



5.2 Dementia and people's need for help from others

Dementia is not a specific disease. Rather, it is a group of conditions characterised by the gradual impairment of brain function. It commonly affects people's ability to think, remember and reason—and their personality—and impairs other core brain functions, such as language and movement. The condition is degenerative and irreversible. Dementia is the second most common underlying cause of death and it contributes to Australia's burden of disease through years of life lost from death and disability. In 2014, it was the leading underlying cause of death for 12,000 people, with an estimated 33 people dying from dementia each day. People may also die with dementia; it was recorded as an associated cause of death for a further 35,600 deaths in 2014. In 2011, it accounted for 3.4% of the overall burden of disease, and was the leading cause of total burden for females aged 85 and over.

Dementia is a substantial challenge to Australia's care systems, particularly as the population continues to age. While it is not caused by age—and should not be considered as an inevitable consequence of ageing—dementia does primarily affect older people. The AIHW report [Dementia in Australia](#) indicates that only 1.3% of the estimated 365,000 people with dementia in Australia in 2017 were aged under 60. The number of people affected by dementia is estimated to rise considerably, to 900,000 people by 2050.

People's health generally declines as dementia progresses; they increasingly need help from others, including informal carers and aged care services. Often, as the impacts of dementia worsen, the increasing burden on informal carers such as family members influences care decisions, such as whether to move to residential aged care or stay at home. It is expected that greater numbers of older people in Australia will choose to stay at home for longer (see Chapter 5.1 'Ageing and aged care'). Hence, it will be increasingly important to ensure that informal carers are adequately supported and that people receive an appropriate level of formal care at home. It is similarly important to ensure that people within residential aged care receive care that is appropriate to their needs.

This article focuses on how dementia affects people's functional ability and their need for assistance and how these factors differ, not only between people with dementia in cared accommodation (commonly permanent residential aged care) and people who still live at home, but also between people with and without dementia in permanent residential aged care.

People with dementia

The Australian Bureau of Statistics Survey of Disability, Ageing and Carers (SDAC) estimated that there were more than 194,000 people with dementia in Australia in 2015 (ABS 2016b). This estimate is lower than that produced by the AIHW for the report [Dementia in Australia](#). While the SDAC criteria were broadened in 2015 to better identify people with dementia (ABS 2016a), the survey primarily collects information from the perspective of disability and impairment and it may underestimate the prevalence of dementia in the population; for more information, see 'What is missing from the picture?'





Based on AIHW analyses of the 2015 SDAC, just over half (51%) of people with dementia lived in households (such as private dwellings and self-care units within retirement villages), with the remaining 49% living in cared accommodation (such as residential aged care facilities, hospitals and other institutions that provide care, as well as group homes) (ABS 2016b).

In 2015, people living with dementia in cared accommodation were more likely to be:

- older (62% were aged 85 and over, compared with 28% of people with dementia living in households—the average age of a person with dementia in cared accommodation was 85.3, compared with 77.9 for households)
- women (70%, compared with 53% for men)
- widowed (59%, compared with 29%. This varied further by sex—70% of women living in cared accommodation were widowed, compared with 32% of men) (ABS 2016b).

Overall, people with dementia in cared accommodation were more likely to indicate restrictions in line with common dementia symptoms than people living in households. These included memory problems or confusion (86%, compared with 68% in households), social or behavioural issues (67%, compared with 18%) and partial or complete loss of speech (52%, compared with 9.3%) (ABS 2016b).

Almost all people with dementia identified by the survey had a disability (99% of people with dementia living in cared accommodation, and 94% of people with dementia living in households). As might be expected, the likelihood of needing assistance with core activities was greater for people with dementia living in cared accommodation: 95% of these people always needed assistance with at least one core activity (mobility, self-care or communication) and 16% with all three, compared with 56% and 7.8%, respectively, for people with dementia living in households (ABS 2016b).

Dementia in permanent residential aged care

After people enter permanent residential aged care, their care needs are assessed using the Aged Care Funding Instrument (ACFI). This tool is not a comprehensive assessment, but it does provide some information on people's care needs as they relate to service provision in residential aged care. People are assessed on 12 items that measure care needs on three broad domains—activities of daily living, behaviour, and complex health care.

Almost 92,000 people with dementia were living in permanent residential aged care as at 30 June 2016 (representing 52% of the total). People with dementia were more likely to be rated as requiring a 'high' level of assistance on all three domains (42%, compared with 23% of people without dementia). For many specific items, the differences were even greater (Table 5.2.1).





Table 5.2.1: Proportion of people in permanent residential aged care with/without dementia who were assessed as being most dependent, by ACFI domain^(a) and individual item^(b), as at 30 June 2016

ACFI domain/item	With dementia (%)	Without dementia (%)
Activities of daily living	63	48
 Nutrition	26	9
 Mobility	61	56
 Personal hygiene	90	76
 Toileting	77	63
 Continence	86	70
Behaviour	80	43
 Cognitive skills	46	9
 Wandering	16	5
 Verbal behaviours	65	50
 Physical behaviours	53	32
 Symptoms of depression ^(c)	14	18
Complex health care	61	61
 Taking medications	45	44
 Health-care procedures and activities	33	35

(a) Proportion of people who received the highest rating (H, or high) on a domain based on the ratings on the underlying individual items.

(b) Proportion of people who received the highest rating (D, or most dependent) on an individual item relating to day-to-day care needs (defined by need for assistance, frequency, or degree of impairment/inference in function, as relevant to item).

(c) Fewer than 1 in 6 people were assessed as showing symptoms of depression that caused major interference with their ability to function and participate in activities. However, ACFI data also showed that 2 in 5 (42%) people with dementia had been diagnosed with depression, and slightly more than half (51%) of people without dementia.

Source: AIHW analysis of ACFI data.

Further information on health conditions that affect people's care needs in permanent residential aged care is also available through information collected via the [ACFI](#).





What is missing from the picture?

It can be difficult to determine the exact number of people with dementia. There are no national data or population-based surveys with diagnostic criteria on dementia to identify how many people are diagnosed with dementia—and diagnoses cannot be relied on to accurately capture the number of people with dementia, as the condition may go unrecognised (particularly in its early stages).

Some data on people with dementia are available from administrative data sources, such as those relating to deaths, hospitalisations, aged care assessments and pharmaceutical prescriptions. Each of these sources provide some information on particular groups of people with dementia. However, people with dementia may not be reliably identified as they come into contact with various services; for example, data on how people with dementia use aged care outside of permanent residential aged care are not readily available, although this can be analysed in more detail using the Pathways in Aged Care (PIAC) linkage map. Data linkage could be used to improve our understanding of how different services are used by people with dementia, as well as to improve estimates of the number of people living with dementia in Australia.

Where do I go for more information?

More information about people with dementia is available at www.aihw.gov.au/dementia/, and the report [Dementia in Australia](#) is available for free download. Recent publications drawing on PIAC linkage work include information on how some people with dementia used aged care—to find out more about PIAC and other aged care data, see [GEN](#).

References

ABS (Australian Bureau of Statistics) 2016a. Survey of Disability, Ageing and Carers: summary of findings, 2015. ABS cat. no. 4430.0. Canberra: ABS.

ABS 2016b. Survey of Disability, Ageing and Carers 2015. ABS cat. no. 4430.0. Findings based on the use of TableBuilder data. Canberra: ABS.

