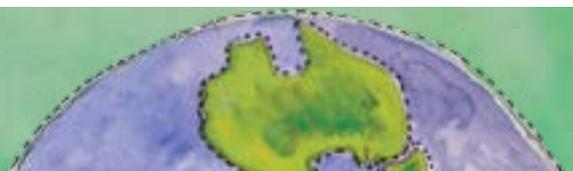


6.10 Dementia, dementia treatment and the future



Dementia is a major health problem in Australia. It has profound consequences for the health and quality of life of people with the condition, as well as for their families and friends. Dementia describes a syndrome caused by many different diseases affecting the brain (see next section, 'What is dementia?'). Dementia is generally progressive in nature, and its impact increases with the growing severity of the condition. People with dementia eventually become dependent on their care providers in most, if not all, areas of daily living (unless they die from another condition first).

Although dementia is not an inevitable part of ageing and can affect younger people, it becomes more common with increasing age and primarily affects older people. Thus, one of the expected consequences of the continued growth and ageing of Australia's population is an increase in the number of people with dementia over time.

The increasing number of people with dementia will pose numerous challenges to Australia's health and aged care systems, arising from the increased need for care services, support for carers, training for health professionals and aged care workers, and research into effective treatment and prevention strategies.

What is dementia?

Dementia is not a single specific disease, but an umbrella term describing a syndrome—or group of symptoms—associated with more than 100 different diseases. It is characterised by the impairment of brain functions, including language, memory, perception, social awareness, reasoning and cognition. Although the type and severity of symptoms and their pattern of development varies with the type of dementia, it is usually of gradual onset, progressive in nature, and irreversible.

There is no single or simple test that will definitively diagnose dementia (see Box 6.6), and dementia is often unrecognised and/or undiagnosed until it is in the later stages. There tends to be a substantial gap between when symptoms are first noticed and when assistance is first sought from a health professional, and a further gap before the condition is actually diagnosed.

The most common types of dementia are Alzheimer disease (thought to account for about 50% to 75% of cases worldwide), vascular dementia (20% to 30%), frontotemporal dementia (5% to 10%) and dementia with Lewy bodies (up to 5%) (ADI 2009).

In addition to the 4 most common types of dementia, there are many other less common types, including dementia caused by other diseases (such as Parkinson disease, Huntington disease and Creutzfeldt-Jakob disease), HIV/AIDS-related dementia, and dementia due to metabolic causes or trauma.

The literature is inconsistent in terms of how common the various types of dementia are. Reasons for this may include the lack of distinct borders between the different types of dementia, and that a definitive diagnosis cannot be made unless autopsy evidence is available (which is rarely the case). Also, some studies suggest that mixed forms of dementia (for example, the coexistence of Alzheimer disease and vascular dementia) may be more common than 'pure' forms (ADI 2009).

The course of dementia is often characterised as occurring in 3 stages: mild or early-stage dementia, moderate or middle-stage dementia, and severe or late-stage dementia (see AIHW 2012: Table 1.1). There are overlaps between the stages, and identifying the stage that a person has reached is not always straightforward (Draper 2011).

Box 6.6

Assessment and diagnosis of dementia

The assessment process for dementia may vary according to both the person conducting the assessment and the symptoms the person presents with. In general, the aim of the assessment is to gather sufficient information about changed behaviours, functional capacity, psychosocial issues and relevant medical conditions to allow for a diagnosis to be made and a management plan to be formulated.

Often, the information-gathering process includes input from third parties (for example, carers, family members and service providers) and the use of screening tools. A wide range of screening tools are available, including the Mini-Mental State Examination (MMSE), the General Practitioner assessment of Cognition (GPCOG), the Rowland Universal Dementia Assessment Scale (RUDAS), and the 7-Minute Screen.

If the results from a screening test suggest cognitive impairment, a more comprehensive assessment is required. This may require referral to a medical specialist such as a geriatrician, psychiatrist or neurologist. During this second assessment stage, a number of other tests, such as radiological and laboratory investigations, may be undertaken.

