Australian Government
Australian Institute of
Health and Welfare

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.

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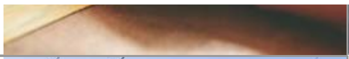
Latest dementia statistics:

In 2021, it is estimated between **386,200 and 472,000** Australians are living with dementia

Dementia prevalence rates among Indigenous Australians 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 2019

In 2018, dementia was the **3rd leading cause of burden of disease** in Australia



Around **2 in 3** Australians with dementia were **living in the community** in 2021

54% of people living in **permanent residential aged care** had dementia in 2019–20

$3 billion of Australia’s health and aged care **expenditure** was spent directly on dementia in 2018–19

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

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.

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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.

Last updated 13/09/2021 v64.0

Australian stories about living with dementia

Carrie's story

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.

Last updated 13/09/2021 v37.0

Australian stories about living with dementia

Len's story

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 Indigenous Australians 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.*

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Australian stories about living with dementia

Martina's story

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.*

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Australian stories about living with dementia

Lucy's story

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.*

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Last updated 13/09/2021 v15.0

Australian stories about living with dementia

Jim's story

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.'

For more information on supporting people with dementia during COVID-19 lockdowns refer to Dementia Australia's Coronavirus (COVID-19) - Tips for carers, families and friends of people living with 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.*

Names and identifying characteristics have been changed. Images are not representative of individuals in the story.

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Understanding dementia

Dementia is not a single, specific disease. There are many types of dementia with symptoms in common, and these are caused by a range of conditions impacting brain function. Dementia is commonly associated with memory loss but it can affect speech, cognition, emotional control, behaviour and mobility (WHO 2019).

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).

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 (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
- 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 2020; Draper 2013).

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).

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Understanding dementia

What puts someone at risk of developing 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 1 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). See Dementia among people with intellectual disabilities for more information on dementia among people with Down syndrome.

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 2019a).

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 2019b).

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 Australian National University (ANU) have developed a tool to assess an individual's exposure to risk factors associated with an increased risk of developing Alzheimer's disease in late-life (over 60 years). The ANU Alzheimer's Disease Risk Index (ANU-ADRI) provides an individualised assessment and report on Alzheimer's disease risk factor exposure.

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Understanding dementia

How is dementia diagnosed?

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 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. This includes:

- history taking from the person and if possible from a person who knows the person well (such as family members or carers)
- cognitive and mental examination with a validated instrument (such as the Mini-Mental State Examination (MMSE), GP assessment of cognition (GPCOG), Rowland Universal Dementia Assessment Scale (RUDAS) for people from culturally and linguistically diverse backgrounds or the Kimberley Indigenous Cognitive Assessment (KICA-Cog) for Aboriginal or Torres Strait Islander people living in rural or remote areas)
- physical examination and blood tests
- brain imaging (where necessary)
- review of current medication use
- consideration of other causes, such as depression, delirium, thyroid disease or vitamin deficiency (Guideline Adaptation Committee 2016).

If dementia is a suspected diagnosis, the clinical guidelines state that best practice is for GPs to make a referral to memory assessment specialists (such as geriatricians or psycho-geriatricians) or services (such as memory clinics) for a comprehensive assessment. The aim of the comprehensive assessment is to gather information about changes in behaviour, functional capacity, psychosocial issues and relevant medical conditions to allow for a diagnosis to be made.

While diagnosing health conditions is not the main function of aged care assessments undertaken for people seeking entry to or currently using aged care services, dementia may be diagnosed during medical assessments by Aged Care Assessment Teams, if this impacts care needs.

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.

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Last updated 4/09/2021 v8.0

Understanding dementia

What care and support is available to people with 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) (Guideline Adaptation Committee 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) (Guideline Adaptation Committee 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).

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Last updated 21/09/2021 v13.0

Australian Government
Australian Institute of
Health and Welfare

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
- Impact of COVID-19 on deaths among people with dementia in 2020
- 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 XLS Prevalence data tables, XLS Mortality data tables and XLS Burden of disease data tables for the underlying data presented in these pages.

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

Key statistics

In 2021, it's estimated between 386,200 and 472,000 Australians are living with dementia

The number of Australians with dementia is predicted to more than double by 2058, from 386,200 people in 2021 to 849,300 in 2058

Dementia was the 2nd leading cause of death in Australia in 2019, accounting for 9.5% of all deaths

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

Last updated 23/09/2021 v13.0

Australian Government
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Health and Welfare

Population health impacts of dementia

Prevalence of dementia

Key statistics

In 2021 it is estimated between 386,200 and 472,000 Australians are living with dementia

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

The exact number of people with dementia in Australia is currently not known. However, it is estimated that in 2021 there are between 386,200 (estimated by AIHW) and 472,000 Australians with dementia (Dementia Australia 2020). These estimates vary because there is no single authoritative data source for deriving dementia prevalence in Australia, and different approaches are used to generate estimates.

This page presents dementia prevalence, as estimated by AIHW:

- by sex and age in 2021
- by place of residence in 2021 (i.e. living in the community versus living in cared accommodation)
- for each year between 2010 and 2058
- by states/territories, remoteness and socioeconomic areas in 2019.

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 XLS Prevalence data tables for the underlying data presented in this page.

See Population health impacts of dementia among Indigenous Australians 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 admissions, aged care services, and causes of death), survey data (such as the Australian Bureau of Statistics (ABS) Survey of Disability, Ageing and Carers) 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.

Due to the varying methods used to estimate the number of Australians with dementia and the lack of robust, up-to-date Australian data, this report presents the overall number of Australians with dementia as a range—the minimum estimate was produced by AIHW and the maximum estimate produced by the National Centre for Social and Economic Modelling.

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. Some promising developments in relation to dementia data include:

- projects linking the available administrative and medical practice data sets to improve dementia prevalence estimates and other key statistics. Bringing together data from multiple sources on the same individual, also known as data linkage or data integration, is a promising opportunity to improve the quality of dementia prevalence estimates in the short term. These projects are funded by the National Health and Medical Research Council National Institute for Dementia Research (NHMRC 2019). For more information about using data linkage to improve dementia statistics, see Chapter 8 in *Australia's health 2020: data insights*
- the development of a dementia clinical quality registry that directly collects data for the diagnosis and management of dementia by the Australia Dementia Network (NHMRC 2019)
- the Registry of Senior Australians (ROSA) has historical data on Australians who were assessed for and/or received government-subsidised aged care from 1997 to 2020; since 2018, ROSA has also sought to enrol all South Australians who have an aged care eligibility assessment in a prospective state-wide registry (ROSA 2019)
- the increasing availability of electronic health records that contain clinical diagnosis information, including the nationwide implementation of *My Health Record*. For example, The NPS MedicineInsight program, which uses nationwide clinical data from 569 general practice information systems, has been used to estimate dementia prevalence among patients visiting participating general practitioners (GPs) and to study differences in patterns of service use by dementia status (NPS MedicineWise 2020).

See the AIHW's Chapter 8 in *Australia's health 2020: data insights* and *Dementia data gaps and opportunities* report for more information on the landscape of dementia data in Australia.

This page will be updated to include national dementia prevalence estimates from relevant studies once available.

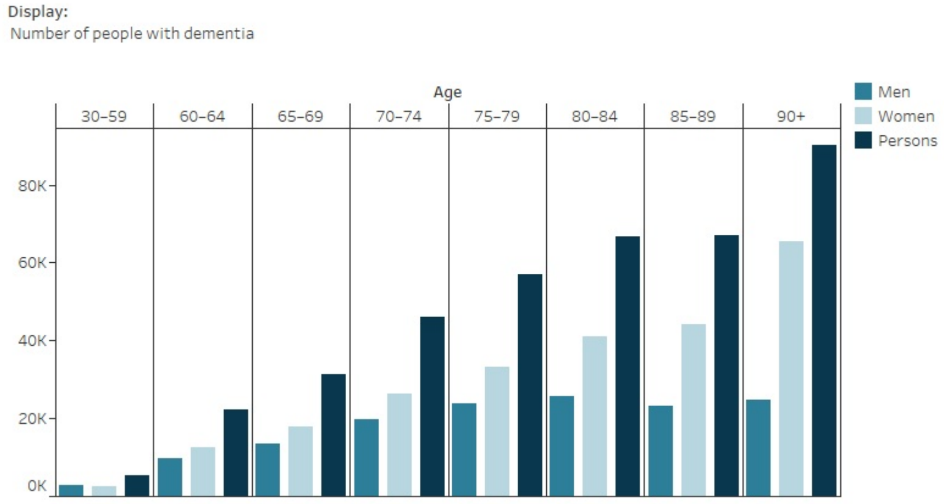
How many people have dementia in Australia?

The AIHW estimates for 2021 indicate that there are around 386,200 people living with dementia in Australia, including 243,200 women and 143,000 men. This is equivalent to 15 people with dementia per 1,000 Australians (18 per 1,000 women and 11 per 1,000 men).

The rate of dementia rises quickly with age—from less than 1 person with dementia per 1,000 Australians aged under 60, to 68 per 1,000 Australians aged 75–79, and then to 399 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 2021: estimated number and rate, by age and sex

Figure 2.1 is a bar graph showing the estimated number and rate of men, women and persons with dementia in Australia by age in 2021. It shows that the number and rate of men, women and persons with dementia increases 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 ABS 2021 population projections, series B.
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

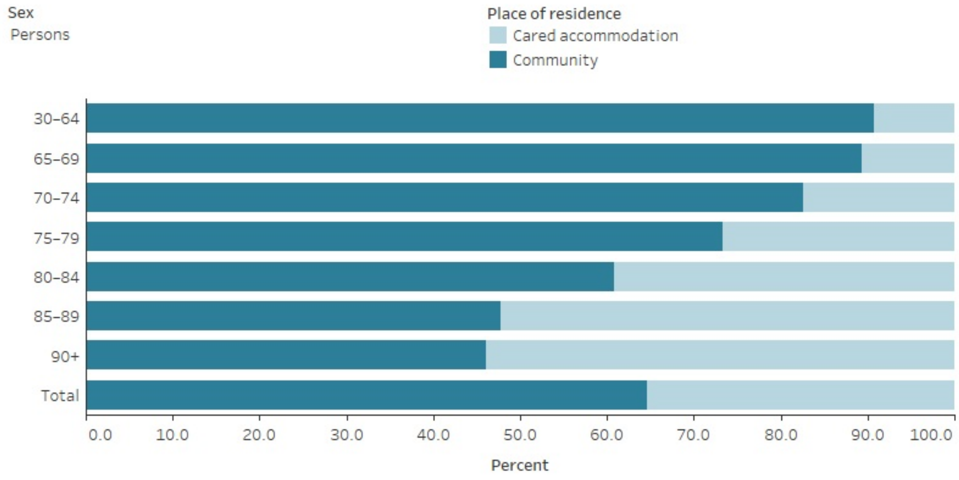
65% of people with dementia live in the community

Based on the AIHW estimates, there are an estimated 246,200 people with dementia living in the community (as opposed to cared accommodation) in 2021 (93,000 men and 153,200 women). This equates to 65% of all people with dementia living in the community (66% of men and 64% 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) are living in the community (91% or 20,300 people). Among the older age groups, just under half of people with dementia live in the community (48% of people with dementia aged 85–89 or 32,100 people and 46% aged 90 and over, or 41,600 people). This decrease is more substantial among women than men.

Figure 2.2: Australians living with dementia in 2021: estimated percentage by age, sex and place of residence

Figure 2.2 is a stacked bar graph showing the percentage of people with dementia in Australia who are living in the community and the percentage who are living in cared accommodation in 2021 by age and sex. It shows that the majority of people with dementia aged under 85 are living in the community but this decreases to around half of people living in the community among those aged 85 and over. This decrease is more substantial among women than men.



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 2019 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.

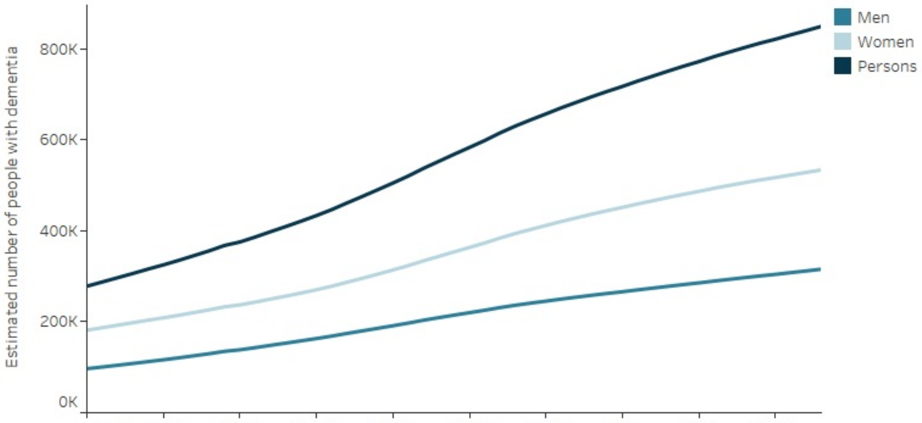
The number of Australians with dementia is projected to more than double by the year 2058

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 386,200 in 2021 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. Further, 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 & 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 2010 and 2058: estimated number by sex and year

Figure 2.3 is a line graph showing the estimated number of males, females and people with dementia in Australia between 2010 and 2058. It shows that the number of people with dementia is expected to continue to increase, due to the projected continued growth and ageing of Australia's population.



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

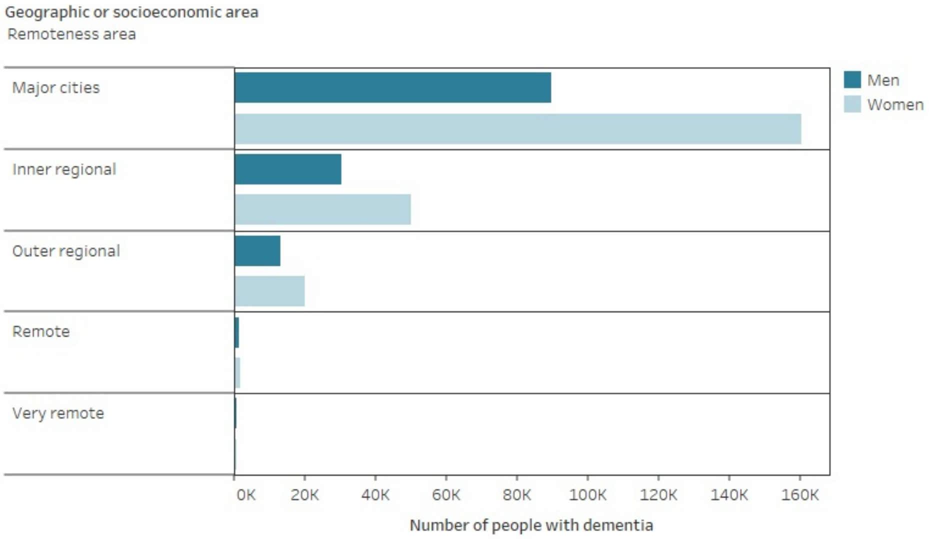
How does dementia prevalence vary by geographic and socioeconomic areas?

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 by state/territory, remoteness and socioeconomic area on how the number of people with dementia varies across Australia.

Figure 2.4 shows the estimated number of people with dementia by state/territory, remoteness, or socioeconomic area based on AIHW estimates for 2019.

Figure 2.4: Australians living with dementia in 2019: estimated number by sex, and geographic or socioeconomic area

Figure 2.4 is a bar graph showing the estimated number of men and women with dementia in Australia in 2021 by state or territory, remoteness and socioeconomic areas. Due to lack of data, the AIHW national age-sex specific rates for dementia were applied to the population in each state, remoteness and socioeconomic area. The numbers of men and women with dementia were highest in the most 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 recent 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.

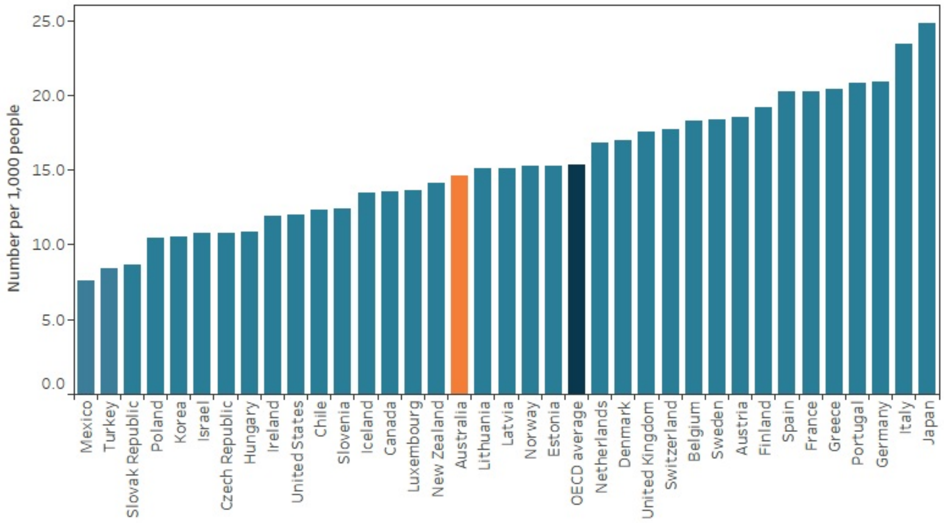
International comparisons of dementia prevalence

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 2019 OECD dementia prevalence rates were similar 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 *World Alzheimer's report 2015* and were subject to varying quality of information across regions, so they should only be used for international comparisons. For example, Australasian rates were based on a small sample of older studies while rates for Western Europe were updated to include information from more recent studies.

In 2019, the OECD estimated that the prevalence of dementia in Australia was 14.6 cases per 1,000 population, close to the OECD average of 15.3 per 1,000 population and ranking 17th lowest out of 36 countries (Figure 2.5). Mexico had the lowest rate, half the Australian rate at 7.6 per 1,000 population, whereas Japan's rate was highest at 24.8 per 1,000 population (OECD 2019). 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 2.5: People living with dementia in Organisation for Economic Co-operation and Development (OECD) member countries in 2019: estimated rate by country

Figure 2.5 is a bar graph showing the estimated rate of dementia in member countries of the Organisation for Economic Co-operation and Development (OECD) in 2019. The rate for Australia was slightly lower than the average rate for OECD countries. Variation in dementia prevalence across countries is due to differences in population age structures, with ageing OECD nations tending to have higher prevalence rates.



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 World Alzheimer report 2015 and the United Nations.
http://aihw.gov.au

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Population health impacts of dementia

Incidence 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 2020c).

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).

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Last updated 21/09/2021 v13.0

Population health impacts of dementia

Deaths due to dementia

Key statistics

Dementia was the 2nd leading cause of death in Australia in 2019, accounting for 9.5% of all deaths			Women aged 85 or over accounted for half of all deaths due to dementia in 2019
Deaths due to dementia increased from 9,200 deaths in 2010 to 14,700 deaths in 2019			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 Indigenous 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 XLS Mortality data tables for underlying data presented in these pages.

Dementia is a leading cause of death in Australia

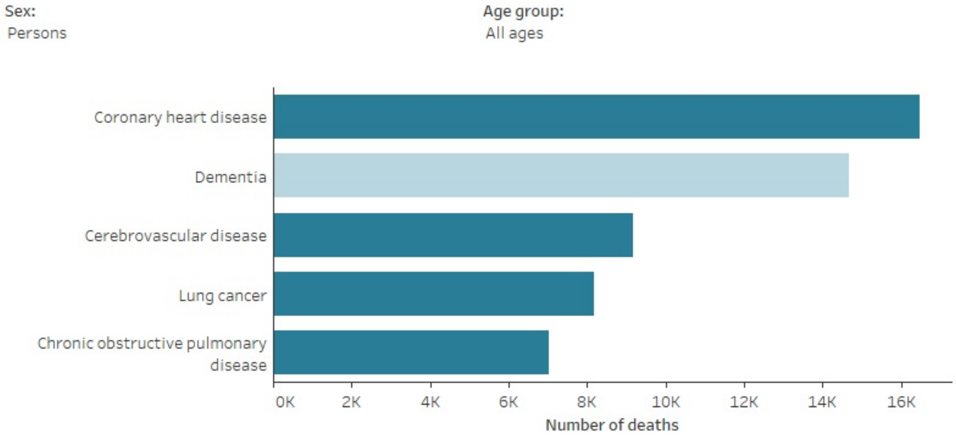
In 2019, dementia was the second leading cause of death in Australia after coronary heart disease, and the leading cause of death for women. There were a total of 14,700 deaths due to dementia, with more women than men dying due to the condition (around 9,200 and 5,400 deaths, respectively). This corresponds to dementia causing 9.5% of all deaths in Australia in 2019 (or 12.4% of all deaths among women and 6.8% of all deaths among men).

Figure 3.1 shows the leading 5 causes of death for Australians in 2019, by age and sex. Dementia becomes an increasingly common cause of death with increasing age, and was the leading cause of death among people aged 85 and over. For women, it was also the leading cause of death among those aged 75 and over.

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

Figure 3.1: Leading causes of death in Australia in 2019, by age and sex

Figure 3.1 is a bar graph showing the leading 5 causes of death in Australia by sex and age in 2019. Overall, dementia is the second leading cause of death in Australia. It shows that dementia becomes a higher ranked cause of death with increasing age. Dementia was the leading cause of death of Australians aged 85 and over, and leading cause of death for Australian women aged 75 and over.

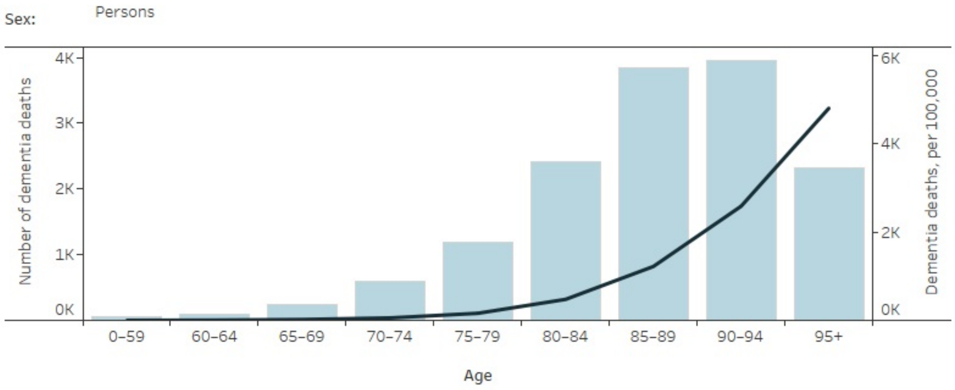


Note: This analysis is only based on the underlying cause of death and not on associated causes of death.
Source: AIHW analysis of the National Mortality Database.
https://www.aihw.gov.au

Figure 3.2 presents more details on deaths due to dementia by age and sex in 2019. The rate of deaths due to dementia among those who died aged 75–79 was 167 and 155 deaths per 100,000 population for men and women, respectively. The rate increased to 3,553 and 5,320 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 2019: number and age-specific rates, by age and sex

Figure 3.2 is a line bar graph showing by age and sex in 2019, the number of deaths with dementia as an underlying cause of death, referred to as ‘deaths due to dementia’ and a line graph showing the number of deaths due to dementia per 100,000 people. The number of deaths and the rate of deaths increased with increasing age, with most occurring among people aged between 85 and 94.



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

Dementia deaths have increased over the 2010–2019 period

The number of deaths due to dementia increased from 9,200 deaths in 2010 to 14,700 deaths in 2019 (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 due to dementia is in part a reflection of more Australians living to older ages.

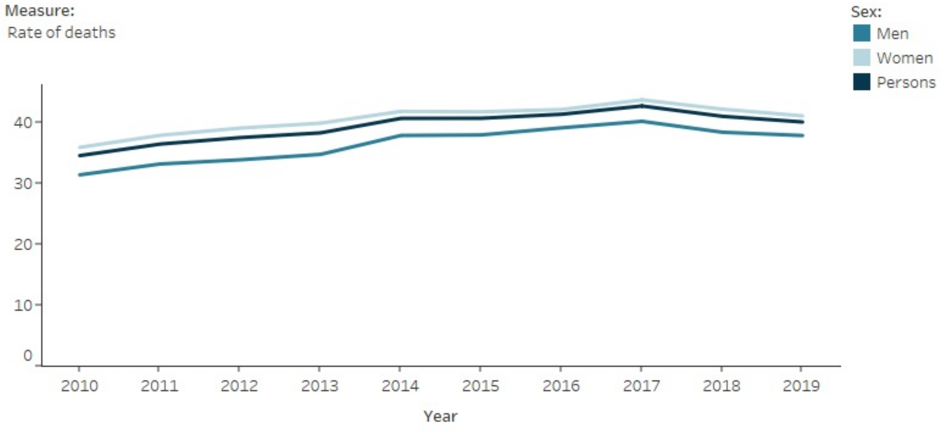
The age-standardised rate of deaths due to dementia, which accounts for changes in the Australian population over time, increased slightly between 2010 and 2019, from 35 to 40 deaths per 100,000 population; this increase mostly occurred between 2010 and 2014 (from 35 to 41 deaths per 100,000 population), and was followed by relatively stable rates from 2014 to 2019.

Over the period 2010 to 2019, death rates increased slightly for both men (from 31 to 38 deaths per 100,000) and women (from 36 to 41 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 between 2010 and 2019. 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 2010 to 2019: number and age-specific rate by sex

Figure 3.3 is a line graph showing the number and age-standardised rates of men, women and people who died due to dementia in Australia between 2010 and 2019. It shows the number of people who died due to dementia increased between 2010 and 2019, which in part is a reflection of Australians living to older ages. The age-standardised rates of people who died due to dementia increased between 2010 and 2017, declined slightly between 2017 and 2018 and remained stable between 2018 and 2019. These patterns were seen for men and women.



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

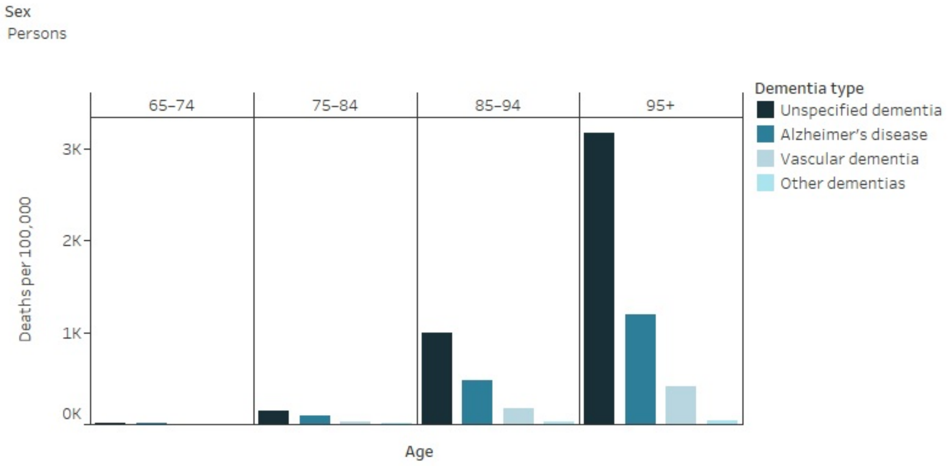
How are dementia types coded in death certificates?

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 2019, for people aged 65 and over, the most common specific dementia types recorded were *Alzheimer's disease* (4,300 deaths) and *Vascular dementia* (1,400 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 540 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 2019: age-specific rates, by sex, age and dementia type

Figure 3.4 is a bar graph showing the age- and sex-specific rates of deaths due to different types of dementia in 2019 (*Alzheimer's disease*, *Unspecified dementia*, *Vascular dementia* and *Other dementias*) from age 65 onwards. The rate of deaths due each type of dementia increased with age. *Unspecified dementia* was responsible for the highest rate of deaths in each age group, 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

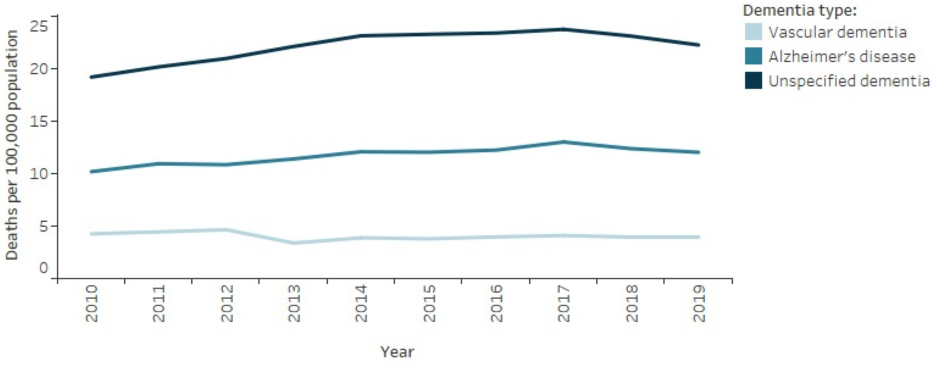
Emerging work in Australia to better understand dementia typing in deaths data

Over the 2010–2019 period, the age-standardised rate of deaths due to *Unspecified dementia* increased from 19 to 24 deaths per 100,000 people between 2010 and 2017, but then decreased slightly to 22 deaths per 100,000 people in 2019 (Figure 3.5). 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 2010 to 2019: age-standardised rates, by dementia type

Figure 3.5 is a line graph showing the age-standardised rates of deaths due to dementia in Australia between 2010 and 2019 by type of dementia (*Alzheimer's disease*, *Unspecified dementia*, *Vascular dementia)*. It shows that the rate of *Unspecified dementia* increased between 2010 and 2017, but then decreased from 2017 to 2019. The reasons for this decrease are not well understood. The rate of *Alzheimer's disease* increased slightly between 2010 and 2019, whereas the rate of *Vascular dementia* decreased slightly between 2012 and 2013, but has remained stable from 2014 onwards.



Notes:
1.Death rates due to dementia over the 2010–2019 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

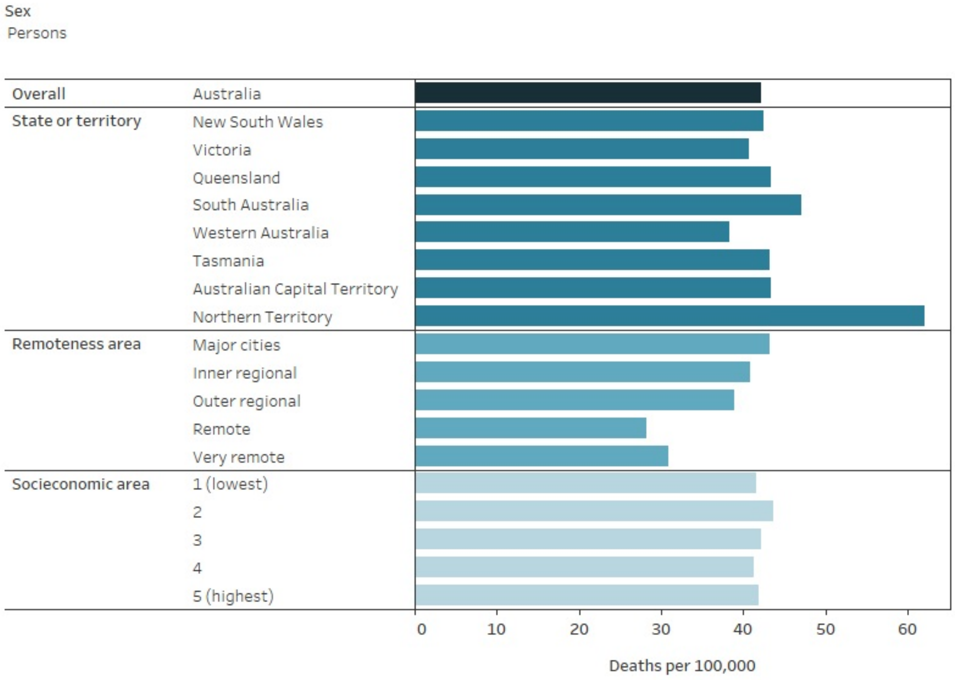
Figure 3.6 shows age-standardised rates of death due to dementia in 2019 by sex, and by different geographic and socioeconomic areas. After adjusting for population differences, the age-standardised rate of deaths due to dementia:

- varied across states and territories—ranging from 38 deaths per 100,000 population in Western Australia to 62 per 100,000 population in the Northern Territory
- varied by remoteness—the rate was highest in *Major cities* (43 deaths per 100,000 population) and lowest in *Remote* areas (28 per 100,000 population)
- was relatively similar across socioeconomic areas—ranging between 41–44 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 health-care and aged care workers, which could be impacting where people with dementia die, and when and how dementia deaths are coded (Royal Commission 2019). However, further research is needed to comprehensively capture important factors related to place of death for people with dementia.

Figure 3.6: Deaths due to dementia in 2019: age-standardised rates, by sex, and by geographic and socioeconomic areas

Figure 3.6 is a bar graph showing the age-standardised rates of deaths due to dementia in Australia in 2019 for men, women and persons by state or territory, remoteness and socioeconomic areas. Rates varied by state or territory as well as by remoteness areas, with the highest rates in the Northern Territory and in *Major cities* and the lowest rates in Western Australia and in *Remote areas*. Rates 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

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Population health impacts of dementia

Dying due to dementia compared to dying with dementia

In addition to the underlying cause of death (UCOD), 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. This means that it is possible to examine not only people who die due to dementia (i.e. UCOD of dementia), but also people who die with dementia (i.e. UCOD or ACOD of dementia).

In 2019, 14,700 people died *due to* dementia (9,200 women and 5,400 men). In comparison, 26,100 people died *with* dementia (15,700 women and 10,400 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 2019, the leading underlying causes of death for people who had dementia recorded as an associated cause of death were:

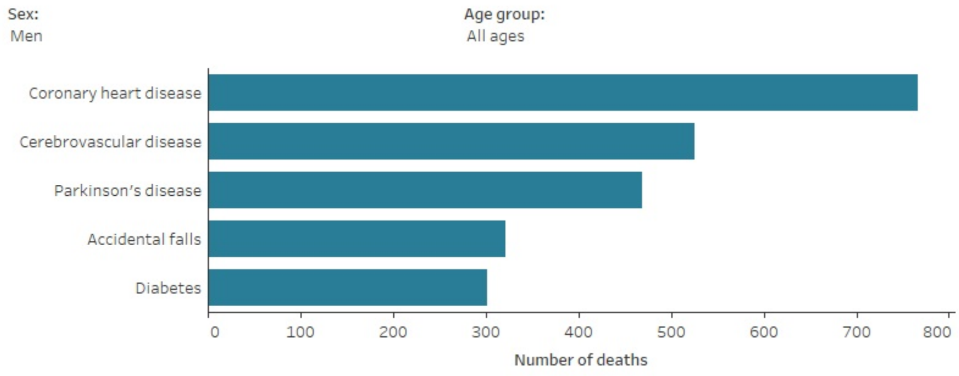
- coronary heart disease (1,800 deaths)
- cerebrovascular disease (1,600 deaths)
- accidental falls (740 deaths)
- Parkinson’s disease (720 deaths)
- diabetes (660 deaths) (Figure 3.7).

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 11,700 people who died with at least 1 type of dementia recorded as an associated cause, 340 (2.9%) 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 2019 when dementia was an associated cause of death, by sex and age

Figure 3.7 is a bar graph showing the leading 5 underlying causes of death in Australia by sex and age in 2019, when dementia was an associated cause of death. For both men and women, the leading underlying causes of death were *Coronary heart disease*, *Cerebrovascular disease*, *Accidental falls*, *Parkinson’s disease* and *Diabetes*. As age of death increases, *Accidental falls* becomes a more common underlying cause of death, whereas *Diabetes* becomes less common.



Note: Due to confidentiality issues, rates 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 2010 and 2019 the rate of deaths where dementia was the underlying cause of death increased from 35 to 40 deaths per 100,000 population. In contrast, the rate of deaths where dementia was an associated cause of death decreased from 45 to 33 per 100,000 population over the same period (Figure 3.8).

