medical conditions impacting care, which are also considered when determining the level of funding required. Health conditions are coded according to the Aged Care Assessment Program (ACAP) health condition list, and dementia is captured using the codes listed in Table 4.

As the ACFI only allowed for up to 3 medical and 3 mental/behavioural conditions to be recorded, for some people it will not provide a comprehensive list of health conditions for that person.

The analyses presented in this report only use the latest ACFI assessment available for an individual's latest episode of care, with the exception of dementia status. As dementia is an irreversible health condition, an individual was considered to have dementia if they had a record of dementia in any of their ACFI assessments. Dementia may not be captured in all ACFI assessments if at the time of a given assessment, 3 other mental/behavioural conditions had a bigger impact on a person's care needs than their dementia.

Table 4: List of health condition codes used to identify dementia in the ACFI

ACAP code	Description
0500	*Dementia in Alzheimer's disease* (includes early onset <65 years, late onset >65 years, atypical or mixed type, unspecified)
0510	*Vascular dementia* (includes acute onset, multi-infarct, subcortical, mixed cortical & subcortical, other vascular, unspecified)
0520	*Dementia in other diseases* (includes Pick's, Creutzfeldt-Jakob, Huntington's, Parkinson's, HIV, Lewy Body, other)
0530	*Other dementia not elsewhere classified or not otherwise specified* (includes alcoholic, presenile & senile, unspecified)

Measuring care needs

As the ACFI was used to allocate funding, it captured the day-to-day care needs that contributed the most to the cost of providing individual care. Care needs were categorised as 'nil', 'low', 'medium', or 'high' based on responses to 12 questions across 3 domains: *Activities of daily living*, *Cognition and behaviour*, and *Complex health care*.

Ratings for each domain were used to determine the level of care funding and to assign care. People with high care ratings in a domain had more severe needs and required extensive assistance and care in that domain, whereas those with a low care rating had less severe needs.

First Nations people and other culturally and linguistically diverse groups

Analysis of permanent residential aged care use among First Nations people is based on whether people were identified as being First Nations (i.e. Aboriginal and/or Torres Strait Islanders) or not (i.e. non-Indigenous), and excludes cases where the First Nations status was unknown. ACFI data do not capture information on First Nations-specific residential aged care services, such as the National Aboriginal and Torres Strait Islander Flexible Aged Care Program.

There are limitations to how well people with dementia from culturally and linguistically diverse backgrounds who are living in permanent residential aged care are identifiable in NACDC data. The permanent residential aged care content of this report only presents data and statistics based on whether people were from a non-English speaking background, which is determined based on whether they were born in a country classified as non-English speaking according to the Australian Bureau of Statistics Standard Australian Classification of Countries (SACC).

Rates and target populations

Where presented, rates refer to the number of people in permanent residential aged care as a proportion of the target population for residential aged care programs – that is, those aged 65 and over for all Australians, and those aged 50 and over for First Nations people.

National Hospital Morbidity Database

The National Hospital Morbidity Database (NHMD) is a compilation of episode-level records from admitted patient morbidity data collection systems in Australian public and private hospitals.

The data supplied are based on the National Minimum Data Set (NMDS) for Admitted patient care and include demographic, administrative and length of stay data, as well as data on the diagnoses of the patients, the procedures they underwent in hospital and external causes of injury and poisoning. The purpose of the NMDS for Admitted patient care is to collect information about care provided to admitted patients in Australian hospitals. The scope of the NMDS is episodes of care for admitted patients in all public and private acute and psychiatric hospitals, free-standing day hospital facilities, and alcohol and drug treatment centres in Australia. Hospitals operated by the Australian Defence Force, corrections authorities and in Australia's off-shore territories are not in scope but some are included.

The counting unit in the NHMD is a separation, referred to as a hospitalisation in this report. Separation is the term used to refer to the episode of admitted patient care, which can be a total hospital stay (from admission to discharge, transfer or death) or a portion of a hospital stay beginning or ending in a change of type of care (for example, from acute care to rehabilitation).

Although hospital separations data are a valuable source of information about admitted patient care, they have limitations as indicators of ill health. Sick people who are not admitted to hospital are not counted and those who have more than 1 separation in a reference year are counted on each occasion. Therefore these data count episodes of care, not patients.

The hospital separations data do not include episodes of non-admitted patient care provided in outpatient clinics or emergency departments. However, patients in these settings may be admitted subsequently, with the care provided to them as admitted patients being included in the NHMD.

The years of data used for this report were for the financial years 2012–13 to 2021–22. Data were extracted in May 2022 and small changes may have occurred since this time.

A complete data quality statement for the NHMD is available online at meteor.aihw.gov.au.

Dementia-related hospitalisations

Data on diagnoses are recorded using the International Statistical Classification of Diseases and Related Health Problems, 11th Edition, Australian Modification (ICD-10-AM 11th edn).

Hospitalisations due to dementia were defined as hospitalisations where dementia was recorded as the principal diagnosis. Hospitalisations with dementia were defined as hospitalisations with at least 1 diagnosis of dementia, recorded as a principal and/or additional diagnosis.

High level data are also reported using supplementary codes, which were implemented in admitted patient care data in 2015. These codes are assigned for chronic conditions that are part of the current health status on admission that do not meet criteria for inclusion as a principal or additional diagnosis on the patient's hospital record.

Refer to Table 5 for relevant ICD-10-AM codes and coding rules for individual dementia types (the total number of hospitalisations for dementia is the sum of hospitalisations for the individual types of dementia).

Table 5: Coding of dementia (by dementia type) in the National Hospital Morbidity Database

Dementia type	**ICD-10-AM diagnosis code**
Alzheimer's disease	F00.0, F00.1, F00.2, F00.9, G30.0, G30.1, G30.8, G30.9
Vascular dementia	F01.0, F01.1, F01.2, F01.3, F01.8, F01.9
Fronto-temporal dementia	F02.0 *and* G31.0[(a)]
Dementia in Creutzfeldt-Jakob disease	F02.1 *and* A81.0[(a)]
Dementia in Huntington's disease	F02.2 *and* G10[(a)]
Dementia in Parkinson's disease	F02.3 *and* G20[(a)]
Dementia in human immunodeficiency virus (HIV) disease	F02.4 *and* B22[(a)]
Lewy Body dementia	F02.8 *and* G31.3[(b)]
Dementia in other diseases (remainder)	F02.8 *and not* G31.3 F05.1 *and* F00.0, F00.1, F00.2, F00.9, G30.0, G30.1, G30.8, G30.9, F01.0, F01.1, F01.2, F01.3, F01.8, F01.9, F02.0, F02.1, F02.2, F02.3, F02.4, F02.8, F03, F10.7, F13.7, F18.7[(b)] F03 *and* F00.0, F00.1, F00.2, F00.9, G30.0, G30.1, G30.8, G30.9, F01.0, F01.1, F01.2, F01.3, F01.8, F01.9, F02.0, F02.1, F02.2, F02.3, F02.4, F02.8, F10.7, F13.7, F18.7[(b)]
Dementia due to psychoactive substance use	F10.7, F13.7, F18.7
Unspecified dementia	F03 and not F00.0, F00.1, F00.2, F00.9, G30.0, G30.1, G30.8, G30.9, F01.0, F01.1, F01.2, F01.3, F01.8, F01.9, F02.0, F02.1, F02.2, F02.3, F02.4, F02.8, F10.7, F13.7, F18.7
Delirium superimposed on dementia	F05.1 and not F00.0, F00.1, F00.2, F00.9, G30.0, G30.1, G30.8, G30.9, F01.0, F01.1, F01.2, F01.3, F01.8, F01.9, F02.0, F02.1, F02.2, F02.3, F02.4, F02.8, F03, F10.7, F13.7, F18.7
Other degenerative diseases of nervous system, not elsewhere classified[(c)]	G31 and F00.0, F00.1, F00.2, F00.9, G30.0, G30.1, G30.8, G30.9, F01.0, F01.1, F01.2, F01.3, F01.8, F01.9, F02.0, F02.1, F02.2, F02.3, F02.4, F02.8, F03, F05.1, F10.7, F13.7, F18.7
Dementia (including Alzheimer's disease)	U79.1

a. Indicates that the dementia type is valid regardless of whether the hospitalisation also includes this code.
b. Indicates that the dementia type is only valid when the hospitalisation also includes this code.
c. AIHW were advised by the AIHW Dementia Working Group to include hospitalisations with a principal diagnosis of G31 *Other degenerative diseases of nervous system, not elsewhere classified* and an additional diagnosis of dementia as a hospitalisation with a principal diagnosis of dementia. This was done previously for the AIHW Dementia in Australia 2012 report.