There are many conditions other than dementia that may have cognitive impairment as part of their presentation. Examples are depression, thyroid disease, vitamin deficiency, side effects from medication and age-related cognitive decline. Thus, a key component of the diagnostic process involves determining if dementia or some other condition is the cause of the symptoms.

Sources: AIHW 2012; Draper 2011; Phillips et al. 2011.

Risk and protective factors

The causes of dementia are complex and influenced by many factors acting in combination. The prevention, delay of onset and treatment of dementia depend on an understanding of these determinants. Many risk and protective factors have been identified. However, evidence for many of these is lacking, inconsistent, or only recently starting to emerge.

The main risk factor for most types of dementia is advancing age. Research on other risk factors has focused on the main types of dementia—Alzheimer disease and vascular dementia.

Apart from age, other factors known to increase the risk of dementia include a family history of the condition, Down syndrome, a common genetic polymorphism—the apolipoprotein E (APOE) ε4 gene—and stroke (Seeher et al. 2011; van den Berg & Splaine 2012).

There is growing evidence that suggests that a number of lifestyle and health factors may influence the risk of developing dementia (Seeher et al. 2011; van den Berg & Splaine 2012). However, relatively few of these factors have been definitively established, with most considered either probable determinants or inconclusive (Seeher et al. 2011).

Studies also indicate that a number of other factors—many of which are modifiable—may increase the risk of dementia. These include diabetes, mid-life hypertension, excessive alcohol consumption, smoking, head injury, depression and obesity (Seeher et al. 2011; van den Berg & Splaine 2012).

In addition, many factors that probably protect against developing dementia have been identified, although none of these have been definitively established. These include better cardiovascular health, maintaining physically, socially and cognitively active lifestyles, and higher levels of education (ADI 2009; Seeher et al. 2011). There are numerous other possible protective factors for which evidence is inconclusive, including intake of omega-3 fatty acids, and use of cholesterol-lowering medications, nonsteroidal anti-inflammatory medications and aspirin.

How many people have dementia?

Prevalence refers to the total number of people who have a particular condition at a specified point in time. Common approaches to determining prevalence, such as counting the number of people diagnosed or reporting the condition, are inadequate for dementia, because it is often unrecognised or undiagnosed, especially in the earlier stages. Thus, surveys which rely on respondents reporting the condition cannot be used to accurately describe the prevalence of the condition. The primary Australian survey of this type, the Survey of Disability, Ageing and Carers (SDAC), appears to underestimate milder forms of dementia and so is not appropriate to use for estimating prevalence, although it remains the primary source of information about the characteristics of people with dementia and their carers.

The prevalence estimates presented in this article are based on data from studies that used both screening tools and clinical diagnostic assessments to identify people with dementia. As no national study has been undertaken using these methods, this article uses rates derived from a number of local and international studies. The rates used to estimate the prevalence of dementia among people aged 60 and over are based on rates published in the World Alzheimer Report 2009 (ADI 2009), while the rates for those aged under 60 were based on other sources. More detailed information can be found in *Dementia in Australia* (AIHW 2012: Appendix D, Notes 2.1–2.3).

Applying these rates to the Australian population suggests there are 332,000 people with dementia in Australia in 2014, of whom 62% are women. Among Australians aged 65 and over, almost 1 in 10 (9%) have dementia, and among those aged 85 and over, 3 in 10 (30%) have dementia (Table 6.3).

Table 6.3: Estimated number of people with dementia, by age and sex, 2014

Age	Age-specific rates ^(a) (per 100 population)			Number ^{(a)(b)}			Per cent		
	Males	Females	Persons	Males	Females	Persons	Males	Females	Persons
Under 65	0.1	0.1	0.1	13,000	11,800	24,700	10.2	5.7	7.4
65–74	3.0	3.3	3.2	29,200	33,200	62,400	23.0	16.2	18.8
75–84	8.7	10.3	9.6	42,600	60,100	102,800	33.6	29.3	31.0
85+	24.7	33.1	30.0	42,300	99,900	142,100	33.3	48.7	42.8
Total: 65+	7.0	10.3	8.8	114,100	193,200	307,300	89.8	94.3	92.6
Total all ages	1.1	1.8	1.4	127,000	204,900	332,000	100.0	100.0	100.0

(a) Rates (per 100 population) and numbers were calculated using projected population data (series B) for 30 June 2014 (ABS 2012).