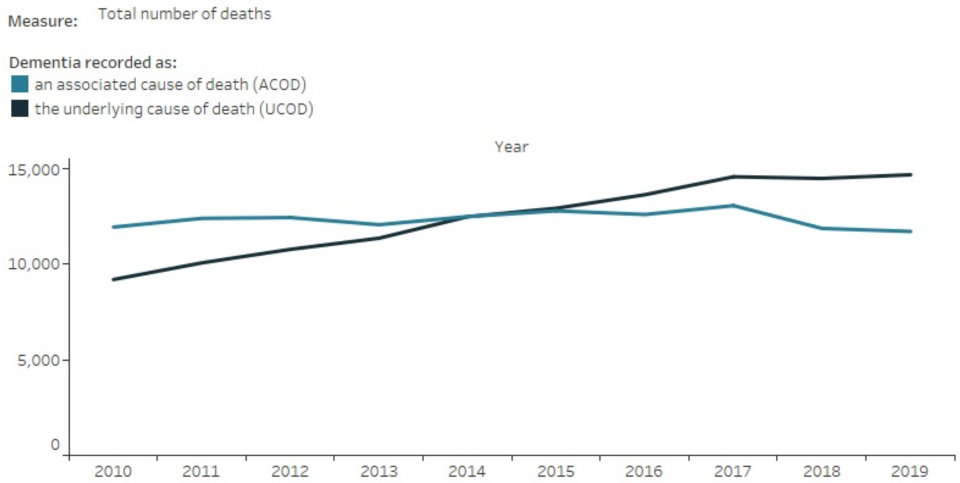
While we cannot be certain why this is occurring, it may be due to various factors:

- Australians are living longer and are more likely to be dying from dementia rather than from other conditions. Notably, there have been decreases in fatal heart attacks and strokes over time. This may be 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).

Figure 3.8: Dementia-related deaths in Australia in 2010–2019: number and age-standardised rates, by whether dementia was recorded as the underlying cause of death (UCOD) or an associated cause of death (ACOD)

Figure 3.8 is a line graph showing the number and age-standardised rates of dementia-related deaths in Australia between 2010 and 2019, by whether dementia was an underlying cause of death or an associated cause of death. The rate of deaths with dementia increased as an underlying cause of death and decreased as an associated cause of death between 2010 and 2019.



Notes:
1.Death rates related to dementia over the 2010–2019 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

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Population health impacts of dementia

Impact of COVID-19 on deaths among people with dementia in 2020

Older people living with dementia are particularly vulnerable during infectious disease outbreaks. Although less than 1 in 10 cases of COVID-19 in Australia in 2020 were among people living in residential aged care, over 7 in 10 COVID-19 deaths were among people living in residential aged care, where it is thought over half of people have dementia (AIHW 2021).

In addition to being exposed to outbreaks in aged care homes, older people living with dementia are at a higher risk of contracting COVID-19 and developing severe COVID-19 for a number of reasons, including that people with dementia often have numerous comorbidities and that they may have difficulties understanding and following public health recommendations. This makes people with dementia a particularly vulnerable group during the COVID-19 pandemic.

To measure changes in mortality patterns during the COVID-19 pandemic and recovery period, the ABS has been publishing provisional mortality statistics for Australia. These statistics indicate that:

- there were 14,500 deaths in 2020 with an underlying cause of dementia, higher than the average number of deaths due to dementia over 2015–19 (13,500)—this increase is, however, mainly a reflection of Australia's ageing population
- once changes in Australia's population over time are taken into account, the rate of deaths due to dementia remained stable—the age-standardised rate of deaths in 2020 was 40 deaths per 100,000 population, whereas it was 41 deaths per 100,000 population on average over 2015–19 (ABS 2021).

As discussed in Dying due to dementia compared to dying with dementia, incorporating associated causes of death is essential to comprehensively capture deaths among people with dementia as they often die due to other health conditions. In these cases dementia is only recorded as an associated cause of death. The AIHW report *Dementia deaths during the COVID-19 pandemic* (AIHW 2021) used ABS provisional mortality data to explore the impact of the pandemic on patterns of deaths among people who had dementia recorded anywhere on their death certificate (either as the underlying cause of death or as an associated cause of death, referred to as 'deaths with dementia'). This report found that during the first 10 months of 2020:

- the rate of deaths with dementia was lower than the average rate of deaths with dementia over 2015–19
    - Measures introduced to limit the spread of COVID-19 probably led to lower transmission of other infectious respiratory diseases (like influenza or pneumonia), and in turn led to an overall lower rate of deaths among people with dementia
- 858 people died due to COVID-19, and among them, 257 (30%) also had dementia recorded on their death certificate.

The statistics presented in the report relate only to the first 10 months of the COVID-19 pandemic. Future work will update our understanding of the impact of COVID-19 on deaths of people with dementia as the pandemic continues, including how this may affect the prevalence and incidence of dementia in Australia in coming years.

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Last updated 21/09/2021 v8.0

Population health impacts of dementia

Burden of disease due to 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 1 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 2020).

The Australian Burden of Disease Study (ABDS) 2018 provides the most recent Australian-specific estimates of disease burden. Preliminary results from the ABDS 2018 study can be found at Australian Burden of Disease Study 2018 key findings. Detailed results and information on the data and methods used in ABDS 2018 are planned for release on the AIHW website in late 2021 (AIHW forthcoming 2021).

The AIHW is currently working on calculating the disease burden in Aboriginal and Torres Strait Islander people in 2018 and preliminary results are planned for release on the AIHW website in late 2021. Refer to Population health impacts of dementia among Indigenous Australians for information on disease burden in Indigenous Australians using the latest available estimates.

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

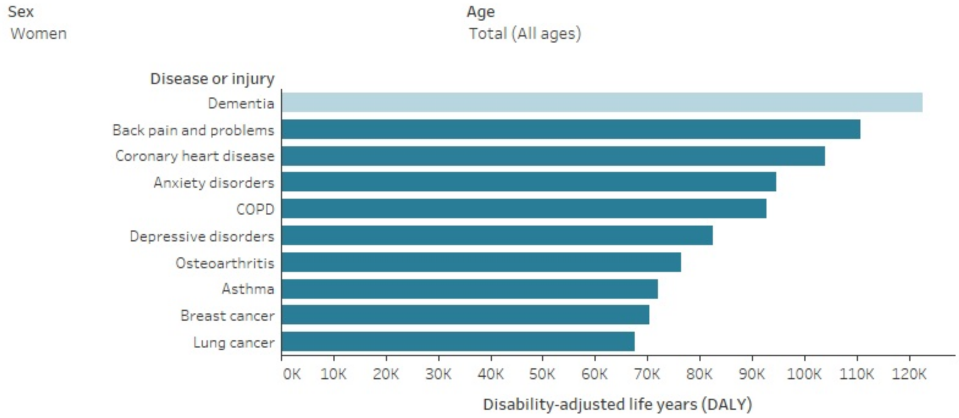
Dementia is a leading cause of disease burden in Australia

In 2018, dementia was the third overall leading cause of burden of disease and injury in Australia, behind coronary heart disease and back pain. Dementia was responsible for just under 198,000 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, and females experienced 62% or 122,600 DALY of the total burden due to dementia. In comparison, dementia was the sixth leading cause of disease burden for males (75,300 DALY).

Age is the biggest risk factor for dementia, and its ranking as a leading cause of disease burden increased as age increased (Figure 4.1). Overall, dementia was the leading cause of disease burden among Australians aged 75 and over. However, this was partially due to the high disease burden among women in older ages. For men aged 80 and over, dementia was the second leading cause of disease burden behind coronary heart disease, whereas among women aged 80 and over, dementia was the leading cause.

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

Figure 4.1 is a bar graph showing the leading 10 causes of disease burden (by disability-adjusted life years) in Australia by sex and age in 2018. Overall, dementia was the third leading cause of disease burden in Australia, behind coronary heart disease and back pain and problems. Overall, dementia is the leading cause of disease burden for women, and the sixth leading cause for men. Dementia becomes a higher ranked cause of disease burden with increasing age; it was the leading cause of disease burden among Australians aged 80 and over. This is mainly due to the high disease burden among women aged 80 and over.



Notes:
1. COPD refers to Chronic obstructive pulmonary disease.
2. Conditions that were grouped into residual categories in the Australian Burden of Disease Study 2018 (such as 'Other musculoskeletal conditions') are not included in the rankings.
3. Lower repiratory infections includes influenza and pneumonia.

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

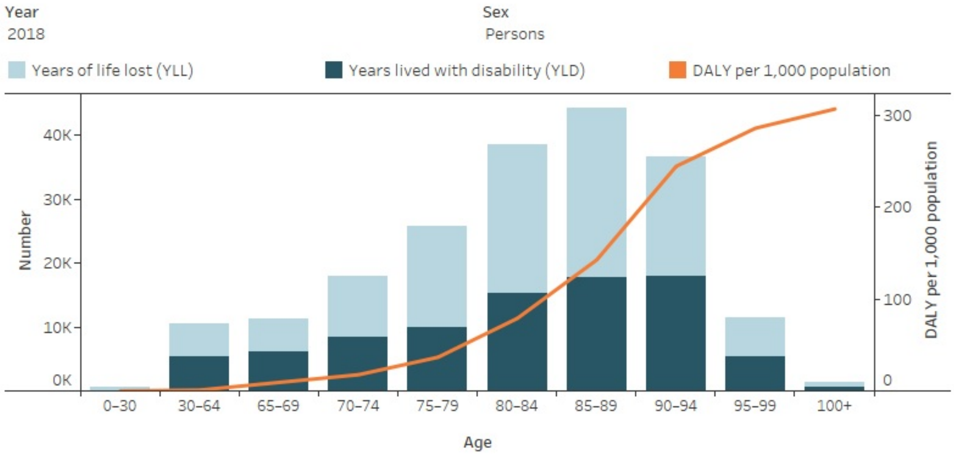
Over half (56%) of the total burden due to dementia was from dying prematurely (111,500 years of life lost or YLL). This percentage was slightly greater in men (62% of the total burden was from dying prematurely, or 46,600 YLL) than in women (53% or 75,300 YLL) (Table S4.3).

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 (see Dying due to dementia compared to dying with dementia for more information).

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 less years of life to lose at older ages). 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 2011, 2015 and 2018, by sex and age: number (YLL, YLD) and age-specific rate (DALY per 1,000 people)

Figure 4.2 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, in Australia by sex and year (2011, 2015 and 2018). It shows that the number of years of life lost and years lived with disability due to dementia increases up to age 85–89 and then decreases in the oldest age groups. Years of life lost due to dementia becomes an increasing cause of the disease burden due to dementia with increasing age. The rate of DALY due to dementia increases with increasing age, and was highest among people aged 100 or over. Overall patterns were similar for each year presented.



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

Burden due to dementia increased between 2011 and 2018

Dementia has risen from the fourth leading cause of disease burden in 2011 (behind coronary heart disease, back pain and lung cancer) to be the third leading cause in 2018 (behind coronary heart disease and back pain).

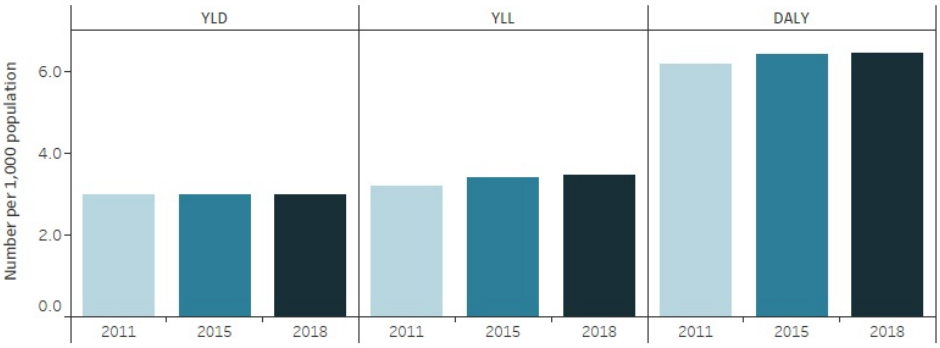
There was a slight increase in the rate of total burden due to dementia between 2011 and 2018, from 5.8 DALY to 6.1 DALY per 1,000 people, due to an increase in fatal burden (from 3.1 YLL to 3.5 YLL per 1,000 people) (Figure 4.3). Due to the lack of high-quality data on dementia prevalence (number of 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 2011, 2015 and 2018. As such, there is no change in the YLD rates between 2011 and 2018.

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

Figure 4.3: Dementia burden in Australia in 2011, 2015 and 2018, by sex: age-standardised YLL, YLD and DALY per 1,000 people

Figure 4.3 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 in Australia in 2011, 2015 and 2018 by sex. There was a slight increase in the rate of disability-adjusted life years due to dementia between 2011 and 2018, due to an increase in the rate of years of life lost due to dementia. Due to the lack of high-quality data on dementia prevalence, the same prevalence and severity rates were used to estimate the years lived with disability due to dementia in each year, resulting in no changes in the rates of years lived with disability due to dementia between 2011 and 2018.

Sex
Women



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 geographic and socioeconomic areas

The disease burden experienced in a population (both the amount and types of disease or injury) 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 and 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 area (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 Indigenous Australians 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.

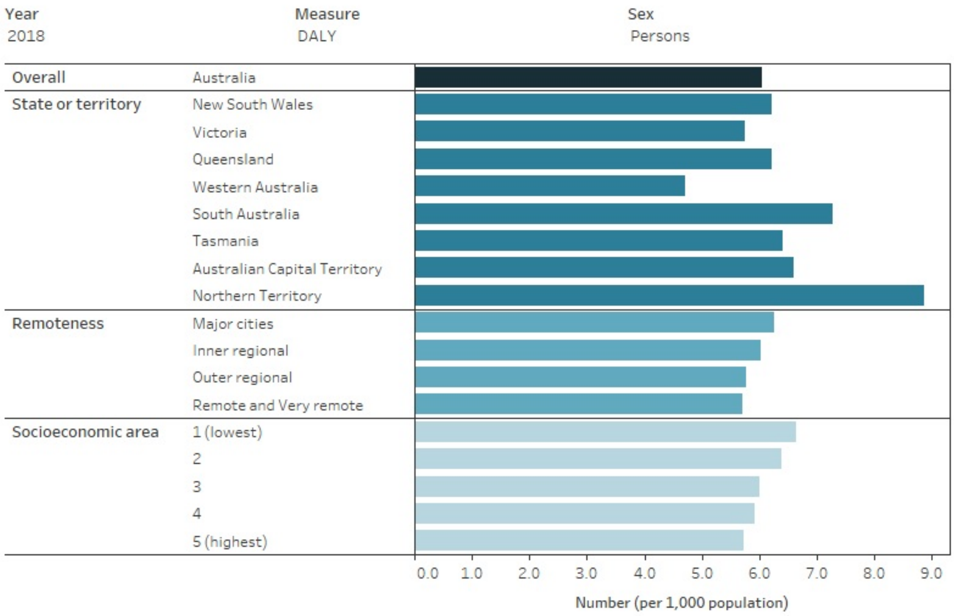
Between 2011 and 2018, changes in the rate of dementia burden varied by state. The rate declined for the Northern Territory, Tasmania and Western Australia (by between 0.5 to 1.0 DALY per 1,000 people); rose for the Australian Capital Territory, New South Wales and Queensland (by between 0.6 to 0.8 DALY 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 the age-standardised rates of years of life lost (YLL), years lived with disability (YLD) and disability-adjusted life years (DALY) due to dementia in Australia in 2011, 2015 and 2018 for men, women and persons by state or territory, remoteness and socioeconomic areas. 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

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Population health impacts of dementia

Dementia burden due 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 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. Refer to What puts someone at risk of developing dementia? for more information on the complete list of established risk factors for 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 here.

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

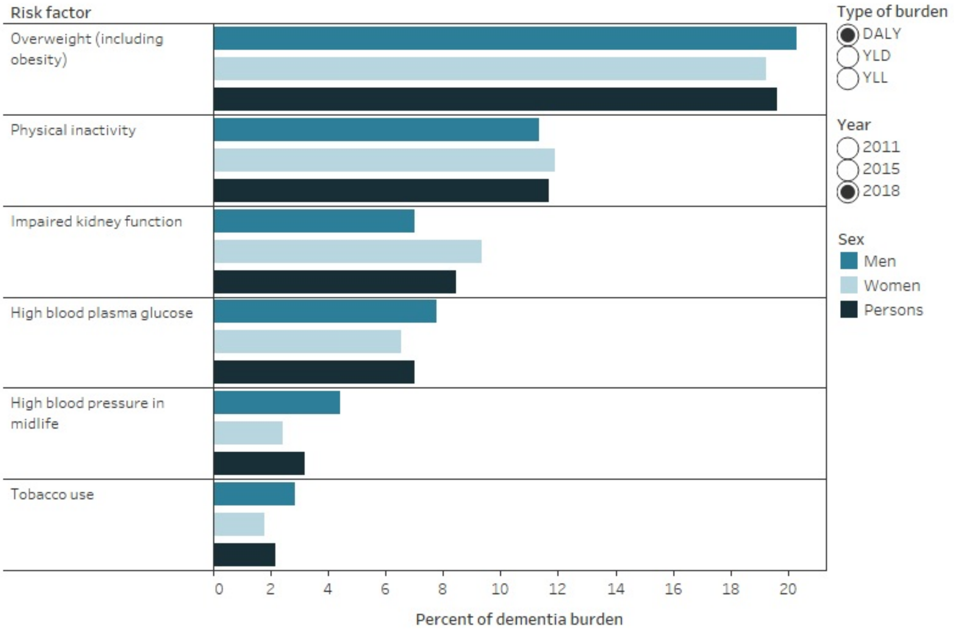
- 20% was attributable to overweight and obesity (38,900 DALY)
- 12% was attributable to physical inactivity (23,100 DALY)
- 8.4% was attributable to impaired kidney function (16,700 DALY)
- 7.0% was attributable to high blood plasma glucose (13,900 DALY)
- 3.2% was attributable to high blood pressure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

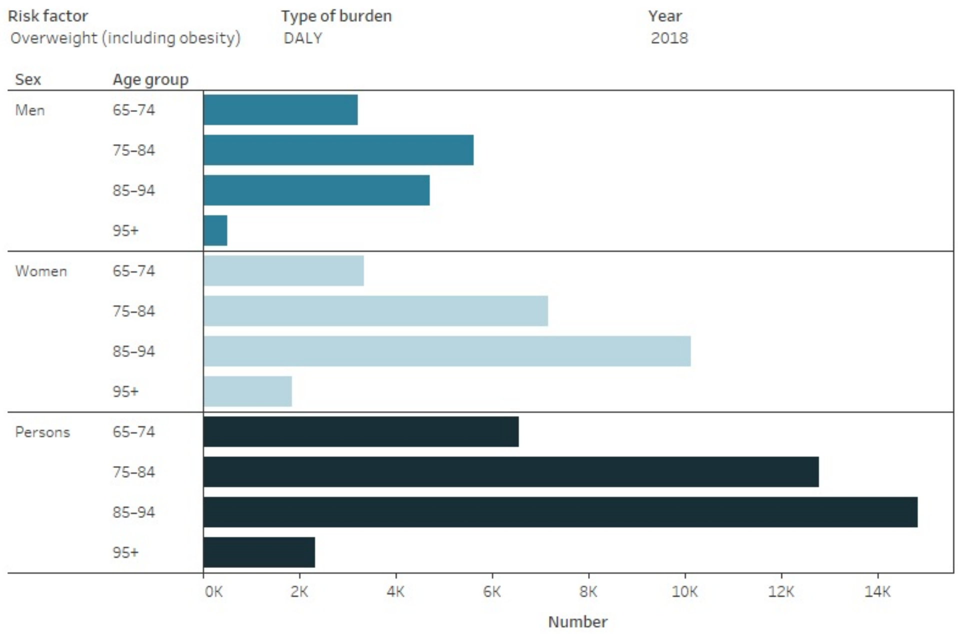
The dementia burden attributable to each risk factor (besides tobacco use) was greatest in people aged 85–94 (Figure 4.6). Dementia burden attributable to tobacco use was greatest in a slightly younger age group (people aged 75–84).

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?

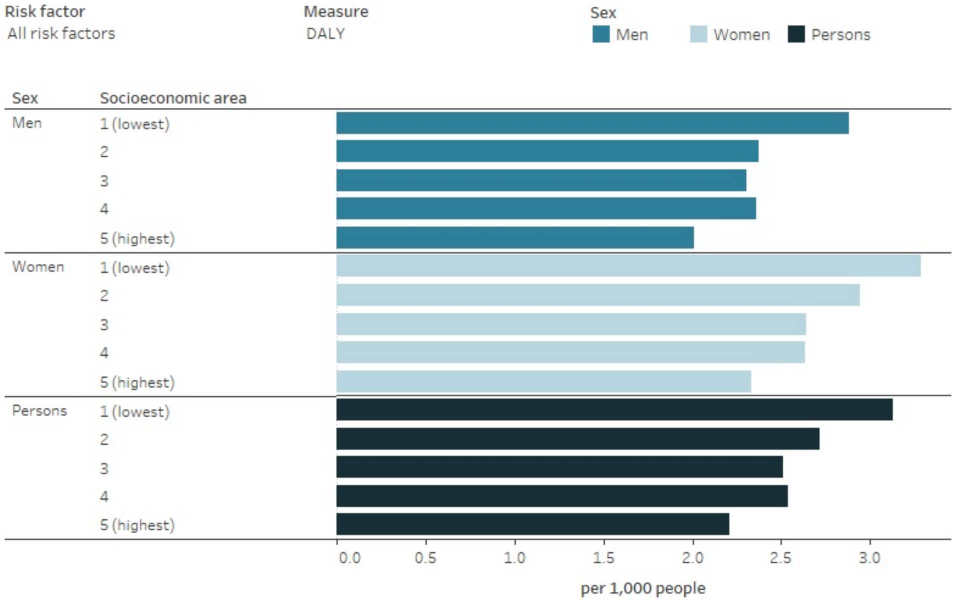
The amount of dementia burden attributable to each risk factor varied by socioeconomic area. Poorer health outcomes are generally observed as greater rates of burden in lower socioeconomic area. This disparity is influenced by a complex and interrelated set of social and economic factors, including reduced access to health services, lower resource availability, lower levels of education and the influence of uptake of risky behaviours (AIHW 2020).

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

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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
- Unmet needs of carers

See Dementia in vulnerable groups for more information on carers and care needs of people with dementia among different population groups, including among Indigenous Australians and people from culturally and linguistically diverse backgrounds.

Refer to the XLS How do care needs differ by place of residence data tables and XLS Carer data tables for the underlying data presented in these pages.

Key statistics

In 2021, it is estimated there are between 134,900 and 337,200 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

47% 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

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Carers and care needs of people with dementia

How do care needs of people with dementia differ by place of residence?

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 *Survey of Disability, Ageing and Carers (SDAC) 2018 and measures of disabilty* section for more information on the SDAC and its limitations for reporting on people with dementia.

Some of the statistics presented here 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. Refer to Aged care and support services used by people with dementia if you are interested in the care needs of people with dementia using aged care services.

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 vulnerable groups (including Indigenous Australians, people from culturally and linguisticall diverse 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 1 or more of the following groups: people with disability; people who are aged 65 or over; and, unpaid carers of people with disability, 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 this 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.

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Co-existing health conditions

People with dementia often have a number of co-existing health conditions, which can increase or complicate their care needs. Here we report on co-existing conditions, as recorded in the SDAC for the year 2018 and compare 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 (e.g. 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.

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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).

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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.

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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.

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

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.

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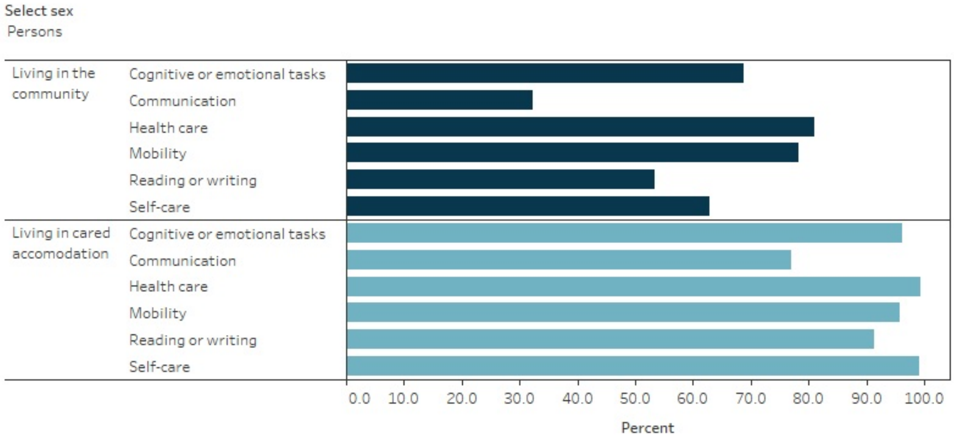
Unsurprisingly, for each activity the proportion of people with dementia who needed assistance was lower for those living in the community than those living in cared accommodation and there was little difference by sex (Figure 5.6). This reflects the greater care needs of people living in cared accommodation,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

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

Visualisation not available for printing

References

Australian Bureau of Statistics (ABS) 2019. Disability, Ageing and Carers, Australia: Summary of Findings, 2018– Explanatory notes. Cat no. 4430.0. ABS: Canberra. Viewed 17 January 2020

Last updated 6/09/2021 v31.0

Australian Government
Australian Institute of
Health and Welfare

Carers and care needs of people with dementia

Carers of people with dementia

Key statistics

In 2021, there were between 134,900 and 337,200 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 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

See Box 6.1 for key carer definitions used in this report.

See Dementia among people from culturally and linguistically diverse backgrounds for information on how carer characteristics differ in people from non-English speaking countries, and Indigenous-specific health and aged care programs and caring roles among Indigenous Australians for information on carers among Indigenous Australians.

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 1 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 1 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 2021, there were between 134,900 and 337,200 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 *Knowledge gaps on carers of people with dementia in Australia* section 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 Indigenous Australians 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 in How do care needs differ by place of residence 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 the number of carers of people with dementia in Australia who live in the community ranges between 134,900 and 337,200 people in 2021. 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 2021. 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.

The maximum estimate was determined by calculating the average number of carers of a person with dementia as reported in the SDAC 2018 and applying this to the number of people with dementia living in the community in 2021 as estimated by AIHW. Using this method the estimated maximum number of informal carers of people with dementia is 2.5 times higher than the minimum estimate derived from the SDAC.

Primary carers of people with dementia

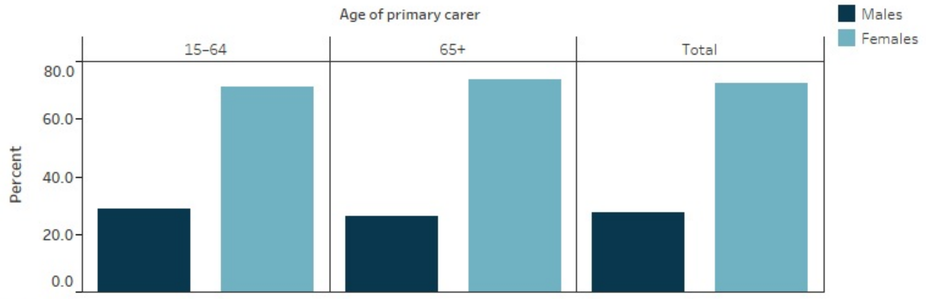
This section presents information from the SDAC on primary carers of people with dementia who live in the same household as the care recipient .

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.

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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.

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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.

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References

ABS (Australian Bureau of Statistics). 2019. Disability, Ageing and Carers, Australia: Summary of Findings, 2018– Explanatory notes. Cat no. 4430.0. Canberra: ABS.

Last updated 23/09/2021 v18.0

Carers and care needs of people with dementia

Impact of the caring role on carers

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

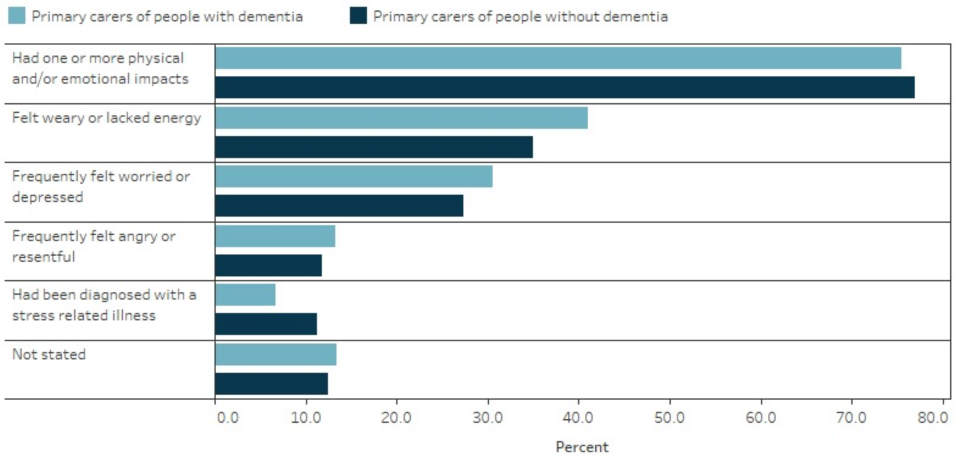
Around 3 in 4 primary carers of people with dementia (75%), as well as primary carers of people without dementia (77%) reported they had 1 or more physical or emotional effects due to the caring role (Figure 6.5).

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 responsibilties 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.

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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.

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Last updated 4/09/2021 v9.0

Carers and care needs of people with dementia

Employment and financial impact on carers

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 the 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).

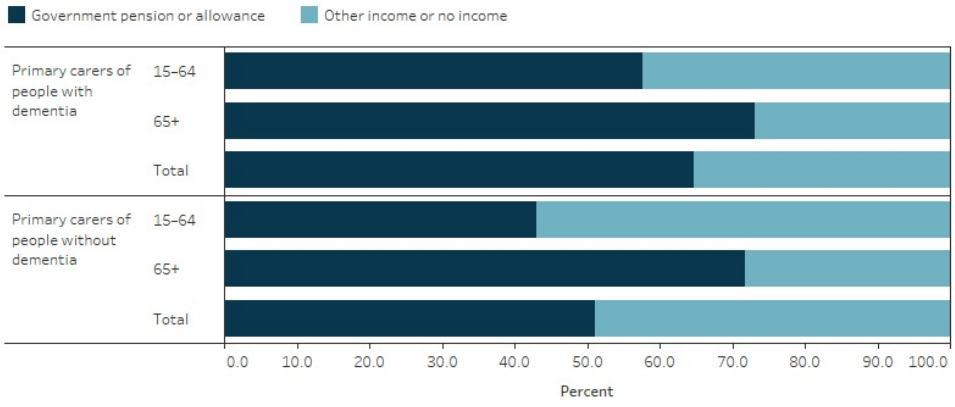
Main source of income

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 2021).

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.

Visualisation not available for printing

References

Services Australia 2021. Carer Payment and/or Carer Allowance Medical Report for a person 16 years or over form (SA332A).

Last updated 4/09/2021 v10.0

Carers and care needs of people with dementia

Carers unmet needs

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.

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Last updated 4/09/2021 v4.0

Health services used by people with dementia

Services provided by health professionals, including general practitioners (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 pages present statistics and information on:

- GP and specialist services overview
- GP consultations, management plans and medications reviews
- Specialist consultations and other health services
- Dementia-specific GP consultations
- Prescriptions for dementia-specific medications
- Antipsychotics and other medications dispensed to people with dementia
- Prescribers of dementia-specific medications
- Hospital care

Refer to the XLS GP and specialist services data tables, XLS Prescriptions data tables and XLS Hospital care data tables for the underlying data presented in these pages.

See Hospital care for Indigenous Australians with dementia for more information on hospital care for Indigenous Australians with dementia.

While some information on dementia-specific consultations is available from GP activity data (see Dementia-specific GP consultations) these data are either out-of-date or do not cover all GPs across Australia. The lack of national GP and other community-based medical specialist data containing dementia diagnosis information is a key data gap for monitoring dementia in Australia (AIHW 2020; Royal Commission 2021). Fortunately, advances with data linkage now enable some examination of GP and other community-based medical specialist services utilised by people with dementia (see GP and specialist services overview). This is possible by linking GP and specialist data with other datasets that have dementia diagnostic information.

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 Australia’s Health 2020 data insights.

Key statistics

49% of MBS services used by people with dementia in 2016-17 were for GP consultations

In 2019–20, there were over 623,000 prescriptions dispensed for dementia-specific medications

There was a 43% increase in scripts dispensed for dementia-specific medications between 2012–13 and 2019-20

In 2018-19 there were 23,200 hospitalisations due to dementia

Last updated 23/09/2021 v8.0

Health services used by people with dementia

GP and specialist services overview

The following pages present data that are currently available on the use of primary and community-based secondary healthcare services by people with dementia through services provided under the Medicare Benefits Schedule (MBS). Data are sourced from linked health and aged care services data in the National Integrated Health Services Information Analysis Asset (NIHSI AA). Expand the *Current data sources for assessing GP and community based specialist healthcare services used by people with dementia in Australia* section for more information on the NIHSI AA. However, as dementia diagnostic information is not available in the MBS, we are unable to distinguish between dementia-specific services and services for the management of other health issues. In addition, as identification of people with dementia depends on their use of other health and aged care services (e.g. through admission to hospital and dementia being recorded in those data), these analyses will not include all people with dementia in Australia.

Refer to the XLS GP and specialist services data tables for the underlying data presented in these pages.

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 Australia's' Health 2020 data insights.

Current data sources for assessing GP and community based specialist healthcare services used by people with dementia in Australia

National Integrated Health Services Information Analysis Asset (NIHSI AA)

The National Integrated Health Services Information Analysis Asset (NIHSI AA) is a newly established enduring linked data asset managed under the custodianship of the AIHW, available for approved projects for analysis by the AIHW and participating jurisdictions.

The first version of this data asset (NIHSI version 0.5) contains linked data from 2010–11 to 2016–17 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 (PBS) and Repatriation Pharmaceutical Benefits Scheme (RPBS) national data
- Medicare Benefits Schedule (MBS) national data
- residential aged care national data
- National Death Index data (contains data up to 31 December 2017).

Bettering Evaluation of Care and Health survey (BEACH)

The Bettering Evaluation of Care and Health survey (BEACH) was an annual survey of around 100,000 patient encounters across 1,000 GPs nationwide, and collected information on reasons for GP encounters, types of prescriptions, referrals, imaging and pathology requests made during the encounter, and associated diagnoses. BEACH ran between April 1998 and April 2016 (The University of Sydney 2017).

NPS MedicineWise General Practice Insights report

The NPS MedicineWise General Practice Insights report includes information on general practice activity in Australia. The most recent report includes data from 569 general practices and over 14.7 million clinical encounters between 1 July 2018 and 30 June 2019.

Who was included in the linked data analysis?

The analysis focused on people aged 30 or over who used an MBS service in 2016–17 and who were alive between July 2016 and December 2017. These people were divided into 2 main groups:

- **People with dementia**: includes people who had a dementia diagnosis recorded in a hospital admission, emergency department presentation, residential aged care record and/or were prescribed dementia specific medication between 2010–11 and 2016–17.
- **People without dementia**: includes people who did not have a record of dementia in a hospital admission, emergency department presentation or residential aged care records, and were not prescribed dementia specific medication between 2010–11 and 2016–17.

Both groups were further sub-divided to examine the different health service usage 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 2016–17.
- **Living in the community**: includes people who were living in the community for all of the year in 2016–17. 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.

Expand the *Key considerations of the analysis and who was included* for factors to consider when interpreting information from this analysis and to the Technical notes for more information on diagnostic codes used to identify dementia in each data set and limitations of this analysis.

Key considerations of the analysis and who was included

There are a number of factors to consider when interpreting the linked data analysis.

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 between July 2016 and December 2017. 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.

As noted above, the analysis is limited to those aged 30 years and over. Despite this restriction, the age distribution of those with dementia is still skewed towards older ages when compared with those without dementia. This should be considered when comparing service use between these 2 groups. The AIHW plans to publish an analysis on the use of health and aged care services by people with younger-onset dementia, in a (as of publication) forthcoming report.

The ‘people with dementia’ group is further restricted due to limitations in the data. This group:

- excludes people with dementia who did not use any health and/or aged care services or services that were not included in the linked data
- excludes people with dementia who used services in the linked data but dementia was not recorded as a condition impacting care
- is more likely to include people who used residential aged care compared with those living in the community, as residential aged care data is a key source for identifying dementia in the analysis

These data limitations mean that the ’people with dementia‘ group likely includes a larger proportion of those with a more severe form of dementia, and a smaller proportion of those who live in the community.

The analysis does not examine MBS service usage by the length of time spent living in permanent residential aged care, if they did not spend the entire year in care. This is known to impact service usage, as a recent study found that people who live in permanent residential aged care for less than 6 months (including those who died in care) had a monthly rate of GP visits which was 2–3 times as high as people in care for 6 months or longer (AIHW 2020). Refer to the AIHW report Interfaces between the aged care and health systems in Australia—GP use by people living in permanent residential aged care 2012–13 to 2016–17 for more information on how the length of time in residential aged care impacts service usage.

Further work is needed to accurately portray the use of GP and specialist services by people with dementia in Australia.