Hospitalisations for newborns without qualified days, hospital boarder and posthumous organ procurement (care types 7.3, 9.0 and 10.0), as well as where age was not reported or sex was recorded as intersex, indeterminate, not stated or inadequately described were excluded from the analysis.

Due to the onset of dementia occurring in older age groups, age-standardised rates were calculated from age 60 and over for the national population and age 40 and over for the First Nations people population.

Palliative care hospitalisations were identified using the methodology followed in the AIHW 2021 web report *Palliative Care Services in Australia*, which is outlined in the Technical information section of that web report.

Geographical data, including state and remoteness area, refer to the usual place of residence of the patient. Data by Socioeconomic areas is based on the Socio-Economic Indexes for Areas (SEIFA) quintiles assigned by area, using the 2016 Index of Relative Socio-Economic Disadvantage (IRSD) scores.

Due to the small number of hospitalisations among First Nations people by geographic area, rates of hospital separations with dementia as a principal diagnosis were examined over a 3-year period (2018–19, 2019–20 and 2020–21). Hospital separations with more than 3,000 bed days were excluded from the analysis of hospital separations among First Nations people.

National Health Data Hub

The National Health Data Hub (NHDH), previously referred to as the National Integrated Health Services Information (NIHSI) analytical asset, is an established enduring linked data asset managed under the custodianship of the AIHW, available for approved projects and analysts from the AIHW and participating jurisdictions.

Version 3.0 of this data asset contains linked data from 2010–11 to 2020–21 on:

- admitted patient care services (in all public and, where available, private hospitals), emergency department services and outpatient services in public hospitals for New South Wales, Victoria, South Australia and Tasmania, sourced from the Admitted Patient Care Database and the National Non-Admitted Patient Emergency Department Care Database
- Pharmaceutical Benefits Scheme (PBS) and Repatriation Pharmaceutical Benefits Scheme (RPBS) national data
- Medicare Benefits Schedule (MBS) national data
- residential aged care national data from the National Aged Care Data Clearinghouse
- National Death Index data (contains data up to 31 December 2021).

Classification of dementia

The analysis presented in the Primary health care services webpage compares the use of MBS services by people who had dementia with people who did not, based on identification (or lack thereof) of a dementia diagnosis evident in NIHSI version 3.0.

A person was identified as having dementia if they were aged 30 or over and had at least one of the following in the NIHSI between 1 July 2010 and June 30 2021:

- a dementia-specific medication dispensed through the PBS / RPBS,
- a principal or additional diagnosis of dementia in an emergency department (ED) presentation or public hospital admission,
- a supplementary chronic code of dementia in a public hospital admission, and/or
- a record of dementia in an Aged Care Funding Instrument (ACFI) assessment

The study cohort was also restricted to people who were:

- alive at 30 June 2021
- recorded in the NIHSI as using a health service in 2020–21
- not missing age, sex and/or geography information
- 30 years or over at their first service event in 2020–21

Table 6 outlines the codes used in each individual dataset to identify dementia and the classification system used in each dataset.

Table 6: Codes used to identify dementia in NIHSI v3.0

Data source	**Classification and dementia-specific codes**
Aged Care Funding Instrument	*Aged Care Assessment Program codes*: 0500, 0510, 0520, 0530
National Death Index	*ICD-10 Underlying or associated cause of death codes*: F00, F01, F02, F03, F05.1, F10.7, F13.7, F18.7, G30, G31.0, G31.8
Admitted patient care	*ICD-10-AM diagnosis codes:* F00, F01, F02, F03, F05.1, F10.7, F13.7, F18.7, G30 Chronic condition supplementary code U791

Emergency department presentations	*ICD-10-AM diagnosis codes*: F00, F01, F02, F03, F05.1, F10.7, F13.7, F18.7, G30, U791 *ICD-9-CM diagnosis codes*: 290.0, 290.1, 290.10, 290.11, 290.12, 290.13, 290.2, 290.20, 290.21, 290.3, 290.4, 290.40, 290.41, 290.42, 290.43, 290.8, 290.9, 291.2, 294.1, 294.10, 294.11, 294.2, 294.20, 294.21, 331.0 *SNOMED CT-AU EDRS diagnosis codes*: 52448006, 12348006, 15662003, 26929004, 191461002
Pharmaceutical Benefits Scheme	*Anatomical Therapeutic Chemical Classification codes:* N06DA02 (donepezil), N06DA03 (rivastigmine), N06DA04 (galantamine) N06DX01 (memantine)

Note: ICD-10 refers to the *International Statistical Classification of Diseases and Related Health Problems, Tenth Revision*. ICD-10-AM refers to ICD-10, Australian Modification; ICD-9-CM refers to the ICD, Ninth Revision, Clinical Modification; SNOMED CT-AU EDRS refers to the Systematized Nomenclature of Medicine - Clinical Terms - Australian version (Emergency Department Reference Set).

Age and sex

The cohort included people aged 30 and over. Younger people were out of scope for this study because people aged under 30 with dementia (including childhood dementias) are likely to use different services than those over 30 years.

Age at the first service event in 2020–21 was calculated from the “age at event zero” variable in the NIHSI patient demography file.

Sex was derived from the NIHSI patient demography file.

Geographical region of residence

State/territory is necessary in order to ensure 3 or more state/territories are contributing to a cell count, and to ensure one or two state/territories do not dominate the cell count (85/90 dominance rule). This is a requirement when using NIHSI data.

State/territory information is based on which state/territory people lived in at the time of their first service event in 2020–21, not where they received services. People are likely to have used services outside of their state/territory of residence.

Place of residence

The use of health services changes after a person enters permanent residential aged care (PRAC). To partly account for these changes, the dementia study cohort was split into 2 study groups:

People living in the community: people who were living in the community for all of 2020–21. This may include people who used residential respite care, people who were living in other supported accommodation, and people who were living in residential aged care facilities not included in the NIHSI.

People living in residential aged care: people who were living in permanent residential aged care for all or part of 2020–21.

Medicare Benefits Schedule

The Medicare Benefits Schedule (MBS) data collection contains claims data for Medicare services subsidised by the Australian Government. This includes services provided by community-based health professionals, including general practitioners (GPs), medical specialists and allied health professionals.

People may receive primary care services in ways that are not captured in MBS data, including services delivered under Department of Veterans’ Affairs arrangements; services provided through hospitals; services provided under a state-funded service; dementia specific services such as the Dementia Behaviour Management Advisory Service or Severe Behaviour Response Teams; and services provided by a salaried GP or any other salaried medical officer arrangement. In-hospital MBS attendances were excluded from all analyses.

MBS events were grouped according to the MBS codes in Table 7.

Terminology used in this study	**MBS code**
GP attendance (total)	BTOS: 0101, 0102, 0103

GP chronic disease management service	BTOS: 0102 Subgroup: A15.1, A40.13, A40.14 or items: 229 – 233, 93469, 93475
Medication management review	BTOS: 0102 Items: 245, 249, 900, 903
Specialist attendance (total)	BTOS: 0200
General medicine attendance	BTOS: 0200 Key registered speciality: 2, 82
Geriatric medicine attendance	BTOS: 0200 Key registered speciality: 16, 96
Geriatrician referred plan	BTOS: 0200 Key registered speciality: 16, 96 Item: 141, 143, 145, 147 Subgroup: A40.31
Neurology attendance	BTOS: 0200 Key registered speciality: 9, 89
Psychiatry attendance	BTOS: 0200 Key registered speciality: 56, 99, 409 Group A08 Subgroups: A40.06 and A40.09 Items: 00855, 00857, 00858, 00861, 00864,00866, 90260, 90262, 90266, 90268, 92162, 92166.
Ophthalmology attendance	BTOS: 0200 Key registered speciality: 54, 406
Cardiology attendance	BTOS: 0200 Key registered speciality: 4, 84
Dermatology attendance	BTOS: 0200 Key registered speciality: 52, 401
General surgery attendance	BTOS: 0200 Key registered speciality: 31, 32, 411
Intensive care attendance	BTOS: 0200 Key registered speciality: 18, 30, 98, 402, 417
Nursing and Aboriginal health worker services (total)	BTOS: 0110 and MBS group M14 and MBS subgroup M18.05 and M18.10
Practice nurse or Aboriginal health worker	BTOS: 0110
Nurse practitioner	MBS group M14 and MBS subgroup M18.05 and M18.10
Allied health attendances (total)	BTOS: 0150, 0900
Optometry	BTOS: 0900
Podiatry	BTOS: 0150 Items 10962, 81340, 93509, 93532, 93554, 93587

