



# Australian Social Trends December 2012

People identified as having dementia  
or Alzheimer's disease

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# People identified as having dementia or Alzheimer's disease

Dementia and Alzheimer's disease are health conditions that most of us have heard of, but few of us fully understand. These conditions are caused by the gradual death of brain cells, and can have a profound impact on the lives of those who have the condition and their carers. As their loss of cognitive ability leads to impairments in memory, reasoning, planning, and behaviour, people with dementia or Alzheimer's disease lose control of many of the essential features of their lives, becoming increasingly dependent and unpredictable.

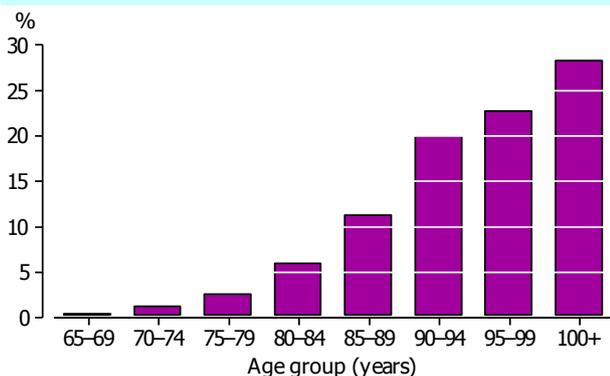
The onset of dementia and Alzheimer's disease is usually in old age. Because the proportion of the population in older age groups is projected to increase, it has been suggested that dementia and Alzheimer's disease represent significant challenges to current health, aged care and social policies.

In 2012, Australian health ministers recognised dementia as the ninth National Health Priority Area, and the Australian Government announced its intention to reform aged care. As part of its \$3.7 billion Aged Care Reform package, the Australian Government stated its intention to allocate \$268.4 million over five years to 'tackle' dementia.<sup>1</sup>

## How common is dementia and Alzheimer's disease?

In the 2009 ABS Survey of Disability, Ageing and Carers (SDAC), around 110,000 Australians were identified as having dementia (ICD-10 codes F01 and F03 only) or Alzheimer's disease (see blue box 'Measuring dementia and Alzheimer's disease'). Although people as young as their late 20s were identified as having dementia or Alzheimer's disease in

Proportion of each age group identified as having dementia or Alzheimer's disease – 2009



Source: ABS 2009 Survey of Disability, Ageing and Carers

## Data sources and definitions

Data presented in this article have been sourced from the ABS Survey of Disability, Ageing and Carers (SDAC), the Australian Institute of Health and Welfare's (AIHW) Australian Hospital Statistics and Principal diagnosis data cubes, and the ABS Causes of Death collection.

To be able to integrate data from these different sources, the same definition of *dementia and Alzheimer's disease* has been used throughout this article. This definition is the World Health Organisation's recommended cause of death dissemination category comprising *International Statistical Classification of Diseases and Related Health Problems Tenth Revision (ICD-10)* codes F01 (Vascular dementia), F03 (Unspecified dementia) and G30 (Alzheimer's disease).<sup>2</sup>

A *health establishment* is a hospital, nursing home, aged care hostel, or the cared component of a retirement village.

A *hospitalisation* is an episode of admitted patient care which can be either 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 palliative care).<sup>3</sup>

2009, these conditions were rarely identified among people under 45 years, and were still uncommon among 45–64 year olds. Among senior Australians, the proportion identified as having dementia or Alzheimer's disease in 2009 progressively increased with age from less than 1% of 65–69 year olds to 28% of centenarians.

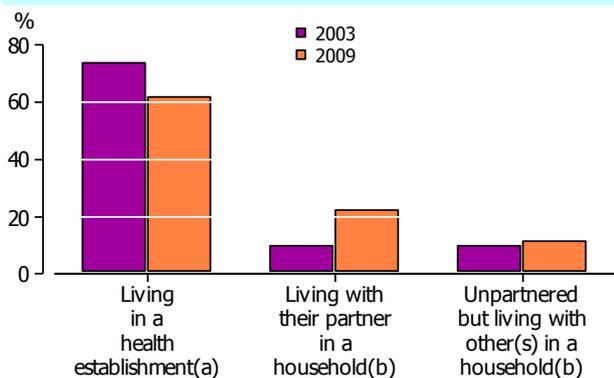
## Who is affected?