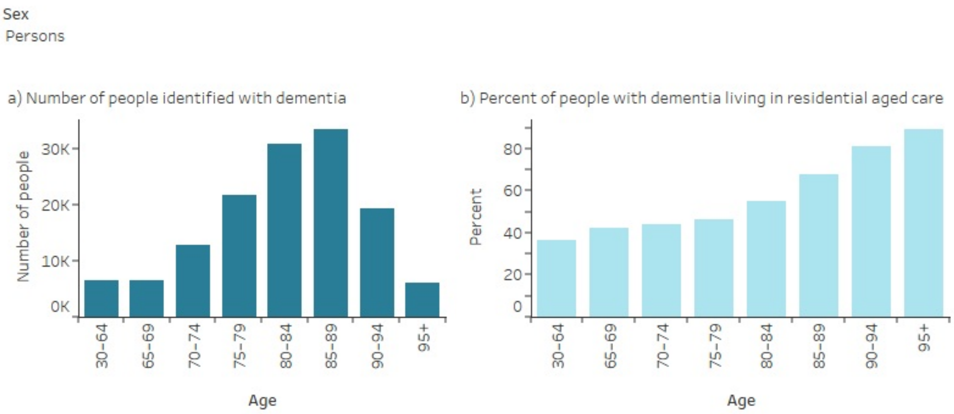
Profile of people with dementia who used an MBS service in 2016-17

In 2016–17, there were over 137,000 Australians who used at least 1 MBS service and were identified as having dementia in the linked data (referred to as ‘people with dementia’). In the same year there were 13.3 million Australians who were not identified as having dementia in the linked data.

Figure 7.1 shows the age profile of people with dementia who used at least 1 MBS service in 2016–17, and the percentage who were living in permanent residential aged care at any point during the year. As the risk of dementia increases with age, it is not surprising the number of people with dementia increased steeply with age and peaked at ages 85–89 (at 33,600 people). The proportion of people with dementia who lived in residential aged care also increased with age; from less than half (44%) of people with dementia aged under 80 to 89% of people with dementia aged 95 and over.

Figure 7.1: People with dementia in 2016-17 identified in the linked data, by age and sex: (a) number of people and (b) percentage who were living in residential aged care

Figure 7.1 is two bar graphs, the first graph shows the number of people with dementia in 2016–17 identified in the linked data, by age and sex. The second graph shows the percentage of people with dementia in the linked data who were living in residential aged care for all or part of 2016–17. The number of people with dementia and the proportion who lived in residential aged care increased with age. The number of people with dementia was highest between ages 85 and 89. The proportion who lived in residential aged care also increased from 37% of people with dementia aged 30–64 to 89% of people with dementia aged 95 and over.



Note: 'People living in residential aged care' includes people who used permanent residential aged care for all, or part of 2016–17.
Source: AIHW analyis of National Integrated Health Services Analysis Asset version 0.5.
http://www.aihw.gov.au

Overall service usage by people with dementia by their place of residence

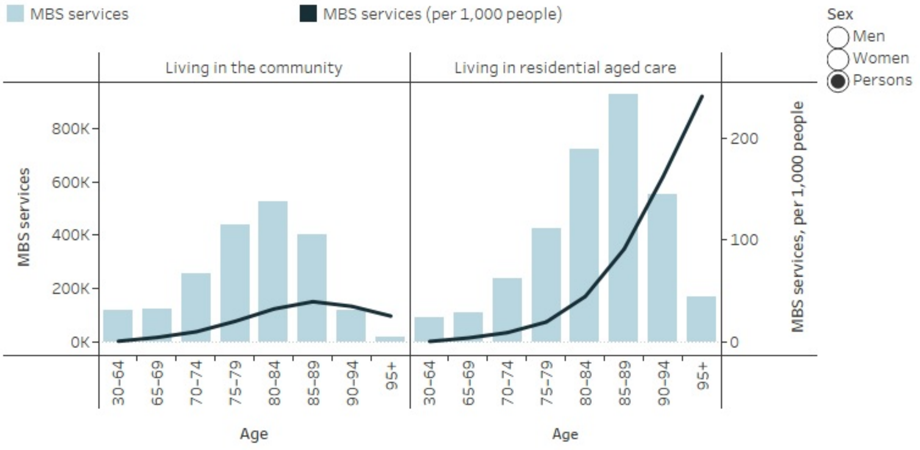
Service usage differed for those who were living in permanent residential aged care compared with those living in the community, but only at older ages (Figure 7.2):

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

The rate of services used by people with dementia living in residential aged care increased steeply with age—from 45 services per 1,000 people among those ages 80–84 to 241 services per 1,000 people among those aged 95 or over. This is likely due to the number of co-existing health conditions increasing and health needs becoming more complex as people age.

Figure 7.2: MBS services used by people with dementia in 2016-17, by sex, age and place of residence: number and rate (services per 1,000 people)

Figure 7.2 is two bar and line graphs showing the number and rate of MBS services used by people with dementia in 2016–17 and by sex and age; the first graph shows this among people with dementia living in the community and the second graph shows this among people with dementia living in residential aged care for all or part of 2016–17. Among people with dementia aged under 80, there was little difference in number of services used by people with dementia by place of residence. From age 80 onwards, the number of services used by people with dementia living in residential aged care was greater than among those living in the community. The rate of services used by people with dementia living in residential aged care increased steeply with age, from 45 services per 1,000 people among those aged 80–84 to 241 services per 1,000 people among those aged 95 or over.



Note: 'People living in residential aged care' includes people who used permanent residential aged care for all, or part of 2016–17.
Source: AIHW analyis of National Integrated Health Services Analysis Asset version 0.5.
http://www.aihw.gov.au

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

Of the MBS services used by people with dementia in 2016–17 (Figure 7.3):

- 49% were for GP consultations—GP consultations accounted for a greater proportion of MBS services used by people living in residential aged care (57%) than for those living in the community (36%)
- 25% were for pathology tests—Pathology tests accounted for a slightly smaller proportion of MBS services used by people living in residential aged care (22%) than they did for those living in the community (28%)

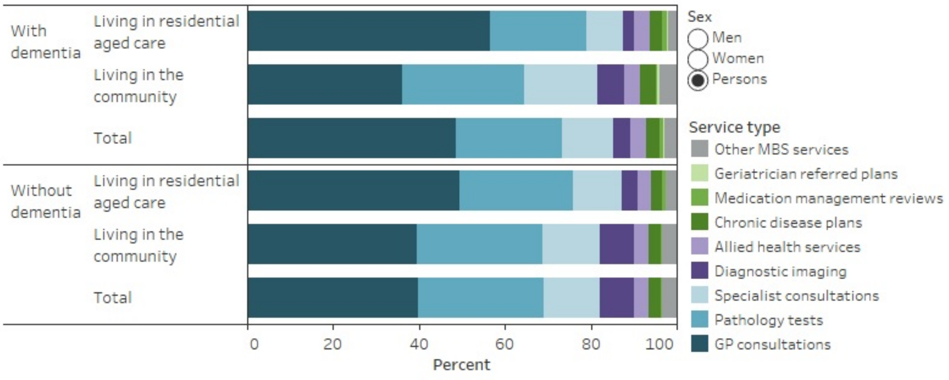
- 12% were for consultations with medical specialists—Consultations with medical specialists accounted for a considerably smaller proportion of MBS services used by people living in residential aged care (8.4%) than they did for those living in the community (17%)
- 4.2% were for diagnostic imaging—Diagnostic imaging accounted for a smaller proportion of MBS services used by people living in residential aged care (2.8%) than they did for those living in the community (6.4%).

When comparing the distribution of services used by people with dementia compared to people without dementia, differences were evident by place of residence. Among people living in residential aged care, GP consultations accounted for a greater proportion of services used by people with dementia (57%) than people without dementia (49%). All other services accounted for a similar or slightly smaller proportion of services used by people with dementia than people without dementia.

Among people living in the community, the distribution of services was more similar for both people with dementia and people without dementia. However, notably, GP consultations accounted for a slightly smaller proportion of services used by people with dementia (36%) than they did for people without dementia (40%) and specialist consultations accounted for a slightly greater proportion of services used by people with dementia (17%) than they did for people without dementia (13%).

Figure 7.3: MBS services provided to people with dementia and people without dementia in 2016–17: percentage by sex and place of residence

Figure 7.3 is a stacked bar graph showing the percentage of MBS services by service type used by people with dementia and people without dementia in 2016–17 for men, women and persons by place of residence. Overall, almost half (49%) of services for people with dementia were for GP consultations, and these accounted for a greater proportion of services used by people living in residential aged care (57%) than for those living in the community (36%). Overall, one-quarter of services (25%) for people with dementia were for pathology tests and 12% were consultations with medical specialists. Consultations with medical specialists accounted for a considerably smaller proportion of MBS services used by people living in residential aged care (8.4%) than for those living in the community (17%).



Notes:
1. 'People living in residential aged care' includes people who used permanent residential aged care for all, or part of 2016–17.
2. GP consultations and specialist consultations excudes geriatrician referred plans, medication management reviews and chronic disease plans.

Source: AIHW analyis of National Integrated Health Services Analysis Asset version 0.5.
http://www.aihw.gov.au

There were slight differences in service patterns between men and women with dementia; GP consultations accounted for a slightly greater proportion of services used by women (51% of MBS services) than men (46%), whereas specialist consultations accounted for a slightly greater proportion of services used by men (14%) than women (11%).

This difference was not seen among people without dementia, suggesting it may specifically be related to differences in the health status and service needs between men and women with dementia. Refer to How do care needs of people with dementia differ by place of residence? for information on the health status of men and women with dementia, including co-morbidities.

References

The University of Sydney 2017. Bettering the Evaluation and Care of Health (BEACH). Viewed 3 February 2021.

Last updated 21/09/2021 v23.0

Health services used by people with dementia

GP consultations, management plans and medication reviews

GP-specific consultations

About half (49%) of all MBS services used by people with dementia were for GP consultations, with an average of 20 GP consultations used by each person with dementia in 2016–17 (Table S7.4). This includes dementia-specific consultations, as well as consultations to manage other health issues among people with dementia.

Irrespective of dementia status, people who were living in residential aged care had more consultations on average than those who were living in the community, likely due to people in residential aged care having more complex healthcare needs (Figure 7.4).

Among people who were living in residential aged care, the number of consultations was similar for men and women:

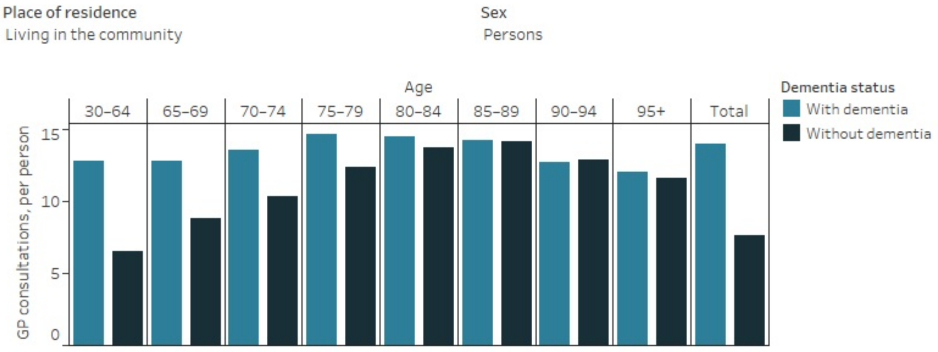
- women with dementia had 23 consultations on average compared with 25 consultations for men with dementia. Men and women without dementia both had 25 consultations on average.
- the average number of consultations decreased with increasing age for men and women with and without dementia.

Among people who were living in the community:

- men and women with dementia had on average 14 consultations each— this was more than men and women without dementia (7 and 8 consultations, respectively)
- the average number of consultations increased with age, up to age 75–79 for people with dementia and age 85–89 for people without dementia, and then decreased. The increase was smaller among people with dementia (from 13 consultations in people aged 30–64 to 15 consultations in people aged 75–79) than people without dementia (from 7 consultations in people aged 30–64 to 14 consultations in people aged 85–89).

Figure 7.4: Average number of GP consultations for people with and without dementia, by sex, age and place of residence in 2016–17

Figure 7.4 is a bar graph showing the average number of GP consultations for people with and people without dementia in 2016–17 by sex, age and place of residence. Among people who were living in residential aged care, the number of consultations was similar for men and women with and without dementia. For people with dementia, there was an average of 25 consultations for men and 23 for women, compared with an average of 25 consultations each for men and women without dementia. The average number of consultations decreased with increasing age for men and women with and without dementia. In contrast, among those living in the community, men and women with dementia had a higher average number of GP consultations each (both 14) compared with men (7 consultations) and women (8 consultations) without dementia. For people living in the community, the average number of consultations increased with age, up to age 75-79 for people with dementia and age 85–89 for people without dementia but then declined.



Note: 'People living in residential aged care' includes people who used permanent residential aged care for all, or part of 2016–17.
Source: AIHW analyis of National Integrated Health Services Analysis Asset version 0.5.
http://www.aihw.gov.au

Box 7.1: 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 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 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.

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.

In 2016–17, on average there were substantially more geriatrician referred plans (17 per 100 people) and chronic disease plans (131 per 100 people) for people with dementia than people without dementia (1.4 and 55 per 100 people, respectively) (Figure 7.5).

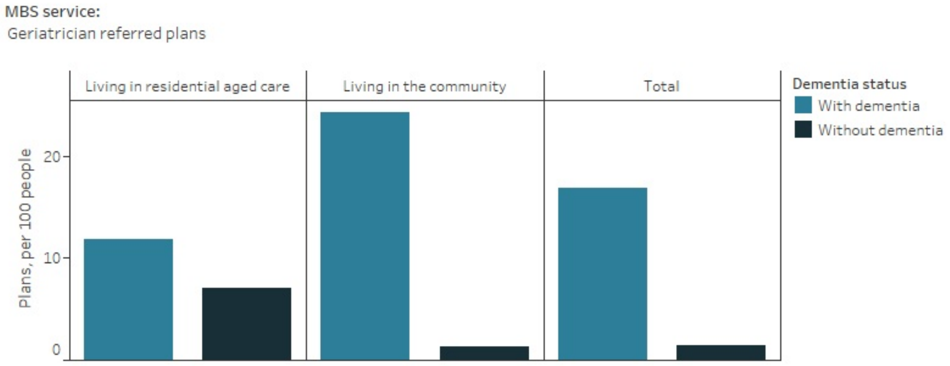
These differences between people with and without dementia were mainly due to differences among people living in the community. On average there were:

- 18 times as many geriatrician referred plans for people with dementia as there were for people without dementia living in the community
- 2.7 times as many chronic disease plans for people with dementia as there were for people without dementia living in the community.

By comparison, there were 1.7 times as many geriatrician referred plans for people with dementia as there were for people without dementia living in residential aged care. However, the average number of chronic disease plans was slightly higher for people without dementia than people with dementia living in residential aged care.

Figure 7.5: Geriatrician referred plans and chronic disease plans for people with and without dementia (plans per 100 people), by place of residence in 2016–17

Figure 7.5 is a bar graph showing the rate of geriatrician referred plans and chronic disease plans for people with and people without dementia (plans per 100 people) in 2016–17 by place of residence. There were substantially more geriatrician referred plans (17 per 100 people) and chronic disease plans (131 per 100 people) for people with dementia than people without dementia (1.4 geriatrician referred plans and 55 chronic disease plans per 100 people). These differences between people with and without dementia were mainly due to differences between people with and without dementia living in the community.



Note: 'People living in residential aged care' includes people who used permanent residential aged care for all, or part of 2016–17.
Source: AIHW analyis of National Integrated Health Services Analysis Asset version 0.5.
http://www.aihw.gov.au

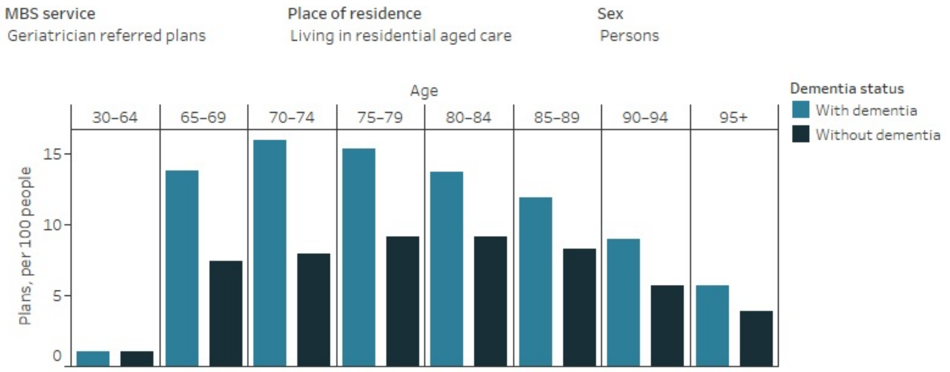
In addition to place of residence, age was a key driver in differences in the average number of geriatrician referred plans and chronic disease plans for people with dementia compared to people without dementia (Figure 7.6). The average number of geriatrician referred plans and chronic disease plans was higher at younger ages among people with dementia (highest among those aged 70–74) than among people without dementia (highest among those aged 85–89).

Geriatrician referred plans are largely provided to people aged 65 or over, however there were plans provided to people with and without dementia aged under 65. On average, people with younger onset dementia were 2.3 times more likely to have had a geriatrician referred plan than people without dementia aged under 65, suggesting these services were specific to managing their dementia. On the other hand, the average number of geriatrician referred plans was similar among people with younger onset dementia and people without dementia aged under 65 who were living in residential aged care (both had on average 1 geriatrician referred plan per 100 people).

This suggests that geriatrician referred plans are likely used in the early stages of diagnosis and management of dementia, where people with younger onset dementia are more likely to be living in the community.

Figure 7.6: Geriatrician referred plans and chronic disease plans for people with and without dementia (plans per 100 people), by age, sex and place of residence in 2016–17

Figure 7.6 is a bar graph showing the rate of geriatrician referred plans and chronic disease plans for people dementia with and people without dementia (plans per 100 people) in 2016–17 by sex, age and place of residence. The rate of chronic disease plans was similar across all ages for people with and without dementia living in residential aged care. However, among those living in the community and in younger age groups, rates of chronic disease plans were higher for people with dementia compared with people without dementia. A higher rate of people with dementia received geriatrician referred plans, compared to those without dementia. This difference was greater for younger ages and for those living in the community.



Notes:
1. 'People living in residential aged care' includes people who used permanent residential aged care for all, or part of 2016–17.
2. Geriatrician referred plans per 100 people are not published for men and women with dementia aged 30–64 living in residential aged care.

Source: AIHW analyis of National Integrated Health Services Analysis Asset version 0.5.
http://www.aihw.gov.au

Medication Management Reviews

As people with multiple chronic health conditions may be prescribed a number of medications to treat these conditions, it is important that the number and type of medications prescribed is reviewed regularly by health professionals to prevent and monitor medicine interactions and adverse side effects. Medication management reviews are undertaken by GPs in collaboration with community pharmacists and specialists as well as in discussion with the patient and their carer.

In 2016–17, for every 100 people with dementia there was an average of:

- 26 medication management reviews—this was 7 times higher than the average number of reviews for people without dementia (3.7 reviews)
  - this was driven by differences among people living in the community—people with dementia living in the community had 3 times as many reviews (9.9 reviews) as people without dementia living in the community (3.5 reviews).
  - whereas this was similar for people with dementia (37 reviews) and people without dementia (38 reviews) living in residential aged care
- 25 reviews for men and 27 reviews for women with dementia—by comparison this was 3.6 reviews for men and 3.8 reviews for women without dementia
- 19 reviews for people with younger onset dementia (aged under 65) and this increased to 28–29 reviews among people aged 85 and over (Figure 7.7).

The vast difference in the average number of medication management reviews between people with and without dementia living in the community was seen in both men and women and across each age group.

Figure 7.7: Medication management reviews for people with and without dementia (reviews per 100 people) by age, sex and place of residence in 2016–17

Figure 7.7 is a bar graph showing the rate of medication management reviews provided to people with dementia and people without dementia (reviews per 100 people) in 2016–17 by sex, age and place of residence. Overall, the rate of medication management reviews was substantially higher among people with dementia (26 reviews per 100) than among people without dementia (4 reviews per 100). Different rates of medication management reviews between people with and without dementia living in the community explains the majority of this difference, , as the rate of reviews was similar across age groups for people with and without dementia living in residential aged care.

Visualisation not available for printing

Last updated 6/09/2021 v13.0

Health services used by people with dementia

Specialist consultations and other health services

Services provided by other medical specialists

Around 12% of all MBS services used by people with dementia were specific consultations with, or services provided by medical specialists (other than GPs). On average, a person with dementia had 5 specialist services in 2016–17.

Of the specialist services provided to people with dementia:

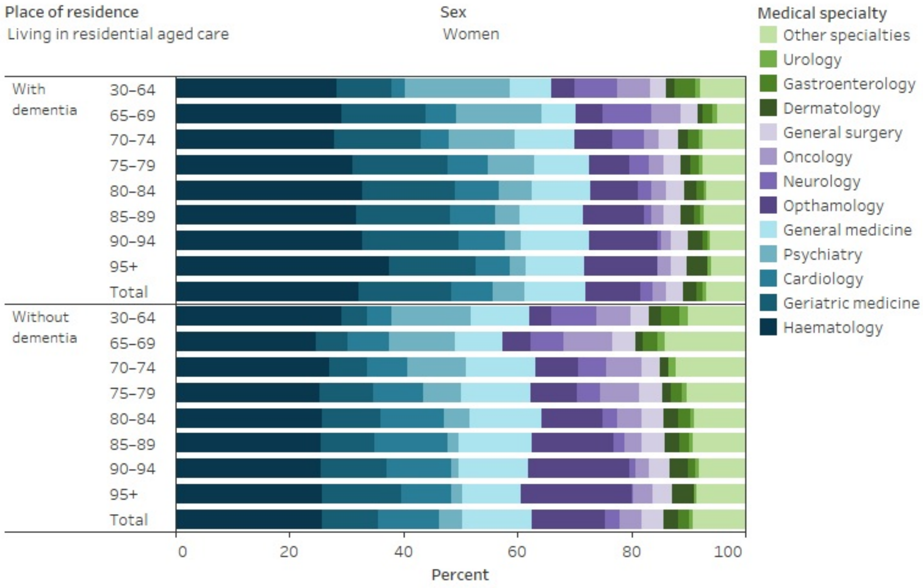
- 1 in 5 (22%) were provided by haematologists (who treat blood-related conditions), and this was slightly lower for people without dementia (19%)
- 1 in 7 (15%) were provided by geriatricians (who treat conditions that affect older people, including dementia), and this was substantially lower for people without dementia (1.1%)
- 1 in 10 (10%) were provided by ophthalmologists (who treat eye-related conditions), and this was similar for people without dementia (11%) (Table S7.7).

Services provided by cardiologists (who treat heart diseases) and oncologists (who treat cancer) contributed to a greater proportion of specialist services for people without dementia (14% and 9.3%, respectively) than with dementia (11% and 3.4%, respectively).

The type of specialist services used by people with and without dementia varied extensively by age, and whether they lived in residential aged care (Figure 7.8). Services provided by psychiatrists and neurologists were most frequent among people with younger onset dementia (aged under 65), irrespective of where they lived. Services provided by specialists who treat age-related conditions including geriatricians and ophthalmologists increased with age among people with and without dementia.

Figure 7.8: Specialist services used by people with and without dementia: percentage by place of residence, sex and age in 2016–17

Figure 7.8 is a stacked bar graph showing the percentage of specialist services (as described by medical specialty) used by people with and without dementia in 2016–17 by sex, age and place of residence. Among people with dementia living in the community, 30% of specialist services were provided by haematologists, 16% through geriatricians and 11% through general practitioners. Among people with dementia living in the community 15% of services were provided through haematologists, 14% through cardiologists and 14% through geriatricians. Overall, 22% of specialist services provided to people with dementia were provided by haematologists, 15% were provided by geriatricians and 10% were provided by ophthalmologists. Among people without dementia, only 1.1% of specialist services were provided by geriatricians. Services provided by psychiatrists and neurologists were most frequent among people with younger onset dementia (aged under 65), irrespective of where they lived. Services provided by specialists who treat age-related conditions including geriatricians and ophthalmologists increased with age among people with and without dementia.



Notes:
1. 'People living in residential aged care' includes people who used permanent residential aged care for all, or part of 2016–17.
2. Due to low counts, proportions for neurology have not been published for those aged 95+ with dementia and proportions for gastroenterology have not been published for males and famles aged 70–74 without dementia. In these cases these specialities have been grouped into 'Other specialties'.

Source: AIHW analyis of National Integrated Health Services Analysis Asset version 0.5.
http://www.aihw.gov.au

Allied health, diagnostic imaging and other services

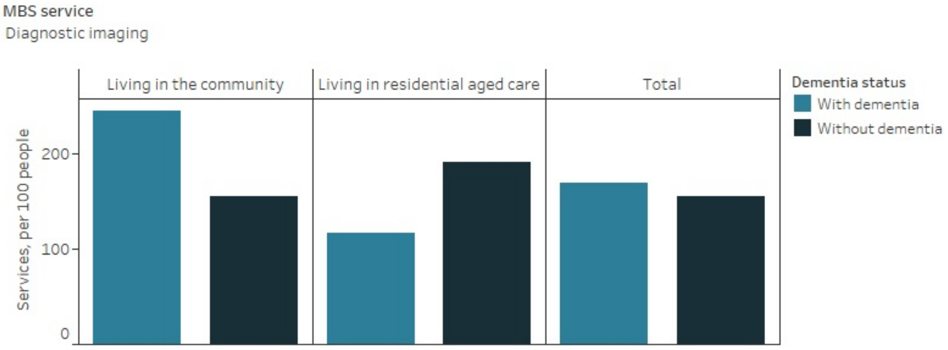
Besides consultations with GPs and other medical specialists, there are a number of other services claimed under the MBS that are specific to diagnosing health conditions (such as pathology tests and diagnostic imaging) as well as treating or managing health conditions (such as services provided by allied health professionals). However, it is not possible to determine whether or not these services are provided for the diagnosis, treatment or management of dementia specifically—only that they are services provided to someone with dementia.

In 2016–17, for every 100 people with dementia there was an average of:

- 999 pathology services—this was 1.8 times as many as used by people without dementia (567 services)
- 146 allied health services—this was 2.1 times as many as used by people without dementia (69 services), and the greatest difference was in the younger age groups. Note this only includes allied health services that are subsidised under the MBS
- 169 diagnostic imaging services—this was similar to the average number used by people without dementia (155 services) (Figure 7.9).

Figure 7.9: Allied health, pathology, diagnostic imaging and other MBS services used by people with and without dementia (services per 100 people) by place of residence in 2016–17

Figure 7.9 is a bar graph showing the rate of allied health, pathology, diagnostic imaging and other MBS services for people with and people without dementia (services per 100 people) in 2016–17 by place of residence. Overall, the rates of pathology services and allied health services used by people with dementia were considerably higher than the rates of these services used by people without dementia, with much of the differences in these rates due to higher rates among people with dementia living in the community. While the overall rate of diagnostic imaging services for people with dementia was similar to the rate for people without dementia, people without dementia living in residential aged care had higher rates of diagnostic imaging services than people with dementia, but this pattern was reversed for those living in the community.



Note: 'People living in residential aged care' includes people who used permanent residential aged care for all, or part of 2016–17.
Source: AIHW analyis of National Integrated Health Services Analysis Asset version 0.5.
http://www.aihw.gov.au

There was little difference in the rate of people who used these services by sex but there were vast differences by age and whether they lived in residential aged care (Figure 7.10).

Among people living in the community the number of services used per 100 people was:

- higher for people with dementia aged under 80 than those without dementia for each group of services, with the greatest differences between those aged under 65. This suggests there are much higher health service needs for people with younger onset dementia to diagnose and manage their dementia than for people of similar age without dementia
- similar or lower for people with dementia aged 80 or over than those without dementia for most service groups.

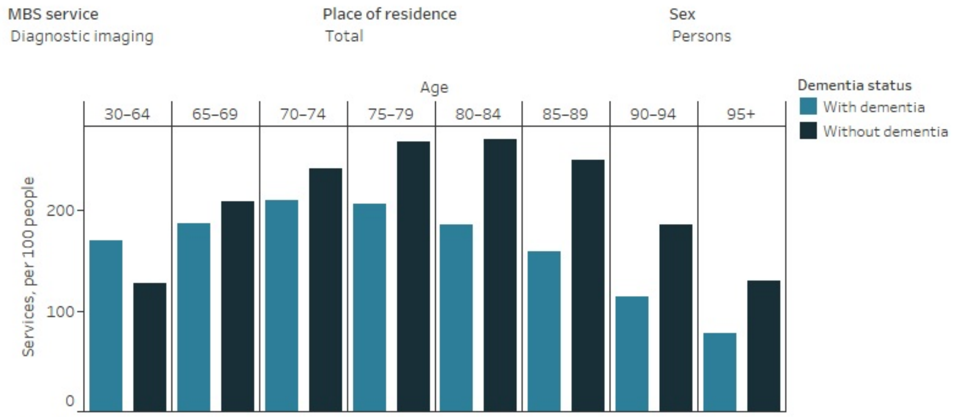
Among people living in residential aged care, the number of services used per 100 people was:

- lower for people with dementia than those without dementia across all age groups for each group of services, with the greatest difference seen for pathology tests and diagnostic imaging services.

The average number of diagnostic imaging and pathology services may be higher among people with dementia who are living in the community and are currently being assessed for dementia but who have not received a formal diagnosis. Unfortunately, this group of people could not be identified in the latest year of data using the available linked data. The AIHW is currently investigating if patterns of MBS service usage can be used to predict dementia using MBS data alone and a report on this should be available on the AIHW website in late 2021.

Figure 7.10: Allied health, pathology, diagnostic imaging and other MBS services used by people with and without dementia (per 100 people) by sex, age, and place of residence in 2016–17

Figure 7.10 is a bar graph showing the rate of allied health, pathology, diagnostic imaging and other MBS services for people with and people without dementia (services per 100 people) in 2016–17 by sex, age and place of residence. Among people aged under 80 living in the community, the rate of services used was generally higher for people with dementia than those without dementia. For people aged 80 and over living in the community, rates were typically similar or lower among those with dementia aged 80 or compared with those without dementia for most service groups. Among people living in residential aged care, the rate of services used for each group of services was generally lower among people with dementia compared to those without dementia across all age groups.



Note: 'People living in residential aged care' includes people who used permanent residential aged care for all, or part of 2016–17.
Source: AIHW analyis of National Integrated Health Services Analysis Asset version 0.5.
http://www.aihw.gov.au

Health services used by people with dementia

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) was an annual survey of around 100,000 patient encounters across 1,000 GPs nationwide. BEACH collected information on reasons for GP encounters, types of prescriptions, referrals, imaging and pathology requests made during the encounter, and associated diagnoses. BEACH ran between April 1998 and April 2016 (The University of Sydney 2017):
  - between 2006–07 and 2015–16, the rate of GP encounters for dementia remained stable, at around 0.5 per 100 encounters
  - dementia was considered a new problem to manage in 11% of patients who had a GP encounter for dementia in 2015–16 (which includes the first presentation of a recurrence of a previously resolved problem but not the presentation of a problem first assessed by another provider) (Britt et al. 2016).
- NPS MedicineWise General Practice Insights report includes information on general practice activity in Australia. At the time of writing, the most recent report includes data from 569 general practices and over 14.7 million clinical encounters between 1 July 2018 and 30 June 2019, comprising 9% of GPs and 13% of Australian patients who saw a GP at least once in 2018–19. According to the Insights report, in 2018–19:
  - 0.6% of all patients and 3.4% of patients aged 65 or over had a dementia diagnosis
  - dementia was evident in 6.8% of patients aged 80–89 and 12.6% of patients aged 90 and over—this rate is much lower than the estimated rate of dementia in Australians aged 80–89 (15.6%) and aged 90 and over (39.9%). Refer to Prevalence of dementia for more information
  - the rate of dementia was similar among men and women, except for patients aged 80 and over, where it was more common among women than men
  - on average, patients with dementia had 15 clinical encounters in 2018–19, accounting for 1.6 per 100 GP clinical encounters—higher than what was reported from BEACH in 2015–16 (0.5 per 100 encounters) (NPS MedicineWise 2020).

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Health services used by people with dementia

Prescriptions for dementia-specific medications

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.

Donepezil, Galantamine and Rivastigmine are approved in Australia for the treatment of mild to moderate Alzheimer's disease (Drug Utilisation Sub-Committee 2016). They are acetylcholinesterase inhibitors and work by blocking the actions of the enzyme acetylcholinesterase, which destroys acetylcholine—a major neurotransmitter for memory. The use of these medicines may lead to increased communication between nerve cells and slow dementia progression (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 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).

The following pages focus 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.

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

Over 623,300 prescriptions were dispensed for dementia-specific medications in 2019–20

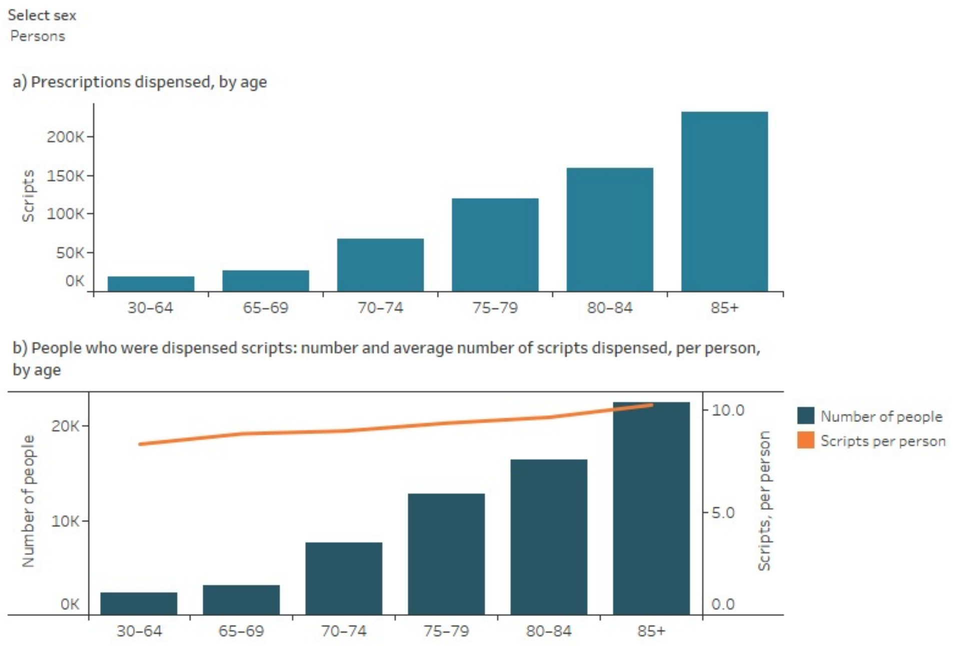
In 2019–20, there were over 623,300 prescriptions dispensed for dementia-specific medications to just under 64,600 Australians with dementia aged 30 and over (Figure 8.1). This is equivalent to 9.7 scripts per person who was dispensed a script for a dementia-specific medication in 2019–20. Each script is usually for a month's supply of medicine.

Among those who were dispensed scripts for dementia-specific medications in 2019–20:

- 42% were men (27,400 men) and 58% were women (37,100 women)
- 1 in 3 people were aged 85 or over
- women were dispensed a greater number of scripts and were about the same age (361,600 scripts and average age of 81) as men (261,200 scripts and average age of 80)
- 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 8.3 scripts per person among those aged under 65 to 10.3 scripts per person among those aged 85 and over.

Figure 8.1: Dementia-specific medications by age and sex in 2019–20: (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 2019–20. 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.



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 Pharmaceutical Benefits Scheme database
http://www.aihw.gov.au

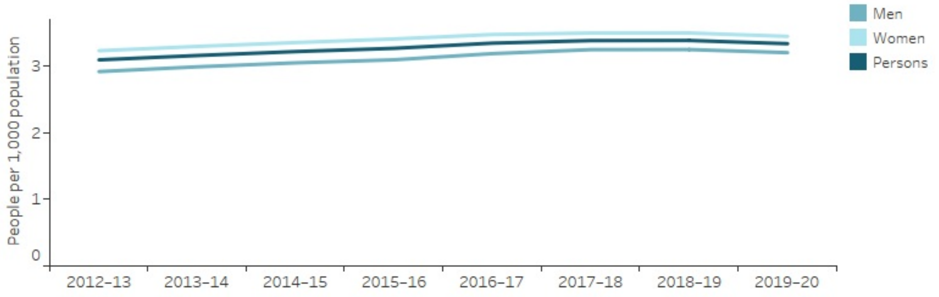
Trends in prescriptions for dementia-specific medications dispensed over time

There was a 43% increase in the number of scripts dispensed for dementia-specific medications to Australians aged 30 and over between 2012–13 and 2019–20. There was a greater increase in the number of scripts dispensed to men (51%) than women (37%) (Table S8.2).

