

INCLUSION AND ISOLATION: The contrasting community attitudes to dementia



September is Dementia Awareness Month and this year's theme, Small actions Big difference, is aimed at inspiring the community to think about how their actions and responses can have a significant impact on the lives of people with dementia, their families and carers.

Knowledge of dementia – which is the second leading cause of death in Australia and the leading cause of death of women in Australia¹ – is on the rise; however, people tell us they don't know how to support or communicate with someone living with the disease.

This comes as updated figures reveal there are more than 436,000 Australians now living with dementia, estimated to be more than 250 new cases every day. This number is projected to increase to 590,000 in just 10 years and almost 1.1 million by 2058.²

This report builds on previous analysis undertaken by Dementia Australia about how individual and community perceptions of dementia have impacted the lives of those living with the disease as well as their families and carers. In a 2017 survey, 94 per cent of people living with dementia

said they had encountered embarrassing situations as a result of their dementia, while one person commented: "People in the public are embarrassed and uncomfortable around me ... having been a social person, it upsets me that they think I am stupid". And in that same survey, almost 50 per cent of the general public felt frustrated because they were unsure how to help people with dementia.³

Dementia Australia set out to explore further why individual and community inclusion may be so challenging for someone living with dementia. What characteristics underpin individual interactions between people living with dementia and those without? What drives the sense of 'discomfort' or 'unease' for someone in communicating with a person living with dementia? How does that manifest itself?

Our survey revealed some interesting contrasts: a community belief that people with dementia are well supported by services but conversely a recognition that, at an individual level, those surveyed were ill-equipped to offer that support themselves.

By exploring in more detail the assumptions and experiences that underpin the way we all respond to and communicate with a person living with dementia, Dementia Australia aims to break down and challenge the barriers to inclusion that people living with dementia, their families and carers may face, as well as building more robust pathways for meaningful communication and engagement.

Research method

To better understand community awareness of and attitudes to dementia, a national online survey of more than 1,500 people aged 18 and over was undertaken, with questions focusing on awareness and knowledge of dementia, perceptions of stigma in the community; and individual perspectives and experiences.

A mixture of multiple choice and open-ended questions was used in the survey.

Survey findings and key themes

Of the more than 1,500 people who responded to the survey, around half identified as male and half identified as female. Every state and territory in Australia was represented, and respondents ranged from single person households to families, couples or share households.

Survey respondent demographics

Location	%
NSW	32%
Victoria	26%
Queensland	20%
Western Australia	10%
South Australia	7%
Tasmania	2%
ACT	2%
Northern Territory	1%
Age range	%
Under 45	46%
45–65	34%
Over 65	20%

The survey findings revealed four related but contradictory themes – firstly that:

1. Awareness of dementia was high (though certain or confident knowledge about the disease was lower); and

2. Awareness of the day-to-day challenges and barriers for people living with dementia was high and those surveyed were able to translate that sense into ‘real-life’ scenarios.

Conversely, the same results revealed that:

3. Despite an awareness of the challenges, there was still a strong sense that people with dementia are well supported by services and by a community that cares about them.

However, this confidence in community empathy and support was not reflected in the way in which individual respondents saw their own role in supporting people living with dementia. In that context:

4. Confidence in talking to someone with dementia was generally low, while fear or unease about the way in which someone with dementia might react to them was high.

Awareness of dementia

Most respondents (80 per cent) had heard of dementia, and this was higher among women and people aged over 65. Of those who were aware of dementia, 57 per cent (46 per cent of all respondents) had been impacted by dementia in some way, mainly through family and/or friend/s with the disease.

When asked to describe what they knew about dementia, two-thirds of respondents were able to correctly describe at least one symptom of the disease (memory loss), though only 6 per cent described it as progressive or degenerative.

The confidence respondents felt about their knowledge of dementia was not as strong.

47% of respondents thought it was probably true that Alzheimer’s disease is one of over a hundred types of dementia, but only 30 per cent were confident in saying that it was definitely true.

This suggests that, while community awareness of dementia is increasing, we need an increased focus on building knowledge of the epidemiology of dementia (that is, incidence, distribution and treatments) as well as the symptoms of the disease.

