

Monday 21 September 2020

Discrimination a real issue for people living with dementia, survey finds

Three out of four people who live with dementia say people don't keep in touch like they used to, while 65 per cent say people they know have been avoiding or excluding them, results from a Dementia Australia survey have found¹.

The survey findings, released at the start of Dementia Action Week 2020, reveal just how big an issue discrimination is and the impacts it has for people living with dementia, their families and carers. Dementia affects close to half a million Australians and that number is set to double in the next 25 years.

Other key findings from those who responded to the survey include:

- 94 per cent of family members, friends or carers who responded to the survey say people haven't kept in touch with a relative who lives with dementia as they used to
- 71 per cent of family members, friends and carers who responded to the survey say they haven't been included in family activities
- 80 per cent of family members, friends or carers who responded to the survey say that people have gone out of their way to avoid their friend or relative who lives with dementia when they are out and about
- 81 per cent of family members, friends and carers who responded to the survey felt that people in shops, cafes and restaurants treat people with dementia differently
- 90 per cent of family members, friends or carers who responded to the survey say that their friend or relative who lives with dementia is treated with less respect than other people

However, people living with dementia who feature in this year's Dementia Action Week campaign demonstrate that with a little support, they can continue to live full and active lives.

The theme for this year's Dementia Action Week, which runs from 21-27 September, is "**Dementia. A little support makes a lot of difference**".

The concept for Dementia Action Week 2020 has been developed in consultation with Dementia Advocates, who have a lived experience of dementia. The stories and voices that will feature across the week are real.

Ann Pietsch, who lives with dementia and shares her story as part of this year's Dementia Action Week campaign, said it was important to see people living with dementia as being regular, everyday people.

"The stereotypes are that we're all elderly and we're all losing our memories and that we can't really manage anything much," Mrs Pietsch said.

"There are so many different people with dementia and there are so many types of dementias with all sorts of symptoms. It's not just forgetting things – it's more than that. It might be being unable to get organised or organise your day or your thoughts, or having a fuzzy day, as I call it.

"One of the most helpful ways of managing my dementia is to remain positive and to live well with dementia. I volunteer at the museum and I really enjoy meeting people and talking to people. It's very rewarding."

Theresa Flavin also features in the campaign and, after her diagnosis, she took up horse-riding.

¹ Dementia Australia. Dementia Action Week Discrimination Survey 2019, 5,767 valid responses collected from people living with dementia, families, carers, volunteers, health and aged care professionals, and people not directly impacted by dementia.



"I found an awesome coach who I really trusted, and she gave me confidence. She was so patient. She broke the whole thing into little pieces of information that my brain could process.

"She gave me that confidence and I felt like a hero – I am just the bee's knees sitting here on my horse."

Tim Granger - also part of the campaign – was diagnosed with dementia five years ago.

Mr Granger's weekly routine involves going to the gym with a support worker who often takes photos of his exercises to give visual prompts.

"Exercise gives me pleasure," Mr Granger said.

"It helps me do what I have to do and get things going. I couldn't live without it, really."

Dementia Australia CEO Maree McCabe said the survey findings are distressing for people living with dementia, however it would not take much to turn those findings around.

"What these findings say is that discrimination stems from a lack of understanding and knowledge of dementia – what it is and how it impacts people," Ms McCabe said.

"A little bit of support can make a really big difference to someone with dementia.

"It could be as simple as giving someone space to do things for themselves, listening to the person, not trying to solve all their problems, giving the person time to find the right words or using technology to support someone in their day-to-day activities.

"Tim, Ann and Theresa's experiences all demonstrate that it really doesn't take much – a little support really can make a lot of difference to someone's life."

To find out more about how to support someone living with dementia, you can head to dementia.org.au/dementia-action-week.

Dementia Action Week 2020 is from 21-27 September. Monday 21 September is World Alzheimer's Day.

During the week, Dementia Australia will share one tip a day showing simple, yet effective, ways to support people living with dementia.

More than 5,000 people responded to the survey during Dementia Action Week in 2019, including people living with dementia, families and carers, people who work in the health and aged care sectors, and members of the general public. The purpose of the survey was to help create an informed, national picture to better understand how discrimination for people living with dementia occurs and what it would take to shift that discrimination.

Dementia Action Week, a Dementia Australia initiative, received funding from the Australian Government.

Dementia Australia is the source of trusted information, education and services for the estimated half a million Australians living with dementia, and the almost 1.6 million people involved in their care. We advocate for positive change and support vital research. We are here to support people impacted by dementia, and to enable them to live as well as possible. No matter how you are impacted by dementia or who you are, we are here for you.

For support, please contact the **National Dementia Helpline on 1800 100 500**. An interpreter service is available and the Helpline is open 8am to 8pm Monday to Friday excluding public holidays. The National Dementia Helpline is funded by the Australian Government. People looking for information can also visit dementia.org.au

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Due to the COVID-19 pandemic, people living with dementia are some of the most vulnerable people in our community right now. Until further notice, Dementia Australia will no longer facilitate any face-to-face, in-person interviews with people living with dementia, their families and carers. **We will continue to facilitate interviews by video conferencing and telephone calls.**

When talking or writing about dementia please refer to [Dementia-Friendly Language Guidelines](https://dementia.org.au/dementia-friendly-language-guidelines).