



Maree McCabe, March 2021

# The Impact of Dementia and Practical Ways You Can Help

Changing how we provide care and support for people living with dementia can significantly improve their independence and ability to feel safe.

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## White Paper

This whitepaper is based on **Maree McCabe's** keynote address at the Catholic Healthcare Insight Exchange Webinar Event on 10 March 2021



Dementia describes a collection of symptoms that are caused by disorders affecting the brain. It is not one specific disease.

It is a serious and terminal condition and is the second leading cause of death in Australia after heart disease, as well as the leading cause of death of women. It can affect people's memory, mood, thinking, mobility, and their ability to complete day-to-day tasks.

There are several myths around dementia. The primary one to dispel is that it is a normal part of ageing.

Another is that it always affects memory. Memory loss is a symptom of Alzheimer's disease, the most common form of dementia. But there are many different types, such as frontotemporal dementia, vascular dementia, and Lewy body disease. They all present differently, and people don't necessarily always experience memory loss.

There is a perception that dementia only happens to older people. In fact, of the 472,000 Australians living with dementia, one in thirteen are 30 to 50 years of age.

It does not distinguish between gender, culture, geography or socio-economic circumstance. It is a global issue. By 2025, the total cost of dementia is predicted to increase to more than \$18.7 billion in today's dollars, and by 2056, to more than \$36.8 billion.

### PERCEPTUAL DISTURBANCES

People living with dementia may experience perceptual disturbances that make it difficult for them to perceive a difference between an object and its background. Their field of view may also narrow, and they may also find it difficult to distinguish

between two colours or judge the distance between objects.

Take, for example, a bathroom with white tiles, a white toilet, a white basin and white shower. Someone living with dementia may not be able to distinguish one fitting from another. This could confuse a person living with dementia when all they are doing is trying to use the bathroom independently.

A simple solution like a coloured toilet seat can make all the difference.

Some of the challenges that people experience when looking after people living with dementia in aged care or the community can be solved by understanding the world of people living with dementia.

### PRINTABLE HELP RESOURCES

The Dementia Australia website has dozens of printable help sheets to provide people living with dementia and carers with ideas to make their home more accessible and enabling for people living with dementia. Here are 10 of the topics covered:

1. Changed behaviours and dementia
2. Looking after families and carers
3. Caring for someone living with dementia
4. Residential care and dementia
5. Information for people living with dementia

6. Dementia-friendly environments
7. Aboriginal and Torres Strait Islander people
8. Lewy body disease
9. Younger onset dementia
10. Tips to assist social engagement

### PERSON-CENTRED CARE

Everybody wants to be respected and treated as an individual. This includes people living with dementia.

It is helpful to understand a person's background. This knowledge will explain many of the things that happen in an aged care environment. Take a resident who gets up at 4am every day and disturbs other residents. It may be that they were a farmer, and they are acting out their previous routine. If you know that, you can try to figure out what is triggering their behaviour and then reassure them. You might say: "John, I know it is 4am, but you do not need to go out today. It is ok. You completed the farm work yesterday."

It is important to investigate the person's history to help you better care for them. For example, someone who refuses to get undressed may have had something happen to them in their past that accounts for this. If you suspect this is the case, seek psychological advice about how to best care for them to remove the angst from the scenario and help them to feel safe and understood.

### BACKGROUND NOISE

Many people living with dementia experience sensitivity to overstimulating environments. It is a bit like using a hearing aid. It is difficult to block out the background noise of a radio or clanging in a kitchen.

Try to avoid competing noises such as TV or radio. Speak in a tone that is warm so that the person feels safe. People living with dementia may not be able to remember what you said to them. But they will remember how you made them feel.

### SHARING HISTORY

Person-centred care includes knowing about that person as an individual and the things that are important to them. One of the challenges is that agency carers do not always receive a complete handover, so they may not know much about the person.

If there is a photo of children or grandchildren and pets in the resident's room, it enables the carer to use that as an engagement tool. They can comment on the beautiful photo and ask leading questions about it. It enables access into the resident's world. It makes a difference to them and helps them feel known and understood.

This is a little thing that can make a huge difference.