(b) Numbers may not sum to the total due to rounding.

Note: See AIHW 2012 for information about the method used to derive prevalence estimates.

Sources: Calculations by AIHW, using rates based on ADI 2009 and Harvey et al. 2003.

Almost half (49%) of women with dementia were aged 85 and over, compared with one-third of men. The estimated number of women with dementia was higher than the estimated number of men in all age groups 65 and over. Further, in each of the age groups from 85–89 onwards, the estimated number of women with dementia was about double or more the estimated number of men.

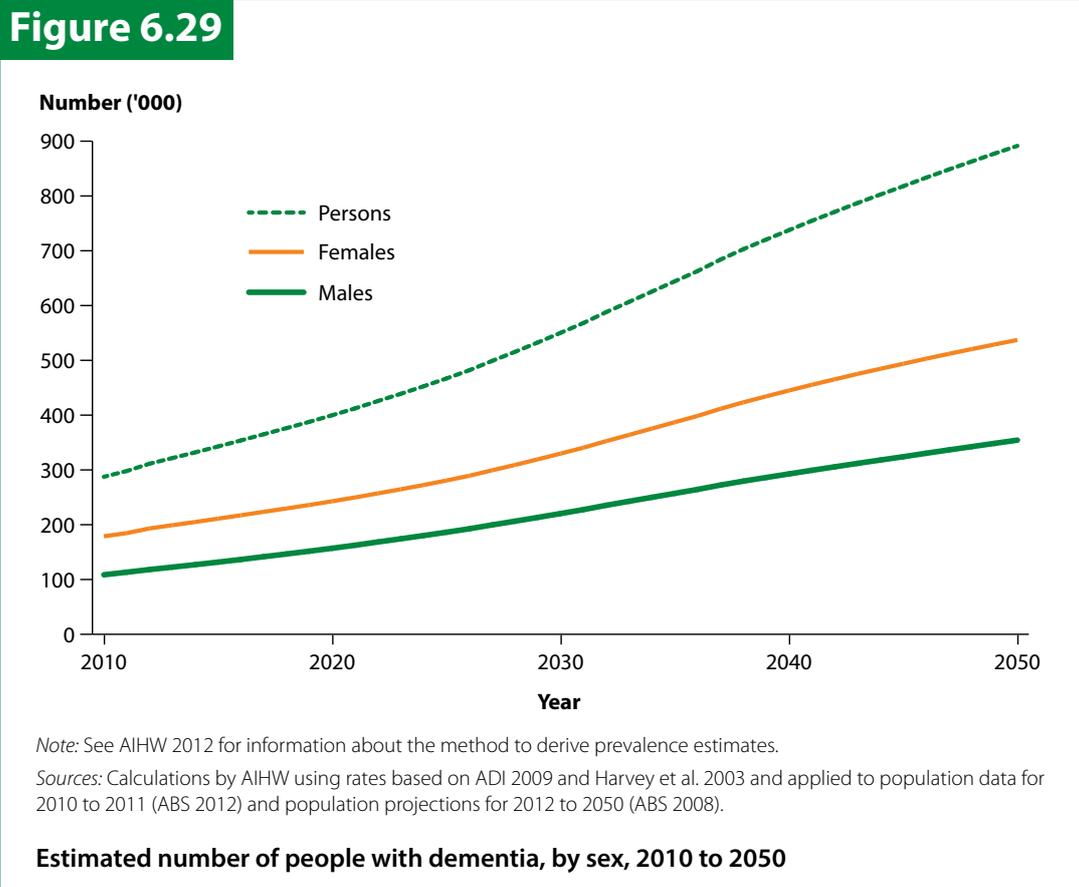
Based on projections of population ageing and growth, the number of people with dementia is projected to reach almost 400,000 by 2020, and around 900,000 by 2050 (Figure 6.29).