Mental health care	BTOS: 0150 MBS group: M6, M7, M17, M25, M26, M27, M28 MBS subgroup: M16.2, M16.3, M16.5, M18.1, M18.2, M18.3, M18.4, M18.6, M18.7, M18.8, M18.9 Items: 10956, 10968, 81325, 81355, 82000, 82015, 93076, 93079, 93084, 93087, 93100, 93103, 93110, 93113, 93118, 93121, 93134, 93137, 93512, 93535, 93557, 93590
Physical health care	BTOS: 0150 Items: 10953, 10960, 10964, 10966, 81110, 81115, 81315, 81335, 81345, 81350, 93504, 93508, 93510, 93511, 93518, 93520, 93527, 93531, 93533, 93534, 93549, 93553, 93555, 93556, 93571, 93573, 93582, 93586, 93588, 93589, 93607, 93614
Diagnostic imaging	BTOS: 0600
Pathology	BTOS: 0501, 0502
Operations	BTOS: 0400, 0700, 0800
Other	BTOS: 0300, 1000 BTOS: 1100 and MBS group not M14 and MBS subgroup not M18.05 or M18.10

Note: BTOS = Broad Type of Service. Telehealth, MBS group M18 and A40, were introduced in March 2020 and June 2021 respectively.

Key data considerations of the Primary health care services analysis

For people living in residential aged care, the Aged Care Funding Instrument was used to assess their care needs to determine government funding to care providers and includes information on dementia status. This means that more people living with dementia in residential aged care will have a record of dementia in the linked data than those living in the community. This should be borne in mind when exploring the results in this report, and direct comparisons between people living with dementia in the community and in residential aged care are not recommended.

As people with dementia have a unique pattern of health service use in their last year of life, the analysis focused on the use of MBS services by people who were alive at 30 June 2021. This exclusion has a larger impact on people in residential aged care, particularly those with dementia, as people with dementia often die in care. Refer to the AIHW report Patterns of health service use by people with dementia in their last year of life for more information.

The analysis included people aged 30 and over. Younger people were out of scope for this study because the number of people aged under 30 living with dementia (including childhood dementias) were too small to analyse separately, and people are likely to use different services.

Reference

AIHW (2020–21) National Health Data System, aihw.gov.au, accessed 10 February 2024.

National Mortality Database

Data on dementia deaths were derived from the National Mortality Database (NMD) and analyses were based on the years 2010–2020. The NMD is maintained by the AIHW and holds records for deaths in Australia from 1964, and comprises information about causes of death and other characteristics of the person, such as sex, age at death, area of usual residence and First Nations status. Cause of death data are sourced from the Registrars of Births, Deaths and Marriages in each state and territory, and the National Coronial Information System. They are compiled and coded by the Australian Bureau of Statistics (ABS) using the latest version of the International Statistical Classification of Diseases and Related Health Problems (ICD-10 for this report), an international standard agreed by the World Health Organization for defining and reporting causes of death. For more information about Australian mortality data, including scope and coverage of the collection and a quality declaration, please refer to Deaths, Australia (ABS cat. no. 3302.0) and Causes of death, Australia (ABS cat. no. 3303.0) available from the ABS website.

Dementia deaths

Cause of death information is derived from conditions listed on Part I and Part II of a death certificate. *Deaths due to dementia* are deaths where dementia was recorded as the underlying cause of death (UCOD), that is, the disease or injury that initiated the train of events leading directly to death, or the circumstances of the accident or violence that produced the fatal injury.

The NMD also contains information on other associated causes of death (ACOD). These are all causes listed on the death certificate, other than the underlying cause of death, which were instrumental or significantly contributed to the death. *Deaths with dementia* refer to deaths where dementia was recorded as the UCOD or ACOD.

This report uses an expanded list of death codes attributed to dementia (that is, relative to the usual dementia codes used to report on deaths – G30, F01, and F03), with the aim of better capturing rarer dementia death types and mixed dementia (see Table 8). The AIHW created this expanded list in consultation with the AIHW Dementia Working Group and the ABS. Note that not all dementia types are reported separately in the report, due to confidentiality issues arising from small numbers.

Table 8: Expanded list of ICD-10 codes used to identify dementia deaths in this report

Dementia type	**Updated ICD-10 diagnosis codes: Underlying causes of deaths (UCODs)**	**Updated ICD-10 diagnosis codes: Associated causes of deaths (ACODs)**
Alzheimer's disease	G30.0, G30.1, G30.8, G30.9	F00.0, F00.1, F00.2, F00.9, G30.0, G30.1, G30.8, G30.9
Vascular dementia	F01.0, F01.1, F01.2, F01.3, F01.8, F01.9	F01.0, F01.1, F01.2, F01.3, F01.8, F01.9
Fronto-temporal dementia	G31.0	G31.0
Lewy body dementia	G31.8	G31.8
Dementia in Creutzfeldt-Jakob disease	N/A	UCOD of A81.0 and ACOD of F03 (Unspecified dementia)
Dementia in Huntington's disease	N/A	UCOD of G10 and ACOD of F03 (Unspecified dementia)
Dementia in Parkinson's disease	N/A	UCOD of G20 and ACOD of F03 (Unspecified dementia)
Dementia in human immunodeficiency virus (HIV) disease	N/A	UCOD of B20 and ACOD of F03 (Unspecified dementia)
Dementia due to effect of substances	F10.7, F13.7, F18.7	F10.7, F13.7, F18.7
Unspecified dementia	F03 and no other dementias as ACODs: G30.0, G30.1, G30.8, G30.9, G31.0, G31.8, F00, F01, F10.7, F13.7, F18.7, F05.1	F03 and no UCOD of: A81.0, G10, G20, B20 and no other dementias as a UCOD: G30.0, G30.1, G30.8, G30.9, G31.0, G31.8, F01, F10.7, F13.7, F18.7 and no other dementias as ACODs: G30.0, G30.1, G30.8, G30.9, G31.0, G31.8, F00, F01, F10.7, F13.7, F18.7, F05.1
Delirium superimposed on dementia	N/A	F05.1

Note: According to ICD-10 coding rules, the codes of F00 Dementia in Alzheimer's disease and F05.1 delirium superimposed on dementia cannot be assigned as an underlying cause of death, but can be used to capture additional causes of death.

Analyses are based on the date on which the death occurred, and are compiled based on the state/territory of usual residence. The analyses exclude deaths for which the date of death, sex, or age, was not reported. Deaths are counted according to year of death occurrence. Deaths registered in 2018 and earlier are based on the final version of cause of death data; deaths registered in 2019 are based on the revised version; and deaths registered in 2020 and 2021 are based on the preliminary version. Revised and preliminary versions are subject to further revision by the ABS; deaths related to dementia in 2019, 2020 and 2021 are likely an undercount as a result of missing late registration.

Analyses of deaths among First Nations people are based on whether people identified as being First Nations people (i.e. Aboriginal and/or Torres Strait Islanders) or not (i.e non-Indigenous), and exclude deaths where the Indigenous status was unknown. In line with national reporting guidelines, data for Victoria, Tasmania, and the Australian Capital Territory have been excluded for all analyses involving First Nations people, with the exception of analysis by remoteness areas, which includes all states and territories.

Due to the onset of dementia occurring mostly in older age groups, age-standardised rates were calculated from age 65 and over for the national population and age 50 and over for the First Nations people population.

Leading underlying causes of deaths overall, and leading causes of death presented where dementia was an associated cause of death, are classified using an AIHW-modified version of Becker et al. (2006). This is based on recommendations of the World Health Organization (WHO) (Becker et al. 2006) with minor modifications to suit the Australian context.

Geography is based on area of usual residence—Statistical Local Area Level 2 (SA2). Unknown/missing includes deaths where place of usual residence was overseas, no fixed abode, offshore and migratory, and undefined.

