

Dementia and the impact of stigma

September is Dementia Awareness Month and this year's theme, *You Are Not Alone*, is aimed at encouraging people living with dementia and their carers to reach out to their communities for support.

Living with dementia is a challenging experience; the social prejudice that is associated with the condition only adds to this challenge, leaving many people with dementia and carers feeling isolated and stigmatised.

There are an estimated 413,000 Australians living with dementia with this figure projected to increase to more than 535,000 by 2025 and 1.1million¹ by 2056. Dementia is the second leading cause of death of Australians²

This report explores community beliefs and attitudes about dementia, and how these impact on the experience of people living with a diagnosis and their carers and loved ones. We hope our findings can help people become more aware of the issues that are faced by people with dementia and their carers, and encourage the public to reach out to family, friends and neighbours living with dementia.

Research method

To investigate beliefs and attitudes about dementia, Alzheimer's Australia developed an online survey to examine stigma experienced by people with dementia and their carers, as well as the general public's attitudes towards people living with dementia.

People living with dementia and their carers were asked select questions from the Stigma Impact Scale. The Stigma Impact Scale is a set of statements developed by researchers³ and has previously been used to measure the impact of

¹ The National Centre for Social and Economic Modelling NATSEM (2016) *Economic Cost of Dementia in Australia 2016–2056*

² Australian Bureau of Statistics (2015) *Causes of Death, Australia, 2015* (cat. no. 3303.0)

stigma on people with dementia.⁴ As well as being asked how they felt themselves, carers were also asked to give a proxy response on behalf of the person they care for. The Stigma Impact Scale includes statements such as "I feel lonely more often than usual" and participants are asked to rate how much they agree with each statement.

To assess the general public's attitudes towards people living with dementia, the general public were asked questions from the Dementia Attitudes Scale. These questions have also been established by researchers as a good measure of attitudes towards dementia.⁵ Like the Stigma Impact Scale, the Dementia Attitudes Scale contains a series of statements and participants rate how much they agree with each item.

Survey findings

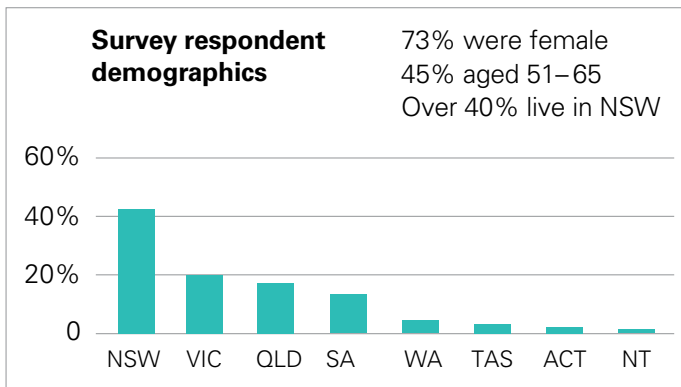
Of the 1,457 people who responded to the survey, 44 identified themselves as a person living with dementia, 751 were carers and 662 were members of the general public.

Each participant's results were scored based on their answers to the Stigma Impact Scale (if they were a person living with dementia or a carer) or the

³ Fife, B. L., & Wright, E. R. (2000). The dimensionality of stigma: A comparison of its impact on the self of persons with HIV/AIDS and cancer. *Journal of health and social behavior*, 50–67.

⁴ Burgener, S. C., & Berger, B. (2008). Measuring perceived stigma in persons with progressive neurological disease: Alzheimer's dementia and Parkinson's disease. *Dementia*, 7(1), 31–53.

⁵ O'Connor, M. L., & McFadden, S. H. (2010). Development and psychometric validation of the Dementia Attitudes Scale. *International Journal of Alzheimer's Disease*, 2010.



Dementia Attitudes Scale (if they were a member of the general public). For the Stigma Impact Scale, higher scores indicate the person has more intense feelings of being stigmatised. Higher scores on the Dementia Attitudes Scale indicate more positive attitudes towards people with dementia.