When population growth and ageing are accounted for, the rate of people who were dispensed scripts for dementia-specific medications also increased—from 3.1 people per 1,000 population in 2012–13 to 3.3 people in 2019–20 (Figure 8.2). This increase was seen in both men (from 2.9 people per 1,000 population in 2012–13 to 3.2 people in 2019–20) and women (from 3.2 people per 1,000 population in 2012–13 to 3.4 people in 2019–20), and the increase was at a similar rate.

Figure 8.2: People who were dispensed scripts for dementia-specific medications: age-standardised rate by sex between 2012-13 and 2019-20

Figure 8.2 is a line graph showing the age-standardised rate of people who were dispensed scripts for dementia-specific medications by sex between 2012–13 and 2019–20. The rate of people who were dispensed scripts for dementia-specific medications increased slightly from 3.1 people per 1,000 population in 2012–13 to 3.3 people in 2019–20. 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 were age-standardised to the 2001 Australian Standard Population and are expressed as per 1,000 population for people aged 30 and over.
Source: AIHW analysis of Pharmaceutical Benefits Scheme database
http://www.aihw.gov.au

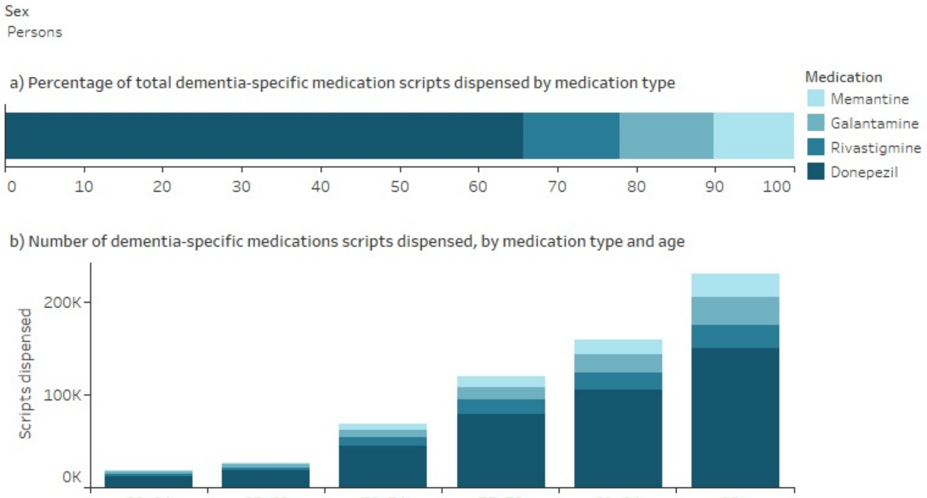
Donepezil was the most commonly dispensed dementia-specific medication

Donepezil was the most commonly dispensed dementia-specific medication in 2019–20, accounting for 409,500 prescriptions or 66% of all scripts dispensed for dementia-specific medications (Figure 8.3). This was followed by Rivastigmine (76,100 scripts; 12%) and Galantamine (74,500 scripts; 12%). Memantine was the least commonly dispensed dementia-specific medication, accounting for 10% of all scripts dispensed for dementia-specific medications (63,300 scripts).

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, Galantamine was the second-most commonly dispensed medication.

Figure 8.3: Dementia-specific medications, by medication type and sex in 2019-20: (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 2019–20. 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 Pharmaceutical Benefits Scheme database
http://www.aihw.gov.au

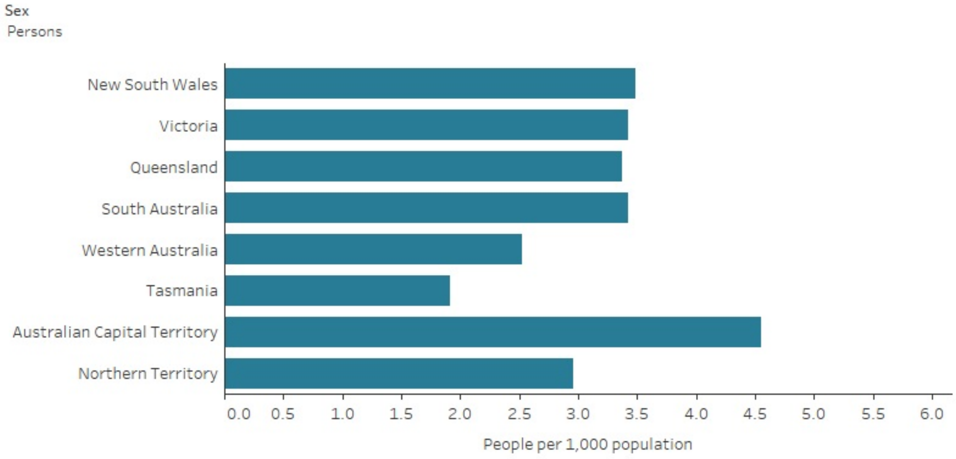
Differences by state and territories

After accounting for population differences, the number of people who were dispensed scripts for dementia-specific medications per 1,000 population varied by state and territory in 2019–20, but was consistently higher among women than men in each state and territory.

The rates of men and women who were dispensed scripts for dementia-specific medications were lowest in Tasmania (1.8 scripts and 2.0 scripts per 1,000 population, respectively). The highest rates among men and women were in the Australian Capital Territory (4.5 per 1,000 population for both men and women), followed by New South Wales for men (3.4 per 1,000 population) and Victoria and South Australia for women (3.6 per 1,000 population, each) (Figure 8.4).

Figure 8.4: People who were dispensed scripts for dementia-specific medications in 2019–20: age-standardised rate by sex and state/territory

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



Note: Rates were age-standardised to the 2001 Australian Standard Population and are expressed as per 1,000 population for people aged 30 and over.
Source: AIHW analysis of Pharmaceutical Benefits Scheme database
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 2019–20, 1 in 4 people (24% or over 15,000 people) who were dispensed scripts for dementia-specific medications were dispensed these medications for the first time. The proportion who were dispensed scripts for dementia-specific medications for the first time varied by age: 1 in 3 people (32%) aged under 65 were dispensed this for the first time (Figure 8.5a). This decreased to almost 1 in 5 people (19%)

among those aged 85 and over.

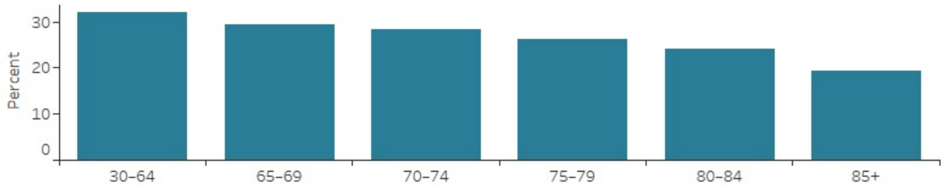
Among those who were dispensed scripts for dementia-specific medications for the first time, the most commonly dispensed type of medication received throughout the year was Donepezil (72%), followed by Rivastigmine (15%), Galantamine (7.9%) and Memantine (10%) (Figure 8.5b).

Figure 8.5: People who were dispensed dementia-specific medications for the first time in 2019–20 by sex: (a) percentage by age, and (b) number by medication type

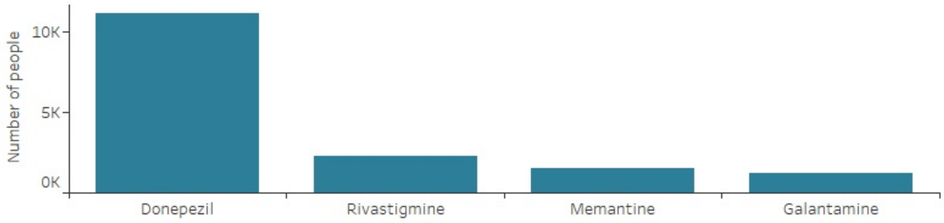
Figure 8.5 shows two bar graphs on people who were dispensed prescriptions for dementia-specific medications for the first time by sex in 2019–20. The first graph shows the number of people who were dispensed scripts for the first time by age and the second graph shows the number of people who were dispensed scripts for dementia-specific medications for the first time by the four types of dementia-specific medications. In total 16,139 people were dispensed scripts for dementia-specific medications for the first time in 2019–20. The proportion who were dispensed scripts for dementia-specific medications for the first time decreased with increasing age. Among those who were dispensed scripts for the first time, the most commonly dispensed medication was Donepezil.

Sex
Persons

a) People who were dispensed scripts for dementia-specific medications for the first time: percent by age



b) Number of people who were dispensed scripts for dementia-specific medications for the first time, by medication type



Note: Figure (a) refers to the percentage of people who were dispensed scripts for dementia-specific medication for the first time out of all people in the population group who were dispensed scripts for dementia-specific medication that year.
Source: AIHW analysis of Pharmaceutical Benefits Scheme database
http://www.aihw.gov.au

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Health services used by people with dementia

Antipsychotics and other medications dispensed to people with dementia

What other medications were dispensed to people who were dispensed scripts for dementia-specific medications?

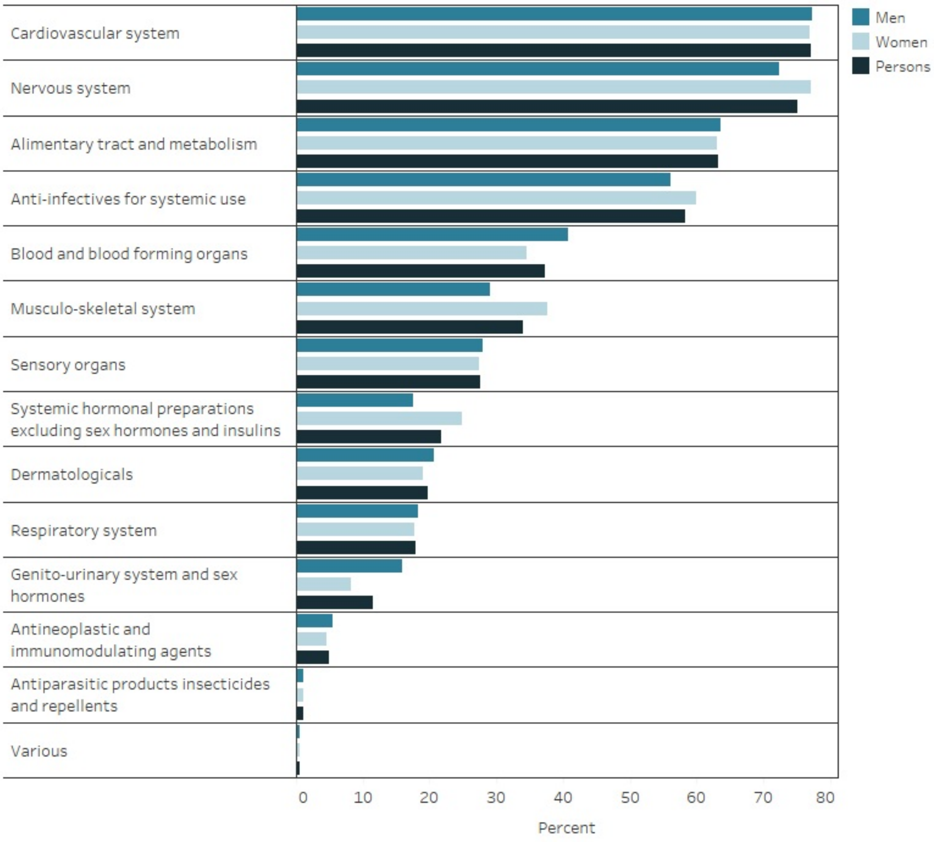
As people with dementia often have other co-existing conditions, they are likely to be prescribed a range of other medicines. Figure 8.6 shows the types of other medications dispensed to people who were dispensed dementia-specific medications in 2019–20, grouped at the highest level (Anatomical Therapeutic 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 77% of both men and 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 (64% of men and 63% of women).

Men were less likely than women to be dispensed medications for the nervous system (72% of men compared with 77% of women), and musculoskeletal system (29% of men and 38% of women), as well as systemic hormonal preparations (18% of men and 25% of women). However, men were more likely than women to be dispensed medications for blood and blood forming organs (41% of men and 34% of women) and medications for the genitourinary system and sex hormones (16% of men and 8.3% of women).

Figure 8.6: People who were dispensed scripts for dementia-specific medications in 2019–20: percentage who were dispensed scripts for other medications at least once, by sex and medications' Anatomical Therapeutic Chemical group

Figure 8.6 is a bar graph showing the percentage of people dispensed dementia-specific medications who were also dispensed other medications in 2019–20, by medication type and sex. The medications are grouped at the highest Anatomical Therapeutic Chemical classification level. About 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, musculoskeletal system medications, and systemic hormonal preparations. However, men were more likely than women to be dispensed medications for blood and blood forming organs and for the genitourinary system and sex hormones.



Note: The Anatomical Therapeutic Chemical (ATC) group 'Various' includes: allergens, diagnostic agents, general nutrients and all other theurapeutic products.
Source: AIHW analysis of Pharmaceutical Benefits Scheme database
http://www.aihw.gov.au

The most common subgroup of other medications was antibacterials for systemic use, dispensed at least once to 58% of people who were dispensed scripts for dementia-specific medications (Figure 8.7). These medications are used to treat a range of bacterial infections. The next most common subgroups were:

- psychoanaleptics (50%; used to treat depression and other neurological and mental health conditions)
- lipid modifying agents (48%; used to lower high levels of fats in the blood, such as cholesterol)
- agents acting on the renin-angiotensin system (46%; used to treat high blood pressure and other cardiovascular diseases)
- analgesics (40%; used to alleviate pain).

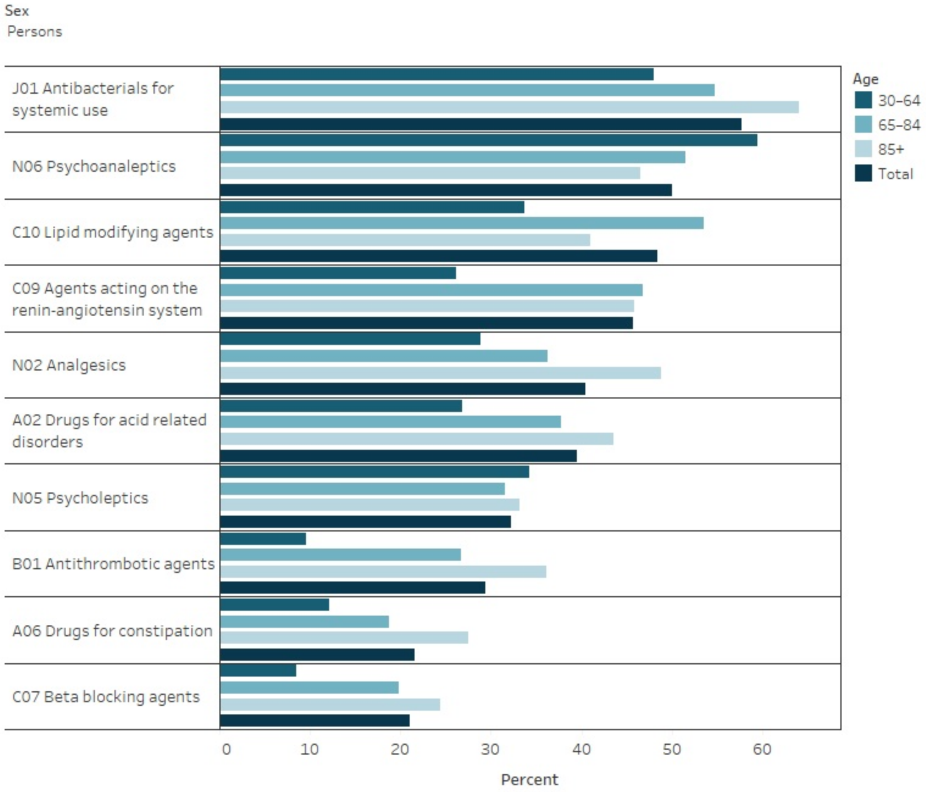
There were notable differences by sex and age in the most common medications dispensed at least once to people who were dispensed scripts for dementia-specific medication.

Overall, men were more likely than women to be dispensed scripts for lipid modifying agents (53% of men and 45% of women) and antithrombotic agents (34% of men and 26% of women). Whereas women were more likely than men to be dispensed scripts for psychoanaleptics (45% of men and 54% of women) and analgesics (37% of men and 43% of women). These differences were often greater in the older age groups.

Psychoanaleptics were dispensed to a larger proportion of those with younger onset dementia (aged under 65) compared with people aged 85 and over (59% compared with 47%). 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 9.6% of people aged 30–64) and beta blocking agents (24% compared with 8.6%).

Figure 8.7: People who were dispensed scripts for dementia-specific medications in 2019–20: 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 2019–20, by medication type, age and sex. The medications are grouped at the second highest Anatomical Therapeutic Chemical classification level. Over half (58%) of people were dispensed scripts for antibacterials for systemic use, which are used to treat a range of bacterial infections. Half were dispensed scripts for psychoanaleptics, which are used for depression and other neurological and mental disorders. Men were more likely than women to be dispensed scripts for lipid modifying agents and antithrombotic agents. However, women were more likely than men to be dispensed scripts for psychoanaleptics and analgesics. 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.



Note: Only the leading 10 medication subgroups are presented.
Source: AIHW analysis of Pharmaceutical Benefits Scheme database
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 2019–20, antipsychotic medications (which are part of the psycholeptics group) were dispensed to about one-fifth (21%) of the 64,600 people who had scripts dispensed for dementia-specific medication (Figure 8.8). This includes all antipsychotic medications and not just Risperidone.

Around 56% or 7,700 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. The average age of people dispensed antipsychotic medications was 80 for men and 81 for women—the same age as men and women who were dispensed scripts for dementia-specific medication (age 80 for men and 81 for women).

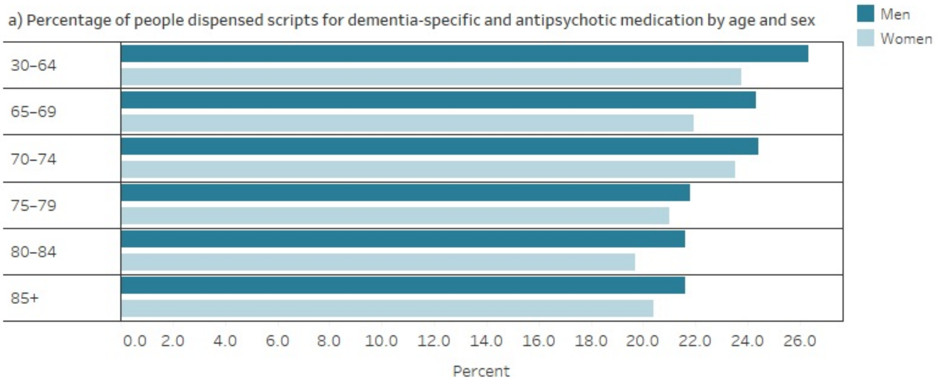
In each age group, men were relatively more likely to be dispensed scripts for antipsychotics at least once than women (Figure 8.8a). However, as more women have dementia, overall more women were dispensed antipsychotic medication than men.

Antipsychotics were more likely to be dispensed to people who were also taking Memantine (35% of people on Memantine) compared with other dementia-specific medicines (27% of people on Rivastigmine, 20% of people on Galantamine and 19% of people on Donepezil) (Figure 8.8b). This probably reflects the fact that Memantine is prescribed for moderately severe to severe Alzheimer's disease, whereas the other 3 dementia-specific medications are prescribed for mild Alzheimer's disease.

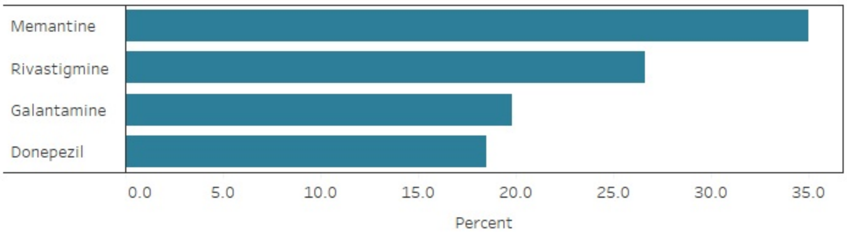
Although Risperidone is the only antipsychotic listed on the PBS for BPSD, scripts for other antipsychotic medications were dispensed to people with dementia. Around 39% of people with scripts dispensed for antipsychotic medication and dementia-specific medication were supplied Risperidone, followed by Quetiapine (29%) and Olanzapine (24%) (Table S8.11).

Figure 8.8: People who were dispensed dementia-specific medications in 2019–20: 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 2019–20. 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.



b) Percentage of people dispensed scripts for antipsychotic and dementia-specific medication by dementia-specific medication type



Source: AIHW analysis of Pharmaceutical Benefits Scheme database
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; Guideline Adaptation Committee 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 2021).

The Royal Commission into Aged Care Quality and Safety final report (Royal Commission 2021) recommends further revisions to the PBS to restrict prescribing of antipsychotics in residential aged care. Recommendation 65 states that ’By 1 November 2021, the Australian Government should amend the Pharmaceutical Benefits Scheme so that:

a. only a psychiatrist or a geriatrician can initially prescribe antipsychotics as a pharmaceutical benefit for people receiving residential aged care, and

*b. for those people who have received such an initial prescription from a psychiatrist or a geriatrician, general practitioners can issue repeat prescriptions of antipsychotics as a pharmaceutical‘ (*Royal Commission 2021).

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Health services used by people with dementia

Prescribers of dementia-specific medications

In 2019–20, 8 in 10 people (82%) who were dispensed script/s for dementia-specific medications were prescribed at least 1 script by a general practitioner (GP). In addition, 38% were prescribed by other medical specialists and less than 1% were prescribed by allied health professionals (for example, nurse practitioners).

The majority (78%) of people who were dispensed dementia-specific medications were prescribed these by 1 type of prescriber. 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 22% 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 (98%) were prescribed by a GP and another medical specialist (Table S8.14).

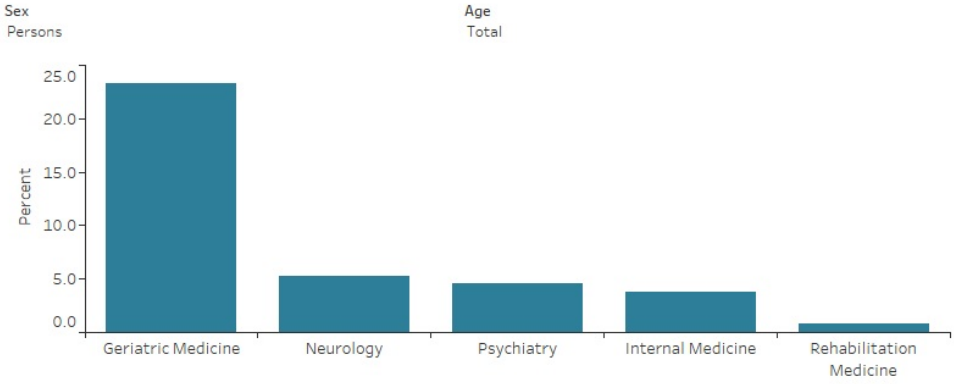
Types of medical specialists prescribing dementia-specific medications

Other than GPs, people were most commonly prescribed dementia-specific medications by specialists in geriatric medicine (23% of people who were dispensed a script for dementia-specific medications that year), followed by neurology (5.3%), psychiatry (4.5%) and internal medicine (3.8%) (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 specialists in neurology (16%) and psychiatry (9.7%) than they were for people aged 65 and over (4.9% and 4.3%, respectively).

Figure 8.9: People who were dispensed dementia-specific medications in 2019–20: 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 2019–20, 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 (5.3%) and psychiatrists (4.5%). There was little difference between men and women but younger people were more likely to be prescribed dementia-specific medicines by neurologists (16%) and psychiatrists (9.7%) than people aged 65 years or more.



Note: Dementia-specific medications prescribed by General Practitioners are excluded from this figure.
Source: AIHW analysis of Pharmaceutical Benefits Scheme database
http://www.aihw.gov.au

Last updated 5/09/2021 v8.0

Health services used by people with dementia

Hospital care

This page presents 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 2018–19 by:

- age and sex
- sex between 2009–10 and 2018–19
- the type of dementia recorded
- how the hospitalisation ended and whether palliative and other end of life care was provided
- geographic and socioeconomic areas (skip to this section).

Each hospitalisation is assigned a principal diagnosis (the main reason for being admitted to hospital) and can also be assigned 1 or more additional diagnoses (conditions that impact the provision of care but are not the main reason for being admitted to hospital). This page largely focuses on hospitalisations with a principal diagnosis of dementia, or 'hospitalisations *due* to dementia'. See Hospitalisations due to dementia versus hospitalisations with dementia for information on hospitalisations with dementia recorded as an additional diagnosis.

See Box 9.1 for key terms and considerations for hospitalisations for people with dementia and the Technical notes for further information on hospitals data.

Box 9.1: Data considerations for hospitalisations related to dementia

This page aims to provide a comprehensive picture of the impact of dementia on Australia's hospital systems. Hospitalisations where dementia was recorded as the principal diagnosis provide information on dementia-specific hospitalisations. In contrast, hospitalisations with dementia recorded as an additional diagnosis provide information on episodes of care where dementia impacted the hospitalisation but the reason for needing hospital care was not dementia.

The following terms are used to distinguish dementia hospitalisations:

- **Hospitalisations due to dementia** are hospitalisations where dementia was recorded as a principal diagnosis.
- **Hospitalisations with dementia** are hospitalisations where dementia was recorded as a principal diagnosis and/or an additional diagnosis.

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'. 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.
- Since 2015 dementia may be recorded in hospitals data using 'supplementary codes' rather than as an additional diagnosis (especially when dementia was not strongly impacting the care received by the patient) (see Box 9.3 for more information). Unfortunately, supplementary codes are currently not available in our data.

There is also a possibility that 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.

Hospitalisations *due* to dementia in 2018-19

In 2018–19, there were more than 11.5 million hospitalisations in Australia (AIHW 2019). Of these, about 23,200 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 2018–19:

- there were more hospitalisations for men than women (12,200 hospitalisations for men compared to 11,000 hospitalisations for women)
- men also had a higher age-standardised rate of hospitalisations than women (51 hospitalisations for men and 35 hospitalisations for women, per 10,000 people aged 60 and over)
- the average length of stay was 13 days—this was almost 5 times as high as the average length of stay of 2.7 days for all hospitalisations (AIHW 2019)
- the average length of stay was longer for men (14 days) than women (12 days).

Table 9.1: Overview of hospitalisations due to dementia in 2018–19 by sex

	Men	Women	Persons
Number of hospitalisations	12,200	11,000	23,200
Age-standardised rate (number per 10,000)	51	35	42
Average length of stay, days per hospitalisation	14	12	13
Total number of bed days	163,900	134,200	298,100

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

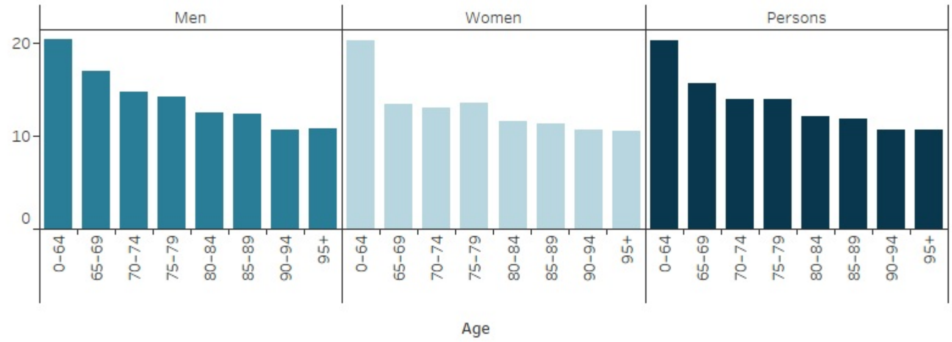
There were distinct patterns in hospitalisations *due* to dementia in 2018–19 by age and sex (Figure 9.1):

- the number of hospitalisations for both men and women increased with age up to age 85–89, then decreased in the oldest ages.
- 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 (20 days) than older people—the average length of stay decreased to 11 days for people hospitalised *due* to dementia aged 95 and over. This was observed among both men and women.

Figure 9.1: Overview of hospitalisations *due* to dementia in 2018-19, by age and sex

Figure 9.1 is a bar graph showing the estimated number of hospitalisations due to dementia in Australia by sex and age in 2018–19, as well as sex and age breakdowns for rate of hospitalisations (per 10,000 population) due to dementia, bed days and average length of stay (days). For both men and women, the number of hospitalisations due to dementia peaked in people aged in their eighties but the age-standardised rate of hospitalisations due to dementia was highest among those in their nineties. . The age-standardised rate of hospitalisations was higher in men than women across all age groups, with the difference greatest among those aged 90 to 94. The average length of stay for hospitalisations due to dementia decreased with increasing age from 20 days for people aged less than 65 to 11 days for people aged 90 and over.

Select statistic:
Average length of stay (days)



Source: AIHW analysis of National Hospital Morbidity Database.
http://www.aihw.gov.au

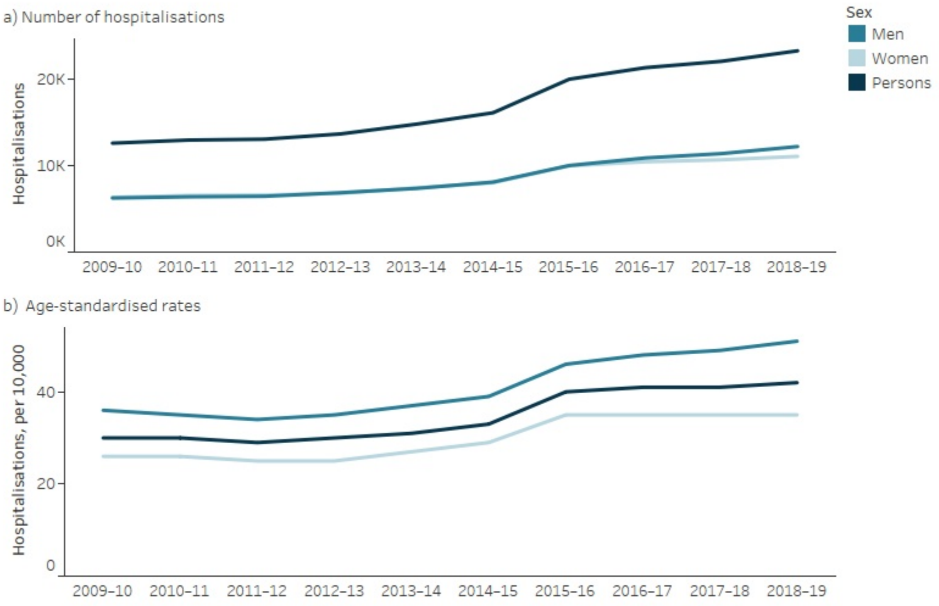
Hospitalisations due to dementia increased over time

Figure 9.2 shows the number and age-standardised rate of hospitalisations due to dementia between 2009–10 and 2018–19:

- the rate of hospitalisations increased gradually each year from 2009–10 to 2014–15 (2.1% annual average increase) and from 2015–16 to 2018–19 (1.8% annual average increase)
- 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)
- men consistently had higher rates of hospitalisations than women.

Figure 9.2: Hospitalisations *due* to dementia between 2009-10 and 2018-19: number and age-standardised rates

Figure 9.2 is two line graphs showing the estimated number and age-standardised rates of hospitalisations due to dementia in Australia by sex between 2009–10 and 2018–19. The number and age-standardised rate of hospitalisations both increased steadily during this period, with a surge observed between 2014–15 and 2015–16, which could be attributed to changes in coding for rehabilitation that came into effect in 2015–16. Men consistently had higher rates of hospitalisations than women.



Note: 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.
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.

30% of hospitalisations *due* to dementia were for Alzheimer's disease

In 2018–19, the most common dementia types recorded in hospitalisations *due* to dementia were:

- Alzheimer's disease (30%)
- Unspecified dementia (18%)
- Vascular dementia (10%) (Figure 9.3).

There were differences by sex in the dementia types recorded in hospitalisations *due* to dementia. There was a slightly smaller proportion of hospitalisations among men compared with women, due to *Alzheimer's disease* (29% of men compared with 31% of women) and *Unspecified dementia* (17% compared with 20%). There was a higher proportion of men with hospitalisations due to *Vascular dementia* than women (13% compared with 8%).

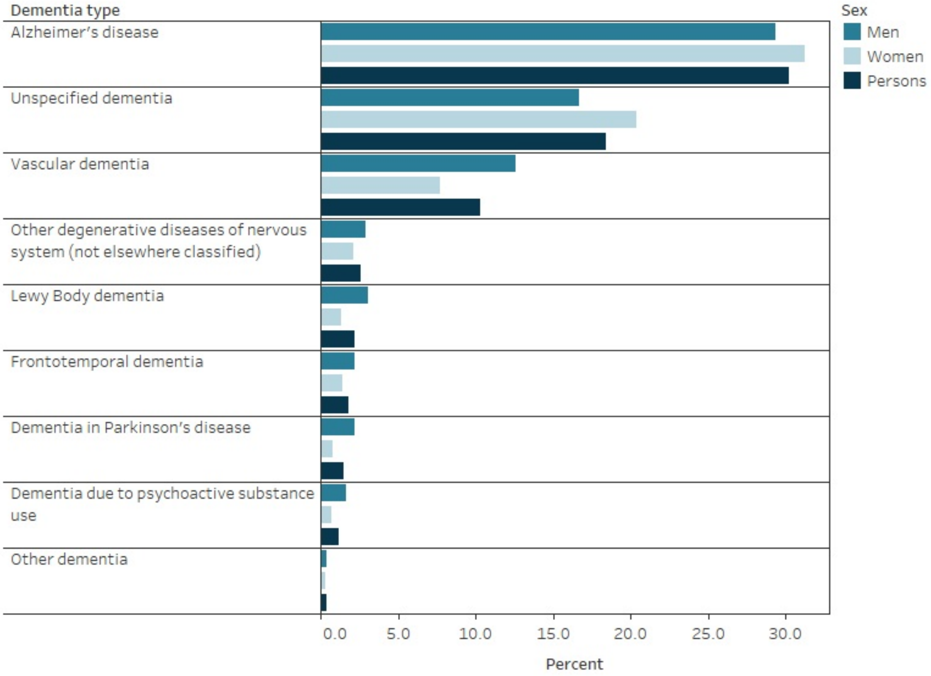
Delirium superimposed on dementia occurs when a person with pre-existing dementia experiences delirium, and is a common cause of hospitalisations among people with dementia. In 2018–19, 31% of hospitalisations *due* to dementia were for *Delirium superimposed on dementia* (Table S9.3).

As a person may have multiple types of dementia, it is possible to have more than 1 type of dementia recorded among hospitalisations with dementia. While the majority of dementia hospitalisations had only 1 type of dementia recorded, 5% (about 5,200 hospitalisations) had 2 or more types recorded.

Figure 9.3: Hospitalisations *due* to dementia in 2018–19: 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 2018–19. The most common dementia types recorded were Alzheimer's disease, Unspecified dementia and Vascular dementia. The proportion of hospitalisations due to Alzheimer's disease and Unspecified dementia was slightly less common among men compared with women, but

Vascular dementia was more common among men. Note that superimposed on dementia' was included in the total number of hospitalisations due to dementia, but is now shown in this figure as it is not a distinct type of dementia.



Notes:
1. 'Other dementia' consists of Dementia in Creutzfeldt-Jakob disease, Dementia in Huntington's diseases, Dementia in human immunodeficiency virus (HIV) disease and Dementia in other diseases (remainder).
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. Refer to the technical notes for more information.
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.

Source: AIHW analysis of National Hospital Morbidity Database.
http://www.aihw.gov.au

How did hospitalisations *due* to dementia end?

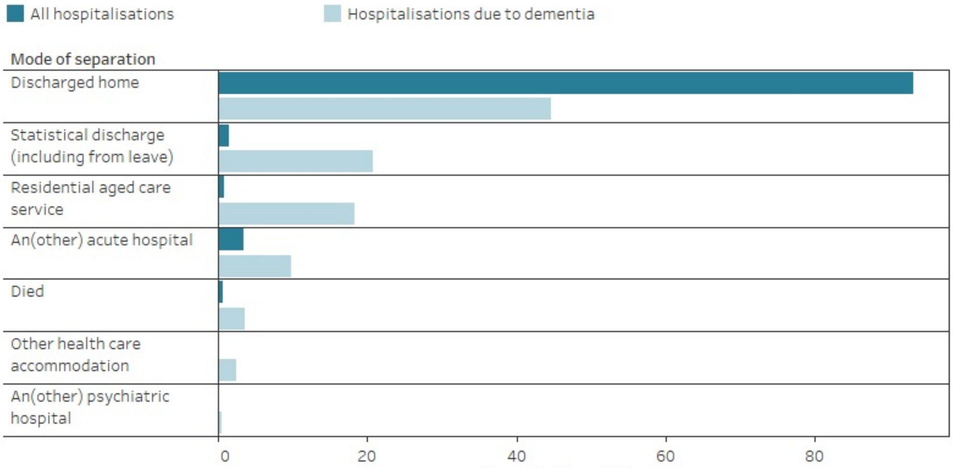
In 2018–19, 45% of all hospitalisations *due* to dementia ended in the patient being discharged home, which includes people returning to a residential aged care facility after a hospital stay (Figure 9.4). This proportion was considerably less than seen for all hospital separations in 2018–19, where 93% ended in the patient being discharged home (AIHW 2019).