Limitations

The number of people with dementia recorded on their death certificate, as presented in this report, is unlikely to include every person with dementia who died during the study period, even when dementia contributed to their death. One recent study using linked data showed that without linking to other datasets, mortality data only captured 31% of Australian women with dementia (Waller et al. 2017), while in another study, mortality data captured 67% of people with dementia who died in New South Wales and Victoria in 2013 (AIHW 2020). Further, coding changes and variations in certification practices over time have likely improved the accuracy of the attribution of deaths due to or with dementia in in recent years (ABS 2015).

Statistics based on Indigenous status should be interpreted with caution, as the identification of First Nations people is often incomplete, or is inconsistently reported across administrative data sets, including in the NMD (AIHW 2019). This report does not apply adjustments to account for the under-identification of First Nations people in the NMD, but does group deaths statistics for First Nations people across 3 years of data to provide more robust estimates and avoid confidentiality issues related to small numbers.

References

ABS (Australian Bureau of Statistics) (2015) *Causes of Death, Australia, 2013*, ABS, Australian Government, accessed 9 December 2022.

AIHW (Australian Institute of Health and Welfare) (2019) *Improving Indigenous identification in mortality estimates*, AIHW, Australian Government, accessed 12 December 2022.

AIHW (2020) *Patterns of health service use by people with dementia in their last year of life: New South Wales and Victoria*, AIHW, Australian Government, accessed 12 December 2022.

Becker R, Silvi J, Ma Fat D, L'Hours A, & Laurenti R (2006) 'A method for deriving leading causes of death', *Bulletin of the World Health Organization*, *84*, 297-304, doi:10.2471/blt.05.028670.

Waller M, Mishra G, and Dobson A (2017) 'Estimating the prevalence of dementia using multiple linked administrative health records and capture-recapture methodology', *Emerging Themes in Epidemiology,* 14(3), doi:10.1186/s12982-017-0057-3.

Pharmaceutical Benefits Scheme

The Pharmaceutical Benefits Scheme (PBS) database contains medications eligible for government subsidy dispensed under the PBS. The PBS database also includes medications supplied under the Repatriation Pharmaceutical Benefits Scheme (RPBS, available for eligible veterans, war widows/widowers and their dependants). The PBS database does not contain data on the dispensing of privately prescribed medications, medications to public hospital in-patients and over-the-counter medications.

In this report, analyses were limited to people aged 30 and over who were dispensed at least 1 dementia-specific medication under the PBS/RPBS between 30 June 2021 and 1 July 2022, as recorded in the PBS database. The statistics presented in the report refer to people who were dispensed medications, which may not equate to the number of prescriptions for medications prescribed by medical professionals (as not all prescriptions are dispensed). These analyses also cannot account for if a dispensed prescription was used and if it was used correctly.

The following should be considered when interpreting prescriptions data presented in this report:

- A very small proportion of records with missing patient identification, age and sex information were excluded from the analysis.
- As a person's age (and subsequent age group) will change in a single year, a person's age at the midpoint of the year was used as their age for the entire year.
- As a person may move between states and territories in a single year, the state or territory recorded in a person's last record in the year was used as their geographical location for the entire year.
- As people may be prescribed multiple dementia-specific medication by different medical specialists in a single year, people may be counted multiple times in some analyses.
- People who were dispensed dementia-specific medication for the first time includes people who had not been dispensed a dementia-specific medication since 2012-13.

Anatomical Therapeutic Chemical (ATC) Classification

PBS items were mapped to the Anatomical Therapeutic Chemical (ATC) Classification, a classification system for medicines maintained by the World Health Organization. The ATC classification groups medicines according to the body organ or system on which they act, and their therapeutic and chemical characteristics. Medicines are given an ATC classification in the Schedule of Pharmaceutical Benefits according to their main therapeutic use in Australia as registered with Therapeutic Goods Administration and listed on the PBS. More information on the ATC classification system can be found at: The World Health Organization website.

Dementia-specific medications included in this report and their corresponding ATC codes include:

- N06DA02 – Donepezil
- N06DA03 – Rivastigmine
- N06DA04 – Galantamine
- N06DX01 – Memantine.

Table 9 shows all the medications presented in this report by ATC1 level (for example, *Alimentary tract and metabolism*) and by ATC2 level (for example, *Drugs for acid related disorders*).

Table 9: Medications defined in this report, by ATC code.

ATC code	Description
A	Alimentary tract and metabolism
A02	*Drugs for acid related disorders*
A06	*Drugs for constipation*
B	Blood and blood forming organs
B01	*Antithrombotic agents*
C	Cardiovascular system
C07	*Beta blocking agents*
C09	*Agents acting on the renin-angiotensin system*
C10	*Lipid modifying agents*
D	Dermatologicals
G	Genito-urinary system and sex hormones
H	Systemic hormonal preparations, excluding sex hormones and insulins
J	Anti-infectives for systemic use
J01	*Antibacterials for systemic use*
L	Antineoplastic and immunomodulating agents
M	Musculo-skeletal system
N	Nervous system
N02	*Analgesics*
N05	*Psycholeptics*
N06	*Psychoanaleptics*
P	Antiparasitic products, insecticides and repellents
R	Respiratory system
S	Sensory organs
V	Various

Survey of Disability, Ageing and Carers

The Survey of Disability, Ageing and Carers (SDAC) is a national survey run by the Australian Bureau of Statistics (ABS) that has been collecting information since 1981.

The survey collects detailed information from three key populations:

- people with disability – people who have at least one limitation, restriction or impairment, which has lasted, or is likely to last, for at least 6 months and restricts everyday activities
- people aged 65 years and over
- carers – people who provide unpaid informal assistance on a regular basis to people with a disability or people aged 65 years and over.

The information presented in this report was sourced from the most survey, conducted in 2018. Previous surveys were conducted in the years 1981, 1988, 1993, 1998, 2003, 2009, 2012 and 2015.

Survey collection

The 2018, SDAC was conducted in two components based on a person's place of residence:

- Household component – people living in private dwellings (such as houses, flats, home units, townhouses), as well as self-care components of retirement villages
- Cared accommodation component – people living in residential aged care facilities, hospitals and other 'homes' who had been, or were expected to be, living there, or in another health establishment, for at least three months.

There were 65,805 people included in the 2018 SDAC – 54,142 people from the household component and 11,663 people living in cared accommodation.

The household component of the survey was interviewer-administered, and involved collecting information from all people residing in the household who were part of the key populations listed above, as well as residents who provided informal care and assistance with the self-care, mobility and communication (core-activities) for a co-resident, and were considered to provide a greater level of care than others for that care recipient (considered the primary carer). Proxy interviews were done for; children under 15 years of age; children aged 15–17 whose parent or guardian did not agree to them being personally interviewed and people who were unable to answer for themselves due to their disability (illness, impairment, injury or language problems). In this report, people with dementia who were included in the household component are referred to as 'living in the community'.

The cared accommodation component was administered via paper forms mailed directly to selected establishments. As such, the information collected was based on staff members' knowledge of the residents and from clinical and administrative records.

Further information on the 2018 SDAC method of collection can be found at: Disability, Ageing and Carers, Australia: Summary of Findings methodology, 2018.

Reporting of dementia

In this report, a person was considered to have dementia in the SDAC 2018 if, the following conditions were reported as a health condition (main condition or otherwise):

- *Dementia* – SDAC diagnosis code 0511
- *Alzheimer's disease* – SDAC diagnosis code 0605
- *Dementia with Lewy bodies* – SDAC diagnosis code 0615
- *Frontotemporal dementia* – SDAC diagnosis code 0616

It is possible that some people with certain types of dementia (such as dementia in Huntington's disease) may have only had the causal condition coded and would not be identified as having dementia. Reporting of dementia by type from the SDAC was considered unsuitable, due to the self-reporting nature of the household component of the survey and the low numbers observed for some of the dementia types.

As the SDAC does not perform clinical assessment of survey respondents, it is acknowledged the SDAC will under-estimate people in the early stages of dementia, particularly those in the community, who have not received a formal diagnosis. In addition, some survey respondents may choose not to disclose their dementia.

Health condition coding in the SDAC is based on the International Classification of Diseases and Health Conditions, 10th Revision (ICD-10). A full list of long term health conditions and equivalent ICD-10 codes used in the SDAC is found at: Disability, Ageing and Carers, Australia: Summary of Findings methodology, 2018.