These projections assume that the underlying age and sex-specific rates of dementia will remain constant. As such, the accuracy of the estimates will be affected by changes in the underlying rates, from, for example, changes in risk factors and in the prevention, management and treatment of the condition. These estimates are also sensitive to deviations from projected changes in the age-sex structure or total size of the projected populations.

Younger onset dementia

Younger onset dementia typically refers to the onset of dementia before the age of 65. There were an estimated 24,700 Australians under the age of 65 who had dementia in 2014, with men accounting for just over half (52%). Those under 65 represented 7% of all people with dementia in Australia in 2014.

Younger onset dementia is much less common than dementias occurring at later ages. Further, research suggests that, compared with late onset dementia (that is, dementia with onset at 65 or over), younger onset dementia is more frequently misdiagnosed (Mendez 2006). One reason is said to be the greater variation in the types of dementia diagnosed among those with younger onset dementia. In particular, compared with those with late onset dementia, Alzheimer disease is believed to be less common (although still the most common dementia diagnosis), while dementias attributed to alcohol abuse, head trauma, HIV and a number of other causes are considered to be more common among those with younger onset dementia (McMurtray et al. 2006; Mendez 2006; Werner et al. 2009).



Dementia among Aboriginal and Torres Strait Islander Australians

Due to the lack of national data on how common dementia is among Indigenous Australians, most information is drawn from a small number of localised, largely community-based studies. One such study in a remote area of Western Australia was undertaken by Smith et al. (2008). This study, which involved screening 363 Indigenous Australians aged 45 and over, found that 12% of those screened had dementia. Preliminary results from another study, the Koori Growing Old Well Study, involving urban Indigenous communities in New South Wales, suggest a prevalence rate of 13% among 336 Indigenous Australians aged 60 and over (NeuRA 2013). In comparison, among all Australians, an estimated 3.6% of those aged 45 and over, and 7% of those aged 60 and over, had dementia in 2014 (calculations by AIHW using rates based on Harvey et al. 2003 and ADI 2009).

These results suggest that dementia is more common in Indigenous Australians than in the general population. However, further studies with larger sample sizes would be required to confirm the overall prevalence of dementia among Indigenous Australians.

Where do people with dementia live?

Estimates of the number of people with dementia are important for service planning purposes. Estimates vary according to whether or not they live in the community (such as in a private home or a retirement village) or in cared accommodation (such as residential aged care facilities—see Glossary) and the severity of the condition. (For information on the method used to estimate prevalence by residency and severity, see AIHW 2012: Chapter 2.)

In 2013, an estimated 71% of people with dementia lived in the community, while 29% lived in cared accommodation. Men were more likely to live in the community than women (78% compared with 68%).

Of people with dementia in 2013, an estimated 55% had mild dementia (176,900), 30% moderate (96,500), and 15% severe (48,200). People living in cared accommodation were more likely to have more moderate (63%) or severe dementia (31%) than those living in the community (17% and 8% respectively).

Even so, of people with severe dementia, an estimated 40% lived in the community, with men more likely to do so than women (54% compared with 32%).

