

Awareness and understanding of dementia in Australia

RESEARCH REPORT OCTOBER 2017



To coincide with the launch of Dementia Australia (formerly Alzheimer's Australia), Ipsos Australia conducted an Omnibus Online survey of 1,049 members of the general public. Dementia Australia included eight specific questions in this survey to examine community understandings, beliefs and attitudes about dementia. The survey findings demonstrate that although there is some understanding of dementia in the general community, it is quite limited. This is despite the fact that approximately one-third of survey respondents reported that someone close to them had been diagnosed with dementia. Consequently, there is still much work to be done in increasing community awareness, understanding and acceptance as well as providing support and advocating for people with dementia and their carers.

Only 17 per cent of respondents correctly ranked dementia as the second leading cause of death. It is concerning that the vast majority of the general public are not aware that dementia is the second leading cause of death; even more so given that dementia is the only one of Australia's top three leading causes of death which has an increasing mortality rate.

More than half of the survey respondents did not understand the relationship between Alzheimer's disease and dementia. Almost 40 per cent of respondents did not know that dementia is not a normal part of ageing. Thirty-nine per cent of people agreed that they felt awkward around someone with dementia, while 41 per cent said they found talking to someone with dementia confronting. Seventy-seven per cent of respondents think they would visit their general practitioner (GP) if they thought they had dementia.

On 18 October 2017, Dementia Australia will be officially launched. Dementia Australia brings together the federated Alzheimer's Australia State and Territory organisations (New South Wales, Victoria, Queensland, South Australia, Tasmania, Northern Territory and Australian Capital Territory). As a unified national organisation, Dementia Australia will be a stronger, more powerful advocate for all people with dementia, their carers and families. The change to Dementia Australia also more accurately describes who we represent and support, and will help the public better understand dementia.

What is Dementia?

Dementia describes the symptoms of a large group of illnesses which cause a progressive decline in a person's functioning. It is a broad term used to describe a loss of memory, intellect, rationality, social skills and physical functioning. Dementia is a fatal condition and it is currently the second leading cause of death of Australians¹. There are many types of dementia including Alzheimer's disease (which is the most common type), vascular dementia, frontotemporal dementia and Lewy body disease.

Dementia in Australia

In 2017, there are estimated to be more than 413,100 Australians living with dementia. Without a significant medical breakthrough, the number of people with dementia in Australia is expected to be more than 1.1 million by 2056². There are an estimated 25,938 people with younger onset dementia, expected to rise to 42,252 people by 2056³.

Currently, three in 10 people over the age of 85 and almost one in 10 people over 65 have dementia⁴. Dementia is the single greatest cause of disability in older Australians (aged 65 years or older) and the third leading cause of disability overall⁵. There are an estimated 1.2 million people involved in the care of someone with dementia⁶.

In 2017, dementia is estimated to cost Australia \$14.67 billion. By 2025, the total cost of dementia is predicted to increase to \$18.7 billion in today's dollars, and by 2056, to over \$36.8 billion⁷.

Dementia Australia Ipsos Survey

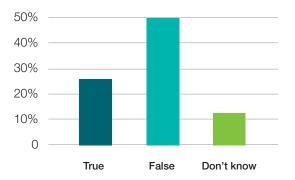
In September 2017, Ipsos Australia conducted an Omnibus Online* survey of 1,049 members of the general public. Dementia Australia included eight specific questions in the survey to examine community understandings, beliefs and attitudes about dementia.

The survey respondents were broadly representative of the general public. The sample included people from all Australian states and territories, and was representative of the distribution of the Australian population in gender and state of residence. The respondents came from a range of age groups, and varied in their work status and level of education.

Knowledge of dementia

Survey respondents were asked whether the statement "Dementia is not a normal part of ageing" is true or false (there was also a "don't know" option). Sixty-one per cent of the 1,049 respondents correctly identified that dementia is not a normal part of ageing. However, 39 per cent of respondents (two in five people) did not know that dementia is not a normal part of ageing (i.e. those who gave "false" or "don't know" responses).

Graph 1: True or False? Dementia is a normal part of ageing

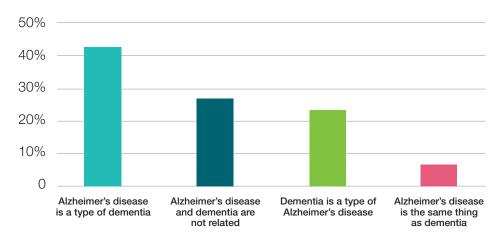


Respondents were asked about the relationship between Alzheimer's disease and dementia. They were asked to select the true statement from four statements provided. Forty-three per cent of respondents understood the relationship between Alzheimer's disease and dementia – that Alzheimer's disease is a type of dementia – however, more than half of the respondents did not understand it.



^{*} The Omnibus survey is a national sample of approximately 1,000 adults (aged 18 years+) which is run fortnightly.