Limitations and level of disability

The SDAC captures information on peoples' limitations and levels of disability. Limitations were assessed in terms of what a persons' level of difficulty was in undertaking each of a number of tasks, their need for assistance in each task and whether aids or equipment were used (Table 10). These tasks were grouped into either core-activities (self-care, mobility or communication related tasks) or other activities.

Table 10: Tasks that were assessed in the SDAC 2018 to determine a persons' limitation

Activity	Tasks
Core activities	
Communication	Understanding family or friends
	Being understood by family or friends
	Understanding strangers
	Being understood by strangers
	Getting into or out of a bed or chair
	Moving about usual place of residence
	Moving about a place away from usual residence

Mobility	Walking 200 metres
	Walking up and down stairs without a handrail
	Bending and picking up an object from the floor
	Using public transport
Self-care	Showering or bathing
	Dressing
	Eating
	Toileting
	Bladder or bowel control
Other activities	
Health care	Foot care
	Taking medications or administering injections
	Dressing wounds
	Using medical equipment
	Manipulating muscles or limbs
Reading or writing	Checking bills or bank statements
	Writing letters
	Filling in forms
Private transport	Going to places away from the usual place of residence
Household chores	Laundry
	Vacuuming
	Dusting
Property maintenance	Changing light bulbs, taps or washers
	Making minor home repairs
	Mowing lawns, watering, pruning shrubs, light weeding or planting
	Removing rubbish
Meal preparation	Preparing ingredients
	Cooking food
Cognition or emotion	Making friendships, maintaining relationships, or interacting with others
	Coping with feelings or emotions
	Decision making or thinking through problems
	Managing own behaviour

Source: Australian Bureau of Statistics, Disability, Ageing and Carers, Australia: Summary of Findings methodology 2018

Level of disability

The level of disability (or limitation) is based on the degree of assistance or supervision required by the survey respondent in one or all core activities. The level of disability is grouped into 4 categories:

- **Mild limitations**: the person needs no help and has no difficulty with any of the core activity tasks, but uses aids or equipment for core tasks, or has other limitations (such as difficulty walking short distances, unable to easily bend over or needs help with using public transport).
- **Moderate limitations**: the person needs no help, but has difficulty with a core activity task.

- **Severe limitations**: the person sometimes needs help with a core activity task, and/or has difficulty understanding or being understood by family or friends, or can communicate more easily using non-spoken forms of communication.
- **Profound limitations**: the person is unable to do, or always needs help with, a core activity task.

A person's overall level of core activity limitation is determined by their highest level of limitation in these activities.

Reporting on primary carers

This report focuses on information from the SDAC on primary carers of people with dementia.

The SDAC defines a primary carer as the person aged 15 or over who provides the most informal, ongoing assistance with one or more core activities (mobility, self-care and communication) for a person with disability. The assistance had to be ongoing, or likely to be ongoing, for at least 6 months. SDAC only collects information on primary carers who live in the same household as their care recipient.

Primary carers excludes people who provide formal assistance (on a regular paid basis, usually associated with an organisation).

The SDAC does not capture information about people who provide informal care to those with dementia living in residential aged care facilities.

Technical notes

Estimating the number of Australians living with dementia

The number of people living with dementia was estimated for this report based on the methodology used in the previous AIHW 2012 Dementia in Australia report (AIHW 2012), with some data source adjustments.

Prevalence rates for those aged 60 and over were derived from the Alzheimer's Disease International 2015 report. At the time of writing, this report provided the most up-to-date global estimates of dementia prevalence, with published prevalence rates based on a systematic review of dementia prevalence literature globally (Alzheimer's Disease International 2015). Age-specific (and where possible sex-specific) estimates were presented by world regions (for example, Australasia, North America, and Western Europe) for people aged 60 and over. Prevalence rates for Australasia alone were based on just three outdated regional studies and are not as reliable as those of other regions. To overcome this challenge, prevalence rates presented here were derived from a combination of the Australasian, North American and Western European prevalence rates. North America and Western European rates were based on a large number of more recent studies, and the estimated dementia prevalence rates for these two regions were most similar to Australasia.

Since sex-specific rates for Australasia were not available in the Alzheimer's Disease International 2015 report, sex-specific rates for Australasia were calculated by averaging sex rate-ratios from Western Europe and North America and applying them to the Australasian sex-specific rates. Age and sex-specific rates for Australia were then calculated by averaging rates from Australasia, Western Europe, and North America, giving each region the same weight.

As the Alzheimer's Disease International 2015 report does not present prevalence rates for people aged under 60, and it is known that there are people living with dementia in Australia in this age group, an alternative data source was used to calculate prevalence rates in this age group. Prevalence rates for people aged under 60 were based on a recent large-scale Australian study by Withall et al. (2014). The authors used a methodology consistent with the 2003 UK study by Harvey et al. that was used to estimate dementia prevalence in the AIHW 2012 Dementia in Australia report. Since the Withall et al. study does not report age-specific prevalence rates by sex, we applied sex rate-ratios from the Harvey et al. (2003) study to derive sex-specific rates.

The newly calculated sex and age-specific rates for people aged 60 and over, and sex-specific rates for people aged under 60 for Australia were then applied to the ABS Australian population estimates to estimate the total number of people with dementia in Australia overall and by geographic areas, including remoteness, jurisdiction, socioeconomic area, Primary Health Network (PHN) and statistical area 2 (SA2). While the prevalence estimates are synthetic and have no potential for being disclosive in smaller areas, cell sizes smaller than 5 estimated people have been suppressed due to unreliability.

As well as providing estimates of dementia prevalence based on the ABS Australian population estimates (ERPs), projections of dementia prevalence are also reported on. Where data is reported as a projection, these estimates are derived using a different population estimate also sourced from the ABS (ABS Series B population projections). As these two population estimates are different, there may be differences where projected data is reported for the current or previous years.

Estimating people living with dementia by place of residence

The number of people estimated to be living with dementia by place of residence (living in community or living in cared accommodation) was calculated using a number of different data sources. This report uses the definition of 'cared accommodation' from the 2018 ABS Survey of Disability Ageing and Carers (SDAC). People living in cared accommodation includes people who are a resident, or expected to be a resident, for three months or more in hospitals, nursing homes, aged care hostels, cared components of retirement villages, psychiatric institutions, and other 'homes' such as group homes.

To calculate the number of people with dementia living in cared accommodation, the number of people with dementia who were living in residential aged care facilities between 1 July 2021 and 30 June 2022 by sex and 5 year age groups from the Aged Care Funding Instrument was inflated using data from the 2018 Survey of Disability Ageing and Carers to obtain the number of people with dementia living in cared accommodation (and not just in residential aged care facilities). According to the 2018 Survey of Disability Ageing and Carers, 2.1% of people with dementia living in cared accommodation were not living in a residential aged care facility but living in another type of cared accommodation setting.

The number of people with dementia living in the community was calculated by subtracting the estimates of people living in cared accommodation from the total number of Australians estimated to be living with dementia in 2022.

This method suggests that in 2022, 67% of Australians with dementia are living in the community and 33% are living in cared accommodation. These proportions are consistent with findings from an Alzheimer's Disease International survey in high-income countries, which indicated that 30% of people with dementia lived in 'care homes' (WHO 2012).

Estimating the number of carers of people with dementia

Due to data quality issues, the AIHW provides a minimum estimate of for the total number of people aged 15 and over who provide consistent care for a person with dementia who is living in the community. It excludes people who provide formal assistance (on a regular paid basis, usually associated with an organisation) to a person with dementia, as well as people who provide ongoing care to a family member or friend with dementia living in residential aged care.

The minimum number of unpaid carers of people with dementia was estimated by applying the rate of carers of people with dementia from the SDAC 2018 to the estimated residential population aged 15 and over. However, the SDAC will be an underestimate as only carers who lived in the same household as the care recipient with dementia (co-resident carer) were included. In addition, the SDAC also underestimates the number of people with dementia living in the community.

Estimating expenditure on dementia

As there is no single source of data to report total expenditure due to dementia, a number of different data sources of varying quality were used, and are detailed below, to estimate health and aged care expenditure attributable to dementia. Data on the dementia-specific programs, packages and services were sourced from the Australian Government Department of Health and Aged Care.