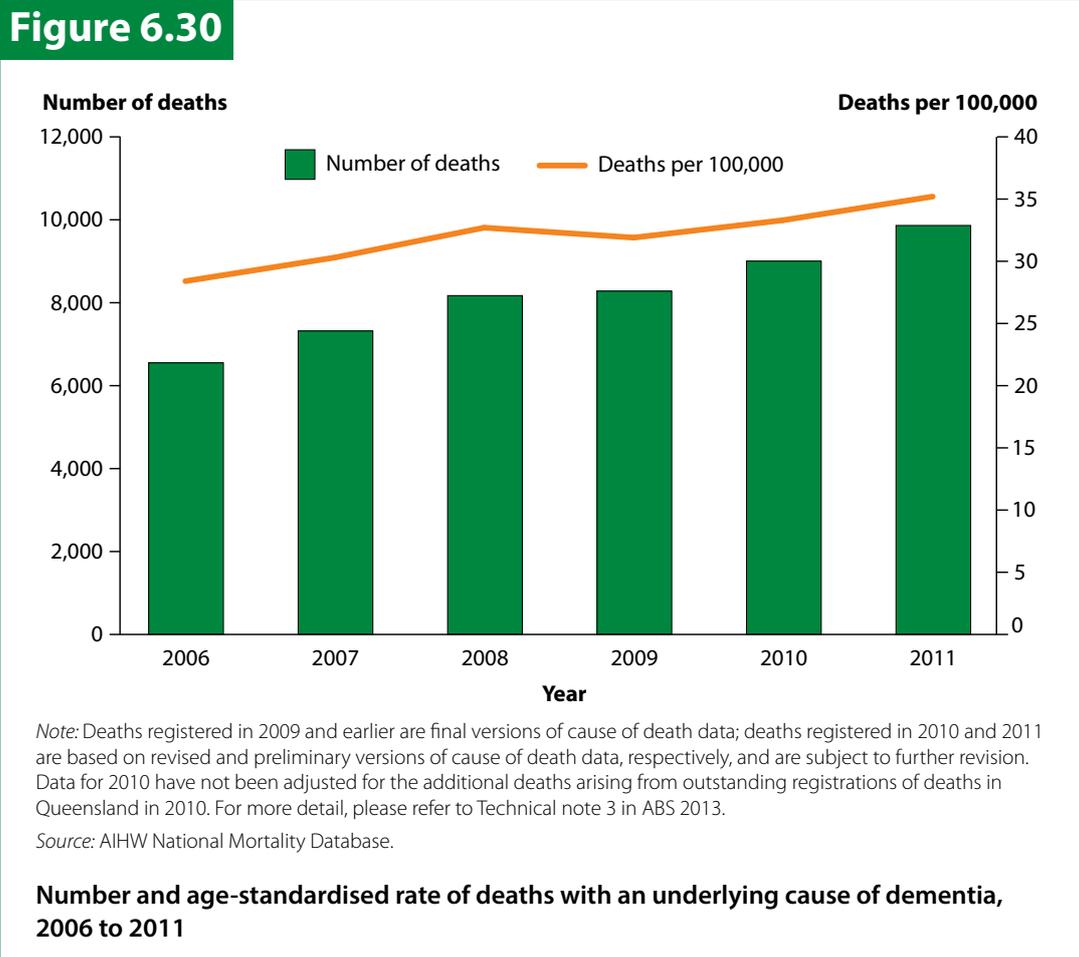
Deaths due to dementia

Dementia was the third leading cause of death in 2011, recorded as the underlying cause of 9,864 deaths across Australia—on average, 27 people died from dementia every day. Twice as many women as men died from dementia.

After adjusting for differences in age structures, the death rate due to dementia was 25% higher for women than men (age-standardised rate of 37.9 versus 30.2 per 100,000 population). Overall, deaths due to dementia accounted for 7% of all deaths in 2011 (9% of female deaths and 4% of male deaths).

Overall, the number of deaths attributed to dementia increased by about half (51%) between 2006 and 2011 (from 6,550 to 9,864 deaths) (Figure 6.30). Not all of that change can be attributed to changes in population ageing and growth since the age-standardised rate rose from 28.4 per 100,000 population in 2006 to 35.2 per 100,000 population in 2011. Some of the increase may be due to changes affecting how and the extent to which dementia is recorded on death certificates (see ABS 2013: Explanatory note 84).

The impact of these changes may be spread over a number of years as awareness of the changes increases. Hence, it is unclear if the continued increase in the rate of deaths due to dementia can be explained by these changes or if they represent an actual increase in the number of deaths due to dementia.



Treatment of dementia

Current treatments are targeted at the symptoms of dementia rather than the underlying causes. Interventions fall into 2 groups: non-drug and drug.