Of people identified with dementia or Alzheimer's disease in 2009, 96% were 65 years or older, nearly two-thirds (64%) were women, and 63% were widowed, divorced, separated or never married. This demographic profile reflects the age at which the symptoms of dementia and Alzheimer's disease become obvious. It also reflects Australian women's tendency to marry older men and live longer than their husbands.

## Where do they live?

In 2009, nearly two-thirds (62%) of people identified as having dementia or Alzheimer's disease were living in a health establishment such as a nursing home, an aged care hostel, or the cared component of a retirement village. Another 22% were living in a household with their partner, and a further 11% were unpartnered but were sharing a household with at least one other person such as a family member.

## Living arrangements of people identified as having dementia or Alzheimer's disease



(a) A hospital, nursing home, aged care hostel, or the cared component of a retirement village.

(b) A household is a group of two or more related or unrelated people who usually reside in the same dwelling and who make common provision for food and other essentials of living, or a person living in a dwelling who makes provision for his or her own food and other essentials for living without combining with any other person.

Source: ABS Survey of Disability, Ageing and Carers

In both 2003 and 2009, Australians identified as having these conditions were not likely to have been living at home alone. However, in line with de-institutionalisation and non-institutionalisation policies initiated in the mid-1980s, they were more likely to be residing in private dwellings (i.e. households) in 2009 (38%) than in 2003 (26%).

Whether a person with dementia or Alzheimer's disease lives in a household or health establishment partly depends upon whether they have someone to live with, such as a spouse, child or other potential care giver. It also depends upon the degree of restriction they experience in performing the tasks of daily living, and their consequent level of need for care and/or supervision. The financial cost of living in a health establishment, and the supply of such accommodation relative to the demand for it, are also likely to be factors.

## How disabling are their conditions?

Almost all (98%) of the people identified as having dementia or Alzheimer's disease in the 2009 SDAC were limited in their ability to perform at least one basic, everyday self-care, mobility or vocal communication task. Such limitations were not necessarily due to dementia or Alzheimer's disease though, as 96% of Australians identified as having dementia or Alzheimer's disease in 2009 had more than one long-term health condition (e.g. arthritis, back problems, hearing loss, heart disease). Nearly two-thirds (63%) had at least five long-term health conditions, and 11% had nine or more.

## Measuring dementia and Alzheimer's disease

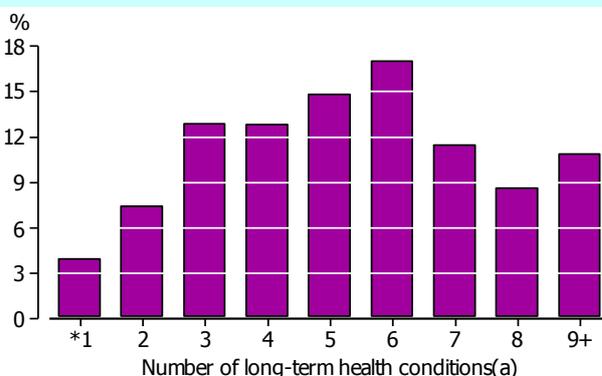
The primary aim of the ABS SDAC is to produce information about people with a disability, older people and carers.<sup>4</sup> SDAC collects information on all health conditions experienced by people living in households or cared accommodation that have lasted or are likely to last for at least 6 months, and whether or not these conditions restrict their activities in some way. It may not capture those people who have mild or early stages of dementia or Alzheimer's disease because they have not yet been diagnosed, or because they attribute impairments to the effects of old age or another condition, rather than to the existence of dementia or Alzheimer's disease.

Other organisations and researchers have indirectly estimated the number of Australians with impaired brain function by applying age-specific prevalence rates derived from various studies to estimated resident population data.<sup>5,3</sup> Most recently, the AIHW estimated that if all Australians had been screened in 2011, and then (when relevant) diagnostically assessed, that 298,000 people would have been found to have impairment of brain function associated with more than 100 different diseases, including dementia, Alzheimer's disease, Parkinson's disease, Huntington's disease, Creutzfeldt-Jakob disease, and AIDS.<sup>3</sup>

A little over half (53%) of those who were living in households were mainly restricted by their dementia or Alzheimer's disease, rather than by some other long-term health condition.

Indicative of the generally more advanced stage of these conditions experienced by those living in health establishments, dementia or Alzheimer's disease was the long-term health condition causing most problems for more than two-thirds (69%) of these people identified as having dementia or Alzheimer's disease.

## Number of long-term health conditions(a) experienced by people identified as having dementia or Alzheimer's disease— 2009



(a) A long-term health condition is a disease or disorder which has lasted or is likely to last for at least six months; or a disease, disorder or event (e.g. stroke, poisoning, accident etc.) which produces an impairment or restriction which has lasted or is likely to last for at least six months.