Due to data limitations, the dementia expenditure estimates presented in this report do not include expenditure for:

- specialised mental health care services
- state and territory government expenditure on aged care
- private aged care services (both home care and supported residential services and facilities)
- indirect expenditure – such as travel costs for patients, the social and economic burden on carers and family, and lost wages and productivity.

Aged care expenditure

The majority of the aged care estimates are based on direct government expenditure. Non-government-expenditure (for example, by individuals, private health insurers and other non-government sources) is however, included in health expenditure estimates in relation to hospital services, out-of-hospital medical services and prescription medications.

Aged care expenditure is allocated to dementia using the proportion of care delivered within programs to clients with dementia diagnoses and supplements. For the purposes of this report, spending on community-based respite care for people with dementia (which is part of the Commonwealth Home Support Program) is shown separately.

Due to limited data availability relating to diagnoses managed through some aged care programs, the Home Care Program (HCP) dementia supplement data were used to estimate dementia spending in the Commonwealth Home Support Programme (CHSP) and the Department of Veterans' (DVA) Community Nursing Program.

- CHSP program dementia spending was estimated using the proportion of days in 2018-19 that clients received dementia supplements in HCP levels 1 and 2.
- DVA Community Nursing Program dementia spending was estimated using the proportion of days in 2018-19 that clients with a DVA entitlement received dementia supplements in HCP levels 2 and 3.

Data from the National Screening and Assessment Form (NSAF) were used to allocate spending on residential and community-based respite care, the transition care program, aged care assessments, and Veterans Home Care Program.

- Residential respite care expenditure for dementia was estimated by determining the proportion of approvals for respite care (residential and mixed) that were associated with a dementia diagnosis, for clients not currently living in residential care.
- Community based respite care expenditure for dementia was estimated according to the proportion of approvals for respite care (community and mixed) that were associated with a diagnosis of dementia, among clients not currently living in residential care.
- Transition care program expenditure for dementia was estimated by determining the proportion of approvals for transition care that were associated with a dementia diagnosis, for clients not currently living in residential care.
- Aged care assessment expenditure for dementia was estimated according to the proportion of aged care assessments where a record included a dementia diagnosis.
- Veterans Home Care Program expenditure for dementia was estimated according to the proportion of clients with a DVA entitlement who are diagnosed with dementia.
- National Aboriginal and Torres Strait Islander Flexible Aged Care Program expenditure on dementia was estimated by determining the proportion of First Nations clients with a dementia diagnosis from the Aged Care Funding Instrument (ACFI) data.

Estimating expenditure in residential aged care facilities directly attributable to dementia

To determine what portion of total funding for a permanent resident in an aged care facility is directly related to dementia, information on the resident's comorbidities is required. While some information on health conditions is collected within the ACFI, these data do not include a complete list of comorbidities, nor do they indicate the relative severity of these conditions. It is therefore not possible to use data collected through the ACFI to separate the cost attributable solely to dementia from the total cost of caring for people with dementia in residential aged care facilities. To allow the estimation of the costs due to dementia, data from the 2018 Australian Bureau of Statistics Survey of Disability Ageing and Carers (SDAC) were used to supplement ACFI data. This approach is consistent with the approach taken for the previous *Dementia in Australia* report (AIHW 2012), and is outlined below.

Data from the 2018 SDAC relating to people living in residential aged care facilities were used to estimate the differences in care needs and funding between people with and without dementia. SDAC questions relating to need for assistance were mapped to related ACFI questions, such that an estimated ACFI score was created for each SDAC respondent living in residential aged care facilities.

Health conditions recorded in the SDAC were allocated across eight categories, grouped according to similarities in the likely need for assistance for the condition. For example, arthritis was grouped with hip damage from injury in the group 'Conditions affecting mobility'. The groups were defined by the ABS categorisations within the SDAC, and include: Dementia and Alzheimer disease, stroke, conditions affecting mobility, mental health, other cardiovascular disease, hearing loss, Parkinson disease, and other conditions. Each group was only counted once, which means that an individual with multiple conditions within a group is treated the same as an individual with one condition in the group.

A regression model was fitted to the data using the estimated ACFI scores as the dependent variable, and all possible combinations of the eight condition groups (more than 200) as the independent variables. The resultant model had 187 degrees of freedom, an F value of 14.40 ($Pr < 0.0001$) and an adjusted R^2 of 0.29. From this model, a predicted ACFI score was generated for each combination of condition groups, which provided an average ACFI score and level of funding for each combination of condition groups within the model.

Comparisons were then made between combinations of conditions with dementia and without dementia, to quantify the impact of dementia on predicted ACFI scores and associated levels of funding. For example, the predicted ACFI score for a resident with dementia, stroke and mobility problems was compared to that of a resident with just stroke and mobility. The higher the ACFI score for a resident, the more complex their care needs and the more funding they receive. The average predicted ACFI score of a resident with dementia was 125, compared to 95 for those without dementia. This translates to 24% of costs for residents with dementia allocated directly to dementia.

These results were applied to 2018–19 data for ACFI residents, with age and sex taken into account, and used to estimate the proportion of Australian Government funding for permanent residents in residential aged care that was attributable to dementia.

Health expenditure

Health care expenditure estimates were sourced from the AIHW Disease Expenditure database. In this database, expenditure across the various components of the health system is estimated and then allocated to the health conditions based on a range of available diagnostic and service use data. Further information on the AIHW Disease Expenditure database can be found at Disease Expenditure in Australia 2020-21.

Estimating expenditure for hospitalisations where a dementia diagnosis was recorded

The approach for estimating expenditure on admitted patients with dementia in this report is similar to what has been used in previous reports, but uses more detailed cost data.

In public hospitals, admitted patient expenditure for dementia is estimated based on the National Hospital Cost Data Collection, and allocated to public hospital separations in the National Hospital Morbidity Database on the basis of principal diagnosis, Diagnosis Related Group (DRG) code, facility, and state. The DRG code is based on a range of data collected about the admitted patient, including the diagnosis and procedures undertaken during the hospitalisation.

In private hospitals, admitted patient expenditure for dementia is estimated based on the Private Hospital Data Bureau data, and allocated to private hospital separations in the National Hospital Morbidity Database on the basis of principal diagnosis, DRG, and state. This data collection includes all costs except for medical charges. Medical charges are allocated to separations using the MBS items recorded for the separation, and the average in-hospital fee charged for each MBS item by state.

Allocation of total expenditure for a separation to additional diagnoses was based on modelling the estimated separation cost and diagnoses record for a patient. A regression model was used to estimate the fraction of each public hospital separation cost that is due to each condition being treated, to take into account the impact of comorbidities on costs, and more accurately reflect the expenditure for each condition.

The excess expenditure for each principal diagnosis due to comorbidities was modelled with a log-linear regression model that estimated expenditure for each principal diagnosis (grouped by condition reported in the Australian Burden of Disease Study), with indicators of additional diagnoses as independent variables. The estimated coefficients of the models quantify the impact of additional diagnoses on expected expenditure; that is, the extent to which the charge associated with a given separation for a given principal diagnosis is expected to increase in the presence of additional diagnoses. The results from the regression model were used to estimate the predicted proportion of expenditure associated with each diagnosis within each separation in the hospital data.

Further information is published in Disease Expenditure in Australia 2020-21

References

AIHW (Australian Institute of Health and Welfare) (2012) *Dementia in Australia 2012*, AIHW, Australian Government, accessed 17 August 2022.

ADI (Alzheimer's Disease International) (2015) *World Alzheimer report 2015: the global impact of dementia: an analysis of prevalence, incidence, cost and trends*, ADI, accessed 17 August 2022.

Harvey RJ, Skelton-Robinson M & Rossor MN (2003) 'The prevalence and causes of dementia in people under the age of 65 years', *Journal of Neurology, Neurosurgery and Psychiatry,* 74(9):1206–9, doi:10.1136/jnnp.74.9.1206.

Withall A, Draper B, Seeher K & Brodaty H (2014) 'The prevalence and causes of younger onset dementia in Eastern Sydney, Australia', *International Psychogeriatrics,* 26(12):1955–1965, doi:10.1017/S1041610214001835.

WHO (World Health Organisation) (2012) *Dementia a public health priority*, WHO, accessed 18 August 2022.