Graph 2: The relationship between Alzheimer's disease and dementia



Respondents were asked to rank four health conditions by cause of death, from highest to lowest. The correct response is Heart Disease, Dementia, Stroke and Lung Cancer. Most people (71 per cent) correctly identified that heart disease is the leading cause of death in Australia. However, only 17 per cent of respondents correctly ranked dementia as the second leading cause of death.

It is concerning that the vast majority of the general public are not aware that dementia is the second leading cause of death; even more so given that dementia is the only one of Australia's top three leading causes of death which has an increasing mortality rate⁸.

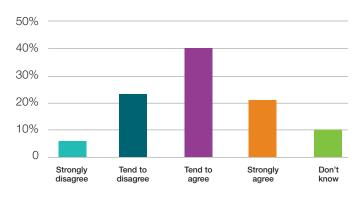
These survey results show that many Australians still do not really understand dementia. A significant proportion of the population do not know basic facts about dementia and its impact. This is despite the fact that approximately one-third of survey respondents reported that someone close to them had been diagnosed with dementia.

Beliefs and attitudes about dementia

When asked about their attitudes towards people with dementia, respondents were divided. They were asked how much they agreed with several statements including "I feel awkward around people with dementia" and "I find talking to people with dementia confronting". A Likert scale ranging from Strongly Agree through to Strongly Disagree (and there was also a Don't Know option) was offered for responses. Thirty-nine per cent of people agreed that they felt awkward around someone with dementia, while 41 per cent said they found talking to someone with dementia confronting. These findings suggest that there are still a number of Australians who feel uncomfortable around people with dementia.

Further to this, 61 per cent of people agreed with the statement "I find it hard to imagine myself getting dementia" (see Graph 3). This could mean that people therefore find it difficult to empathise with people with dementia.

Graph 3: I find it hard to imagine myself getting dementia



While it is perhaps going too far to say that people are afraid of dementia, there are aspects of the condition that people find uncomfortable and mentally distance themselves from. This stigma can act as barrier to public awareness, understanding, acceptance and community education.

Respondents were asked what they would do if they thought they had dementia. In this question participants could select as many options as they thought applied. The responses are displayed in Graph 4 below which shows that a large proportion of respondents (77 per cent) think they would visit their general practitioner (GP), with the second most popular option being to seek the advice of another health professional.



100% 80% 60% 40% 20% 0 Seek the advice Visit Talk to the Do my own lanore it and Do nothing my GP of a health people research hope it goes because there closest to me professional is no cure awav (other than a GP)

Graph 4: Responses to the statement "If I thought I had dementia I would..."

Consulting a GP is an obvious first step. However in a recent report⁹ from the Royal Australian College of General Practitioners, it was found that only six per cent of GPs felt that dementia was an emerging health concern for the future, suggesting that awareness of dementia amongst GPs could be improved. Anecdotal reports to Dementia Australia also suggest that dementia can often be incorrectly dismissed as a normal part of ageing by medical and health professionals.

The findings of the Ipsos survey demonstrate that although there is some understanding of dementia in the general community, it is quite limited. Consequently, there is still much work to be done in increasing community awareness, understanding and acceptance as well as providing support and advocating for people with dementia and their carers. One way to ensure the community fully grasps the extent and impact of dementia across Australia is by renaming Alzheimer's Australia so that all who have this condition are included and recognised.

Introducing Dementia Australia: a unified voice for people with dementia

Alzheimer's Australia has been the federated charity representing people with dementia and their carers and provided advocacy, support services, education and information.

On 18 October 2017, Dementia Australia will be officially launched. Dementia Australia brings together the federated Alzheimer's Australia State and Territory organisations (New South Wales, Victoria, Queensland, South Australia, Tasmania, Northern Territory and Australian Capital Territory). As a unified national organisation, Dementia Australia will be a stronger, more powerful advocate for all people with dementia, their carers and families. It will also continue to provide much-needed support services, education and information to communities across the country.

The change to Dementia Australia also more accurately describes who we represent and support, and will help the public better understand dementia. Dementia Australia will work to dispel common myths and misunderstandings about dementia.

- 1 Australian Bureau of Statistics (2017) Causes of Death, Australia, 2016 (cat. no. 3303.0)
- 2 The National Centre for Social and Economic Modelling NATSEM (2016) Economic Cost of Dementia in Australia 2016-2056
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- 4 The National Centre for Social and Economic Modelling NATSEM (2016) Economic Cost of Dementia in Australia 2016-2056
- 5 Australian Institute of Health and Welfare (2012) Dementia in Australia
- 6 Alzheimer's Australia (2011) Pfizer Health Report Issue #45 Dementia, Pfizer Australia.
- 7 The National Centre for Social and Economic Modelling NATSEM (2016) Economic Cost of Dementia in Australia 2016-2056
- 8 Australian Bureau of Statistics (2015) Causes of Death, Australia, 2015 (cat. no. 3303.0)
- 9 Royal Australian College of General Practitioners (2017) General Practice: Health of the Nation

dementia.org.au National Dementia Helpline 1800 100 500 Helpline is funded by the Australian Government