\* This estimate has a relative standard error of 25% to 50% and, if used, should be used with caution.

Source: ABS 2009 Survey of Disability, Ageing and Carers

## What sort of help do they need?

Need for help to perform physical tasks such as household chores, home maintenance and gardening may be more attributable to the existence and severity of physical health conditions than to dementia or Alzheimer's disease. The ability to perform communicative, cognitive and emotive tasks such as understanding others, decision making, and coping with feelings is more likely to be impaired by dementia or Alzheimer's disease.

In 2009, 29% of people living in households who were identified as having dementia or Alzheimer's disease sometimes or always needed help to understand or be understood by family or friends, and 38% sometimes or always needed help to understand or be understood by a stranger. A strong indication that their

counterparts living in health establishments tend to have more advanced dementia or Alzheimer's disease is that 69% of them needed help sometimes or always to understand or be understood by family or friends, and 81% sometimes or always needed help to understand or be understood by a stranger.

Of people living in households who were identified as having dementia or Alzheimer's disease, 24% needed help to cope with their feelings or emotions, and 35% needed help to make friendships, interact with others, or maintain relationships. More than half of them needed some help with reading and writing tasks such as checking bills or bank statements, writing letters or filling in forms (58%), and with making decisions or thinking through problems (59%). All up, 94% of these people needed help with at least one task of daily living.

### People identified as having dementia or Alzheimer's disease: need for help by activity/task – 2009

	Lives in a household %	Lives in a health establishment %
Selected activities and tasks of daily living		
Self-care – ever needs help or supervision:		
to shower or bathe	48.3	96.8
to dress	53.4	95.9
when eating a meal	33.6	82.7
with controlling bladder or bowel	34.3	85.8
Health care – ever needs help or supervision:		
to cut and clean toe nails and wash and dry feet	70.4	98.5
with other health care tasks(a)	76.2	98.0
Mobility – ever needs help or supervision:		
to move about the house/health establishment(b)	29.8	80.8
when going to or getting around a place away from home(c)	77.0	67.0
Vocal communication – ever needs help:		
to understand or be understood by family or friends	28.6	69.2
to understand or be understood by someone he/she does not know	37.9	80.9
Cognitive and emotive tasks – ever needs help:		
making friendships, interacting with others, or maintaining relationships	34.8	(d)66.9
copng with his/her feelings or emotions	23.9	(d)74.9
with making decisions or thinking through problems	58.7	(d)79.0
Needs help with reading and writing tasks(e) because of health or old age	58.0	87.3
Needs help to prepare his/her meals because of health or old age	62.2	(f)
Needs help to do household chores(g) because of health or old age	62.4	(f)
Ever needs to be driven by someone else in a private vehicle or taxi to travel from home	(h)80.1	(i)

(a) Taking medication (including injections), dressing wounds, manipulating or exercising muscles or limbs, therapeutic massage, using medical equipment or aids (e.g. connecting to machines, pumps, etc.), skin care, and preventing pressure sores.

(b) Those who do not move about their house/health establishment are considered to never need help or supervision to perform this task.

(c) Those who do not leave their home/health establishment are considered to never need help or supervision to perform this task.

(d) Those who do not perform this task at all (e.g. those in a coma) are considered to never need help to perform this task.

(e) Such as checking bills or bank statements, writing letters or filling in forms.

(f) This task is usually performed by paid employees of health establishments.

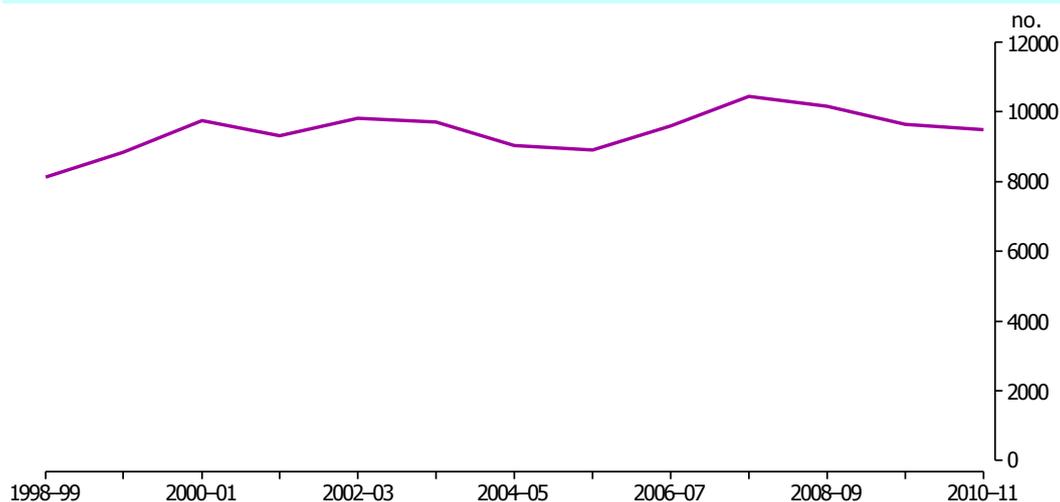
(g) Like laundry, vacuuming or dusting.