Glossary

Aboriginal and/or Torres Strait Islander: A person of Aboriginal and/or Torres Strait Islander descent who identifies as an Aboriginal and/or Torres Strait Islander.

Additional diagnosis: The diagnosis of a condition or recording of a complaint that requires provision of care. In this report, additional diagnoses are from episodes of admitted patient care (hospitalisation) and either coexists with the principal diagnosis or arises during the episode of care. Multiple diagnoses may be recorded.

Age-specific rates: The number of events for a specified age group over a specified period (for example, a year) divided by the total population at risk of the event in that age group.

Age-standardised rates: Age-standardised rates enable comparisons to be made between populations that have different age structures. Direct standardisation was used in this report, in which the age-specific rates are multiplied by a constant population. This effectively removes the influence of the age structure on the summary rate. Where age-standardised rates have been used, this is stated throughout the report.

All age-standardised rates in this report have used the June 2001 Australian total estimated resident population as the standard population.

Alzheimer's disease: A degenerative brain disease caused by nerve cell death resulting in shrinkage of the brain. A common form of dementia.

Anatomical Therapeutic Chemical (ATC) classification: Anatomical Therapeutic Chemical (ATC) codes are used to classify medicines. The ATC classification of medicines is recommended by the World Health Organization, and is the Australian standard for presenting and comparing drug usage data. The ATC classification groups medicines according to the body organ or system on which they act, and their therapeutic and chemical characteristics. More information on the ATC classification system can be found at structure and principles.

Associated cause(s) of death: A cause(s) listed on the medical certificate of cause of death, other than the underlying cause of death. They include the immediate cause, any intervening causes, and conditions that contributed to the death but were not related to the disease or condition causing death. See also cause(s) of death.

Attributable burden: The disease burden attributed to a particular risk factor. It is the amount of burden that could be avoided if the risk factor were removed or reduced to the lowest possible exposure.

Australian population: The Estimated Resident Population (ERP) is used to count the Australian population in this report (see Estimated Resident Population in data sources). The ERP includes all people, regardless of nationality or citizenship, who usually live in Australia (except for foreign diplomatic personnel and their families).

Average length of stay: The average number of patient-days for admitted patient episodes (referred to as hospitalisation in this report). Patients who have an admission and a separation on the same date are allocated a length of stay of 1 day.

Behaviours and psychological symptoms of dementia (BPSD): Refer to a range of non-cognitive symptoms common among people with dementia. These include – agitation, anxiety, apathy, depression, hallucinations or delusions, insomnia, risky behaviour, resistive behaviour, verbal aggression and wandering.

Burden of disease (and injury): The quantified impact of a disease or injury on a population using the disability-adjusted life years (DALY) measure. 1 DALY is equivalent to 1 healthy year of life lost.

Carer: Carer refers to people who provide any informal assistance (help or supervision) to people with disability or older people. In the ABS Survey of Disability, Ageing and Carers (SDAC) for an individual to be considered a carer, the assistance they provide must be ongoing, or likely to be ongoing, for at least 6 months. People who provide formal assistance (on a regular paid basis, usually associated with an organisation) are not considered to be a carer for the purpose of this report. In the ABS SDAC, a carer is either a primary carer or an other carer.

Cause(s) of death: All diseases, morbid conditions or injuries that either resulted in or contributed to death – and the circumstances of the accident or violence that produced any such injuries – that are entered on the medical certificate of cause of death. Causes of death are commonly reported by the underlying cause of death or associated cause(s) of death.

Community-based aged care: Support services that assist older people to continue to live independently at home. This may include healthcare and nursing services, home modifications and assistance with daily activities. This report focuses on government-subsidised community-based aged care services.

Comorbidities/ co-existing health conditions: Defined in relation to an index disease/condition, a comorbidity or co-existing health condition includes any additional disease that is experienced by a person while they have the index disease (in this instance, dementia).

Comprehensive assessment: A comprehensive assessment is 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). By law, a comprehensive assessment is required before someone can receive government-subsidised residential, home, or transition care.

Confidence intervals: A confidence interval is a range of values that is used to describe the uncertainty around an estimate, usually from a sample survey. Generally speaking, confidence intervals describe how different the estimate could have been if the underlying conditions stayed the same but chance had led to a different set of data (for example a different survey sample). Confidence intervals are calculated with a stated probability, 95% is used throughout the report; using this probability, there is a 95% chance that the confidence interval contains the true value. Confidence intervals are only reported for survey data in this report.

COVID-19: A disease of the respiratory system, particularly in the early stages of the illness, caused by the coronavirus SARS-CoV-2. Common early symptoms are similar to other respiratory illnesses, but the infection can have a wide variety of manifestations. In some people the infection can progress to become a more severe disease, with the immune system overreacting, resulting in inflammation and lack of oxygen to many parts of the body. This can lead to multiple organ failure and death. Severe symptoms tend to develop in the second week of the disease.

Crude rates: A crude rate is defined as the number of events over a specified period (for example, a year) divided by the total population at risk of the event.

Culturally and linguistically diverse (CALD): There are a number of ways to define culturally and linguistically diverse people. Generally, people who were born overseas, have a parent born overseas and/or who speak a variety of languages are considered to be in the CALD population. In this report, information on people with dementia from CALD backgrounds is presented for available measures (i.e. people who were born in non-English speaking countries) rather than as a group (i.e. people from CALD backgrounds).

Data linkage/linked data: Bringing together (linking) information from two or more data sources believed to relate to the same entity, such as the same individual or the same institution. The resulting data set is called linked data. In this report, data linkage is used to bring together information from datasets that indicates a population of interest (such as people with dementia) with other datasets that include information on other characteristics or service usage.

Dementia: A term used to describe a group of similar conditions characterised by the gradual impairment of brain function. It is commonly associated with memory loss, but can affect speech, cognition (thought), behaviour and mobility. An individual’s personality may also change, and health and functional ability decline as the condition progresses. Dementia is a fatal condition.

Dementia-specific medications: Prescription medications specifically used to treat the symptoms of dementia. There are 4 dementia-specific medications – Donepezil, Galantamine, Rivastigmine and Memantine – currently subsidised under the Pharmaceutical Benefits Scheme and Repatriation Pharmaceutical Benefits Scheme. These medications can be prescribed to patients with a confirmed diagnosis of Alzheimer’s disease made by (or in consultation with) a specialist or consultant physician under specific clinical criteria. In order to continue treatment, patients must demonstrate a clinically meaningful response to the treatment. This may include improvements in the patients’ quality of life, cognitive function and/ or behavioural symptoms.

Direct expenditure: Expenditure directly related to the treatment or provision of services for a specific disease. It does not include indirect expenditure, such as travel costs for patients, the social and economic burden on carers and family, and lost wages and productivity.

Disability adjusted life years (DALY): A year (1 year) of healthy life lost, either through premature death or equivalently through living with disability due to illness or injury. It is the basic unit used in burden of disease estimates.

Donepezil: A dementia-specific medication approved in Australia for the treatment of mild to moderate Alzheimer’s disease. It is an acetylcholinesterase inhibitor and works by blocking the actions of the enzyme acetylcholinesterase, which destroys acetylcholine – a major neurotransmitter for memory. The use of this medicine may lead to increased communication between nerve cells and slow dementia progression

Fatal burden: The burden of disease from dying prematurely as measured by years of life lost (YLL). Often used synonymously with years of life lost.

First Nations people: A person who identifies themselves as being of Aboriginal and/or Torres Strait Islander origin.

First Nations status: A term used to describe whether or not a person identifies as being of Aboriginal and/or Torres Strait Islander origin.

Frontotemporal dementia: A type of dementia caused by progressive damage to the frontal and/or temporal lobes of the brain. Frontotemporal dementia is more commonly seen in people with younger onset dementia.

Galantamine: A dementia-specific medication approved in Australia for the treatment of mild to moderate Alzheimer’s disease. It is an acetylcholinesterase inhibitor and works by blocking the actions of the enzyme acetylcholinesterase, which destroys acetylcholine – a major neurotransmitter for memory. The use of this medicine may lead to increased communication between nerve cells and slow dementia progression.

Home Support Assessment: A home support assessment is provided by Regional Assessment Services for people seeking community-based entry-level support that is provided under the Commonwealth Home Support Programme.

