

Conversation insights

From people living with dementia, carers and families

Talking about dementia with people who are directly affected by it can feel difficult. Many people worry they'll say the wrong thing, ask the wrong question or make someone uncomfortable.

Every experience of dementia is different. But when people living with dementia, carers and families shared their insights into what helps them feel connected, understood and supported, common themes emerge time and again. Their message is simple: it's not about finding the perfect words. It's about being willing to start the conversation, making time for connection and listening.

1. Start the conversation

The first step is often the hardest. But for many people affected by dementia, reaching out matters more than saying the right thing. Simply acknowledging dementia can open the door to a meaningful conversation.

"Sometimes the best place to start is simply by acknowledging dementia. You can use the word." – Chris, Dementia Australia Advocate

2. Be curious

You don't need to be an expert on dementia to have a meaningful conversation. Asking questions, listening and being open to different experiences can help build understanding and connection.

"Remaining curious and staying informed about dementia means I have something to say when conversing with others that may be useful and encourage conversations." – Gina, Dementia Australia Advocate

3. See the person, not the diagnosis

Dementia is part of a person's life, but it does not define who they are. People living with dementia should be recognised for who they are, not reduced to a label.

"Rather than approaching me and only talking about dementia, it would be nice if people got to know who I was, who I am, and who I am becoming as a person." – Gina, Dementia Australia Advocate

4. Don't avoid the topic

Many people are afraid they'll say the wrong thing. But silence can sometimes be harder than an imperfect conversation. Talking openly about dementia can help reduce stigma and make people feel less alone.

"You're not reminding me that I have dementia by bringing it up – I think about it all the time, and would be glad to talk about it with those that care"

– Grahame, Dementia Australia Advocate

5. Life doesn't stop with a diagnosis

Many people speak about how painful it can be when others focus only on who someone used to be. Dementia changes life, but life continues. Relationships, experiences and meaningful moments continue too.

"A diagnosis doesn't put someone's life in the past. Their life is still happening now and there are still memories to make" – Chris, Dementia Australia Advocate

6. Connection can change, but it still matters

Dementia can change the way people communicate and spend time together. But connection, love, humour and companionship can still be present. Sometimes connection doesn't disappear. It simply takes a different form.

"Having dementia doesn't mean having to do everything alone. Sometimes you find a way around things by inviting people in and letting them give you a hand."

– Heather, Dementia Australia Advocate

7. Find a way in

Conversations about dementia don't always have to begin with a direct question. Sometimes mentioning a film, podcast, book or news story about dementia can provide a natural starting point. Some people will be open to a direct conversation straight away. For others, it'll take time. That's okay too.

"You don't have to have the whole conversation at once. You serve the volley... and perhaps some months later, it comes back over the net."

– Heather, Dementia Australia Advocate

Key Takeaways

- You don't need the perfect words to talk about dementia.
- What matters is that you start the conversation. Be curious. Make time to connect.
- Life doesn't stop after a diagnosis and neither does joy.
- The best moments often happen when we make the time to talk.