About 18% of hospitalisations *due* to dementia ended with a discharge or transfer to a residential aged care facility. Of those discharged or transferred to a residential aged care facility, 2 in 3 patients were aged over 80 (Table S9.9). Note that only people being newly admitted to a residential aged care facility are captured, since those already living in residential care are considered to be 'discharged home'.

Around 21% 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 9.8% ended with discharge or transfer to another acute hospital and 3.6% ended with the death of the patient.

Figure 9.4: All hospitalisations and hospitalisations *due* to dementia in 2018–19: 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 in 2018–19. It shows that almost half (45%) of hospitalisations due to dementia ended in the patient being discharged home, which includes people returning to a residential aged care facility after a hospital stay. In contrast, 93% of all hospital separations involved a discharge home. Nearly one fifth of hospitalisations due to dementia ended with patients transferring to residential aged care.



Note: 'Discharged home' includes people who were living in residential aged care prior to their hospital admission and are returning to residential aged care after their hospital stay.
Source: AIHW analysis of National Hospital Morbidity Database.
http://aihw.gov.au

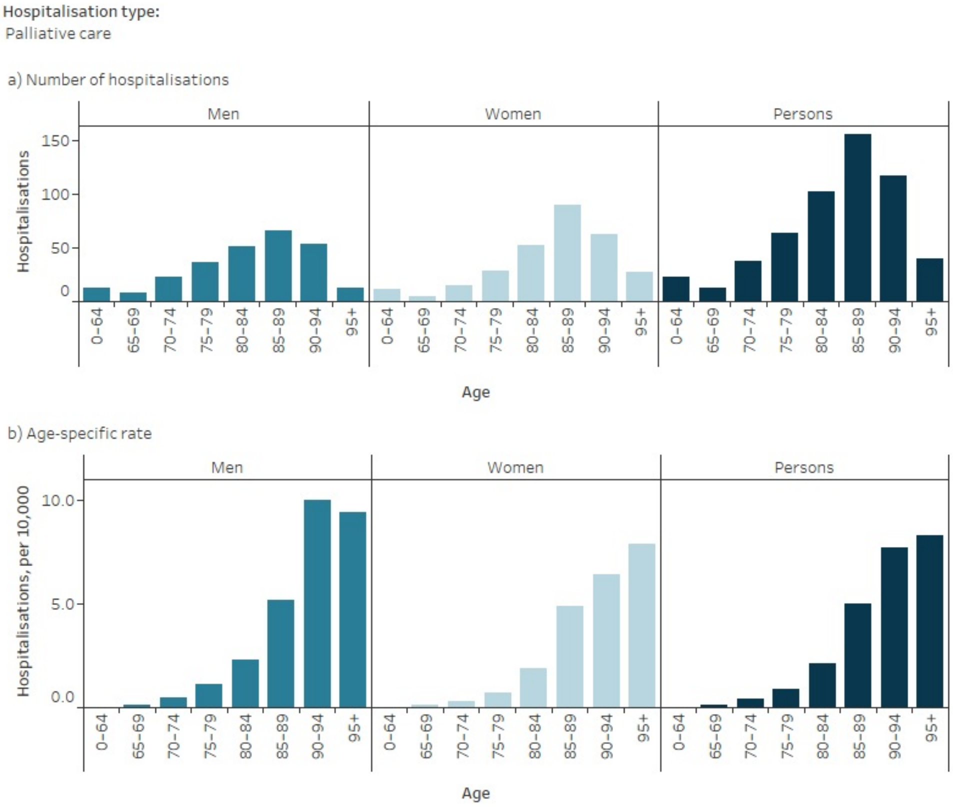
4% of all hospitalisations *due* to dementia involved palliative and other end-of-life care

In 2018–19, there were over 900 palliative care-related hospitalisations due to dementia, accounting for 3.9% (2.4% palliative care and 1.5% other end-of-life care) of all hospitalisations *due* to dementia (Figure 9.5a). Palliative care-related hospitalisations include hospitalisations with a care type of palliative care, in which specialist palliative care is provided (referred to as *palliative care*) 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 2018–19, by age and sex: (a) number and (b) age-specific rate

Figure 9.5 is 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 2018–19. Men had higher rates of hospitalisations due to dementia involving palliative care or other end-of-life care than women across most age groups. There was generally an increasing trend in the rate of hospitalisations with age for both men and women.



Notes:
1. The age-specific rate of hospitalisations for those aged 0–64 is rounded to 0.0 due to low counts.
2. Due to low counts, the number and rate of hospitalisations for other end of life care is not reported for males or females aged 0–64 or 65–69 years.

Source: AIHW analysis of National Hospital Morbidity Database.
http://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 groups for 2018–19.

In 2018–19, 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 33 hospitalisations per 10,000 population in Tasmania to 64 hospitalisations per 10,000 population in the Northern Territory
- varied by remoteness— the rate of hospitalisations due to dementia was highest in *Major cities* (46 hospitalisations per 10,000 population) and lowest in *Remote* and *Very remote* areas (35 hospitalisations per 10,000 population each)
- was lower among people living in the lowest 2 socioeconomic areas than among people living in the highest 3 socioeconomic areas (ranging from 39 to 44 hospitalisations per 10,000 population).

Socioeconomic and demographic factors such as income, education, employment, geographic access to health and social support services, as well as belonging to a culturally and linguistically diverse (CALD) community, may impact hospitalisations with dementia. These and other barriers may affect a person's ease of access to hospital services. Refer to Dementia in vulnerable groups for more information.

Figure 9.6: Hospitalisations *due* to dementia in 2018–19: age-standardised rate, by state and territory, remoteness area and socioeconomic area

Figure 9.6 is a bar graph showing the age-standardised rates of hospitalisations due to dementia by state or territory, remoteness areas and socioeconomic areas in 2018–19. After adjusting for population differences, the rates varied by state or territory as well as by remoteness areas, with the highest rates in the Northern Territory and Major cities, and the lowest rates in Tasmania and Remote and Very remote areas. Rates of hospitalisations due to dementia were lowest in the two lowest socioeconomic areas and the three highest socioeconomic areas had similar rates.

Note: 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.
Source: AIHW analysis of National Hospital Morbidity Database.
http://www.aihw.gov.au

Hospitalisations *due to* dementia versus 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) provides important insights on the wide-ranging conditions that can lead people living with dementia to use hospital services.

In 2018–19, there were just over 95,700 hospitalisations *with* dementia (46,700 men and 49,000 women), which is equivalent to 8 out of every 1,000 hospitalisations in Australia (AIHW 2019).

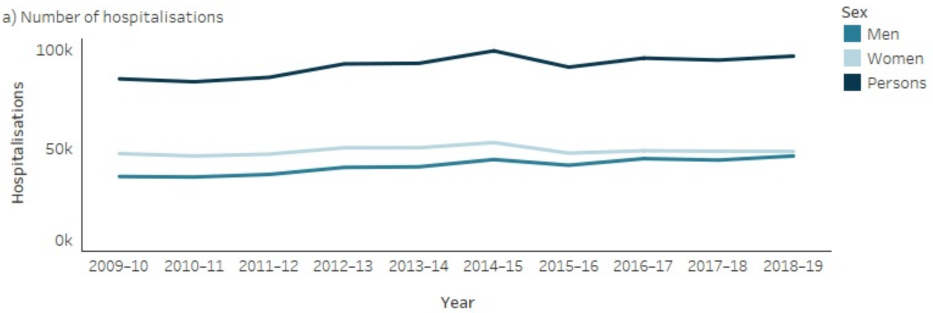
Trends over time in hospitalisations *with* dementia were different to trends in hospitalisations *due* to dementia (Figure 9.7). The age-standardised rate of hospitalisations *with* dementia were fairly stable between 2009–10 and 2014–15 (0.1% annual average increase) and decreased slightly between 2015–16 and 2018–19 (1.1% annual average decrease). Between 2014–15 and 2015–16, there was a decrease in both the number (8.1% decrease) and the age-standardised rate (10.5% decrease) of hospitalisations. By comparison, the age-standardised rate of hospitalisations *due* to dementia increased between 2014–15 and 2015–16 (as shown in the Hospitalisations *due* to dementia increased over time section).

Refer to Box 9.3 for more information on how changes to the way dementia has been recorded in hospital data over this period may have contributed to the decrease in hospitalisations *with* dementia.

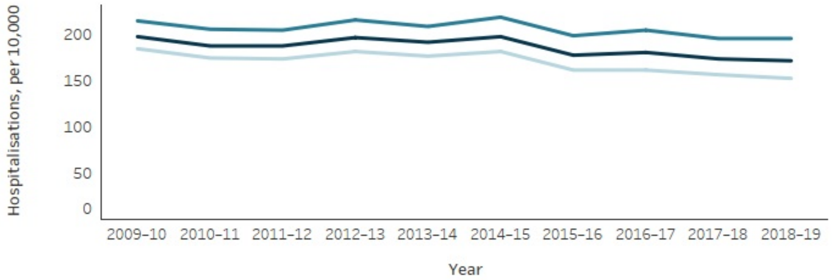
Figure 9.7: Hospitalisations with dementia between 2009-10 and 2018-19 by sex: (a) number and (b) age-standardised rate

Figure 9.7 is two line graphs showing the estimated number and age-standardised rates of hospitalisations with dementia in Australia by sex between 2009–10 and 2018–19. The age-standardised rate of hospitalisations with dementia were fairly steady between 2009–10 and 2014–15, and decreased slightly between 2015–16 and 2018–19. Between 2014–15 and 2015–16, there was a decrease in both the number and the age-standardised rate of hospitalisations, which is in contrast to the age-standardised rate of hospitalisations due to dementia where there was an increase.

a) Number of hospitalisations



b) Age-standardised rates



Note: 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.
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. Data on supplementary codes were not available for analysis in this report. The exclusion of supplementary codes may explain the sudden decrease in the rate of hospitalisations *with* dementia between 2014–15 and 2015–16, and subsequently, the slightly declining rates to 2018–19 (Figure 9.7).

The quality of the supplementary codes data is currently being assessed and a decision will be made in due course regarding whether or not these data will be made available for analysis and reporting purposes.

What were the most common principal diagnoses when dementia was an additional diagnosis?

In 2018–19 there were almost 78,500 hospitalisations where dementia was recorded as an additional 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:

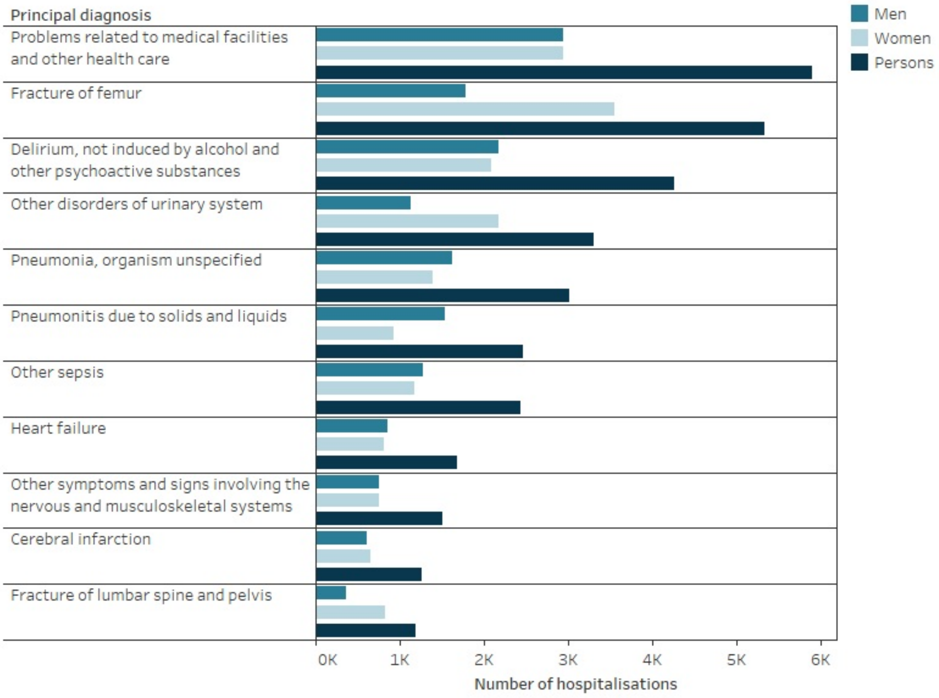
- *Problems related to medical facilities and other health care*, ICD-10-AM codes Z75.0–9 (5,900 hospitalisations or 7.5% of hospitalisations where dementia was an additional diagnosis)
    - these hospitalisations are where patients are required to stay in hospital longer to rehabilitate or are waiting 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)
    - the majority of these hospitalisations (86%) related to people awaiting admission to residential aged care services
- *Fracture of the femur*, ICD-10-AM codes S72.0–9 (5,300 hospitalisations or 6.8%)
- *Delirium, not induced by alcohol and other psychoactive substances*, ICD-10-AM codes F05.0–9 (4,300 hospitalisations or 5.4%)
- *Other disorders of urinary system*, ICD-10-AM code N39X (3,300 hospitalisations or 4.2%) (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 nearly 97% of all hospitalisations due to fractures of the femur, 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 2018-19, by sex

Figure 9.8 is 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 2018–19. The most common principal diagnoses were Problems related to medical facilities and other health care, Fracture of the femur, Delirium and Other disorders of urinary system.



Source: AIHW analysis of National Hospital Morbidity Database.
http://www.aihw.gov.au

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Last updated 21/09/2021 v25.0

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
- Dementia Support Australia
- What carer support services are available?

Refer to the XLS Aged care data tables and the XLS Dementia support services data tables for the underlying data presented in these pages.

See Dementia in vulnerable groups for more information on aged care and support services used by people with dementia among different population groups, such as by Indigenous Australians and people from culturally and linguistically diverse backgrounds.

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.

Key statistics

Over 41,000 people with dementia completed a comprehensive or home support assessment in 2019–20

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

Last updated 23/09/2021 v9.0

Aged care and support services used by people with dementia

Overview of Australia's aged care system

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 2020, around 335,900 Australians were using residential aged care (permanent or respite), home care or transition care services. In 2019–20 nearly 840,000 people received assistance under the Commonwealth Home Support Programme (CHSP), and some of them may have also accessed residential aged care (AIHW 2020).

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 2020 there were 845 organisations providing residential aged care through 2,722 services, 920 organisations providing home care services, and 1,452 organisations were funded to provide home support during 2019–20 through 3,724 outlets in Australia (AIHW 2020). 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 2019–20 about 1,100 men and 930 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* (DSS 2020).

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 XLS 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 2021), 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 (Royal Commission 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 behavioural and psychological symptoms, and require skilled staff to help them effectively manage symptoms (Royal Commission 2021).

The Australian Government is implementing workforce reforms in accordance with the Aged Care Workforce Strategy, and has made recent investments to improve dementia-specific workforce training through the Dementia Training Program.

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).

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Aged care and support services used by people with dementia

Aged care assessments

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 persons' 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 2019–20. This information was supplied to AIHW in late 2020, as part of the first supply of NSAF data to the National Aged Care Data Clearinghouse. It should be noted that the NSAF data are a new data source and not all information is yet reportable. Further work is needed to develop the dataset into a comprehensive resource for statistical reporting on aged care services.

Around 41,100 people with dementia completed an aged care assessment in 2019–20

In 2019–20, 41,100 Australians who completed an aged care assessment (either a comprehensive or home support assessment) had dementia (Figure 10.1). This equates to 9.7% 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 (54% or 22,200 women, and 18,900 men). The average age for women with dementia was 82 and for men it was 81.

Figure 10.1: People with dementia who completed an aged care assessment in 2019–20, 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 2019–20, by age group and sex. Women and men in the 75–84 year age group accounted for the largest number of assessments (10,191 and 8,898 respectively), followed by women (7,709) and men (6,075) aged 85–94.

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People with dementia were more likely to be seeking (or were more likely to be directed to seek) a higher level of aged care. Almost 3 in 4 (74%) aged care assessments undertaken by people with dementia in 2019–20 were comprehensive assessments (for people with more complex care needs) compared with 40% of people without dementia.

Almost half (45%) of people with dementia who completed a comprehensive assessment and 50% 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 (28%) (Figure 10.2).

Around 3 in 5 people with dementia had their dementia reported as the main condition impacting their need for assistance (62%). This was slightly higher among people who completed a comprehensive assessment (65%) compared with those who completed a home support assessment (52%) (Table S10.2).

Figure 10.2: People with dementia who completed an aged care assessment in 2019–20: 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 2019–20, by age group and assessment type. Half of people who completed a home support assessment were aged 75–84, about a quarter 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.

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An additional 18,400 people with cognitive impairment (with no record of dementia) completed an aged care assessment in 2019–20. This equates to 4.4% of people who completed an aged care assessment that year (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 (98%) of people with dementia who completed an aged care assessment in 2019–20 (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—69% of men who completed a home support assessment compared with 42% of women, and 62% of men who completed a comprehensive assessment compared with 34% of women. This is likely due to the fact that women live longer on average and are therefore more likely to live longer than male partners.

In contrast, women with dementia were much more likely to be living alone than men with dementia—15% of men who completed a home support assessment compared with 32% of women, and 20% 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—14% of men who completed a home support assessment compared with 24% of women, and 16% of men who completed a comprehensive assessment compared with 25% of women.

Figure 10.3: Living arrangements of people who completed an aged care assessment in 2019–20: 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 2019–20. The graph is disaggregated by assessment type (home support or comprehensive) and sex and show 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.

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The majority of people who completed a home support assessment (93% of people with dementia and 94% of people without dementia) and 3 in 5 people who completed a comprehensive assessment (61% of people with dementia and 61% without dementia) in 2019–20 completed the assessment in their own home. Comprehensive assessments can also take place in a hospital, and 26% of people with dementia had their comprehensive assessment performed in a hospital setting. This was slightly less than among people without dementia who completed a comprehensive assessment that year (30%) (Table S10.5).

The majority of people with dementia (85%) were receiving assistance from an informal carer (such as family and friends) rather than a carer who was associated with a service provider or paid service—this was much higher than for people without dementia (50%) (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 2019–20, 86% of people with dementia who completed a comprehensive assessment and 55% who completed a home support assessment had more than one trigger for needing an assessment. This was higher than for people without dementia; 81% who completed a comprehensive assessment and 38% 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—74% who completed a comprehensive assessment and 46% who completed a home support
- Change in care needs—66% who completed a comprehensive assessment and 30% who completed a home support assessment
- Medical condition—62% who completed a comprehensive assessment and 57% who completed a home support assessment
- Frailty—46% who completed a comprehensive assessment and 25% 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 18% 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 2019–20: 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 2019–20. 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. Three quarters of 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 (over half of people) and a change in cognitive status (46%). The most common trigger for both types of assessment for people without dementia was a medical condition.

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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 health conditions (including dementia) listed on their aged care assessment. This was similar to the average for people without dementia (5 health conditions). However, people with dementia who had a comprehensive assessment had more conditions recorded on average (6 health conditions) than those who had a home support assessment (4 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 2019–20, and how this compared to people without dementia. The most common conditions among people with dementia who completed an aged care assessment in 2019–20 were:

- High blood pressure (46% of all people with dementia)
- Osteoarthritis (25%)
- High cholesterol (23%).

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 (48%, 32% and 24% 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 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 2019–20: 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 2019–20: the percentage for people with and without dementia by sex. Hypertension (high blood pressure) was the most common condition, affecting just under half of men and women, both with and without dementia. Other common conditions were osteoarthritis and high cholesterol.

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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.

The rate of older Australians (those aged 65 and over) who had dementia and completed an aged care assessment in 2019–20 varied by state and territory (Figure 10.6). Rates were highest in Queensland for home support assessments; for every 1,000 people aged 65 and over living in Queensland, there were 3.5 people with dementia who had a home support assessment. For comprehensive assessment, rates were highest in the Northern Territory (9.9 per 1,000 people) and lowest in Tasmania for both home support (1.4 per 1,000 people) and comprehensive assessments (5.5 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 2019–20: 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 2019–20, by state or territory of residence. For every 1,000 people aged 65 and over living in Australia, 2.7 people with dementia completed a home support assessment. Home support assessment rates were highest in Queensland and lowest in Tasmania. For every 1,000 people aged 65 and over living in Australia, 7.4 people with dementia completed a comprehensive assessment. Comprehensive assessment rates were highest in Northern Territory and lowest in Tasmania.

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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 2019–20, the majority of people with dementia who completed a comprehensive assessment were approved for:

- residential respite care (70% of people with dementia who completed a comprehensive assessment, or 21,100 people)
- permanent residential aged care (61% or 18,600 people)
- community-based care under the Home Care Packages Program (60% or 18,300 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

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Aged care and support services used by people with dementia

Community-based aged care

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 2019, over 9,700 people were receiving the Dementia and Cognition Supplement as part of their Home Care Package (6,200 women and 3,500 men). Around 75% 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: Dementia and Cognition Supplement

The 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 information will not identify all people with dementia receiving community-based services, for a number of reasons:

- A dementia diagnosis alone does not mean that a client 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.
- Each person is only eligible for one supplement. Therefore, veterans who are also eligible for the Veterans' Supplement will not receive the Dementia and Cognition Supplement if they are receiving the Veterans' 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 into Aged Care Quality and Safety (Royal Commission) 2020. Research Paper 4: What Australians Think of Ageing and Aged Care. Viewed 10 October 2020.

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Aged care and support services used by people with dementia

Residential aged care

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 2019–20, by:

- age and sex, and how age and sex patterns compare to people without dementia living in permanent residential aged care
- state/territoy, remoteness and socieconomic 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 2015–16 and 2019–20 (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 2019–20, there were over 244,000 people living in permanent residential aged care, and 54% of these people had dementia (about 132,000 people). In 2019–20, of those living in permanent residential aged care:

- over half of both women (54% or nearly 85,700) and men (54% or over 46,200) had dementia
- men tended to be younger than women, irrespective of whether or not they had dementia
- both men and women with dementia were slightly older (aged 84 and 87 on average, respectively) than those without dementia (average of 82 and 86 years)
- 1 in 3 people aged under 65 (33% or 2,000 people) had dementia (known as younger onset dementia when aged under 65)
- unlike those with dementia at older ages where women outnumber men, there were more men with younger-onset dementia than women (about 1,100 men and 900 women) (Figure 10.7).

The Royal Commission into Aged Care Quality and Safety in its interim 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 2019). 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 2019–20: number by age and sex

Figure 10.7 is a bar graph showing the number of people who were living in permanent residential aged care in 2019–20, by age, sex, and whether or not they had dementia. The number of people living in permanent residential aged care increased with age. The number of people with dementia peaked at 85–89 years, while the number of people without dementia peaked at 90–94 years. Between the age groups 75–79 and 90–94, there were more people with dementia than without dementia living in residential aged care. Patterns were similar for men and women but there were more women living in permanent residential aged care in all age groups except 0–64.

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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)** is used to allocate government funding to aged care providers based on the day-to-day needs of the people in their care.

The ACFI data do not capture people with dementia who access 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 is a funding instrument and not a diagnosis or comprehensive service tool, it does 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 will be captured in the ACFI assessment. An ACFI reappraisal can be conducted for various reasons, such as when a person has a significant change in care needs or after 12 months from when their classification has taken effect. Therefore, the ACFI data can provide information about people in permanent residential aged care and how their care needs change over time.

As the care needs and health conditions reported in the ACFI are reported by providers for funding purposes, it is important to remember the ACFI is 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 allows for up to 3 medical and 3 mental or behavioural conditions to be recorded, so it will often not 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 2019–20, 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:

- across states and territories, there were slight variations in the proportion of people with dementia living in permanent residential aged care, ranging from 275 people per 10,000 people in Tasmania to 322 people per 10,000 people in South Australia.
- the rate of people with dementia living in permanent residential aged care increased as areas became less remote, from 117 per 10,000 people in *Very Remote* areas to 316 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 323 per 10,000 people in the second lowest quintile to 293 per 10,000 people in the highest quintile.

Figure 10.8: People with dementia who were living in permanent residential aged care in 2019-20; age-standardised rate by state/territory, remoteness and socioeconomic area

Figure 10.8 is a panel of bar graphs showing the age-standardised rates of people with dementia living in permanent residential aged care in 2019–20 by state or territory, remoteness and socio-economic areas. South Australia had the highest rate of people with dementia living in permanent residential aged care while the lowest rate was in Tasmania. There was a large difference in the rates of people with dementia living in residential aged care across remoteness areas. Major cities had the highest rate (316 residents per 10,000 people) and the rate decreased as remoteness increased, with just 117 people with dementia living in residential aged care facilities per 10,000 people living in very remote areas. In comparison to the remoteness areas, there was only a small amount of variation in rates of people with dementia living in residential aged care across socioeconomic area, but the rates were highest in the lowest socioeconomic areas.

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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 (47%) and a range of arthritic disorders (45%) 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 (32%), anxiety and stress related disorders (23%), pain (22%), and hypertension (16%).

Compared to those without dementia, people with dementia were more likely to have arthritic disorders (45% compared with 41%), urinary incontinence (32% compared with 24%), hypertension (16% compared with 13%) and frequent falls with unknown aetiology (12% 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 that impact the resident's 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 10.3 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 2019-20: percent by dementia status

Figure 10.9 is a bar graph showing the 10 most common health conditions of people with and without dementia living in permanent residential aged care in 2019–20. The most common health condition, for nearly half of people with and without dementia, was 'depression and mood disorders', followed by 'other arthritis and related disorders'. The third most common health condition for people with dementia was 'urinary incontinence'. For people without dementia, the third most common health condition was 'anxiety and stress related disorders'.

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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 2019–20, 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):

- 4 in 5 people with dementia (81%) required high levels of care in the *Cognition and behaviour* domain (including cognitive skills, wandering, verbal behaviour, physical behaviour and depression) compared to 47% of people without dementia.
- over 2 in 3 people with dementia (71%) required high levels of care in the *Activities of daily living* domain (including mobility, continence and nutrition), compared to 63% of people without dementia.
- over 1 in 2 people with dementia (56%) 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 (59%).

Figure 10.10: People living in permanent residential aged care in 2019-20: percent with the highest care needs in each ACFI domain by dementia status

Figure 10.10 is a bar graph showing the percentage of people with and without dementia living in permanent residential aged care in 2019–20 who needed help in three ACFI domains: activities of daily living, cognition and behaviour and complex health care. For people with dementia, 81% needed help with cognition and behaviour, 71% needed help with activities of daily living and 56% needed help with complex health care. For people without dementia, 47% needed help with cognition and behaviour, 63% needed help with activities of daily living, and 59% needed help with complex health care.

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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
- *Complex health care* domain—the proportion of people requiring high levels of care increased steadily with age for both men and women
- *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.

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 2019-20: percent with the highest care needs in each ACFI domain by sex and age

Figure 10.11 is a bar graph showing the percentage of people with dementia living in permanent residential aged care in 2019–20 who were assessed as having the highest care needs in each of the three ACFI domains, by age group and sex. The proportion of people with dementia with high care needs for complex health care increased with age, from 46% at 0–64 years to 66% at 95 years and older. The proportion of people with dementia with high care needs for cognition and behaviour was about 80–85% irrespective of age. The proportion of people with dementia with high care needs for activities of daily living increased with age, from 60% at 65–69 years to 83% at 95 years and older. These patterns were similar for men and women.

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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 2019–20 varied by geographic and population groups (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
- while Western Australia had the highest proportion of people with dementia who required high levels of care in *Activities of daily living* and *the Cognition and behaviour* domains, Victoria had only a slightly lower proportion requiring high levels of care in these domains and had the highest proportion with needs in *the Complex health care* domain. The Australian Capital Territory had the lowest proportion for the *Activities of daily living* and *Complex health care* domains and South Australia had the lowest proportion for the *Cognition and behaviour* 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 2019–20, among people with dementia living in permanent residential aged care, 78% required complex pain management at least weekly, and 49% 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 2019–20 were assessed as needing palliative care (about 2,100 or 1.6%) at the time their ACFI appraisal was completed, which was slightly less than for the proportion of people without dementia (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 2019–20, 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 2019–20) (Table S10.22).

For people living in permanent residential aged care who did not separate from their latest episode of care during 2019–20, those with and without dementia had spent roughly the same length of time in care (median stay of 2.1 and 1.9 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 2.2 years in care compared to 1.3 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 2019-20: percent by dementia status and whether the person separated from care or remained in care

Figure 10.12 is a bar graph showing how long people with and without dementia had spent in permanent residential aged care in 2019–20, by whether they separated from care in 2019–20 or not. For those who did not separate from care, 14–16% of people with and without dementia spent 0–6 months in care. This proportion increased to a peak of about 20% of people spending 1–2 years in care, and gradually decreased over longer time periods. For those who separated from care, nearly 30% of people without dementia spent 0–6 months in care, compared with 18% of people with dementia. The proportion who spent 6–12 months in care dropped to 11% of people with dementia and 13% of people without dementia, and about 17% of both groups spent 1–2 years in care. The proportion gradually dropped over longer time periods for both groups, but people with dementia were more likely to have longer stays.

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Trends in the use of residential care

The number of people living in permanent residential aged care has increased over the last five years: from around 234,000 people during 2015–16, to over 244,000 people during 2019–20. 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 proportion of people in permanent residential aged care with dementia remained relatively stable during this time at around 54–55%. The number of men increased over this period, irrespective of dementia status—by 7.8% for men with dementia and by 9.9% for men without dementia. In contrast, changes in the number of women differed by dementia status—the number decreased by 0.3% for women with dementia and increased by 4.3% for women without dementia (Figure 10.13).

Figure 10.13 also shows how the number of people with dementia in permanent residential aged care have changed over the last 5 years, as a proportion of the target population—that is, the population of Australians aged 65 and over. All rates have been age-standardised to adjust for population differences.

Between 2015–16 and 2019–20 the rate of people living in permanent residential aged care decreased overall, irrespective of if they had dementia or not, but the decrease was slightly greater among those with dementia—the rate decreased over this period from 329 to 303 per 10,000 people among those with dementia, while it decreased from 261 to 251 per 10,000 people among those without 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). The decrease of people with dementia living in residential aged care was observed among both men and women with dementia.

Figure 10.13: People living in permanent residential aged care from 2015-16 to 2019-20: number and age-standardised rate by dementia status and sex

Figure 10.13 is two line graphs showing trends in the number and age-standardised rates of people living in permanent residential aged care between 2015–16 and 2019–20, by sex and dementia status. There were slightly more men with dementia than men without dementia living in residential aged care. The number of men with and without dementia increased slightly over the time period, but the age-standardised rates decreased for both. There were more women with dementia than women without dementia living in aged care. The number of women with dementia living in aged care remained steady, while the number of women without dementia increased slightly, and the age-standardised rates decreased for both.

Visualisation not available for printing

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Dobson AJ, Waller MJ, Hockey R, Dolja-Gore X, Forder PM & 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.

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Aged care and support services used by people with dementia

Overview of dementia support services and initiatives

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 are sourced directly through personal correspondence with Dementia Australia and Dementia Support Australia.

Refer to the XLS Dementia support services data tables for the underlying data presented in these pages.

What dementia-specific support services are available?

The Dementia and Aged Care Services Fund held by the Australian Government provides funding for multiple dementia-related services and initiatives. The overarching aim of the fund is to improve awareness and understanding of dementia and support people experiencing changed behaviours due to their dementia, and support care-givers. Funding is offered to national ongoing programs, as well through one-off competitive grants available to aged care providers, researchers, peak bodies and advocacy groups. A full list of the grants awarded for projects under the Dementia and Aged Care Services Fund is available at the Australian Government's grants information system.

Non-governmental organisations such as Dementia Australia and HammondCare provide management of the delivery of the national, ongoing programs and initiatives supported by the Dementia and Aged Care Services Fund. 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. Following additional investment announced in the 2021–22 Federal Budget, the Australian Government will provide approximately $24 million per year between 2021–22 and 2024–25 for the National Dementia Support Program.
- Dementia-Friendly Communities—a program delivered by Dementia Australia that builds understanding, awareness and acceptance of dementia in the community. The Australian Government provided targeted assistance of $3.9 million over 3 years (July 2016 to June 2019) and $3.7 million from December 2019 to June 2022 to Dementia Australia to implement the Dementia-Friendly Communities initiative.
- Dementia Training Program—a national approach to accredited education, upskilling and professional development in dementia care delivered by Dementia Training Australia. The Australian Government provides approximately $9.3 million annually to Dementia Training Australia to provide the Dementia Training Program.
- Dementia Behaviour Management Advisory Service—a mobile workforce provided by Dementia Support Australia (DSA) (led by HammondCare) to support people with mild to moderate behaviours and psychological symptoms of dementia, and their carers, with client-focused information, assessment and advice. The Australian Government provided $13 million to DSA to run this service in 2018–19.
- Severe Behaviour Response Teams—a mobile workforce provided by DSA (led by HammondCare) to support people with severe behaviours and psychological symptoms of dementia, and their carers, with client focused information, assessment and advice. The Australian Government provided around $15 million to DSA to run this service in 2018–19.
- Specialist Dementia Care Program—a tailored program offering temporary, transitional care to people who are experiencing severe behavioural and psychological symptoms of dementia and who can no longer be cared for in a mainstream residential aged care facility. The program is being implemented in phases and is expected to cost the Australian Government $70 million annually when fully operational. In 2018–19, $1.3 million was spent on the Specialist Dementia Care Program. Eligibility for the Specialist Dementia Care Program is determined by the Needs Based Assessment program of DSA (led by HammondCare).

Need more information?

If you require more information about services and initiatives for people with dementia, their friends, family and carers refer to:

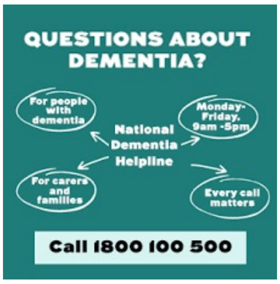
- *Dementia Australia* website
- *The Dementia Guide* by Dementia Australia
- *National Dementia Helpline*: 1800 100 500 (a free and confidential service to discuss dementia and memory loss concerns for yourself or others)
- *Dementia Support Australia*: 1800 699 799 (if needing help to manage behaviour 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 and Dementia Friendly Communities

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.



The first point of contact for most people engaging with Dementia Australia’s NDSP-funded activities is the National Dementia Helpline (1800 100 500 or via a helpline webchat).

The National Dementia Helpline is staffed with experienced professionals who provide support to people with dementia and their friends and family; carers of people with dementia, or anyone with concerns about memory loss. 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.

In 2019–20, there were 39,500 contacts to the National Dementia Helpline. This accounted for over half (53%) of all contacts to the NDSP. Other contacts were via email and online webchat.

In 2019–20, Dementia Australia surveyed NDSP-funded program participants following their engagement with these services. After participating in a NDSP program:

- 85% of respondents reported an improvement in coping capacity among clients receiving **counselling/support**
- 87% of respondents reported an improvement in coping capacity among clients receiving **early intervention**
- 87% of respondents reported an improvement in coping capacity among clients receiving **education** (Dementia Australia 2021, pers. comm., 15 February).

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.

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

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Dementia Illawarra Shoalhaven 2020. Dementia Friendly Kiama. Accessed 4 May 2020.

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Aged care and support services used by people with dementia

Dementia Support Australia

Dementia Support Australia (DSA) is a service led by HammondCare's Dementia Centre and supported by the Australian Government under the Dementia and Aged Care Services Fund. HammondCare's Dementia Centre was founded in 1995 as a provider of impartial research and expertise to the aged and dementia care community, both in Australia and internationally.

DSA aims to improve the quality of life for people with dementia and their carers; up-skill, assist and support aged care providers in improving care for people with dementia and related behaviours; and ensure care services for people with dementia are responsive to their individual and often diverse needs and circumstances. Support from DSA is provided in a variety of ways: 24/7 contact with a Dementia Consultant for advice and referrals; phone or in person assessments and support; communication with the carer/support network to gain more knowledge; individually tailored recommendations and strategies; ongoing support and guidance to implement recommendations; access to current research and guidelines; and referrals to other services.