(h) Those who do not leave home are considered to never need to be driven to places away from home by someone else in a private vehicle or taxi.

(i) This data was not collected on behalf of people living in health establishments.

Source: ABS 2009 Survey of Disability, Ageing and Carers

## Hospitalisations(a) for which dementia or Alzheimer's disease was the principal diagnosis



(a) Episodes of admitted patient care which can be total hospital stays (from admission to discharge, transfer or death) or portions of hospital stays beginning or ending in a change care type (for example, from acute care to palliative care).<sup>3</sup>

Source: Australian Institute of Health and Welfare [Separation statistics by principal diagnosis in ICD-10-AM, Australia, 1998-99 to 2007-08](#); Australian Institute of Health and Welfare [Separation statistics by principal diagnosis in ICD-10-AM, Australia, 2008-09 to 2009-10](#); Australian Institute of Health and Welfare [Australian hospital statistics 2010-11](#) (AIHW cat. no. HSE 117)

### How many hospitalisations are mainly because of dementia or Alzheimer's disease?

During 2010-11, dementia or Alzheimer's disease was the principal diagnosis for 9,492 hospitalisations. This was up from 8,135 in 1998-99, but down from the 21st century peak of 10,438 in 2007-08.

In 2010-11, the average length of a hospitalisation when dementia or Alzheimer's disease was the principal diagnosis was 16 days.<sup>6</sup> While this was shorter than the average during the previous year (18 days),<sup>7</sup> and the year before that (19 days),<sup>7</sup> it was over five times longer than the average length of other hospitalisations in 2010-11 (3 days).<sup>6</sup>

**The hospital stay of patients principally diagnosed with dementia or Alzheimer's disease is over five times longer than it is for other hospital patients.**

Hospital care is far from being the only formal care received by people with dementia or Alzheimer's disease. Recent decades have witnessed an expansion of the delivery of formal care inside recipients' own homes via organisations such as the Blue Nurses and Meals on Wheels. Additionally, many retirement villages now offer assisted living accommodation where residents receive considerable formal care outside of a hospital setting.

### How many Australians die from dementia or Alzheimer's disease each year?

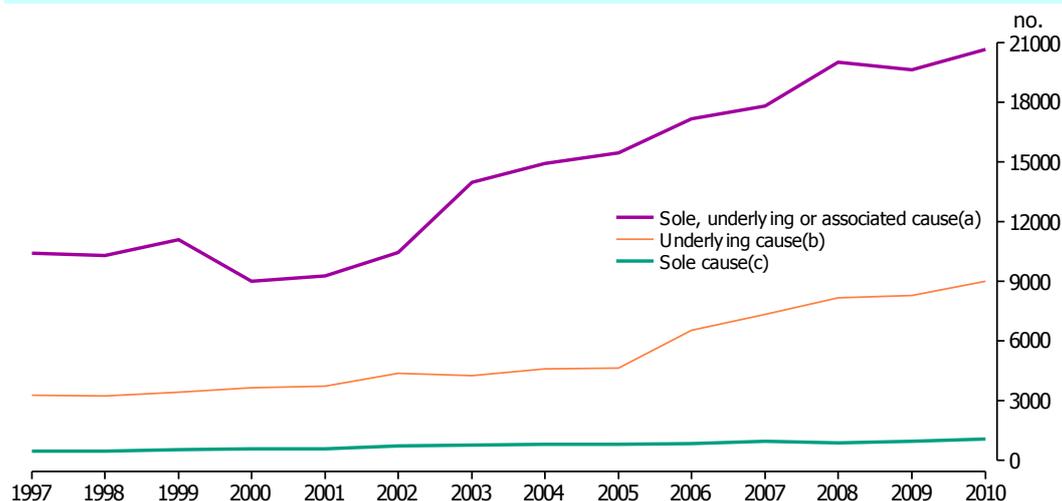
A health condition can be certified by a doctor or coroner as the underlying (i.e. main) cause of death, or as an associated (i.e. contributing) cause of death when a person dies mainly from something else. Dementia and Alzheimer's disease was the third leading underlying cause of death in 2010, behind Ischaemic heart diseases (21,708 deaths) and Cerebrovascular diseases (11,204 deaths). The number of deaths for which dementia or Alzheimer's disease was the underlying cause increased from 3,740 in 2001 to 9,003 in 2010. This is largely due to an increase in the number of deaths for which dementia was the underlying cause (from 2,133 in 2001 to 6,297 in 2010).<sup>8</sup>