94% OF PEOPLE LIVING WITH DEMENTIA HAVE ENCOUNTERED EMBARRASSING SITUATIONS AS A RESULT OF THEIR DEMENTIA

The overall Stigma Impact Scale scores for people with dementia were higher than those for the carers. This suggests that people with dementia are impacted more by stigma than carers. When examining which questions on the survey people with dementia and carers responded most to, it was evident that both people with dementia and carers had strong feelings of social isolation.

Our sample of people with dementia indicated that they had more severe feelings of social isolation and stigma compared to results of previous research using the Stigma Impact Scale with people with dementia.⁶ Their Stigma Impact Scale results also suggest our sample of people with dementia experience more intense feelings of being stigmatised than people with other chronic diseases.⁷

Key themes identified for people with dementia and carers

When all of the survey responses were examined it was clear that some statements from the Stigma Impact Scale consistently rated higher than others.

The four statements that people with dementia most agreed upon were (from highest to lowest):

1. I feel less competent than I did before having dementia.
2. I encounter embarrassing situations as a result of having dementia.
3. Due to having dementia I sometimes feel useless.
4. I feel lonely more often than usual.

In the proxy ratings given by carers, the same four statements were the most highly rated, albeit in a different order. Both the proxy ratings and ratings by people with dementia selected “I feel less competent than I did before having dementia” as the most consistently agreed upon statement.

The survey results also suggest that people with dementia have a strong sense of feeling separate from others. Comments from people with dementia reflect the feelings of stigma and social isolation:

‘People in the public are embarrassed and uncomfortable around me at times and having been a social person it upsets me that they think I am stupid.’

‘Having dementia I have lost friends and family members who don’t want to know about the dementia journey... People often talk about me to others and not to me when I am sitting right next to the person.’

60% OF CARERS HAVE FOUND THEMSELVES IN EMBARRASSING SITUATIONS

The most agreed upon statements from carers were similar to those given by people with dementia, however in a different order. These were:

1. I feel lonely more often than usual.
2. I encounter embarrassing situations because the person I care for has dementia.
3. I feel set apart from others who do not care for someone with dementia.

⁶ Burgener, S. C., & Berger, B. (2008). Measuring perceived stigma in persons with progressive neurological disease: Alzheimer’s dementia and Parkinson’s disease. *Dementia*, 7(1), 31–53.

⁷ Fife, B. L., & Wright, E. R. (2000). The dimensionality of stigma: A comparison of its impact on the self of persons with HIV/AIDS and cancer. *Journal of health and social behavior*, 50–67.

4. Due to the person I care for having dementia, I sometimes feel useless.

This suggests that like people with dementia, carers also struggle with feeling disconnected from others. Carers' comments also expressed themes of social isolation:

'Friends and family do not help in practical ways when needing extra reassurance and company. My husband's work mates have not kept in contact since his diagnosis.'

'My experience was that all the concern was for my late husband. I had no problem with that but I would have liked to be asked how I was doing.'

'It is such a lonely and isolating condition. My mother's friends stopped seeing her because she was difficult to engage with. She would often comment she hadn't heard from them anymore. Heartbreaking.'

OVER 96% OF PEOPLE LIVING WITH DEMENTIA FEEL LESS COMPETENT THAN THEY DID BEFORE HAVING DEMENTIA

Key themes identified for the general public

The general public's scores on the Dementia Attitudes Scale were high overall, reflecting generally positive attitudes towards people with dementia. This is somewhat at odds with the findings of high internalised stigma perceived by people with dementia and carers. It could be assumed that with more positive attitudes in society, internalised stigma would be less likely to develop, and therefore, our results seem unusual. However, it is possible that our general population sample was skewed as a number of people identified themselves as aged care staff or health care professionals in the comments section of the survey. Such people, having more experience working with people with dementia, are likely to have more positive attitudes than someone outside the sector. Nonetheless, while the general public reported low stigma towards people with dementia, their comments

suggested that there is still a lack of understanding:

'It is something many people still don't understand (including myself). I don't know anyone with dementia. Maybe I did, but I just thought it was a sign of "getting old".'