DSA provides 3 key national support services that can be accessed independently:

- **Dementia Behaviour Management Advisory Service (DBMAS)** 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. DBMAS delivers this support through a detailed case management framework that includes person-centred recommendations, 24/7 access to specialist dementia consultants, and the timely delivery of a detailed assessment and interview usually within 7 days of referral.
- **Severe Behaviour Response Teams (SBRT)** 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 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. SBRT delivers this support through a detailed case management framework that includes person-centred recommendations, access to specialist dementia consultants 24/7, and the timely delivery of a detailed assessment and interview within 48 hours of referral.
- **Needs Based Assessment program** is a mobile workforce of health and allied health professionals who determine eligibility for the Specialist Dementia Care Program through a nationally consistent and standardised assessment.

Between January to June 2018 and January to June 2020 there was a 40% increase in the total number of referrals that were supported by DSA—a 36% increase for the DBMAS and 77% increase for SBRTs. This increase is likely due to increased awareness of DSA, combined with a growing 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 2020) in Figure 11.1 to explore the profile of DSA referrals during this time.

Figure 11.1: Profile of referrals to Dementia Support Australia (DSA)

Figure 11.1 is 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 2020. For each 6 month period, women accounted for a slightly greater percentage of referrals than men. 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*.

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Between January and June 2020, there were 5,452 referrals to DSA. This had increased by 17% (from 4,670 referrals) from the number of referrals in the previous 6 months (July to December 2019). The January to June 2020 period covers the beginning of the COVID-19 pandemic in Australia, and during this time, DSA were able to continue to deliver services 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.

Specialist Dementia Care Program

The Specialist Dementia Care Program (SPDC) is an Australian Government initiative committed to establishing specialist dementia care units in purpose built facilities across Australia—providing individualised care to people who are experiencing severe behaviours and psychological symptoms of dementia and who can no longer be managed by their carers or by mainstream residential aged care services. The benefit of specialised dementia care units is that the person experiencing severe behaviours and psychological symptoms of dementia can receive personalised, specialist care in an environment uniquely designed for a person with dementia.

DSA assesses eligibility for the SDCP through their Needs Based Assessment program.

Once approved, a person will be required to enter the program within 3 months and their length of stay in a SDCP unit will vary (usually up to 12 months). When specialist care is no longer required, providers must support the person’s move into a less-intensive care setting.

The first prototype of the specialist dementia care unit under the SDCP began operating in Perth, Western Australia in 2019. Approved residential aged care providers can apply for program grants to set up units in their facility, and there have been a number of specialist dementia care units funded for operation to date. By 2022–23, the Australian Government aims to have at least 1 specialist dementia care unit in each of the 31 Primary Health Network regions.

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Aged care and support services used by people with dementia

What carer support services are available?

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.

The services include, but are not limited to:

- phone counselling
- carers' forum where carers can connect to each other
- online carer coaching
- carer skills courses
- respite services
- information and links to financial support available (DSS 2020).

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 aims to:

- advocate for policy and service actions that support the caring role and enhance the health, wellbeing, resilience and financial security of carers
- advocate for the inclusion of carers as a priority group within mainstream and specialist service programs
- advocate for having caring recognised as a shared responsibility of family, community, business and government, with the aim of achieving improved outcomes for carers
- undertake other policy, advocacy and service actions which the Carers Australia Board considers to be of benefit to carers.

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.

The Dementia Carers Australia website provides insight into dementia care for people who are caring for their family or friends with dementia. The website also allows for carers to share their stories, ideas and resources to assist each other and remain connected while taking on the carer role. The Dementia Carers Australia website is run by Dementia Reframed, a not-for-profit organisation aimed at improving information about living with dementia, and supporting carers of people with dementia.

References

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Dementia in vulnerable 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 Indigenous Australians
- Population health impacts of dementia among Indigenous Australians
- Hospital care for Indigenous Australians with dementia
- Aged care service use by Indigenous Australians with dementia
- Indigenous-specific health and aged care programs and caring roles among Indigenous Australians
- 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

Refer to the Technical notes for more information on the data sources and methods used to examine dementia in vulnerable population groups.

Refer to the Indigenous Australians data tables and Vulnerable populations data tables for the underlying data presented on these pages.

Key statistics

In 2018, 28% of people with dementia in Australia were born in a non-English speaking country

People with dementia from non-English speaking countries are more likely to rely on informal carers only

During 2017–2019, dementia was the 5th leading cause of death among Indigenous Australians aged 65 and over

Down syndrome was the leading cause of death in people aged under 65 with dementia as an associated cause of death

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Dementia in vulnerable groups

Understanding dementia among Indigenous Australians

Dementia has a deep impact on Aboriginal and Torres Strait Islander people (respectfully referred to as Indigenous Australians) and communities. The following pages present the impact of dementia among Indigenous Australians in relation to:

- Population health impacts (incidence, prevalence, deaths and burden of disease)
- Hospital care
- Aged care service use
- Indigenous-specific health services and aged care programs and caring for family and friends with dementia.

The pages also discuss what is being done to address the impact of dementia and the availability of services to meet the needs of Indigenous Australians.

It is essential to understand how dementia is understood and managed among Indigenous Australians in order to devise culturally appropriate and effective policies and services. However, there are important data gaps in relation to dementia in Indigenous Australians, which limit the robustness of analyses and the generalisability of findings for Indigenous Australians. These gaps include the lack of Indigenous Australian 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.

Indigenous Australians: key demographics

The term ‘Indigenous Australians’ refer to hundreds of different groups of people with distinct cultures, traditions and languages.

The Australian Bureau of Statistics (ABS) estimates that in 2016, there were over 798,400 Indigenous Australians, making up 3.3% of the total Australian population. According to the ABS (2018), among Indigenous Australians in 2016:

- 50% were males and 50% females
- 91% identified as Aboriginal people, 5% as Torres Strait Islander people, and 4% as Aboriginal and Torres Strait Islander people
- 4.3% were aged 65 years and over, compared to 16% of non-Indigenous Australians. However, the Indigenous Australian population has been ageing and it is expected to continue to do so in the future (Temple et al. 2020)
- 81% lived in *Major cities, Inner regional,* or *Outer regional* areas (compared to 98.5% of non-Indigenous Australians), and 19% lived in *Remote* or *Very remote* areas (compared to 1.5% of non-Indigenous Australians).

How is dementia perceived by Indigenous Australians and what enables people to live well with dementia?

Experiences of dementia and awareness of risk factors for developing dementia vary greatly among Indigenous Australians, as with non-Indigenous Australians (Flicker & Holdsworth 2014). However, as long as dementia doesn’t affect connection to family, community, and culture, many Indigenous Australians 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

Policies and service enablers that support Indigenous Australians with dementia to live well include those that: incorporate Indigenous 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 of living well with dementia among Indigenous Australians

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 Indigenous Australian 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 Indigenous Australians 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 and 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; and Western Australian Centre for Health and Ageing 2010.

Need more information?

If you require more information about dementia in Indigenous Australians, 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* website, including:
  - Resources for Aboriginal and Torres Strait Islander communities
  - Useful websites with a focus on Indigenous health
  - Resources for Aboriginal workers
- *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 Indigenous Australians accessing aged care).

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Dementia in vulnerable groups

Population health impacts of dementia among Indigenous Australians

This page presents the latest data showing the population health impacts of dementia among Indigenous Australians including:

- prevalence and incidence of dementia
- deaths due to dementia
- deaths *due to* dementia versus deaths *with* dementia
- burden of disease

Prevalence and incidence of dementia

Although there are no national-level estimates of the number of Indigenous Australians with dementia, studies examining different communities of Indigenous Australians 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 Indigenous Australians:

- rates of dementia for Indigenous Australians in remote and rural communities are among the highest in the world. For Indigenous Australians 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 Indigenous Australians aged 45 and over was 6.5%, compared with 2.6% among the non-Indigenous Australians (Li et al. 2014)
- Indigenous Australians 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 Indigenous Australians 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 Indigenous Australians aged 60 and over, the prevalence of dementia was about 3 times higher than 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 Indigenous Australians were slightly lower compared to rates among Indigenous Australians 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.

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 Indigenous Australians will continue to grow in coming years.

Preventing dementia in Indigenous Australians requires an understanding of the underlying medical and social risk factors for developing dementia. Some important risk factors that present at higher levels among Indigenous Australians include: head injury, stroke, diabetes, high blood pressure, renal disease, cardiovascular disease, obesity, hearing loss, childhood stress and trauma, and lower socioeconomic status (Flicker & Holdsworth 2014; Radford et al. 2019; Goldberg et al. 2018). 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 Indigenous identifiers in administrative data sets would support better dementia prevalence estimates for Indigenous Australians across Australia (Griffiths et al. 2019; AIHW 2020). 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 Indigenous Australians. The Kimberley Indigenous Cognitive Assessment (KICA) tool is an example of such a tool, which allows for the cognitive screening of older Indigenous Australians 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 Indigenous Australians

This section reports on deaths where dementia was recorded as the underlying cause of death, and refers to these 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 Indigenous Australians in any given year. 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 Indigenous Australians.

During 2017–19, 314 Indigenous Australians died due to dementia (196 women and 118 men). During this period, dementia was the fifth leading cause of death among Indigenous Australians aged 65 and over (after coronary heart disease, chronic obstructive pulmonary disease, diabetes, and lung cancer), accounting for 7.7% of all deaths among Indigenous Australians 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 2010–2014 were compared to the number of deaths in the most recent 5-year period (2015–19). The number of deaths due to dementia among Indigenous Australians increased in the most recent 5-year period (2015–19) for men and women across all ages (Figure 12.1). During 2010–2014, there were 270 deaths due to dementia among Indigenous Australians, while there were 461 deaths due to dementia during 2015–19; this is equivalent to a 71% increase in deaths due to dementia among Indigenous Australians during this period.

Between 2015 and 2019, most deaths due to dementia among Indigenous men and women occurred among those aged 85 and over, but a larger proportion of Indigenous men (67%) were aged less than 85 compared to Indigenous women (54%). With an ageing Indigenous Australian 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 Indigenous Australians during 2010–2014 and 2015–2019, by age and sex

Figure 12.1 is a bar graph showing the number of deaths due to dementia among Indigenous Australians during 2010–2014 and 2015–2019 by age and sex. Indigenous Australians aged 85 or older accounted for the largest number of deaths due to dementia for both time periods, but the number of deaths in 2015–19 were greater than in 2010–2014.

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The majority of deaths among Indigenous Australians due to dementia in 2017–19, were recorded as due to *Unspecified dementia* (219 deaths or 70% of deaths due to dementia), followed by *Alzheimer's disease* (17%) and *Vascular dementia (9.0%)* (Table S12.4). These dementia types were also the most common types recorded overall among Australians who died due to dementia in 2019 (see the Deaths due to dementia).

A recent nationwide study of mortality data between 2006–2014 showed that deaths with dementia were 57% higher among Indigenous Australians compared to non-Indigenous Australians, with the biggest difference occurring among men and those aged less than 75. Indigenous Australians 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 Indigenous Australians 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 Indigenous Australians. 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 2017–19 (Figure 12.2). Age-standardised rates of deaths due to dementia among Indigenous Australians were:

- lowest in New South Wales (42 per 100,000 Indigenous Australians) and highest in the Northern Territory (116 per 100,000 Indigenous Australians)
- lowest in *Inner* and *outer regional areas* (52 per 100,000 Indigenous Australians) and highest in *Remote* and *very remote areas* (119 per 100,000 Indigenous Australians).

Figure 12.2: Deaths due to dementia among Indigenous Australians during 2017—19: age standardised rate by geographic area

Figure 12.2 is a bar graph showing the age standardised rate of deaths due to dementia among Indigenous Australians during 2017–19 by state or territory and remoteness areas. The highest rate was in the Northern Territory with 116 deaths due to dementia per 100,000 Indigenous Australians and lowest in New South Wales (42 deaths per 100,000 Indigenous Australians). Remote and very remote areas had the highest rate of deaths due to dementia among Indigenous Australians (119 deaths per 100,000 Indigenous Australians) and the lowest rate was in Inner and outer regional areas (52 deaths per 100,000 Indigenous Australians).

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Deaths *due to* dementia versus deaths *with* dementia

The discussion about dementia deaths among Indigenous 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 1 underlying cause of death recorded, it is important to also account for all other cases where Indigenous Australians died *with* dementia (where dementia was recorded as the underlying or an associated cause of death).

During 2017–19, 314 Indigenous Australians died *due to* dementia. In comparison, a total of 618 Indigenous Australians died *with* dementia (Figure 12.3). Around half (51%) of the deaths *with* dementia among Indigenous Australians in 2019 were deaths *due* to dementia (that is, dementia was the underlying cause of death). This proportion increased by age at death, from 43% of deaths *with* dementia among Indigenous Australians who died aged under 75, to 57% among Indigenous Australians 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 Indigenous Australians during 2017–19, by age

Figure 12.3 is a bar graph showing deaths due to dementia and deaths with dementia among Indigenous Australians during 2017–19 by age. Just over one quarter of all the deaths of Indigenous Australians with dementia were accounted for by those aged less than 75 years during 2017–19. The number of deaths with dementia increased with age to 228 among those aged 85 years or older (or 37% of all deaths of Indigenous Australians with dementia). Overall, deaths due to dementia accounted for about half of the deaths with dementia of Indigenous Australians during this period.

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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 non-Indigenous Australians when dementia was an associated cause of death (Table S3.6).

Burden of disease

The Indigenous component of the Australian Burden of Disease Study (ABDS) 2011 was the last national study providing estimates of disease burden among Indigenous Australians (AIHW 2016). Burden of disease analysis measures 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)—1 DALY is equivalent to 1 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 also the severity and duration of illness and age at death for fatal conditions (AIHW 2019).

From the 2011 ABDS, dementia was the leading cause of disease burden for Indigenous women and the third leading cause for Indigenous men aged 75 and over (behind coronary heart disease and chronic obstructive pulmonary disease). The age-standardised rate of disease burden due to dementia was 12.8 DALY per 1,000 Indigenous Australians (or just under 2,900 DALY). This was 2.3 times as high as the burden due to dementia among other Australians (5.7 DALY per 1,000 non-Indigenous Australians).

The AIHW is currently revising the estimates for disease burden in Australia overall and for Indigenous Australians for the year 2018. See Burden of disease due to dementia for the overall dementia burden in Australia in 2018. Estimates for Indigenous Australians are scheduled for release on the AIHW website in late 2021.

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Dementia in vulnerable groups

Hospital care for Indigenous Australians with dementia

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

Indigenous men were more likely to be hospitalised due to dementia (25 hospitalisations per 10,000 Indigenous Australians) than Indigenous women (20 per 10,000 Indigenous Australians) (Figure 12.4).

See Hospital care for more information on overall hospitalisations for dementia in Australia and the Technical notes for more information on hospitals data. For information about the quality of Indigenous identification in hospitals data, see the following AIHW report *Indigenous identification in hospital separations data: quality report*.

Figure 12.4: Hospitalisations due to dementia in 2018–19: age-standardised rate, by sex

Figure 12.4 is a bar graph showing the age standardised rate of hospitalisations due to dementia for male and female Indigenous Australians in 2018–19. For every 10,000 Indigenous men, there were 25 hospitalisations due to dementia whereas for Indigenous women there were 20 hospitalisations due to dementia per 10,000 Indigenous women.

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The average length of stay among Indigenous Australians for hospitalisations due to dementia was 12.5 days, similar to the average length of stay for hospitalisations due to dementia in 2018–19 for all Australians (13 days).

There are many reasons why Indigenous Australians 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 Indigenous Australians 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 for Indigenous Australians vary by geographic area?

Given the small number of hospitalisations due to dementia for Indigenous Australians in a given year, the rate of hospitalisations due to dementia presented in this section was aggregated over a 3-year period (2016–17, 2017–18 and 2018–19).

After adjusting for population differences, between 2016–17 and 2018–19, the age-standardised rate of hospitalisations due to dementia for Indigenous Australians aged 40 and over, was:

- highest in Queensland (29 hospitalisations per 10,000 Indigenous Australians) closely followed by the Northern Territory and Western Australia (28 and 27 hospitalisations per 10,000 Indigenous Australians, respectively), and was lowest in Victoria and New South Wales (17 and 19 hospitalisations per 10,000 Indigenous Australians, respectively)
- highest in *Remote* and *very remote areas* (29 hospitalisations per 10,000 Indigenous Australians) closely followed by *Major cities* (27 hospitalisations per 10,000 Indigenous Australians), and was lowest in *Inner* and *outer regional areas* (17 hospitalisations per 10,000 Indigenous Australians) (Figure 12.5).

Figure 12.5: Hospitalisations for Indigenous Australians due to dementia between 2016-17 and 2018-19: age-standardised rate, by state and territory and remoteness area

Figure 12.5 is a bar graph showing the age standardised rate of hospitalisations due to dementia among Indigenous Australians between 2016–17 and 2018–19 by remoteness area and state or territory. The rates of hospitalisation due to dementia for Indigenous Australians were highest in Remote and very remote areas, Major cities, Queensland, Northern Territory and Western Australia.

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What were the most common principal diagnoses for Indigenous Australians when dementia was an additional diagnosis?

The statistics presented in the previous section relate to hospitalisations *due* to dementia, which are those where dementia was the principal diagnosis or main reason for hospitalisation. However, hospitalisation data also include information relating to 'additional diagnoses', which are those conditions that impact the provision of care but are not the principal diagnosis.

In 2018–19 there were 1,365 hospitalisations *with* dementia among Indigenous Australians.

When dementia was an additional diagnosis, the most common principal diagnoses among hospitalisations among Indigenous Australians aged 40 and over were:

- *Problems related to medical facilities and other health care*—15 hospitalisations per 10,000 Indigenous Australians
    - the majority of these hospitalisations (83%) related to people awaiting admission to residential aged care services
- *Fracture of the femur*—11 hospitalisations per 10,000 Indigenous Australians
- *Pneumonia, organism unspecified*—10 hospitalisations per 10,000 Indigenous Australians.

Other common principal diagnoses recorded for these hospitalisations included urinary system disorders, sepsis and a number of chronic conditions such as chronic obstructive pulmonary disease, cardiovascular diseases, and diabetes (Figure 12.6).

Indigenous men were more likely than Indigenous women to have a principal diagnosis of *Acute myocardial infarction* (20 hospitalisations per 10,000 for men compared with 6.4 per 10,000 for women), *Other chronic obstructive pulmonary disease* (11 per 10,000 for men compared with 6.5 per 10,000 for women) *and Type 2 diabetes mellitus* (6.9 per 10,000 for men compared with 2.6 per 10,000 for women). In contrast, Indigenous women were more likely than men to have a principal diagnosis of *Fracture of the femur* (25 per 10,000 for women compared with 7.2 per 10,000 for men), *Other sepsis* (18 hospitalisations per 10,000 for women compared with 4.9 per 10,000 for men) and *Pneumonitis due to solids and liquids* (14 per 10,000 for women compared with 4.1 per 10,000 for men).

Figure 12.6: Common principal diagnoses for hospitalisations of Indigenous Australians where dementia was an additional diagnosis in 2018-19: age-standardised rate, by sex

Figure 12.6 is a bar chart showing the age standardised rates of hospitalisations by common principal diagnoses and sex for Indigenous Australians where dementia was an additional diagnosis in 2018–19. Overall, the most common principal diagnosis was problems related to medical facilities and other health care, followed by fracture of femur and pneumonia, organism unspecified. There were substantial differences by sex across the principal diagnoses. For example, men with an additional diagnosis of dementia had higher rates of hospitalisation due to acute myocardial infraction, other COPD and type 2 diabetes mellitus while women had higher rates of hospitalisations due to fracture of femur, other sepsis and pneumonitis due to solids and liquids.

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Dementia in vulnerable groups

Aged care service use by Indigenous Australians with dementia

Indigenous Australians 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 2019). Differences in use are due to various factors, including (but not limited to):

- **government policies:** Indigenous Australians are identified as 1 of 10 'special needs groups' under the *Aged Care Act 1997*. As a result of the specific needs of Indigenous Australians, planning for aged care services focuses on Indigenous Australians 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 Indigenous Australians 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, Indigenous Australians may face challenges with accessing services that provide culturally appropriate care. Older Indigenous Australians 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 Indigenous Australians and should be designed to provide them with appropriate care, there are Indigenous-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 Indigenous Australians, in a culturally safe environment. Associated NATSIFACP providers work mainly in regional, remote, and very remote areas, and help Indigenous Australians 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 will all be 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 Indigenous and non-Indigenous Australians are experiencing population ageing, but Indigenous Australians 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 Indigenous Australians. Rates of aged care use are also generally higher for Indigenous Australians than for non-Indigenous Australians.

This page presents information on how Indigenous Australians 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 Indigenous-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, and by 2022, all will be 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 Indigenous and non-Indigenous Australians. Childhood stress and trauma has also been linked as a risk factor for developing dementia in later life among Aboriginal Australians (Radford et al. 2019).

While Stolen Generations survivors often prefer health and aged care services tailored to Indigenous Australians 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 & 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 (Royal Commission) 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 & 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 2019–20 is available from NSAF data as part of the National Aged Care Data Clearinghouse. Note that further work is needed to develop the NSAF dataset into a comprehensive resource for statistical reporting. Pending further development of the NSAF data set, the statistics presented here may be subject to change.

Aged care assessments

In 2019–20, just over 8,900 people, or 2.1% of all people who completed an aged care assessment (either a comprehensive or home support assessment) identified as being an Indigenous Australian. Dementia was recorded as a condition contributing to the care needs of over 500 Indigenous Australians, or 5.6% of all Indigenous Australians who completed an aged care assessment in 2019–20.

Among Indigenous Australians who completed an aged care assessment in 2019–20, those with dementia were older than those without dementia. Over half (55%) of Indigenous Australians with dementia were aged 75 and over compared with 24% of Indigenous Australians without dementia (Figure 12.7).

Figure 12.7: Indigenous Australians with and without dementia who completed an aged care assessment in 2019–20: percentage, by age

Figure 12.7 is a bar chart showing the percentage of Indigenous Australians with and without dementia who had completed an aged care assessment in 2019–20 by age. Just over 40% of Indigenous Australians with dementia who completed an aged care assessment, either a home support or a comprehensive assessment, were aged 75 to 84. A further 30% were aged 65–74 years. Indigenous Australians without dementia who completed an aged care assessment tended to be younger than those with dementia, with about three quarters being under the age of 75.

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The majority of Indigenous Australians with dementia (95%) who completed an aged care assessment were living in the community at the time of their assessment. Indigenous Australians with dementia were more likely to be living with family (46% of Indigenous Australians with dementia living in the community) and less likely to be living alone (26%) than non-Indigenous Australians with dementia (20% and 29%, respectively).

Assessment type and setting

Dementia is a common reason for needing a comprehensive assessment. Around 3 in 4 Indigenous Australians with dementia who completed an assessment in 2019–20 (74% or 370 people) completed a comprehensive assessment rather than a home support assessment (26% or 133 people). Of those with dementia who completed a comprehensive assessment, 3 in 5 had dementia recorded as the main condition impacting their care needs (59% or 218 people).

Over half (51%) of Indigenous Australians with dementia who completed a comprehensive assessment and 90% 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 Indigenous Australians with dementia (27%) 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 Indigenous Australians with dementia who completed an aged care assessment in 2019–20 were:

- High blood pressure (53% of all Indigenous Australians with dementia)
- Type 2 Diabetes mellitus (39%)
- High cholesterol (25%)
- Osteoarthritis (24%)
- Chronic lower respiratory diseases (18%) (Figure 12.8).

Figure 12.8: Leading 10 health conditions among Indigenous Australians who completed an aged care assessment in 2019–20: percentage, by dementia status

Figure 12.8 is a bar chart showing the top 10 comorbidities of Indigenous Australians with and without dementia who completed an aged care assessment in 2019–20, over half of Indigenous Australians with dementia who completed an aged care assessment also had hypertension (high blood pressure) and 39% had type 2 diabetes mellitus. While there were generally similar patterns in comorbidities between those with and without dementia, a higher proportion of Indigenous Australians with dementia also had hypertension and acute or chronic ischaemic heart disease than those without dementia.

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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 Indigenous Australians with dementia who completed a comprehensive assessment in 2019–20:

- 67%, or 249 people were approved for residential respite care
- 59%, or 218 people were approved for community-based care under the Home Care Packages Program
- 56%, or 206 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 Indigenous Australians 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 2019–20, about 244,000 people were living in permanent residential aged care services across Australia. Of these, just over 2,400 (1%) identified as being Indigenous. About half (52% or 1,260) of the Indigenous people living in permanent residential aged care had dementia.

Figure 12.9 shows the age profile of Indigenous Australians living in permanent residential aged care by dementia status. Indigenous men and women with dementia were older than Indigenous Australians without dementia.

Figure 12.9: Indigenous Australians living in permanent residential aged care 2019-20: number, by dementia status, age and sex

Figure 12.9 is a bar chart showing the number of Indigenous Australians living in permanent residential aged care in 2019–20 by age and sex. The number of Indigenous Australians with dementia living in residential aged care increases with age until 80–84. There is a weaker pattern by age for Indigenous Australians without dementia.0–. Both Indigenous men and women with dementia were older than Indigenous men and women without dementia living in residential aged care.

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The number of Indigenous Australians with dementia living in permanent residential aged care has increased in recent years from just under 1,100 in 2014–15 to just under 1,300 in 2019–20. Consistently, just over 50% of Indigenous Australians living in permanent residential aged care were living with dementia during this 5-year period.

Time spent living in permanent residential care

A person can have more than 1 episode of care in a residential aged care facility in a given year if for example, they moved from 1 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. Indigenous Australians with dementia who separated from their latest episode of care during 2019–20 had a median stay of 2.0 years, with the majority of separations due to death (89%).

Use of residential aged care services by state/territory and remoteness area

Figure 12.10 shows how the age-standardised rate of permanent residential aged care use among Indigenous Australians varied by dementia status and across geographic areas in 2019–20. After accounting for population differences:

- across states and territories, the rate of permanent residential aged care use for Indigenous Australians with dementia was highest in Western Australia (263 people with dementia per 10,000 Indigenous Australians) and lowest in New South Wales and Victoria (158 and 148 people with dementia per 10,000 Indigenous Australians, respectively). Due to data limitations, rates for Tasmania and the Australian Capital Territory are not included
- Indigenous Australians with dementia tended to use permanent residential aged care services at higher rates in more remote areas—224 people with dementia per 10,000 Indigenous Australians in *Remote* and *Very remote areas* compared with 178 and 197 people with dementia per 10,000 Indigenous Australians in *Inner and outer regional areas* and *Major cities,* respectively.

Figure 12.10: Indigenous Australians with dementia living in permanent residential aged care 2019-20: age standardised rate, by state/territory and remoteness

Figure 12.10 is a bar graph showing the age standardised rate of Indigenous Australians with dementia living in permanent residential aged care in 2019–20 by state and territory and remoteness area. The highest rates were in Western Australia and the Northern Territory (263 and 253 Indigenous residents with dementia per 10,000 Indigenous Australians respectively) as well as in *Remote and very remote* areas (224 Indigenous residents with dementia per 10,000 Indigenous Australians).

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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 3 medical conditions impacting care needs.

During 2019–20, depression and mood disorders (35%), arthritis and related disorders (33%), and urinary incontinence (28%) were the 3 most common health conditions among Indigenous Australians with dementia living in permanent residential aged care. Other common conditions included: type 2 diabetes mellitus (23%) hypertension (18%), chronic lower respiratory diseases (16%), stroke (14%), anxiety and stress related disorders (13%), pain (12%), and other mental and behavioural disorders (9.1%).

Care needs

The ACFI determines the funding allocation for a resident based on the level of care they require in 3 domains: *Activities of daily living*, *Cognition and behaviour* and *Complex health care*.

Among Indigenous Australians with dementia who were living in permanent residential aged care in 2019–20:

- 64% 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 Indigenous Australians without dementia (56%)
- 80% 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 Indigenous Australians without dementia (48%)
- 44% required high levels of care related to *Complex health care*, which includes ongoing medication needs and complex health-care procedures—this was slightly lower than for Indigenous Australians without dementia (53%).

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 Indigenous Australians 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 Indigenous Australians accessing residential aged care services.

Figure 12.11: Indigenous Australians living in permanent residential aged care with the highest care needs in each ACFI domain 2019–20: percentage, by sex and dementia status

Figure 12.11 is a bar chart showing the percentage of Indigenous Australians living in residential aged care with and without dementia who required high levels of care in each ACFI domain in 2019–20 by sex. The patterns for men and women are similar. Eighty percent of Indigenous Australians with dementia who lived in residential aged care required high levels of care in the cognition and behaviour domain, while 64% required high levels of care in the activities of daily living domain. A smaller proportion (44%) of Indigenous Australians with dementia living in residential aged care required high levels of care in the complex health care domain than Indigenous Australians without dementia (53%).

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Last updated 6/09/2021 v22.0

Dementia in vulnerable groups

Indigenous-specific health and aged care programs and caring roles among Indigenous Australians

Indigenous-specific health and aged care programs

There is uncertainty regarding how Indigenous Australians use government-subsidised health and aged care services due to issues related to: health and aged care workers preferring not to ask about Indigenous status; under-disclosure of Indigenous status when asked; inadequate data collection; and small Indigenous samples in surveys limiting meaningful extrapolations.

There is however robust evidence that Indigenous Australians prefer Indigenous-specific services. Studies have also shown that Indigenous Australians 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 Indigenous Australians 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 & 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 Indigenous Australians 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 Aboriginal 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.

Indigenous-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 Indigenous Australians with dementia. ACCHS can also act as a referral point to other available services like specialist care, and can help Indigenous Australians 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). Aboriginal health services and other primary health-care providers are also integral for managing risk factors for developing dementia, including providing services such as subsidised Indigenous-specific health checks and follow-up care, as well as pharmaceutical subsidies for Indigenous Australians with (or at risk of developing) a chronic disease (DoH 2020).

The National Health and Medical Research Council (NHMRC) has recently developed a roadmap for driving strengths-based, high-priority research on dementia among Indigenous Australians (NHMRC 2020). The NHMRC has also funded a number of targeted research projects that collaborate with Aboriginal Community Controlled Health Services and Indigenous communities to improve the prevention, detection and management of cognitive impairment and dementia (NHMRC 2018).

While Indigenous-specific services are important providers of high-quality dementia care for Indigenous Australians, 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 Indigenous Australians, including in services that are not Indigenous-specific (Royal Commission, 2021).

Caring for others with dementia

Family and other community members tend to play a strong caring role in Indigenous communities, and caring roles are often shared across the community. Elders play a key role in many Indigenous 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 Indigenous carers of people with dementia and/or carers of people with Indigenous Australians with dementia are not available. While there is limited information available on Indigenous Australians caring for someone with dementia specifically, previous work has highlighted challenges faced by Indigenous 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 Indigenous Australians than among non-Indigenous Australians. Indigenous 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 Aboriginal 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.

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Last updated 21/09/2021 v5.0

Dementia in vulnerable groups

Dementia among people from culturally and linguistically diverse backgrounds

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.

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 2016 Census of Population and Housing, almost half of the general Australian population (45% or 10.6 million people) were either born overseas or had one or both parents who were born overseas (ABS 2017). 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 & 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.

CALD among Australians with dementia

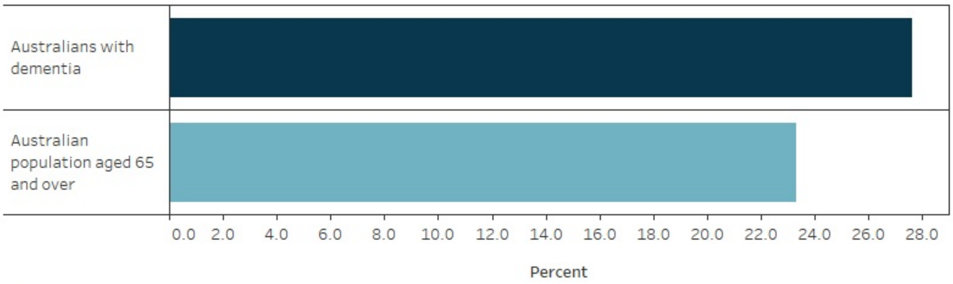
According to the SDAC, in 2018, 28% of people with dementia in Australia were born in a non-English speaking country (Figure 13.1). This proportion is slightly greater than what is reported for all Australians aged 65 and over in 2018 according to the ABS Estimated Resident Population (23% of Australians 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.

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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.

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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 2019–20 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 the SDAC (28%). Italy was the most common non-English speaking country of birth among people with dementia living in permanent residential aged care (4.0%). This was followed by mostly European countries, including Greece (2.0%), 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 2019–20: 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 2019–20. It shows that a slightly lower proportion of Australians with dementia living in residential aged care were born in a non-English country (23%), compared with all Australians aged 65 and over (24%).

Visualisation not available for printing

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.

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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.

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Dementia in vulnerable groups

Cultural and linguistic diversity among Australians who died with dementia

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
- religous 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%).

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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.

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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.

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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.

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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.

Visualisation not available for printing

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Dementia in vulnerable groups

Dementia among people with intellectual disabilities

People with intellectual disability are at a higher risk of developing dementia than the general Australian population (Evans & Troller 2018). Down syndrome in particular carries a higher risk of dementia, specifically for Alzheimer's disease (Evans & 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 & 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 2019–20, 62% 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). Whereas, dementia was recorded among 54% of residents who did not have Down syndrome.
- In 2019, 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).

Note, there are limitations with these data. The ACFI 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 & 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 & 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).

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Dementia in vulnerable groups

Dementia among veterans

As of 30 June 2018, the Department of Veterans' Affairs (DVA) estimated that there were 641,000 living Australian veterans who have ever served in the Australian Defence Force, either full time or in the reserves (AIHW 2018).

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, veterans are able to access the Veterans Home Care Program for medical and personal care services and a DVA home care program 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.

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Dementia in vulnerable groups

Dementia in the LGBTIQ+ community

There is limited literature and data exploring the needs of LGBTIQ+ Australians living with dementia. However, there is discussion surrounding the prior treatment of LGBTIQ+ Australians, and how this may impact the experiences of LGBTIQ+ people living with dementia. Historically, LGBTIQ+ Australians have faced the possibility of arrest and imprisonment, psychiatric incarceration and enforced attempted 'cure' treatments as a result of disclosure (Crameri et al. 2015).

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 conducted in partnership with Alzheimer's Australia documented the experiences and needs of LGBTI people living with dementia and the *Trans Ageing and Aged Care* project conducted in collaboration with the Gender Centre NSW, Transgender Victoria and FTM Shed documented trans people's experiences of ageing and aged care, including their experiences of dementia. Both projects undertook a series of detailed interviews; including 10 interviews with 17 participants in the *LGBTI Dementia* project, and 15 interviews with 15 participants in the *Trans Ageing and Aged Care* project.

Despite the lack of current research available on LGBTIQ+ Australians' with dementia, programs, resources and frameworks have been produced recognising the LGBTIQ+ population as a priority group among those with dementia and more broadly in the ageing population:

- The *LGBTI and dementia* guide is a free resource from Dementia Australia for people living with dementia who are part of the LGBTI community, their partners, family and friends, with information on dementia, support services and finding inclusive service providers, legal rights and advanced care planning. Dementia Australia also provide links to a range of resources specifically for LGBTIQ+ people with dementia, their carers, friends and family.
- The Rainbow Tick Standards is a current national accreditation program that was created to help guide LGBTIQ+ Australians in choosing inclusive service providers. The Standards are a set of six quality standards developed by GLHV (formerly known as Gay and Lesbian Health Victoria), in collaboration with Quality, Innovation and Performance. The Rainbow Tick is an optional accreditation for service providers, and are not the sole measure for inclusivity practice.
- 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 to older LGBTI people.

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Health and aged care expenditure on dementia

Key statistics

$3 billion of the total direct health and aged care system expenditure in 2018–19 was spent directly on dementia

$1.7 billion was spent on residential aged care services

$596 million was spent on community-based aged care services

$383 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 2018–19. It includes the estimated expenditure on:

- aged care services—including aged care assessments, community-based and residential aged care services
- health services—including hospital services and out-of-hospital medical services such as general practitioner (GP) and other medical specialist services, diagnostic services, allied health services and medications
- dementia support services.

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

The year 2018–19 is presented as this is the latest year of data available from the AIHW Disease Expenditure Database. In this report we focus on presenting 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. Our estimates have been adjusted to reflect the contribution of comorbidities to the costs for treatment and care of people with dementia and do not include estimates of 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 by expanding the box *Information sources and coverage of dementia expenditure estimates.*

Information sources and coverage of dementia expenditure estimates

As there is no single source of data to estimate total expenditure due to dementia, a number of different data sources of varying quality were used. The majority of the aged care estimates presented are based on direct government expenditure. However, non-government expenditure (for example, by individuals, private health insurers and other non-government sources) is included in health expenditure estimates in relation to hospital services, out-of-hospital medical services and prescription medications.