Community attitudes to dementia

Most respondents felt it was likely that people with dementia experience challenges with relationships and socialising, though the strength of these convictions was heightened in those that had heard of dementia or had a personal experience of dementia.

These results indicate that respondents typically were able to conceive of some of the day-to-day challenges for people living with dementia, including the emotional and practical impact of the disease in the community. It also reinforces the importance of initiatives like Dementia Friends and Dementia-Friendly Communities (dementiafriendly.org.au) in continuing to increase awareness of dementia and how it impacts those around us.

Perceptions of day to day challenges of living with dementia

	Likelihood that people with dementia experience	Heard of dementia	Not heard of dementia
		Likely % / Very Likely %	
Relationships & Socialising	Feeling that people don't understand them	95	81
	Feeling lonely	92	81
	Feeling that family and friends are avoiding them	87	71
	Getting lost	97	84
In Public	Feeling unsafe using footpaths and crossing roads	88	80
	Difficulties communicating with staff in shops	93	80
At home	Needing help and support to manage at home	97	87

Community supports for people with dementia

One of the most interesting results of the survey was that, despite an awareness of the challenges that dementia could create for those living with the disease, there was also a sense that there are a lot of services to support people with dementia (72 per cent) and that the community cares about people with dementia (70 per cent).

This suggests that there is an expectation of community empathy towards people with dementia, but that ultimately, it is 'other people' and 'other services' that provide the practical day-to-day support to them.

This perception is in sharp contrast to the views reported by many people living with dementia, their families and carers about the level of services and supports they receive. Common experiences reported to Dementia Australia include difficulty in accessing and securing services, as well as challenges finding services that appropriate to needs, preferences, background or age.⁴

Barriers to inclusion

Responses revealed that, despite increased awareness and empathy, community and individual unease around people with dementia is still significant.

Eight out of 10 of all respondents agreed that people in the community are uncomfortable around someone with dementia, while two thirds also agreed that the community views people with dementia in a negative way. As one respondent commented, "not everyone in society is caring".

At an individual level, 37 per cent of those surveyed stated that they felt confident around someone with dementia, and a quarter indicated that they were uncomfortable around people with dementia.

"I don't know how [or] what to talk to them about to make them feel comfortable and connect with them. I feel awkward and uncertain".

44 per cent said that they were unsure how to talk to someone with dementia, with a range of reasons underpinning that uncertainty.

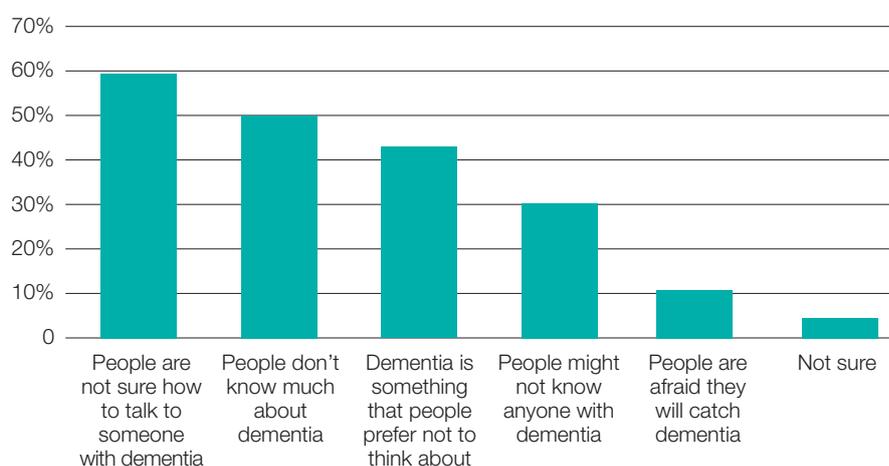
A smaller proportion of people added that they were worried the person with dementia would get upset; that they wouldn't know who the person was; that they were unsure how the person with dementia would react; or that the challenge of repeating themselves if the person with dementia forgot something would be too difficult.

"I am afraid that whatever I say, they are not really listening and understanding".

The survey also revealed that respondents who had been touched by dementia were more likely to feel confident around people with dementia (45 per cent compared with 26 per cent of those that had no direct experience), indicating that personal experience plays a significant role in how people living with dementia are perceived.