Non-drug treatments

A wide range of non-drug treatments are used for treating the cognitive symptoms of dementia; however, the evidence base for the effectiveness of many of these is limited.

Some research suggests that engaging more frequently in cognitive activity is associated with a lower risk of developing dementia (Wilson et al. 2007), and a recent review by Alzheimer's Disease International (ADI) found that there is strong evidence that cognitive stimulation is an effective intervention in mild



dementia (Prince et al. 2011). Cognitive stimulation targets cognitive and social function through reality orientation, activities, games and discussions, prioritising information-processing rather than knowledge (Prince et al. 2011). However, the efficacy of cognitive training (which involves guided practice on a set of standard tasks designed to reflect particular cognitive functions such as memory, attention or problem solving) has not been demonstrated for those who already have dementia (Prince et al. 2011, Seeher et al. 2011).

The ADI review also found that there was some evidence that support groups (for quality of life and depression), behavioural treatment (for depression), and cognitive rehabilitation (for goal performance, satisfaction and subjective memory impairment) can be helpful in the early stages of the condition.

For people with mild to moderate dementia, there is strong evidence that caregiver-focused psychosocial interventions, such as care support, counselling and respite, improve the caregiver's mood and quality of life (Prince et al. 2011). These interventions can also delay entry of the person with dementia into institutional care (Prince et al. 2011).

Drug treatments

Drug interventions target cognitive functioning, and behavioural and psychological symptoms of dementia or other co-occurring diseases (Seeher et al. 2011). There are currently no known drugs that can reverse or cure the various forms of dementia, but some medications have been found to reduce some symptoms experienced by those with Alzheimer disease.

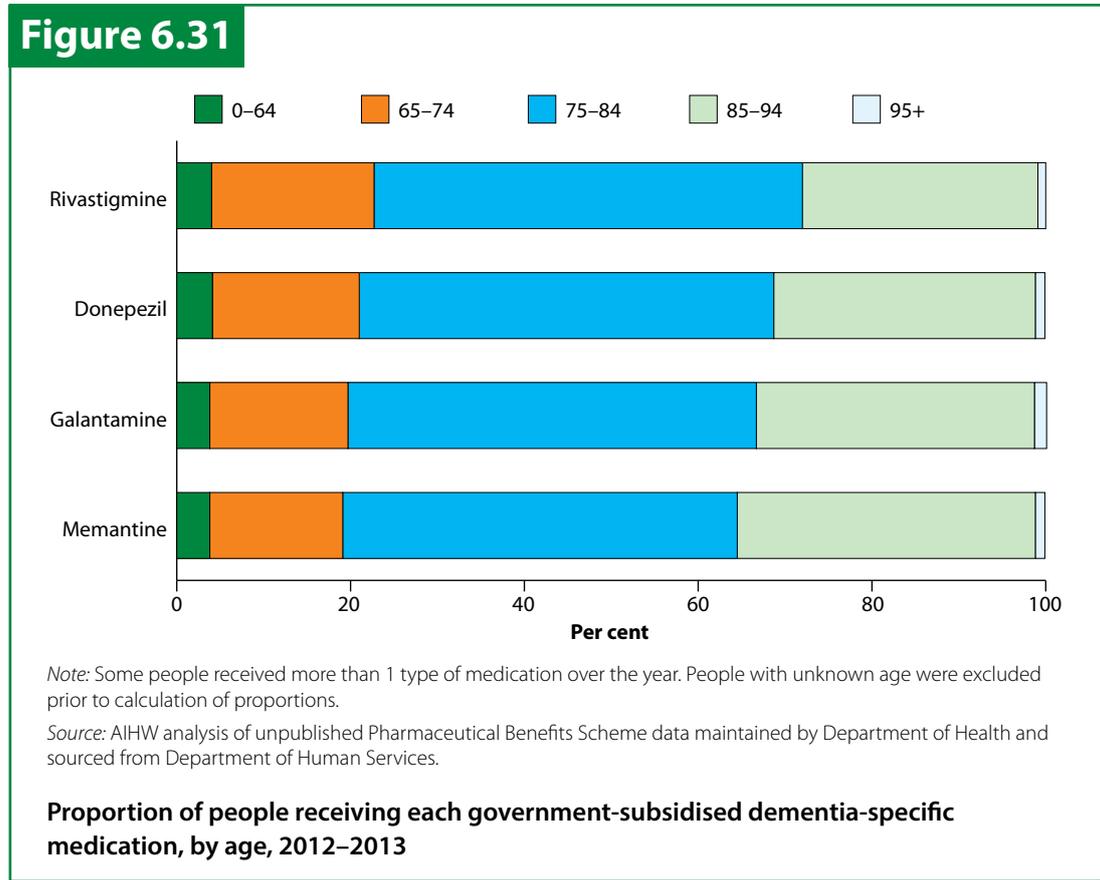
Four dementia-specific drugs are subsidised by the Australian Government through the Pharmaceutical Benefits Scheme (PBS) and the Repatriation Pharmaceutical Benefits Scheme (RPBS) for patients who have a diagnosis of Alzheimer disease confirmed by (or in consultation with) a specialist or consultant physician, subject to specific clinical criteria being met (Department of Health 2013). The drugs (and their trade names) are: donepezil (Aricept®); galantamine (Reminyl®, Galantyl®); rivastigmine (Exelon®); memantine (Memanxa®, Ebixa®, APO-Memantine®). Memantine is approved for use in moderate to severe Alzheimer dementia, while the others are approved for use in mild to moderate Alzheimer dementia. Note that people with Alzheimer disease and other types of dementia may use medications other than these (see Prince et al. 2011). For example, there is some evidence that ginkgo biloba may have some beneficial effects on cognitive function in people with mild to moderate dementia (Prince et al. 2011).

