

“We deserve to be welcomed and our wants and needs respected”
New report highlights older people’s insights into dementia
Dementia Action Week 16 – 22 September

Monday 16 September 2024

In time for Dementia Action Week 16 –22 September, almost 1500 older people have shared their insights about dementia in [a new research report](#) by National Seniors Australia.

The research was based on a 2024 survey of Australians aged 50 or older, who were asked what they had learned about dementia they would like people to know.

More than 90% of the participants had personal experience of dementia through family members or friends. They shared their stories of delight and despair, plus their handy tips and hard-won advice.

“We were overwhelmed with the response to this survey question,” National Seniors’ Head of Research, Dr Diane Hosking said.

“Through the incredible generosity of our survey participants we are able to share with the public some deeply personal stories and insights that reveal the complexities of living with dementia today.

“In time for this year’s Dementia Action Week, we hope people touched by dementia will find experiences in the report that resonate with their own, and that people who haven’t yet encountered anyone with dementia will learn more about it.”

The research report groups almost 1500 shared experiences and comments into ten themes, each representing a unique set of insights including: how to act when a person has dementia, what dementia feels like, impacts on others, how different dementia is for each person and the value of early diagnosis.

Within the themes, the survey participants speak for themselves through 140 comments reproduced in full.

Some of these comments are below:

“Laugh with the person. I have long ‘conversations’ with a special friend with dementia about nothing but we laugh a lot and that is so good for her and for me. We still have [a] relationship but sharing is just being there and communicating in a very different way.”

“It is very hard looking after somebody with dementia. And it makes you feel as if you never do enough.”

“Treat the person with dementia as a person. Be honest, accept them as they are, encourage them in what they can do, help them with what they are unable to do. Be kind and courteous always.”

“Even though my friend has dementia it is very important to be there for her and give as much understanding and caring support as is possible in the situation. This is not easy and can affect my thoughts after spending time with her.”

"I saw how scared Dad could feel at times. I was horrified by the way [his residential care] home placed those close to the end in a little room all together with nothing to do. At first Dad was in the low care area and loved the sound of chatter around him."

"Conversations about dementia are now much more common and not judgmental as they used to be and that is a good thing."

"Each person experiences dementia differently. Be prepared to be flexible in how you deal with it."

This report is accompanied by [a second companion report](#) from National Seniors that examines older people's dementia planning, information seeking, and levels of worry.

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