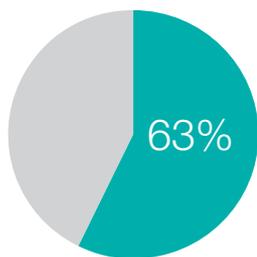
However, some respondents found that personal experience made it more difficult to interact with other people living with dementia, with one person commenting that, "after seeing my mother's [experience] ... over many years, seeing others with the same affliction upsets me deeply".

Perceived reasons for negative community attitudes*

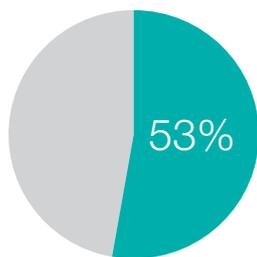


*Percentages add to more than 100 per cent as respondents were able to select more than one option

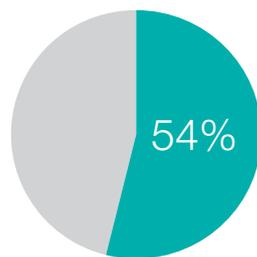
Reasons for feeling unsure about talking to someone with dementia*



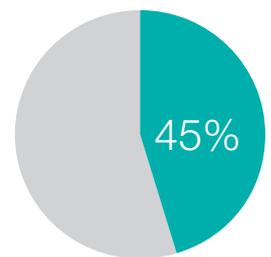
I don't know what to say to them



I'm worried I'll say the wrong thing



I'm worried they won't understand me



I'm afraid I might hurt their feelings

*Percentages add to more than 100 per cent as respondents were able to select more than one option

Conclusions

It is clear from the survey results that knowledge of dementia was strong but that perceptions of people living with the disease took what we might call a 'deficit approach' – that is, they focused primarily on the challenges of interacting with or supporting a person with dementia.

Fear of poor communication was one of the strongest findings in the survey and reveals that, in order to combat the social isolation that so many people living with dementia feel, a stronger emphasis in public awareness campaigns on meaningful communication is needed.

Similarly, an awareness that dementia is everyone's business is important: up to 70 per cent of people with dementia live in the community, and more than half of those living in residential aged care have dementia.⁵ The way that every person responds, communicates and interacts with a person with dementia has an enormous impact on their day-to-day life, regardless of whether they are a carer, family member, friend, work colleague, bus driver or the person that serves them their coffee in the local café.

When it comes to breaking down barriers in the community, small acts can make a big difference.

Further information

If you know someone with dementia or someone caring for a person with dementia, reaching out to them is the first step. In order to combat the social isolation that so many people living with dementia feel, knowledge of how to confidently communicate is often a barrier to reaching out. When it comes to breaking down barriers in the community, small acts can make a big difference.

Dementia Australia has a range of Help Sheets available. You might find the ones listed below particularly useful:

Tips for friends

https://www.dementia.org.au/files/helpsheets/Helpsheet-TipsToAssistSocialEngagement01-TipsForFriends_english.pdf

Communication

https://www.dementia.org.au/files/helpsheets/Helpsheet-CaringForSomeone01-Communication_english.pdf

Dementia-Friendly Communities

You can learn more about dementia and what it means to be a Dementia Friend at dementiafriendly.org.au

For more information visit dementia.org.au or call the National Dementia Helpline on 1800 100 500

1 Australian Bureau of Statistics (2015) Causes of Death, Australia, 2015 (cat. no.3303.0)

2 Dementia Australia (2018). Dementia Prevalence Data 2018–2058, commissioned research undertaken by NATSEM, University of Canberra.

3 Alzheimer's Australia (2017) Dementia and the impact of stigma, Research Report.

4 Many of the issues raised by people living with dementia, their families and carers are reflected in Dementia Australia's submissions – go to www.dementia.org.au/submissions.

5 The National Centre for Social and Economic Modelling NATSEM (2016) Economic Cost of Dementia in Australia 2016–2056

dementia.org.au

National Dementia Helpline 1800 100 500

The National Dementia Helpline is funded by the Australian Government.