The data presented in this section do not capture non-dementia specific medications received by those with dementia, nor do they capture drugs that may have been prescribed specifically to manage a person's dementia but can also be used to treat other diseases, as these data are not separately available.

In 2012–13, 48,277 people received government-subsidised dementia-specific medications. Based on estimates of the number of people who have dementia, this suggests that about 15% of those with any type of dementia were receiving dementia-specific medications. (Note that the estimate of the number of people with dementia includes those who have not received a diagnosis, and people with forms of dementia other than Alzheimer disease, who would thus not qualify to receive these medications under PBS or RPBS subsidy.) About 60% of people receiving dementia-specific medications in 2012–13 were female.

Donepezil was the most commonly dispensed prescription (received by 64% of people), and memantine the least (7%). However, prescription also varied according to age, with older patients more commonly prescribed memantine—the drug approved for moderate to severe dementia (Figure 6.31).

The number of people who received government-subsidised dementia-specific medications increased by an annual average of 2.4% between 2008–09 and 2012–13, with a greater increase for men (3.2%) than women (1.9%).



How will dementia affect us in the future?

Due to the growth and ageing of the population, the number of people with dementia is projected to reach around 900,000 by 2050 (Figure 6.29). Dementia has profound personal and social costs for individuals with the condition, their families, and the community at large. Dementia is already a leading cause of death, disability and overall burden of disease and, on a personal level, a condition feared by many Australians. People with dementia often rely heavily on health and aged care services, and there is also a significant burden on informal carers. There are also substantial challenges for society in supporting people living (and in the mild stages, even working) with the condition. In the absence of effective prevention, treatment or cure options, the impact of dementia is likely to increase with the projected increase in the number of people with the condition.

As mentioned earlier, the projections of dementia prevalence presented here assume that the underlying prevalence rates will remain constant. However, the rates could change in the future, due to, for example, changes in risk factors and in the prevention, management and treatment of the condition.

On the one hand, improved medical and social care may result in a higher prevalence of dementia by allowing more people to survive longer with the condition (Vickland et al. 2010). Increases in the prevalence of dementia risk factors may also result in dementia being more common. On the other hand, computer modelling indicates that medical breakthroughs which delay dementia onset (Vickland et al. 2010) and reduce risk factors such as obesity (Nepal et al. 2010) have the potential to substantially reduce the prevalence of dementia.