Health-care expenditure estimates are 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 health conditions based on a range of available diagnostic and service use data.

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 Programme) is shown separately.

Due to data limitations, the dementia expenditure estimates presented in this section do not include expenditure for:

- specialised mental health care services
- state and territory government expenditure on aged care

- government payments to support people with dementia (such as payments made under the National Disability Insurance Scheme) and payments to support carers of people with dementia who are prevented from undertaking substantial paid employment due to their caring role
- indirect expenditure—such as travel costs for patients, the social and economic burden on carers and family, and lost wages and productivity.

The dementia expenditure estimates also exclude government funding for dementia research, which is made largely through grant opportunities provided by the National Health and Medical Research Council (NHMRC). However, over $438 million in direct funding to over 400 dementia research projects has been awarded since 2014. A full list of projects funded through the NHMRC is available at Dementia research NHMRC.

The quality and availability of data on dementia-specific programs, packages and services vary widely, so the ability to estimate expenditure attributable to dementia (as opposed to expenditure on people with dementia) also varies. Further, funding for services provided to the general public to bring awareness to and support dementia in the community (such as the *Dementia Friendly Communities* program, which is funded under the Australian Government Dementia and Aged Care Services Fund) was not included in the direct expenditure for dementia.

The total estimated direct expenditure for dementia presented in this report should be considered a conservative estimate and interpreted with caution. Refer to the Technical notes for more information on the methodology used to estimate the direct health and aged care expenditure estimates for dementia.

Total estimated expenditure on dementia

It is estimated that almost $3.0 billion of the total direct health and aged care system expenditure in 2018–19 was directly attributable to the diagnosis, treatment and care of people with dementia.

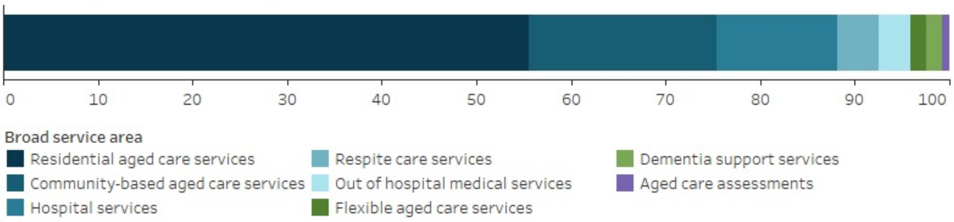
The health and aged care system expenditure directly attributable to dementia was mainly for:

- residential aged care services—$1.7 billion, or 56% of the total direct health and aged care system expenditure for dementia
- community based aged care services—just under $596 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 $383 million, or 13%
    - public and private admitted patient hospital care, public hospital outpatient clinics and public hospital emergency department care
- community-based and residential respite care—$133 million, or 4.4%
- out-of-hospital medical services—$99.2 million, or 3.3%
- dementia support programs and initiatives—$50.6 million, or 1.7% (Figure 14.1).

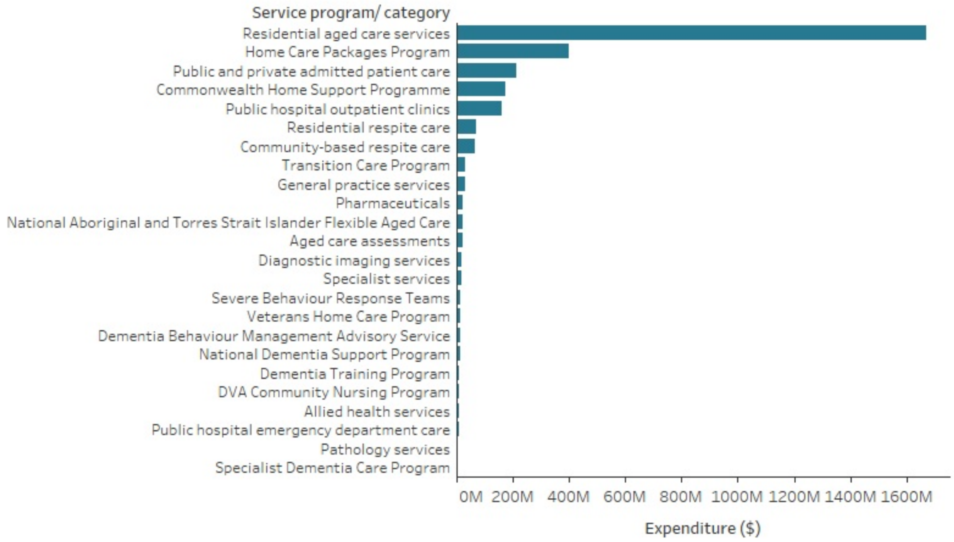
Figure 14.1: Health and aged care system expenditure attributable to dementia in 2018-19: (a) percentage by broad area and (b) expenditure by service area

Figure 14.1 is two bar graphs that show the distribution of Australian Government expenditure that was directly attributable to dementia in 2018–19. The first bar graph shows 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. The second graph shows the distribution of dementia expenditure by service area sub-categories. The majority of expenditure was on residential aged care services, followed by the Home Care Packages Program and public and private admitted patient care

a) Percentage of total dementia expenditure by broad service area



b) Dementia expenditure by service area



Notes:
1. DVA refers to Department of Veterans' Affairs
2. See technical notes for sources and methods used to derive estimates for each of the service areas/programs.

http://www.aihw.gov.au

The health and aged care expenditure estimates above reflect costs that are thought to be directly attributable to dementia and therefore they do not include expenditure related to other conditions. However, it is important to recognise that many people have co-existing conditions, some of which may be directly associated with dementia. In addition, dementia is often the main reason for people using certain health and aged care services, particularly residential aged care. For example, the estimated costs of care related to managing co-existing conditions in people with dementia who are living in residential aged care totals $6.8 billion. If these costs were included, the total direct health and aged care system expenditure for people with dementia (rather than directly attributable to dementia) would be $9.8 billion.

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Health and aged care expenditure on dementia

Expenditure on aged care services

Total aged care expenditure

Aged care services are a vital resource for older Australians, including the growing number of people with dementia. There are a number of government-funded aged care services available to provide care and assistance to those in need. These include: home-based care and support, short-term care and respite, and residential aged care services. In 2018–19, $18.6 billion was spent on aged care services and $2.5 billion of this was directly for dementia.

Aged care accounted for most (82%) of the total direct health and aged care system expenditure on dementia. Aged care expenditure for dementia included:

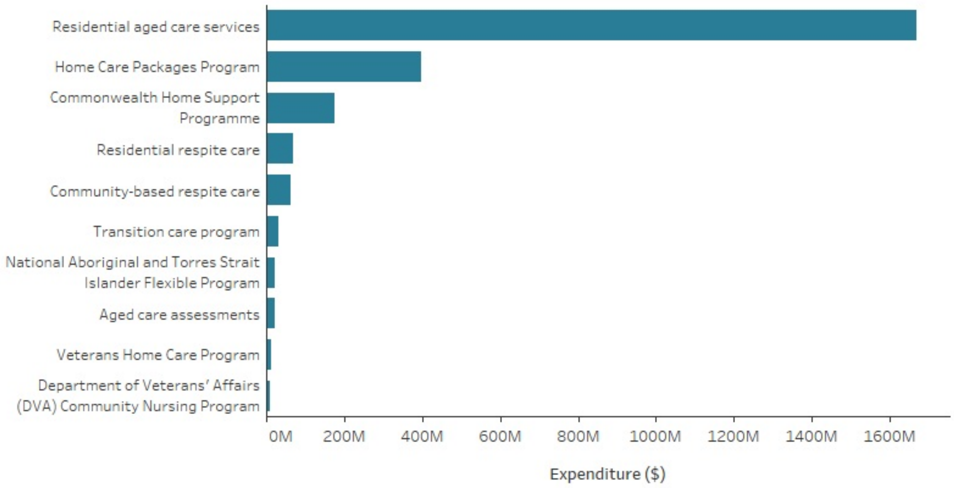
- $1.7 billion for people with dementia in permanent residential aged care facilities
- $397 million for people with dementia receiving Home Care Packages—services that provide home-based care to people with greater or more complex care needs living in the community
- almost $176 million for people with 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
- $133 million for community-based and residential respite care services (Figure 14.2).

Other aged care related funding for people with dementia included: over $31 million for the Transition Care Program—which provides short-term care for up to 12 weeks for people who have been discharged from hospital and over $21 million for providing aged care assessments for people who are eligible for government-funded aged care services in order to assign appropriate services to suit that person's needs. Almost $22 million was also provided for people with dementia receiving culturally appropriate aged care services through the National Aboriginal and Torres Strait Islander Flexible Aged Care Program.

A further $23 million was for aged care services for Veteran Gold Card or White Card holders with dementia. This included $8.9 million for the Department of Veteran Affairs (DVA) Community Nursing program—which provides a range of medical and personal care services to DVA clients to support them living in their own homes and $14 million for the Veterans' Home Care Program, which provides practical care for DVA clients who require minimal help to remain living independently.

Figure 14.2: Estimated Australian Government expenditure on aged care programs that was attributable to dementia in 2018–19

Figure 14.2 is a bar graph that shows Australian Government expenditure on different aged care programs in 2018–19 that was directly attributable to dementia. The largest area of spending was residential aged care services (with spending of $1.7 billion) followed by Home Care Packages ($397 million), the Commonwealth Home Support Programme ($176 million) and community-based and residential respite care services ($133 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

The proportion of each programs' annual expenditure that was directly for dementia ranged from 7.9% of the Commonwealth Home Support Programme (excluding respite care) to 49% of spending on the National Aboriginal and Torres Strait Islander Flexible Aged Care Program (Table S14.2).

It is important to note that the dementia expenditure estimates for Home Care Packages, Commonwealth Home Support Programme and the DVA Home Care Program are based on the length of time a person with dementia was receiving the Dementia and Cognition Supplement in each of the Home Care Package levels. This supplement is available to people with moderate or severe cognitive impairment to offset the additional costs associated with their care. However, as not every person with dementia receives this supplement, the expenditure estimates presented here will be an underestimate of the true cost.

Refer to Community-based aged care services for more information on the Dementia and Cognition Supplement and the provision of aged care services for people with dementia.

Residential aged care

Residential aged care services are available for older Australians who are approved for entry following an assessment by an Aged Care Assessment Team. The Australian Government provides payments to approved aged care providers to cover care-associated costs for each permanent resident. Refer to Box 14.2 for more information on residential aged care funding.

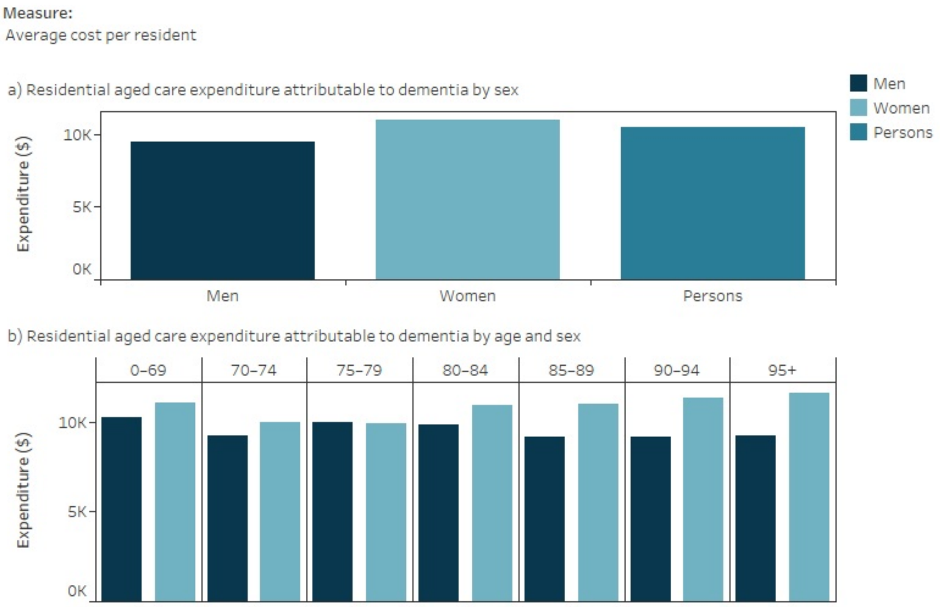
In 2018–19, the total cost of care for permanent residents with dementia was almost $6.8 billion. When the costs associated with other co-existing conditions in residents with dementia are excluded, the total cost of care directly attributable to dementia was just under $1.7 billion (Figure 14.3).

Women with dementia accounted for 68% or $1.1 billion of the residential aged care expenditure directly attributable to dementia. Expenditure was highest for women aged 90–94 ($306.4 million), closely followed by women aged 85–89 ($302.1 million). By contrast, expenditure was highest for men aged 85–89 ($130.2 million), followed by men aged 80–84 ($114.6 million). As women tend to live longer than men, women account for both a greater proportion of people with dementia in Australia and a greater number of permanent residents in aged care facilities.

The average yearly cost that was attributed to dementia per resident was approximately $10,500 in 2018–19. The average cost was higher for women ($11,000 per resident) than men ($9,500) overall. This was also the case in each age group, except for those aged 75–79, where average expenditure for men was slightly higher ($10,000 compared with $9,900 for women).

Figure 14.3: Estimated Australian Government expenditure on permanent residents of aged care facilities in 2018–19 that was directly attributable to dementia: (a) by sex and (b) by age and sex

Figure 14.3 is two bar graphs that shows estimated Australian Government expenditure on residents of aged care facilities in 2018–19 that was directly attributable to dementia, both in terms of total expenditure and average cost per resident. The first graph disaggregates this expenditure by sex, and shows that females accounted for approximately two thirds of expenditure. Average cost per resident was also slightly higher than males. The second graph disaggregates this expenditure by age and sex and shows that the difference in both total expenditure and average cost per resident between sexes, was largely due to higher expenditure attributable to females aged 80 years and over.



Note: Expenditure for residential aged care services is for permanent residents only.
Source: AIHW analysis of Aged Care Funding Instrument and ABS Survey of Disabilility, Ageing and Carers, 2018.
http://www.aihw.gov.au

Box 14.2: Residential aged care funding and estimated residential aged care expenditure for dementia

Residential aged care is primarily available to older Australians who can no longer live at home, and includes accommodation in a 24-hour staffed facility along with health and nursing services (Department of Health 2021). For approved applicants, places in residential aged care facilities are subsidised by the Australian Government, and the Aged Care Funding Instrument (ACFI) is used to allocate government funding to aged care providers based on the day-to-day needs of the residents in their care.

Additional supplements may also be provided for residents with specific care needs, such as people who require oxygen to assist with breathing or need to be fed through a tube (enteral feeding), as well as veterans and people who are experiencing homelessness. The basic subsidy is means tested, and may be reduced for an individual for a number of reasons, including if an individual's income is above a set threshold as they then should be able to afford to contribute to payment of their own care (Department of Health 2020). More information on the payments for residential aged care is found at: My Aged Care.

Data collected though the ACFI, along with related administrative data maintained by the Department of Health were used to estimate Australian Government expenditure for permanent residents with dementia in residential aged care facilities. Note that these expenditure estimates relate only to permanent residents of facilities which are subsidised by the Australian Government and who received an ACFI assessment and had dementia recorded on their assessment. A snapshot of people in permanent residential care on 30 June 2019 showed that ACFI data capture almost all people in permanent residential aged care subsidised by the Australian Government (99.7%) (AIHW 2020). The ACFI data excludes people with dementia who live in aged care homes which are not subsided by the Australian Government.

Therefore, the residential aged care expenditure estimates attributable to dementia in this report are a minimum estimate of government expenditure on residential aged care services for dementia.

Home-based aged care

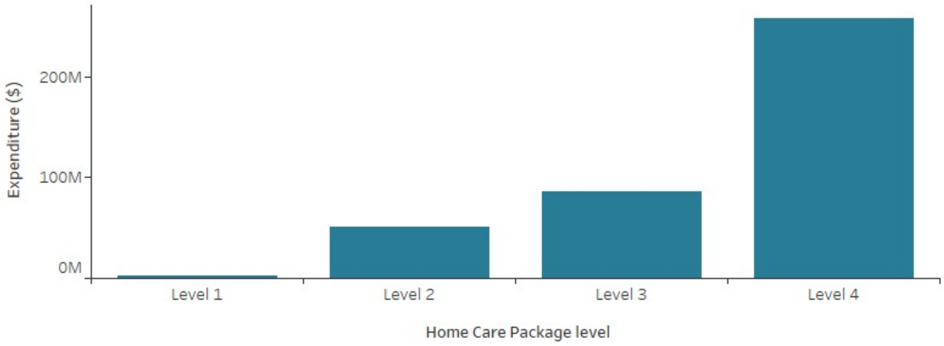
The Australian Government provides 2 main home-based service programs—the Commonwealth Home Support Programme and the Home Care Packages Program—available for eligible older Australians so that they can continue to live in their own home.

The Home Care Packages Program had more expenditure and a greater proportion of its total funding directly on dementia ($397 million and 16%) compared with the Commonwealth Home Support Programme ($176 million and 7.9%) because Home Care Packages are designed for more complex care needs (including dementia).

There are 4 levels of Home Care Packages with different funding amounts that cover basic support needs through to high care needs. Of the $397 million spent on people with dementia receiving Home Care Packages, $258 million or 65% was for Level 4 packages, which are designed for people with high care needs, and who require the most extensive home-based aged care services (Figure 14.4).

Figure 14.4: Australian Government expenditure for recipients of Home Care Packages with dementia, by Home Care Package level, 2018–19

Figure 14.4 is a bar graph that shows estimated Australian Government expenditure on recipients of Home Care Packages with dementia in 2018–19, by Home Care Package level. It shows that spending is higher for higher levels of Home Care Packages, with approximately two-thirds (nearly $258 million) of the total expenditure attributable to recipients of Level 4 packages.



Source: AIHW Analysis of National Aged Care Data Clearinghouse.
http://www.aihw.gov.au

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Last updated 22/09/2021 v28.0

Health and aged care expenditure on dementia

Total health expenditure and expenditure on hospital services

Key statistics

In 2018–19, almost $482 million was spent on health services directly for dementia

$185 million was spent on public hospital admitted patient care and $29 million for private hospital admitted patient care

Almost $162 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 without

This page presents the total health expenditure directly attributable to dementia in 2018–19, as well expenditure on hospital services, including:

- Admitted patient care in public hospitals
- How expenditure for hospitalisations differed between public and private hospitals
- How dementia affects the cost of hospitalisations in public hospitals for common principal diagnoses
- Public hospital outpatient clinics and emergency department care expenditure

Total health expenditure

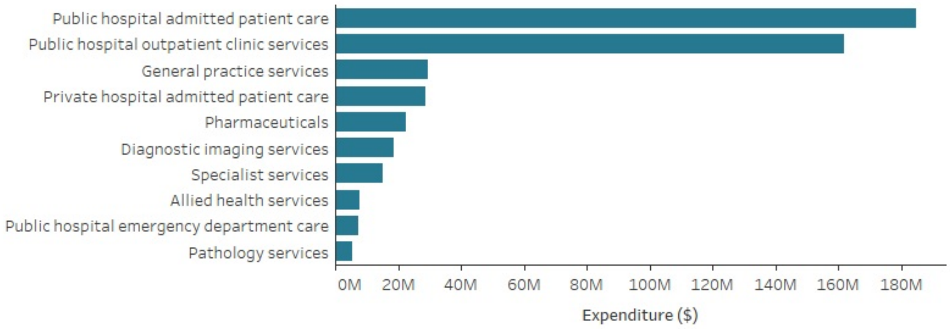
In 2018–19, it was estimated that almost $482 million (or 16% of the total direct health and aged care system expenditure on dementia) was for health expenditure alone. The majority of this expenditure was for:

- hospital-related services—almost $383 million, which included:
  - $185 million for public hospital admitted patient care and $29 million for private hospital admitted patient care
  - $162 million for outpatient clinics in public hospitals
  - $7.5 million for emergency department care in public hospitals
- GP services—almost $30 million
- pharmaceuticals—just under $23 million (Figure 14.5)

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 40% of the total cost of hospitalisations with a principal diagnosis of dementia.

Figure 14.5: Estimated health-care system expenditure attributable to dementia in 2018-19: by health-care area

Figure 14.5 is a bar graph that shows Australian Government health-care system expenditure attributable to dementia in 2018–19, by health-care area. The graph shows that the majority of expenditure was on public hospital admitted patient care (nearly $185 million) and public hospital outpatient clinic services (nearly $162 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

Admitted patient care in public hospitals

In 2018–19, $185 million was spent on public hospital admitted patient care for dementia. Of this, 54% or $100 million was for hospitalisations where dementia was the principal diagnosis or the main reason for admission (Figure 14.6). The remaining $85 million (46%) 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.

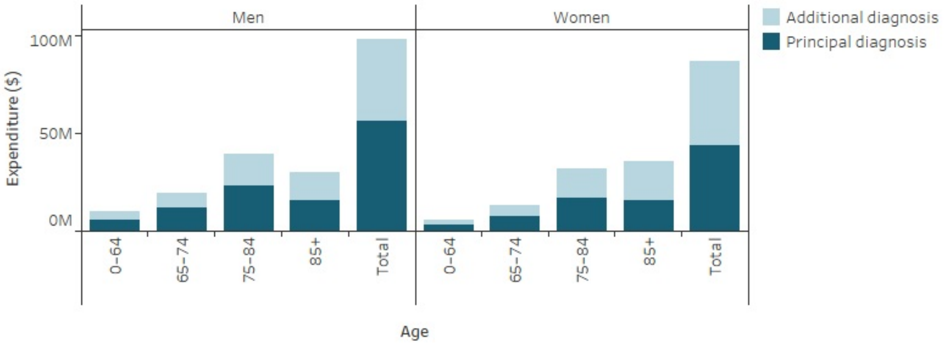
Of the admitted patient care expenditure for dementia in public hospitals:

- males with dementia accounted for a greater proportion (53% or $98 million) than females with dementia (47% or almost $87 million). This was mainly due to expenditure on males with dementia as the principal diagnosis ($56 million compared with just under $44 million for females)
- $136 million was for people aged 75 and over (74% of the admitted patient care expenditure related to dementia)
- $72 million was for hospitalisations of people aged 75 and over where dementia was the principal diagnosis (or 52% of the admitted patient care expenditure related to dementia for that age group)—this proportion was higher among people aged under 65 (56%)
  - this is likely due to people often having poorer health and a greater number of comorbidities at older ages and at times being hospitalised for these conditions rather than their dementia
- when dementia was an additional diagnosis, expenditure was fairly similar by sex ($42 million for males compared with just under $43 million for females).

These patterns are reflective of hospitalisations for dementia. See Hospital care for more information on hospitalisations for dementia in recent years.

Figure 14.6: Public hospital admitted patient care expenditure for dementia by age and sex in 2018–19: by whether dementia was a principal or additional diagnosis

Figure 14.6 is a bar graph that shows Australian government expenditure on public hospital admitted patient care attributable to dementia in 2018–19, by age, sex and whether dementia was a principal or additional diagnosis. Total expenditure was slightly higher for males, compared with females, primarily due to higher spending on those where dementia was a principal diagnosis. Expenditure was also higher for those aged 75–84 and 85 and over. A little over half (54%) of expenditure was on hospitalisations where dementia was the principal diagnosis.



Source: AIHW analysis of National Hospital Morbidity Database and National Hospital Cost Data Collection
http://www.aihw.gov.au

How does dementia expenditure for hospitalisations differ between public and private hospitals?

This section focuses on the total cost of hospitalisations with a principal diagnosis of dementia in public hospitals compared with the cost for hospitalisations in private hospitals. Due to limitations in additional diagnosis information in private hospital admitted patient data, the costs in this section include costs associated with other health conditions. On average, there were 5–6 health conditions (other than dementia) recorded per hospitalisation in public hospitals compared with 3 conditions in private hospitals (Table S14.6). This may reflect differences in how diagnoses are recorded between private and public hospitals, as opposed to the number of health conditions impacting care provision.

In 2018–19, the average total cost of a hospitalisation with a principal diagnosis of dementia was just under $12,200 for public hospitals and $7,700 for private hospitals (Figure 14.7a). This difference was largely due to differences in the average length of stay, because the average cost per patient per day was similar (approximately $930) in both public and private hospitals (Figure 14.7b). The differences in the total cost likely reflect the complexity of cases that are treated in different hospital types, and patients in public hospitals possibly having more comorbidities than patients in private hospitals.

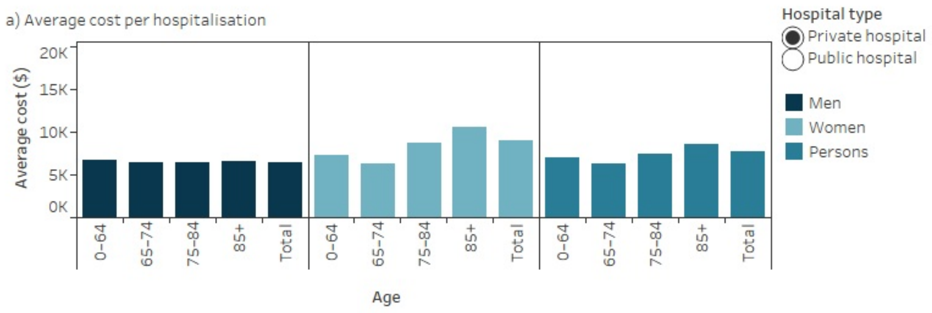
The average cost per patient per day decreased only slightly as the age of the patient increased (Figure 14.7b). Those with younger onset dementia (aged under 65) had the highest costs per patient per day (almost $1,200 for public and over $1,300 for private hospitals). However, these hospitalisations accounted for only 6.0% of public hospital and 4.3% of private hospital hospitalisations where dementia was the principal diagnosis. By comparison, patients with dementia aged 85 and over had the lowest average cost per patient per day ($840 for public and $898 for private hospitals) but accounted for 39% of public hospital and 42% of private hospital hospitalisations where dementia was the principal diagnosis.

For most age groups, the average cost per patient per day was similar for males and females except among those aged under 75 in private hospitals. This was $1,201 for males aged under 65 and $929 for males aged 65–74, compared with $1,409 for females aged under 65 and $1,130 for females aged 65–74.

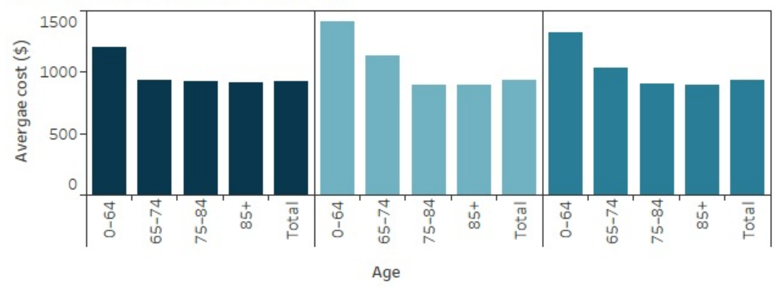
Figure 14.7: Hospitalisations where dementia was the principal diagnosis by sex, age and hospital type in 2018–19: (a) average cost per hospitalisation and (b) average cost per admitted patient per day

Figure 14.7 shows two bar graphs related to Australian government expenditure on admitted patient care for people with a principal diagnosis of dementia in 2018–19. This expenditure is not just limited to the proportion of spending attributable to dementia. The first bar graph shows the average cost per hospitalisation, by age, sex and whether the hospital was public or private. The average cost per hospitalisation was $12,200 for public hospitals and $7,700 for private hospitals. The average costs were slightly higher for males across all age groups in public hospitals but higher for females in private hospitals, particularly in the older age groups. The second graph shows the average cost per admitted patient, per day. There is little difference between private and public hospitalisations. Those aged under 65 had a larger average cost per day. Average cost per day was similar between sexes for most age groups.

a) Average cost per hospitalisation



b) Average cost per admitted patient, per day



Source: AIHW analysis of National Hospital Morbidity Database and National Hospital Cost Data Collection.
http://www.aihw.gov.au

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 a number of common principal diagnoses seen among older people, as well as people with dementia. These included principal diagnoses for a number of cardiovascular conditions, type 2 diabetes, fractures, infections and signs and symptoms commonly seen in those with advanced dementia (Table 14.1).

Of the principal diagnoses examined here, the most common in 2018–19 were *Fracture of femur (S72)* where dementia was an additional diagnosis (almost 7,200 hospitalisations). On average, people with dementia stayed 1 to 6 days longer in hospital than those without dementia, depending on the main condition.

The average cost per hospitalisation was greater among people with dementia than people without dementia for the majority of the other common principal diagnoses, including the most expensive condition: *Fracture of femur (S72)*. This was just over $19,300 on average, per hospitalisation for people with dementia compared with just over $15,000 on average, per hospitalisation for people without dementia.

Compared to people without dementia, the greatest difference in the average cost of hospitalisations for people with dementia was for:

- *Atrial fibrillation and flutter (I48)*—2.5 times greater for patients with dementia ($11,300) than without dementia ($4,600)
- *Urinary tract infection, site not specified (N390)*—1.9 times greater for patients with dementia ($9,000) than without dementia ($4,800)
- *Abnormalities of gait and mobility (R26)*—1.8 times greater for patients with dementia ($5,500) than without dementia ($3,100) (Table 14.1).

Osteoarthritis of knee (M17) had a similar cost for those with and without dementia, and *Pneumonitis due to solids and liquids (J69), Sepsis unspecified (A419)* and *Osteoarthritis of hip (M16)* had on average, a lower cost per hospitalisation for those with dementia than without dementia.

Table 14.1: Average cost per hospitalisation in a public hospital for patients with dementia compared to patients without dementia in 2018–19: by select principal diagnoses

Principal diagnosis (ICD-10 code)	**Average cost, per hospitalisation ($)**		**Average cost difference ($)**	**Rate ratio**
	With dementia	**Without dementia**		
Atrial fibrillation and flutter (I48)	11,311	4,562	6,749	2.5
Urinary tract infection, site not specified (N390)	9,015	4,805	4,211	1.9
Abnormalities of gait and mobility (R26)	5,538	3,106	2,433	1.8
Type 2 diabetes mellitus (E11)	16,282	11,395	4,888	1.4
Fracture of rib(s), sternum and thoracic spine (S22)	11,844	8,763	3,082	1.4
Pneumonia, organism unspecified (J18)	10,456	7,542	2,915	1.4
Fracture of femur (S72)	19,333	15,421	3,912	1.3
COPD with acute lower respiratory infection (J440)	11,164	8,379	2,785	1.3
Heart failure (I50)	12,475	9,855	2,620	1.3
Fracture of lumbar spine and pelvis (S32)	11,221	9,735	1,486	1.2
Cerebral infarction (I63)	11,561	10,049	1,513	1.2
Delirium, not induced by alcohol and other psychoactive substances (F05)	10,308	9,694	614	1.1
Osteoarthritis of knee (M17)	16,022	16,612	-591	1.0
Pneumonitis due to solids and liquids (J69)	9,187	10,010	-822	0.9
Sepsis, unspecified (A419)	12,414	13,305	-891	0.9
Osteoarthritis of hip (M16)	13,908	16,967	-3,059	0.

Notes:

1. ICD-10-AM refers to the International Classification of Diseases 10th revision Australian Modification.

2. Average cost difference is the average cost per hospitalisation with dementia minus the average cost per hospitalisation without dementia. Numbers may not add up due to rounding.

3. Rate ratio is the average cost per hospitalisation with dementia divided by the average cost per hospitalisation 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.

As the cost differences shown in Table 14.1 may be attributable to dementia as well as other co-existing conditions, the contribution of dementia to the average cost per hospitalisation was examined. Dementia was directly attributable for between 7% (for *Fracture of lumbar spine and pelvis (S32)*) and 24% (for *Abnormalities of gait and mobility (R26)*) of the average cost per hospitalisation among the examined principal diagnoses (Table S14.8).

Public hospital outpatient clinics and emergency department care expenditure

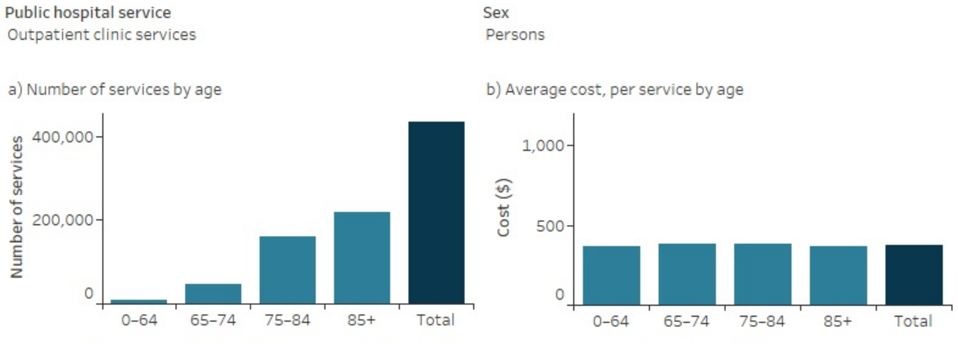
In 2018–19, $162 million was spent on non-admitted patient care for dementia in public hospital outpatient clinics, equivalent to 5.4% of the direct health and aged care expenditure attributable to dementia. Services provided in outpatient clinics include; consultations with specialist medical practitioners; allied health and specialist nursing care; diagnostic and other procedures; dispensing of medicines; and some community health services provided by hospitals (AIHW 2019). Aged care assessments, geriatric medicine, hospital avoidance programs, and palliative care accounted for the greatest outpatient expenditure for dementia.

A further $7.5 million was spent on emergency department (ED) care in public hospitals, equivalent to 0.25% 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. Refer to the Technical notes for more information on health condition coding in ED data.

The average cost of a service for dementia in a public hospital outpatient clinic was $375 and for an ED presentation was almost $1,000 (Figure 14.8). There was little difference in these costs between male and female patients and by age.

Figure 14.8: Public hospital outpatient clinic services and emergency department presentations for dementia by age and sex in 2018–19: (a) number of services and (b) average cost, per service

Figure 14.8 is a set of two bar graphs showing the number and average cost of public hospital outpatient clinic services and emergency department presentations for dementia in 2018–19, by age and sex. The number of services for both emergency department presentations and outpatient clinic services increases with age, although there is little difference in the average cost per service. Number and average cost per service does not vary substantially by sex.



Source: AIHW analysis of National Hospital Morbidity Database and National Hospital Cost Data Collection.
http://www.aihw.gov.au

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Last updated 23/09/2021 v31.0

Health and aged care expenditure on dementia

Expenditure on out-of-hospital services

In 2018–19, over $99 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 21% of the total direct health expenditure on dementia and 3.3% 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.

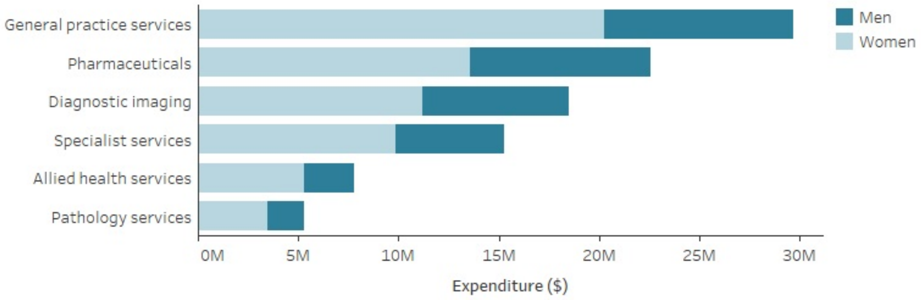
Services contributing to the out-of-hospital medical expenditure for dementia were (Figure 14.9):

- general practice services—almost $30 million, or 30% of the out-of-hospital medical expenditure for dementia
- pharmaceuticals dispensed under the Pharmaceutical Benefits Scheme (PBS)—$23 million, or 23%
    - This includes dementia specific medicines and a range of other medications prescribed for the management of dementia symptoms.
- diagnostic imaging—$18 million, or 19%
- specialist services—over $15 million, or 15%

Almost two-thirds (64% or almost $64 million) of the out-of-hospital expenditure was for females with dementia. For each out-of-hospital area, females comprised a much greater proportion of the expenditure than males, largely due to the greater number of females with dementia than males.

Figure 14.9: Expenditure on out-of-hospital medical services for dementia by sex in 2018-19

Figure 14.9 is a bar graph that shows expenditure on out-of-hospital medical services for dementia in 2018–19 by sex. General practice services was the highest area of expenditure, followed by pharmaceuticals, diagnostic imaging and specialist services. Females comprised the majority of expenditure in each out-of-hospital area, comprising almost two-thirds of out-of-hospital expenditure overall.