'I really don't know what I can do as a member of the public. I am not sufficiently competent in this area.'

ALMOST 50% OF THE GENERAL PUBLIC FELT FRUSTRATED BECAUSE THEY WERE UNSURE OF HOW TO HELP PEOPLE WITH DEMENTIA

The two statements from the Dementia Attitudes Scale that had the highest levels of agreement were:

1. Every person with dementia has different needs.
2. We can do a lot now to improve the lives of people with dementia.

This result suggests that the public recognises the individuality of people with dementia and are aware that their lives can be improved. However, the statements with the most negative ratings were:

1. I cannot imagine caring for someone with dementia.
2. I am not very familiar with dementia.
3. I feel frustrated because I do not know how to help people with dementia.

This suggests that there are a number of people in the general public who are unfamiliar with dementia and feel confronted by these ideas. The overwhelming sentiment from the general public was a need for more education about dementia:

'I would like to learn more about the things I can do in someone's company with dementia to make them and their carers more comfortable.'

'We as the general public need to support families living with this terrible disease. Such a lot of people do not understand and haven't got the patience around people who struggle every day.'

'I think we need to continue to educate people about dementia and learn more about how to better care for people with dementia.'

This sentiment was also voiced by comments from people with dementia and carers.

‘I feel that there is generally a significant dearth of knowledge about dementia in the general population. If an individual wants information on this subject it is quite easy to find; on the other hand it is not a subject likely to appear in the regular media outlets.’

– Person with dementia

‘Most people think the person with dementia has just lost their memory. They have no idea how devastating and complex dementia can be, especially in the later stages.’ – Carer

‘Education is the key, which is why I talk about it, whilst I still can ... Although some find it difficult to talk about the condition, most appear interested and want to understand more once they realise it doesn’t upset me to talk about it.’

– Person with dementia

50% OF THE GENERAL PUBLIC WANT TO KNOW MORE ABOUT HOW THEY CAN HELP

Conclusions

Examining the Stigma Impact Scales scores and comments given by people with dementia and their carers it is clear that these groups feel stigma strongly. In particular, both people with dementia and carers feel socially isolated, as demonstrated by the consistently high ratings given to the statements that centre on that theme.

The general public’s scores on the Dementia Attitudes Scale suggest that, overall, the public has a positive attitude towards dementia, yet the comments suggest a lack of understanding. This was further emphasised by the fact that the statements with the most negative ratings included the item “I am not very familiar with dementia.”

Another of the Dementia Attitudes Scale statements that was given low ratings was “I feel frustrated because I do not know how to help people with dementia.” From these results, it seems that

although people in the general public are sympathetic to people with dementia, they may be unsure of how they can help.

This survey points to ways the community and individuals can better support people living with dementia, their families and carers.

ABOUT 33% OF THE GENERAL PUBLIC COULD NOT IMAGINE CARING FOR SOMEONE WITH DEMENTIA

Support is available

If you know someone with dementia or someone caring for a person with dementia, reaching out to them is the first step. As evidenced in comments and survey results, loneliness and isolation is a key concern for people with dementia and their carers. You can help break down social isolation by starting a conversation and letting your friend or family member living with dementia know that they are not alone. It can be as simple as being open and ready to listen.

Alzheimer’s Australia has a range of Help Sheets available. You may find the ones listed below particularly useful:

Tips for Friends

https://nsw.fightdementia.org.au/files/helpsheets/Helpsheet-TipsToAssistSocialEngagement01-TipsForFriends_english.pdf

Communication

https://nsw.fightdementia.org.au/files/helpsheets/Helpsheet-CaringForSomeone01-Communication_english.pdf

Language and Communication

https://nsw.fightdementia.org.au/files/helpsheets/Helpsheet-YoungerOnsetDementia04-LanguageAndCommunication_english.pdf

For more information visit

fightdementia.org.au or call the National Dementia Helpline on **1800 100 500**.