Hospitalisation: An episode of hospital care that starts with the formal admission process and ends with the formal **separation** process. An episode of care can be completed by the patient being discharged, being transferred to another hospital or care facility, or dying, or by a portion of a hospital stay starting or ending in a change of type of care (for example, from acute to rehabilitation).

Impairment: Any loss or abnormality of psychological, physiological or anatomical structure or function.

Incidence: The number of new cases (of an illness or event) that occur during a given period. Compare with prevalence.

Lewy body dementia/ dementia with Lewy bodies: A type of dementia caused by the 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.

Life expectancy: Indication of how long a person can expect to live, depending on the age they have reached. Technically, it is the average number of years of life remaining to a person at a particular age if age-specific death rates do not change.

Mean/average: The expected value of a particular variable if you were to select an observation at random from a population. Calculated by adding together the values of a variable across the total population and dividing the result by the number of observations in the population.

Median: The midpoint of a list of observations that have been ranked from the smallest to the largest.

Mild cognitive impairment: Significant memory loss, more than expected for the individual's age, with no other changes in cognitive function. People with mild cognitive impairment are still able to function independently. Mild cognitive impairment increases the risk of Alzheimer's disease, but it does not mean that the development of dementia is certain.

Mixed dementia: Multiple types of dementia affecting the same person. Mixed dementia is common in the population. The most common combination is Alzheimer's disease and vascular dementia.

Memantine: A dementia-specific medication approved in Australia for the treatment of 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.

Mode of separation: The status of a patient at the end of the hospital episode, in terms of where they were discharged to or if they died.

Modifiable risk factors: Risk factors that can be modified or reduced (such as tobacco smoking).

Morbidity: The ill health of an individual and levels of ill health in a population or group.

Mortality: Number or rate of deaths in a population during given time period.

Non-fatal burden: The burden of disease from living with ill-health as measured by years lived with disability. Often used synonymously with years lived with disability (YLD).

Non-Indigenous: People who have not indicated that they are of Aboriginal or Torres Strait Islander descent.

Non-modifiable risk factors: Risk factors that cannot be modified or reduced (such as aging or genetics).

Out-of-pocket costs: The total costs incurred by individuals for health care services over and above any refunds from Medicare and private health insurance funds.

Palliative care: Care in which the clinical intent or treatment goal is primarily quality of life for a patient with an active, progressive disease with little or no prospect of cure.

Patient days: Total patient days is the total number of days for all patients who were admitted for an episode of care and who separated during a specified reference period. A patient who is admitted and separated on the same day is allocated 1 patient day.

Pharmaceutical Benefits Scheme (PBS): A scheme through which the Australian Government subsidises the cost of a wide range of prescription medicines. Most prescriptions for General Schedule medicines (Section 85) are dispensed through community pharmacies, but the PBS is also available through eligible public hospitals to patients on discharge, and day patients. Several drugs are also distributed under alternative arrangements where these are considered more appropriate (Section 100).

Prescription: An authorisation issued by a medical profession for a patient to be issued a particular medication. For dementia-specific medications, typically a prescription (script) authorises a person to receive one month's supply of medication.

Prevalence: The number or proportion (of cases or events) in a population at a given time. For example, the number of people alive who have been diagnosed with dementia in a single year. Compare with incidence.

Primary carer: A primary carer is the carer who provided the most informal, ongoing assistance for a person with a disability. In the ABS Survey of Disability, Ageing and Carers , for a person to be considered a primary carer they must be aged 15 or over and assist with 1 or more core activity tasks (mobility, self-care or communication). Their assistance must be ongoing, or likely to be ongoing, for at least 6 months. In this report, the primary carer had to be living in the same household as their care recipient.

Principal diagnosis: The principal diagnosis is the diagnosis considered to be chiefly responsible for occasioning an episode of patient care (hospitalisation).

Prion diseases: Prion diseases are a group of rare neurodegenerative conditions caused by abnormally folded proteins in the brain.

Rate: One number (numerator) divided by another number (denominator). The numerator is commonly the number of events in a specified time. The denominator is the population 'at risk' of the event. Rates (crude, age-specific and age-standardised) are generally multiplied by a number such as 100,000 to create whole numbers. In some instances, for example with prescription volumes or expenditure amounts in magnitude, a multiplier of 100 is used to aid comprehension.

Remoteness: Remoteness is classified according to the Australian Statistical Geography Standard 2016 Remoteness Areas structure, usually based on location of current residence. Data on the location of usual residence may be collected differently across data sources. ABS correspondences are used to assign data from one type of geographic region to another, for example, Statistical Area Level 2 (SA2) to Remoteness Areas.

Repatriation Pharmaceutical Benefits Scheme (RPBS): A scheme through which the Australian Government subsidises the cost of a wide range of prescription medicines for veteran (DVA) health care card holders. Like the Pharmaceutical Benefits Scheme (PBS) most prescriptions for General Schedule medicines (Section 85) are dispensed through community pharmacies, but the PBS is also available through eligible public hospitals to patients on discharge, and day patients. Several drugs are also distributed under alternative arrangements where these are considered more appropriate (Section 100).

Residential aged care: A program that provides personal and/or nursing care to people in a residential aged care facility. As part of the service, people are also provided with meals and accommodation, including cleaning services, furniture and equipment.

Respite care: An alternative care arrangement for dependent people living in the community, giving people – or their carers – a short break from their usual care arrangements. Friends, family or the community may also provide informal respite.

Risk factor: Any factor that represents a greater risk of a health condition or health event.

Rivastigmine: A dementia-specific medication approved in Australia for the treatment of mild to moderate Alzheimer's disease. It is an acetylcholinesterase inhibitor and works by blocking the actions of the enzyme acetylcholinesterase, which destroys acetylcholine – a major neurotransmitter for memory. The use of this medicine may lead to increased communication between nerve cells and slow dementia progression.

Separation: A separation is the formal process where a hospital records the completion of an episode of treatment and/or care for an admitted patient – in this report, described by the term hospitalisation.

Socioeconomic areas/disadvantage: Defined in this report using the Socio-Economic Index for Areas (SEIFA), summary measures of socioeconomic disadvantage and advantage. Socioeconomic disadvantage data in this report is typically reported using the Index of Relative Socioeconomic Disadvantage (IRSD). The Index of Relative Socio-economic Disadvantage (IRSD) is a general socio-economic index that summarises a range of information about the economic and social conditions of people and households within an area. A low score indicates relatively greater disadvantage in general. A high score indicates a relative lack of disadvantage in general.

This report disaggregates some results by five socioeconomic groups. Each group has the fifth of the population with an increasing IRSD score: the first group has the 20% of the population of interest who live in areas with the highest IRSD score (are the most disadvantaged) and the fifth group contains the 20% of the population of interest who live in areas with the highest IRSD score (are the least disadvantaged).

Statistical discharge: A statistical discharge is a mode of separation assigned to patients for whom the intent of care changed during their stay in hospital (for example, from acute care to palliative care).

Supplementary code: A supplementary code is assigned for chronic conditions that are part of the current health status on admission that do not meet criteria for inclusion as a principal or additional diagnosis on the patient's hospital record.

Underlying cause of death: The disease or injury that initiated the train of events leading directly to death, or the circumstances of the accident or violence that produced the fatal injury. See also cause(s) of death and associated cause(s) of death.

Vascular dementia: A form of dementia mainly caused by haemodynamic (blood flow to the brain) disorders (e.g. strokes), thromboembolism (small blood clots that block small blood vessels in the brain), small blood vessel disease in the brain and bleeding into or around the brain.

Years lived with disability (YLD): The number of years of what could have been a healthy life that were instead spent in states of less than full health. YLD represent non-fatal burden.

Years of life lost (YLL): The number of years of life lost due to premature death, defined as dying before the ideal life span. YLL represent fatal burden.

Younger onset dementia: Dementia that develops in people aged under 65.

Notes

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Amendments

November 2023

- The data for hospitalisations with dementia including supplementary codes was amended from 251,000 to 197,000 people with a gender split of 95,000 men and 102,000 women.
- The data for hospitalisations with dementia including supplementary codes in First Nations people was amended from 4,200 to 3,100.

October 2023

Table 15.9 'resistive behaviours' rows had 'no symptoms' and 'not stated' transposed incorrectly.

November 2022

- Table S2.3 heading was updated to reflect the correct data year.
- A small typographical error in the 'Burden of disease' section was amended.

Data

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