Note: Pharmaceuticals include prescriptions dispensed under the Pharmaceutical Benefits Scheme.
Source: AIHW analysis of Bettering the Evaluation and Care of Health data and AIHW disease expenditure database.
http://www.aihw.gov.au

As the number of people with dementia increases with age, so does the out-of-hospital expenditure for dementia: $3.5 million, or 3.6% of the out-of-hospital expenditure for dementia was for people with younger onset dementia (aged under 65) whereas 40% or $40 million was for people with dementia aged 75–84 and 43% or just under $43 million was for people aged 85 and over (Figure 14.10).

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 over $88 million) was from Australian Government benefits.

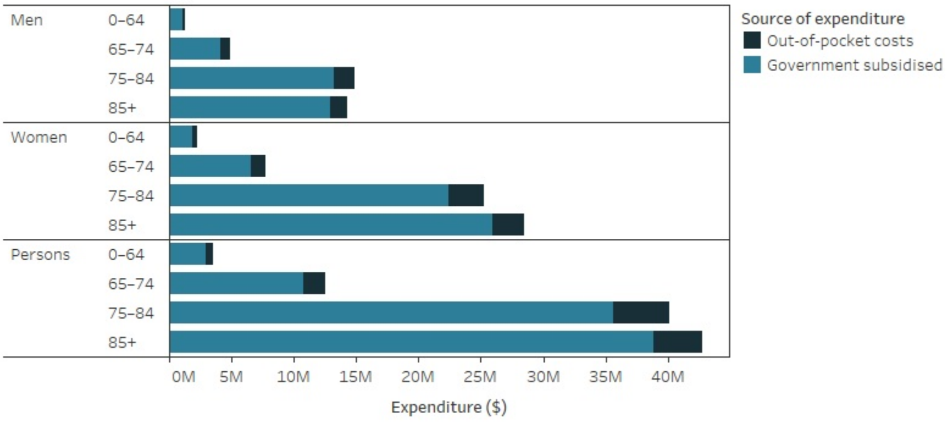
There was little variation in the percentages of out-of-hospital medical expenditure from benefits and out-of-pocket costs by sex, but these differed by age. While the overall out-of-hospital medical expenditure was considerably less for those with younger onset dementia, out-of-pocket expenses accounted for a greater proportion of the out-of-hospital medical expenditure for those aged under 65 (18%) than those aged 85 and over (9.2%).

These differences are likely due to the Medicare safety net thresholds. These thresholds are designated amounts that a person can spend out-of-pocket for MBS services. Once a person reaches this threshold, Medicare benefits increase, which reduces out-of-pocket costs (Services Australia 2021). Older people have greater access to concession cards, which reduce the safety net thresholds, resulting in lower out-of-pocket costs. In addition, older patients are more likely to be reaching these thresholds earlier as they tend to have more comborbidities than younger patients and thus utilise health services more frequently.

Figure 14.10: Out-of-hospital medical expenditure for dementia in 2018-19 by age, sex and source of expenditure

Figure 14.10 is a bar graph that shows out-of-hospital medical expenditure for dementia in 2018–19 by age, sex and source of expenditure. There were higher levels of expenditure at older ages, as the number of people with dementia increases, particularly for those aged 75–84 and 85 and over. Government expenditure accounted for the majority of expenditure (89%), with the remainder being out-of-pocket costs.

A larger proportion of expenditure for those at older ages was government expenditure. This is likely due to older people being more likely to have concession cards which reduce out-of-pocket costs.



Note: Out-of-hospital expenditure for dementia includes expenditure for GP and specialist services, allied health services, pharmaceuticals and tests involved in the diagnosis and management of dementia.
Source: AIHW analysis of Bettering the Evaluation and Care of Health data and AIHW disease expenditure database.
http://www.aihw.gov.au

Medications for dementia

There are 4 dementia-specific medicines—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. Refer to Prescriptions for dementia-specific medications for information on the dispensing of scripts for these medications in Australia in recent years.

In 2018–19, the total expenditure on dementia-specific medications was almost $20 million. This included Australian Government expenditure ($15 million, or 77% of expenditure on dementia-specific medications) and out-of-pocket expenses by patients ($4.6 million or 23%). Note, these estimates may include a small amount of expenditure for off-label prescribing of these medications which isn't captured in the PBS/RPBS.

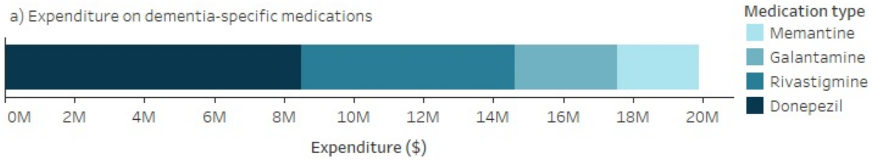
Of the total expenditure for dementia-specific medications, 43% was on Donepezil ($8.5 million), followed by Rivastigmine (31% or $6.1 million), Galantamine (15% or $2.9 million) and Memantine (12% or $2.3 million) (Figure 14.11a). These proportions are similar to the proportion of scripts dispensed for each type of medication in 2019–2020 (see Prescriptions for dementia-specific medications for further information).

The Australian Government subsidised the majority of the expenditure on each type of dementia-specific medication (Figure 14.11b). 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 $14 for Donepezil to $74 for Rivastigmine.

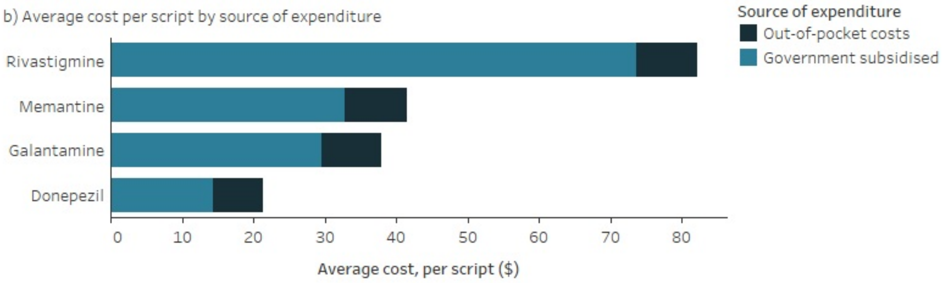
Figure 14.11: Dementia-specific medication expenditure by medication type in 2018–19: (a) total costs and (b) average price per script by source of expenditure

Figure 14.11 is two bar graphs describing expenditure on four dementia-specific medications (Memantine, Galantamine, Rivastigmine and Donepezil) in 2018–19. The first graph shows the distribution of expenditure on the four medications—43% ($8.5 million) of expenditure was on Donezepil, 31% ($6.1 million) on Rivastigmine, 15% on Galantamine and 12% on Memantine. The second graph shows average cost per script for each medication, by source of expenditure. At $82 per script, Rivastagmine cost approximately twice as much as Memantine and Galantamine and four times as much as Donepezil ($21). The majority of the cost per script was covered by government subsidies for all four medications.

a) Expenditure on dementia-specific medications



b) Average cost per script by source of expenditure



Source: AIHW analysis of Disease Expenditure database.
http://www.aihw.gov.au

In addition to dementia-specific medicines, people with dementia may also be prescribed other types of medicines by GPs and other medical specialists (such as geriatricians and neurologists) to manage dementia symptoms. Due to data limitations, GP-prescribing patterns are used to estimate the share of each prescribed medication related to dementia (including those prescribed by specialists).

Besides dementia-specific medications, a range of other prescription medications were commonly prescribed for dementia management, costing $4.0 million in 2018–19. The medicines in this group with the highest expenditure included:

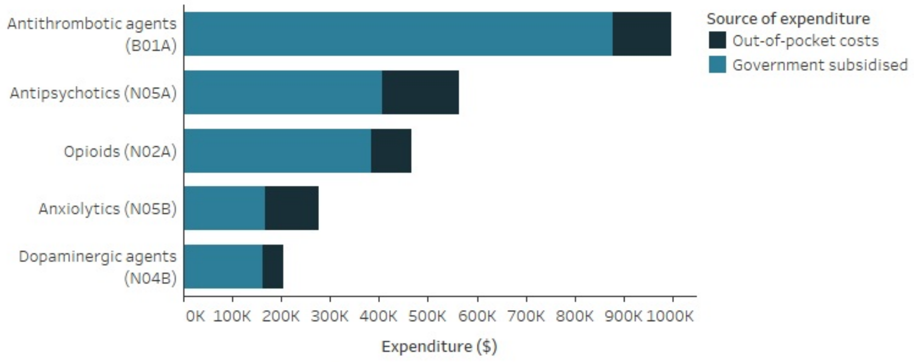
- $998,000 for antithrombotic agents (medicines to reduce blood clot formation)
- $563,000 for antipsychotics
- $465,000 for opioids (for pain relief)
- $276,000 for anxiolytics (to manage anxiety)
- $205,000 for dopaminergic agents (to treat symptoms of Parkinson’s disease)

The percentage of funding which was out-of-pocket costs for these medicines ranged between 12% for antithrombotic agents and 40% for anxiolytics.

For more information on medications prescribed to people with dementia, in particular antipsychotics, see Antipsychotics and other medications dispensed to people with dementia.

Figure 14.12: Estimated expenditure on other medications prescribed to manage dementia in 2018–19: by medication group and source of expenditure

Figure 14.12 is a bar graph that shows expenditure on other medications prescribed to manage dementia in 2018–19, by medication group and source of expenditure. Almost $1 million was spent on antithrombotic agents, followed by $563,000 for antipsychotics and $465,000 for opioids.

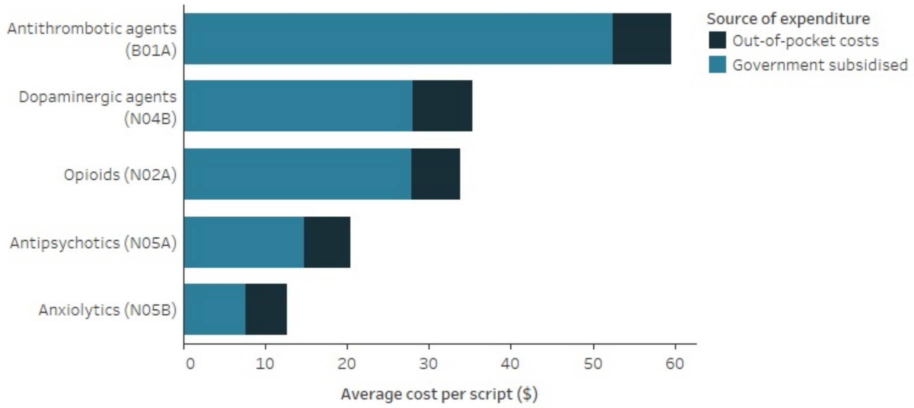


Note: The Anatomical Therapeutic Chemical (ATC) classification is shown in brackets for each relevant medication group. Refer to the Technical notes for more information on the ATC classification system.
Source: AIHW Disease Expenditure database
http://www.aihw.gov.au

Examination of the average cost per script shows that the Australian Government subsidised the majority of the costs for each of the top 5 medication groups (Figure 14.13). For patients, the average out-of-pocket expense for the top 5 prescribed medications for dementia management ranged between $5 and $7. The average subsidised amount per prescription varied, from around $8 for anxiolytics to $52 for antithrombotic agents.

Figure 14.13: Average cost per script for medications used in dementia management in 2018–19: by medication group and source of expenditure

Figure 14.13 is a bar graph that shows the average cost per script for other medications used in dementia management in 2018–19, by medication group and source of expenditure. The majority of the cost was subsidised by the Australian government for each medication group. Out-of-pocket costs ranged between $5–$7. Anti-thrombotic agents had the highest average cost per script, followed by dopaminergic agents and opioids.



Note: The Anatmoical Therapeutic Chemical (ATC) classification system is shown in brackets for each relevant medication group. Refer to the technical notes for more information on the ATC classification system.
Source: AIHW Disease Expenditure database
http://www.aihw.gov.au

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Last updated 22/09/2021 v19.0

Health and aged care expenditure on dementia

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.

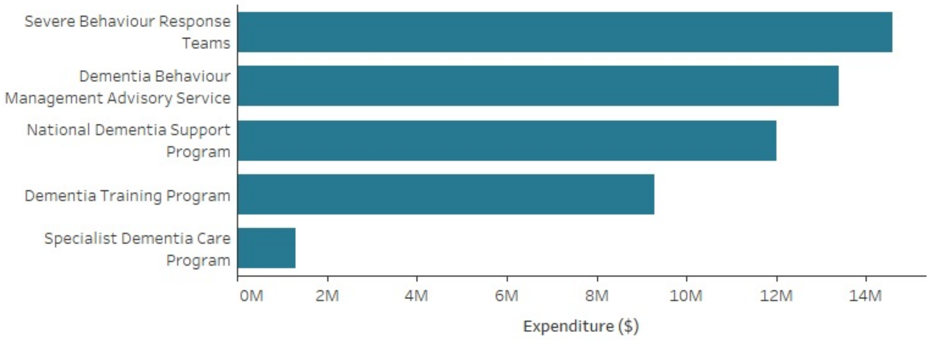
In 2018–19, the Australian Government provided almost $50.6 million to fund dementia support programs and initiatives under the Dementia and Aged Care Services Fund (Figure 14.14). This was equivalent to 1.7% of the total direct health and aged care system expenditure on dementia and included:

- $14.6 million for Severe Behaviour Response Teams—a mobile workforce provided by Dementia Support Australia (led by HammondCare) to support people with severe behaviours and psychological symptoms of dementia, and their carers, with client-focused information, assessment and advice
- $13.4 million for the Dementia Behavioural Management Advisory Service—a mobile workforce provided by Dementia Support Australia (led by HammondCare) to support people with mild-to-moderate behaviours and psychological symptoms of dementia, and their carers, with client focused information, assessment and advice
- $12.0 million for the National Dementia Support Program—an initiative delivered by Dementia Australia, with an overarching aim to improve dementia awareness and knowledge, and empower people with dementia and their support system
- $9.3 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
- $1.3 million for the Specialist Dementia Care Program—a tailored program offering temporary, transitional care to people who are experiencing severe behavioural and psychological symptoms of dementia and who can no longer be cared for in a mainstream residential aged care facility. Dementia Support Australia assesses eligibility for the program through their Needs Based Assessment program and approved residential aged care providers can apply for program grants to set up units in their facility.

Refer to Overview of dementia support services and initiatives and National policy response to dementia for further information on the Dementia and Aged Care Services Fund and provision of dementia support services in recent years.

Figure 14.14: Australian Government expenditure on national dementia support services and initiatives in 2018–19

Figure 14.14 is a bar graph that shows Australian Government expenditure on national dementia support services and initiatives in 2018–19. The initiatives with the largest amount of expenditure included the Severe Behaviour Response Teams ($14.6 million), the Dementia Behaviour Management Advisory Service ($13.4 million) and the National Dementia Support Program ($12.0 million).



Source: Australian Government Department of Health.
http://www.aihw.gov.au

Last updated 5/09/2021 v15.0

National policy response to dementia

Australia was one of the first countries to design comprehensive dementia-specific policy initiatives at a national level, as a 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 & Doyle 2014).

The first federal dementia policy initiative was launched in 1992 (the National Plan for Dementia Care 1992–97) 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 & 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 (World Health Organization 2017).

This webpage focuses on:

- the Royal Commission into Aged Care Quality and Safety, which concluded in early 2021 (see Box 15.1), including dementia-focused recommendations and the Australian Government's response to these recommendations
- recent national policies and developments in response to the challenges posed by dementia
- the Australian Government's response to the COVID-19 pandemic and the impact that the pandemic had on people living with dementia.

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 like: 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 behavioural and psychological symptoms of dementia (Royal Commission 2019). Some of these essential services also receive federal government funding, for example through the Medicare Benefits Schedule or through specific programs and initiatives (e.g. Dementia Behaviour Management Advisory Service, Severe Behaviour Response Teams and the Specialist Dementia Care Program).

Box 15.1: 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 4 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).

Furthermore, the Royal Commission also recommended substantial improvements to aged care data and research, which are a promising source of information to close existing dementia data gaps. Recommendations include the creation of a National Aged Care Data Asset to monitor and report on: people accessing aged care, their needs and services used; the aged care workforce; financial and other characteristics of providers including quality of care measures (Royal Commission 2021).

The Australian Government's response to the Royal Commission into Aged Care Quality and Safety

In response to the final report of the Royal Commission, the Australian Government, through the 2021–22 Federal Budget, announced a $17.7 billion aged care reform package over 4 years. These measures are expected to deliver significant reform in aged care, providing care, dignity and respect to senior Australians.

As part of this reform, the government is investing over $229 million over 4 years to support people living with dementia and their carers. The investment 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 are able to access high-quality, dementia-informed aged care services. Key measures include:

- **Improved early intervention assistance:** When a person is first diagnosed with dementia there will be more support to help them access the services they need to maintain their health, wellbeing and independence. This includes a dementia-specific health pathway program to be used by general practitioners (GPs) during consultation with patients.
- **Face-to-face help to navigate the aged care system:** When a person living with dementia needs aged care services, they will be supported by improved linkages between services and there will be a specific focus on dementia in aged care assessment.
- **More staff trained in dementia care:** An uplift in dementia-specific workforce measures means that people living with dementia will receive better, more targeted care when accessing aged care services.
- **Improved respite experience for people living with dementia**: This includes efforts to expand dementia-friendly respite care models, engage a national provider to prepare respite care plans for people living with dementia and provide training to respite care providers to implement the plans.
- **Improvements in capacity and quality of dementia care:** People living with dementia and their carers will feel more confident accessing aged care services due to improvements in aged care regulation. These improvements extend to services to enhance positive approaches to behavioural and psychological symptoms of dementia, further reducing the reliance on restrictive practices.
- **More support for carers to maintain their caring role:** Additional carer-focused psychological supports, including innovative early intervention activities, will help informal carers to continue caring for a person living with dementia, delaying their entry to residential aged care.

The reform also includes funding to improve dementia data collection and understanding and 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 Framework for Action on Dementia

The National Framework for Action on Dementia 2015–2019 ('the Framework') was developed under the Australian Health Ministers' Advisory Council to set high-level priorities of dementia care, guide the development and implementation of plans and policies, including measurable actions in order to reduce the risk of dementia, and improve outcomes for people with dementia and their carers (Department of Health 2015). A review of the Framework was undertaken in 2019 and finalised in early 2020. The review was conducted in order to assist development of a future national dementia strategy. Engagement on the development of this strategy was put on hold during 2020 due to COVID-19 and the re-prioritisation of activities managed through the National Cabinet structures.

In late 2021 the Australian Government will commence development of a new national dementia plan that will be informed by the 2019 Framework review and the Australian Government's response to the recommendations of the Royal Commission. This work will occur in consultation with state and territory governments and other key stakeholders, including people living with dementia and their families, Dementia Australia, health professionals, aged care providers and researchers.

In 2017 the Australian Government also 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.

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 (Hunter & Doyle 2014). 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) (Royal Commission 2019a). 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 has also awarded funding to the Australian Dementia Network (ADNeT)—a network of scientists and researchers across a number of institutions. ADNet aims to: establish 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 establish 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 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 stream of this fund focuses on funding research aimed at improving the lives of ageing Australians. To date, $185 million had been budgeted to research grants under this stream over a 10-year period (between 2018–19 and 2028–29), with $17.5m available for 2020–21.
- The Dementia and Aged Care Services Fund provides funding for multiple dementia-related services and initiatives such as the National Dementia Support Program, the Dementia Training Program and the Specialist Dementia Care Program. Further information on these programs is presented in Dementia support services and initiatives.
- The Aged Care Centre for Growth and Translational Research (CGTR) is designed to address long-standing barriers to the development, evaluation and uptake of aged care workforce research. The CGTR focuses 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 recent investment of funding for a national dementia monitoring program and dementia data improvements and development will look to address these gaps over the next decade. For more information on current dementia data gaps, and ways in which these gaps can be systematically and strategically addressed, see the 2020 AIHW report: Dementia data gaps and opportunities.

The impact of COVID-19

The COVID-19 pandemic has had an especially devastating impact on older Australians, including those with dementia. Through the National COVID-19 Aged Care Plan developed in January 2020, the Australian Government has made significant investment to support people through the pandemic. The plan has since been adapted to respond to outbreaks in residential aged care homes. As of 22 July 2021, 8.6% of residential aged care residents and staff members have had reported cases of COVID-19 (accounting for over 7 out of every 10 deaths due to COVID-19) (Department of Health 2021a).

In October 2020, the Royal Commission delivered a special report on COVID-19 in aged care and made the following recommendations to better prepare the aged care sector, its staff and people accessing services, for any future outbreaks:

- funding aged care providers to ensure there is adequate staff to deal with external visitors and enable more meaningful visits to residential aged care homes
- creating new Medicare Benefits Schedule (MBS) items to increase the provision of allied health and mental health services for people in residential aged care homes
- publishing a national aged care plan for COVID-19 and establishing a national aged care advisory body
- requiring aged care providers to appoint infection control officers and arrange for the deployment of accredited infection prevention and control experts (Royal Commission 2020).

The Australian Government accepted these recommendations with actions underway to address these recommendations (Department of Health 2020).

The Australian Government has also introduced a number of measures to assist in improving COVID-19 vaccination uptake and delivery among people living in residential aged care and aged care staff. This includes vaccination reporting requirements for residential and in-home aged care providers, as well as funding grants to support residential aged care employee vaccinations (Aged Care Quality and Safety Commission 2021).

As of 17 August 2021, 73% of Australians aged 50 and over and 84% aged 70 and over, had received the first dose of the COVID-19 vaccine. Around 40% aged 50 and over and 54% aged 70 and over, had received their second dose and were considered fully vaccinated (Department of Health 2021b).

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Last updated 23/09/2021 v29.0

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
- 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. See Data sources for more detailed information on each of the data sources.

See Methods for information on the methodologies used to derive estimates (e.g. dementia prevalence or health and aged care expenditure) and other statistics presented in this report. 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 between 1,000 and 999,999 are rounded to the nearest hundred and numbers over and including 1 million are rounded to the nearest 100,000. Numbers less than 1,000 are not rounded. Percentages and rates are generally rounded to whole numbers, except for numbers less than 10% which are rounded to 1 decimal point. Refer to the Supplementary data tables of this report for unrounded numbers.

See Glossary for the definition of technical concepts used throughout this report.

Table 1: Summary of the main data sources used in Dementia in Australia

Source	**Data Source**	**Main source year**	**Frequency of updates**	**Description**
Australian Institute of Welfare	Australian Burden of Disease Study	2018	Ad hoc	Data on the fatal, non-fatal and total burden of disease in Australia.
	Disease Expenditure Database	2018–19	Ad hoc	Data on government expenditure on disease estimated using multiple data sources.
	National Aged Care Data Clearinghouse	2019–20	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 National Screening and Assessment Form data and the Aged Care Funding Instrument are presented.

	National Hospital Morbidity Database	2018–19	Annual	Episode-level records from admitted patient morbidity data collection systems in Australian hospitals. The data set for the reference period 2018–19 includes records for admitted patient separations between 1 July 2018 and 30 June 2019.
	National Integrated Health Services Information Analysis Asset (NIHSI)	2016–17	Version 0.5 produced in 2020	NIHSI version 0.5 contains linked data from 2010–11 to 2016–17 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.
	National Mortality Database	2019	Annual	Data on records for deaths in Australia from 1964.

	Pharmaceutical Benefits Scheme/ Repatriation Pharmaceutical Benefits Scheme	2019–20	Daily	Data on medications prescribed and prescriptions dispensed under the Pharmaceutical Benefits Scheme and Repatriation Pharmaceutical Benefits Scheme.
Australian Bureau of Statistics	Estimated Resident Population	Various	Yearly	ABS estimates of the usual resident population of Australia.
	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.
	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.
Dementia Australia	National Dementia Helpline administrative data	2019–20	Ad hoc	Data on contacts to the National Dementia Helpline. Further information on these data is not available.
Dementia Support Australia	Dementia Behaviour Management Advisory Service and Severe Behaviour Response Teams administrative data	2019–20	Ad hoc	Data on cases supported by the Dementia Behaviour Management Advisory Service and Severe Behaviour Response Teams.

Last updated 5/09/2021 v9.0

Technical notes

Data sources

Australian Burden of Disease Study 2018

The Australian Burden of Disease Study (ABDS) 2018 provides Australian-specific burden of disease estimates for the total population for 2018, 2015, 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 & 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.

At the time of writing, the latest estimates for the burden of disease and injury among Aboriginal and Torres Strait Islander people were for the year 2011. It is important to note data and methods used to estimate dementia burden in this study differ to the ABDS 2018. See Australian Burden of Disease Study 2011: methods and supplementary material for more detail.

The AIHW is currently working to estimate disease burden among Aboriginal and Torres Strait Islander people for the year 2018, which will supersede estimates from the ABDS 2011. The Dementia in Australia report will be updated to reflect the latest estimates when they become available.

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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 2020 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 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

The National Screening and Assessment Form (NSAF) is used to collect information on people who are interested in accessing government-subsidised aged care services co-ordinated through the My Aged Care system. This includes the initial screening of the interested person over-the-phone by My Aged Care contact centre staff, as well as information from either a home support assessment conducted by Regional Assessment Services or a comprehensive assessment conducted by Aged Care Assessment Teams for people who are found eligible to use of government-subsidised aged care services.

NSAF data are a new data source and further work is needed to develop the dataset into a comprehensive resource for statistical reporting. Due to data quality issues, only information from people who completed a home support assessment or a comprehensive assessment in 2019–20 was presented. Further development of the data may lead to revisions of the information presented in future reports.

The following should be considered when interpreting NSAF data presented in this report:

- Individuals were only included if they had finalised a comprehensive assessment or home support assessment in 2019–20. Only information relating to the latest assessment during this period was considered.
- While the information is reflective of people who completed a home support assessment or a 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 (main 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 Indigenous status were not included in counts of Indigenous 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

The Aged Care Funding Instrument (ACFI) is 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%).

Although the ACFI is a funding instrument and not a diagnosis or comprehensive service tool, it does collect information on the assessed care needs of people in 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 will be captured in the ACFI assessment. An ACFI reappraisal can be conducted for various reasons, such as when a person has a significant change in care needs or after 12 months from when their classification has taken effect.

People in temporary respite care in an aged care facility do not have an ACFI assessment unless they also receive permanent care at some point. Therefore, information on residential respite care using the ACFI data is not presented. Further, the ACFI data do 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 captures 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 allows 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 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*.

Ratings for each domain are used to determine the level of care funding and to assign 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.

Indigenous Australians and other culturally and linguistically diverse groups

Analysis of permanent residential aged care use among Indigenous Australians is based on whether people were identified as being Indigenous (i.e. Aboriginal and/or Torres Strait Islanders) or not (i.e. non-Indigenous), and excludes cases where the Indigenous status was unknown. ACFI data do not capture information on Indigenous-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 Indigenous Australians.

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 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 2009–10 to 2018–19. Data were extracted in August 2020 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, 10th Revision, Australian Modification (ICD-10-AM).

Dementia-related hospitalisations were defined as hospitalisations with at least 1 diagnosis of dementia, recorded as a principal and/or additional diagnosis. 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
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

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 Indigenous Australian 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.

Due to the small number of hospitalisations among Indigenous Australians by geographic area, rates of hospital separations with dementia as a principal diagnosis were examined over a 3-year period (2016–17, 2017–18 and 2018–19). Hospital separations with more than 3,000 bed days were excluded from the analysis of hospital separations among Indigenous Australians.

National Integrated Health Services Information Analysis Asset

The National Integrated Health Services Information Analysis Asset (NIHSI AA) is a newly established enduring linked data asset managed under the custodianship of the AIHW, available for approved projects and analysts from the AIHW and participating jurisdictions.

The first version of this data asset (NIHSI version 0.5) contains linked data from 2010–11 to 2016–17 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 (R-PBS) 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 2017).

Classification of dementia

The analysis presented in the GP and specialist 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 0.5.

A person was identified as having dementia, where dementia was evident in NIHSI version 0.5 between 1 July 2010 and 30 June 2017 as:

- a principal or additional diagnosis in any hospital admission
- a principal or additional diagnosis in any emergency department presentation
- they had 1 or more prescriptions for a dementia-specific medication
- dementia was recorded on their aged care funding assessment when they used a residential aged care service (either permanent residential aged care and/or respite residential aged care)

Table 6 outlines the codes used in each individual dataset to identify dementia and the classification system used in each dataset. Refer to the National Hospital Morbidity Database, Pharmaceutical Benefits Schedule and Aged Care Funding Instrument (for residential aged care) sections for more information on coding in these datasets.

Table 6: Codes used to identify dementia in NIHSI version 0.5

Data source	Classification and dementia-specific codes
Hospital admissions	*ICD-10-AM diagnosis code*
Dementia (collectively)	F00, F01, F02, F03, F05.1, G30
Emergency department presentations	
Dementia	*ICD-10-AM diagnosis code*: F00, F01, F02, F03, F05.1, G30
	ICD-9-AM diagnosis code: 290.0, 290.1, 290.10, 290.11, 290.12, 290.13, 290.2, 290.20, 290.21, 290.3, 290.4, 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: 52448006, 12348006, 15662003, 26929004, 191461002
Prescriptions	*Anatomical Therapeutic Chemical Classification code*
Drug name	
Donepezil	N06DA02
Rivastigmine	N06DA03
Galantamine	N06DA04
Memantine	N06DX01
Residential aged care	*Aged Care Funding Instrument code*

Dementia (collectively)	0500, 0510, 0520, 0530

Note: ICD-10-AM refers to the International Statistical Classification of Diseases and Related Health Problems, Tenth Revision, Australian Modification; ICD-9-AM refers to the International Statistical Classification of Diseases and Related Health Problems, Ninth Revision, Australian Modification; SNOMED CT-AU EDRS refers to the Systematized Nomenclature of Medicine - Clinical Terms - Australian version (Emergency Department Reference Set).

As dementia is thought to be under-recorded in administrative health data, the number of people with dementia is likely to be underestimated in this analysis. Additionally, as hospitals data were only available for New South Wales, Victoria, South Australia and Tasmania in NIHSI version 0.5, people with dementia from other states and territories who only had dementia recorded in a hospital service would not be included. Therefore, the group of people without dementia may include people with dementia, if dementia was not recorded in their administrative records in NIHSI version 0.5 in the time period analysed.

Exclusion criteria

Analysis of the NIHSI version 0.5 was restricted to people who were:

- aged 30 and over—due to dementia being uncommon in younger ages
- alive from 30 June 2016 to 31 December 2017—due to differing service needs and usage among people in their last year of life
- recorded as using an MBS service in 2016–17
- not missing age and/or sex information entirely from the linked data

If age and sex information was not recorded in the MBS service record, this information was collected from other data sources in NIHSI version 0.5 where possible.

It is acknowledged that there are a number of issues with comparing services used by people with dementia aged 30–64 to services used by people without dementia aged 30–64, as the 'people with dementia' group is skewed towards older ages. This should be considered when comparing service use between these two groups.

Classifying place of residence

To examine the impact that living in a permanent residential aged care facility has on health service usage, people with dementia and people without dementia were grouped based on whether or not they used a permanent residential aged care service in 2016–17.

The *Living in residential aged care* group includes people who were living in a permanent residential aged care facility for all, or part of the year in 2016–17 and used an MBS service that year. This does not include people who used respite services in a permanent residential aged care facility. All other people who used an MBS service in 2016–17 were considered to be in the *Living in the community* group. This group may include people who used respite services in a permanent residential aged care facility, as well as people who were living in other supported accommodation.

The group of people with dementia is more likely to include people who used residential aged care compared with those living in the community, as residential aged care data is a key source for identifying dementia in the analysis. This means that the group of people with dementia likely includes a larger proportion of those with a more severe form of dementia, and a smaller proportion of those who live in the community.

Medicare Benefits Schedule

The MBS data collection contains MBS claims data for Medicare services subsidised by the Australian Government. MBS services by age, sex, dementia status, type of service and leading specialist types among services provided by medical specialists were analysed for this report.

Table 7 outlines the variables used to identify GP and specialist services (by speciality type). For GP services, this includes GP and Vocationally Registered GP attendances, enhanced primary care and other non-referred attendances (including attendances in residential aged care facilities). Data on GP services from the MBS exclude services provided to Department of Veterans' Affairs (DVA) card holders where care is reimbursed through the DVA, as well as services provided by salaried GPs in residential aged care or outpatients departments.

Specialty types were classified into subspecialties based on the Derived Major Specialty—used to allocate practitioners to a single specialty each period for statistical purposes. As specialists may have more than 1 registered specialty, service patterns for each specialist are used to classify the most appropriate specialty.

Table 7: GP and specialist service analysis variables and descriptions

GP attendance	*Broad type of service group code*
GP attendances[(a)]	A/101, M/102, B/103
Specialist attendance	***Registered specialty codes***
General Medicine	0002, 0082
Cardiology	0004, 0084
Haematology	0005, 0026, 0085

Neurology	0009, 0089
Geriatric Medicine	0016, 0096
Medical Oncology[(b)]	0017, 0049, 0097, 0804
General Surgery	0031, 0032, 0411
Urology	0038
Dermatology	0052, 0401
Ophthalmology	0054, 0406
Psychiatry	0056, 0099, 0409
Other specialties	0001, 0008, 0014, 0042, 0043, 0081, 0088, 0094
Other services	***MBS group code, MBS item number or Registered specialty codes***
Geriatrician referred patient assessment and management plans	*MBS Item*: 141, 142, 143, 144, 145, 146, 147
Chronic disease management	*Group*: A15
Medication management reviews	*MBS Item*: 900, 903
Allied health	*Group*: M03, M06, M07, M09, M11, M15
Pathology tests	*Group*: P01, P02, P03, P04, P05, P06, P07, P09, P12
Diagnostic imaging	*Group*: I01, I02, I03, I04, I05, I06
Operations	*Group*: T08
Other MBS services	*Group*: D01, D02, M01, M12, M14, O01, O02, O03, O04, O05, O06, O07, O08, O09, O10, O11
Psychology[(c)]	*Registered specialty code*: 0426

a. MBS item numbers for attendances in a residential care facility are also included in Broad type of service group A/101 or B/103
b. Includes radiation oncology and gynaecological oncology.
c. Psychology services were included in the total number of MBS services but excluded from the total number of specialist services.

National Mortality Database

Data on dementia deaths were derived from the National Mortality Database (NMD) and analyses were based on the years 2010-2019. 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 Indigenous 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)	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 2016 and earlier are based on the final version of cause of death data; deaths registered in 2017 are based on the revised version; and deaths registered in 2018 and 2019 are based on the preliminary version. Revised and preliminary versions are subject to further revision by the ABS; deaths related to dementia in 2018 and 2019 are likely an undercount as a result of missing late registration.

Analyses of deaths among Indigenous Australians are based on whether people identified as being Indigenous (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 Indigenous Australians, 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 Indigenous Australian 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 Indigenous identification 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 Indigenous under-identification in the NMD, but does group deaths statistics for Indigenous Australians across 3 years of data to provide more robust estimates and avoid confidentiality issues related to small numbers.

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Pharmaceutical Benefits Scheme

The Pharmaceutical Benefits Scheme (PBS) database contains government-subsidised medications 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 medicines, medicines to public hospital in-patients and over-the-counter medicines.

In this report, analyses were limited to people aged 30 and over who were dispensed at least 1 dementia-specific medication under the PBS between 30 June 2019 and 1 July 2020, 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).

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) may change in a single year, a person’s age in their earliest record in 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 earliest record in the year was used as their geographical location for the entire year
- as people may be prescribed 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 2005–06.

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 WHOCCD 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 9th 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
Mobility	Getting into or out of a bed or chair
	Moving about usual place of residence
	Moving about a place away from usual residence
	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.

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Technical notes

Methods

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 (e.g. 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.

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) for 2021 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 living in residential aged care facilities as at 30 June 2021 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 2021.

This method suggests that in 2021, 65% of Australians with dementia are living in the community and 35% 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, in this report the total number of carers of people with dementia who live in the community in 2021 is presented as a range. The estimate includes 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 for the year 2021. 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.

The maximum number of unpaid carers of people with dementia was estimated by applying the average number of carers of a person with dementia as reported in the SDAC 2018 to the number of people with dementia living in the community in 2021 as estimated by AIHW. Using this method the estimated maximum number of informal carers of people with dementia is 2.5 times higher than the minimum estimate derived from the SDAC.

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.

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 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 Indigenous 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 Aged Care Funding Instrument (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 2018–19.

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 2018–19

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Glossary

Key term	Definition
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 burden of disease attributed to a particular risk factor.
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 **hospitalisations** in this report). Patients who have an admission and a separation on the same date are allocated a length of stay of 1 day.
Burden of disease	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.
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**.
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).
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).
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-modifiable risk factors	**Risk factor**s 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.
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**).
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.
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).
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.

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