Recent international studies have reported reductions in dementia prevalence rates overseas (Matthews et al. 2013). However, due to the lack of Australian data, it is not possible to determine the extent to which there has been any change in Australia.

What is missing from the picture?

Despite the growing body of information available about people with dementia and their carers, there are a number of data gaps and issues that impact on our ability to monitor and report on the condition.

Australia lacks national data which can be used to derive reliable estimates about the prevalence of dementia. Thus, international data and modelling are required to produce estimates. There is also limited information about the prevalence of different types of dementia.

Multistage surveys in which participants are systematically assessed for dementia using both screening tools and clinical diagnostic assessments may be of most value in deriving comprehensive estimates of how common dementia is, because they are more likely to detect mild and moderate cases of dementia, and cases are clinically established. This approach was taken in Canada, for example, where a national study of the prevalence of dementia among those aged 65 and over was conducted in the early 1990s (CSHAWG 1994). In Australia, no such national study has been undertaken. In addition, there is also limited information about the number and characteristics of people with dementia from several important population groups, including people from culturally



and linguistically diverse backgrounds, Aboriginal and Torres Strait Islander people, and people with younger onset dementia. Results from a study (not yet published) in Eastern Sydney will provide some more information about the number and experiences of Australians diagnosed with younger onset dementia (Withall et al., forthcoming), while the Koori Growing Old Well Study (NeuRA 2013; see also earlier section, 'How many people have dementia?') is expected to provide further information about dementia within the Indigenous population.

There are also many other gaps in our knowledge about dementia, including in relation to the underlying mechanisms of the condition (Seeher et al. 2011). For example, the boundaries between 'normal' age-related decline and mild dementia are not clearly defined at either a research or clinical level, particularly in the oldest age groups (Draper 2011). As well, it is difficult to distinguish mild cognitive impairment from early dementia, and the ability of pre-clinical symptoms to predict the development of dementia is currently unclear (Le Couteur 2013). Data from studies such as the Sydney Centenarian Study (Sachdev et al. 2013), the Sydney Memory and Ageing Study (Sachdev et al. 2010), and the CSIRO's Australian Imaging, Biomarker and Lifestyle (AIBL) study of ageing (Ellis et al. 2009; CSIRO 2013) may help fill some of these data gaps.

Further research is also required to identify factors that can reduce a person's risk of developing dementia, as well as those that might slow progression in those who already have the condition. A number of longitudinal studies currently under way may provide further information about dementia and its determinants, for example, the AIBL study of ageing, as mentioned above. This is a large-scale prospective longitudinal study of cognition involving more than 1,100 people aged 60 and over. This study aims to investigate which biomarkers, cognitive characteristics, and health and lifestyle factors determine the development of Alzheimer disease.

In terms of information about the characteristics, service use and care of people with dementia, existing data collections include a wide array of relevant information. However, many of the data sets relating to service use are maintained separately. People with dementia and their carers often access multiple services, which means that on their own these data do not provide a comprehensive picture of the nature and extent of services individuals use. Fragmentation and inconsistency are also evident across data collections in terms of the type of data collected, and there is sometimes limited comparability of definitions. For example, the way in which people with dementia are identified varies in approach and quality across collections. Data linkage projects may fill some of these gaps—for example, the Pathways in Aged Care Project (AIHW 2011) has provided valuable information about the aged care service use pathways of people with dementia.

Where do I go for more information?

For more information about people with dementia see www.aihw.gov.au/dementia/. The report [Dementia in Australia](#) provides a comprehensive overview of dementia in Australia, including information on prevalence, mortality, characteristics of people with dementia, and their use of aged care services.

[Dementia care in hospitals: costs and strategies](#) presents information about the costs of caring for people with dementia in New South Wales hospitals, and reports on strategies and practices being implemented in Australia and internationally that might improve the quality and cost efficiency of dementia care in hospitals. These and other recent publications are available for free download via the link above.

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