Some health conditions are more likely than others to accompany death from dementia or Alzheimer's disease. For example, nearly a third (31%) of the deaths attributed to dementia or Alzheimer's disease as the underlying cause in 2010 were also due to influenza and pneumonia as an associated cause.

Hypertensive diseases and Ischaemic heart disease were each associated causes for 12% of deaths where dementia or Alzheimer's disease was the underlying cause. In contrast, malignant cancers were an associated cause of death for just 5% of deaths when dementia or Alzheimer's disease was the underlying cause.<sup>8</sup>

There are three reasons for the rising death toll from dementia and Alzheimer's disease. Firstly, the number of Australians in older age groups,

## Registered deaths certified to have been caused by dementia or Alzheimer's disease



(a) Deaths for which dementia or Alzheimer's disease was entered on the medical certificate of cause of death as a disease or morbid condition that either resulted in the death, or contributed to the death. For most of these deaths, dementia or Alzheimer's disease contributed to the death as an associated cause but was not the main (i.e. sole or underlying) cause. The dip in deaths registered in 2000, 2001 and 2002 is the result of a known data quality issue associated with coding software used internationally at that time. This issue reduced the number of deaths for which dementia or Alzheimer's disease was an associated cause only, and was rectified in 2003 with a new version of the software.

(b) Deaths for which dementia or Alzheimer's disease initiated the train of morbid events leading directly to death.

(c) Deaths for which dementia or Alzheimer's disease was the only morbid condition, disease or injury entered on the medical certificate of cause of death.

Source: ABS [Causes of Death, Australia, 2010](#) (cat. no. 3303.0); ABS Causes of Death collection

where dementia and Alzheimer's disease is more prevalent, has been increasing. This has occurred partly because life expectancy at all ages has been increasing (see *Australian Social Trends, March 2011* '[Life expectancy trends – Australia](#)'). Longer life expectancy means that Australians are becoming increasingly likely to live long enough to develop and eventually die from dementia or Alzheimer's disease.

Secondly, updates to the coding instructions in the *International Classification of Diseases and Related Health Problems (Tenth Revision)* resulted in the assignment of some deaths to Vascular dementia where previously they may have been coded to a cerebrovascular disease.<sup>8</sup>

Finally, changes to the *Veterans' Entitlements Act 1986* and the *Military Rehabilitation and Compensation Act 2004*, and a subsequent promotional campaign targeted at health professionals, allowed for death from Vascular dementia of veterans or members of the defence forces to be related to their relevant service. This is believed to have had an effect on the number of deaths attributed to dementia.<sup>8</sup>

### Looking ahead

Changes in diet, exercise levels and smoking rates have the potential to change dementia prevalence rates, because these behaviours are considered to be risk factors for developing Vascular dementia from strokes.

Ongoing research into causes, treatments and cures may eventually lead to the adoption of other preventative health measures,<sup>9</sup> and/or to pharmaceuticals, medical equipment and medical techniques which could slow, halt or reverse the onset of dementia and Alzheimer's disease. For example, there has been recent, well-publicised research into the long-term effects of traumatic brain injuries (e.g. concussion) more commonly experienced by ex-boxers and past participants of collision sports such as gridiron and rugby.<sup>10</sup>

On the other hand, if in the future there is earlier diagnosis of dementia and Alzheimer's disease combined with greater willingness to disclose diagnosis of these health conditions, then the proportion of Australians identified as having dementia or Alzheimer's disease could increase in all age groups.

### Endnotes

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10. Centers for Disease Control and Prevention, 2012, *What are the Potential Effects of Traumatic Brain Injury?*, viewed 21 May 2012, <[www.cdc.gov](http://www.cdc.gov)>.

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