“ **People living with dementia may not always be able to remember what you said to them. But they will remember the feeling it left with them.** ”

## OPPORTUNITIES FOR JOY

It is essential to create opportunities for laughter and fun and to facilitate opportunities for people to participate in different activities. This is another area in which the value of knowing a person's history is invaluable.

If you know someone loved card games, chess, or bingo, then it is likely that they will continue to enjoy those activities. If their

dementia is too advanced to participate in a structured game, think about ways to adapt the game to suit their current abilities. Carers and families can try connecting to them by reading to them, talking about past experiences and reassure them that they are part of their circle of loved ones.

Watching old favourite movies or listening to familiar audiobooks may also be enjoyable for some people.

## Royal Commission learnings

Dementia Australia welcomes the Royal Commission into Aged Care Quality and Safety's Final Report: Care, Dignity and Respect.

Since September 2018, people living with dementia, their families and carers have entrusted the Commissioners with their views, personal experiences and often traumatic stories.

The Final Report captures the essence of those issues and demonstrates the Commissioners have listened to Australians impacted by dementia.

Within the 148 recommendations there are 14 key areas with a specific focus on dementia. We welcome these recommendations and now call on the Federal Government to demonstrate they are serious about making quality dementia care a core element of aged care in Australia.

These recommendations broadly cover the need for clearer support pathways; assessing the impact of dementia-specialist support, introducing new regulations on chemical and physical restraint, a review of aged care

standards as they relate to quality dementia care and fast-tracking a national aged care worker registration program and specifying that all workers in direct contact with people seeking or receiving services in the aged care system undertake regular training about dementia care. Other recommendations focus on the importance of carers, the impact of quality indicators and a need to clarify roles and responsibilities across the sector.

Dementia Australia will be focusing on the detail of the Final Report and will continue to advocate to the Federal Government to ensure they act on this once-in-a-generation opportunity to transform dementia care and the aged care system overall.

People with the lived experience of dementia have told us: if you get dementia care right, you get it right for everyone.

Dementia Australia has provided the Federal Government with a clear plan on what is needed to deliver quality dementia care and to respond to the Final Report – this includes:



**Dementia Support Pathways:** An integrated and specialist national telephone and online service that sits alongside My Aged Care.



**Transformed Dementia Workforce Capability:** An integrated approach to build dementia capability and expertise of the aged care workforce by mandating minimum levels of dementia education. Developing dementia practice leaders will support the application of this learning as well as promote practice change.



**Dementia-Friendly Design:** Developing and embedding a set of robust, evidence-based and practice-informed dementia-friendly standards. This will enable physical environments that support people living with dementia to be as independent as possible

## Technological solutions from Dementia Australia

### A BETTER VISIT

Family and carers can use technology such as mobile phone or tablet apps to help relatives and carers engage with people living with dementia.

A Better Visit is a useful app developed by Dementia Australia. It is tablet-based, fun and intuitive. It has simple games such as Tic Tac Toe, Noughts and Crosses and Go Fish. It also has fabulous music that people can relate to and images of iconic Australian locations that can be used to prompt conversation and connection.

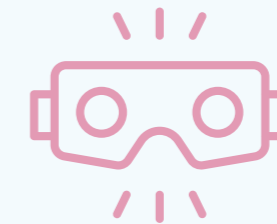
The app makes engagement easier for relatives and carers and can help reduce the social isolation experienced by many people living with dementia.

Another Dementia Australia tool to explore is The Virtual Forest™. It provides people with a peaceful and enjoyable immersive environment designed to improve their quality of life.

Three other technological solutions from Dementia Australia:



**A day in the life – Mealtime experience:** A virtual reality workshop that challenges you to see mealtime through the eyes of a person living with dementia and their carer.



**Enabling EDIE™ Workshop** – Immersive three-hour virtual reality workshop enables you to see the world through the eyes of a person living with dementia.



**The Dementia-Friendly Home™ app:** Provides carers with ideas to make their home more accessible for people living with dementia.

### SOMETHING TO AVOID

Regardless of the stage of dementia, it is crucial not to fall into the trap of talking about the person as if they are not there. To be respectful and treat people with dignity is essential regardless of the stage they are at.

Always involve people in the conversation as much as possible. And there are ways to include them even if they cannot respond.

It might be sharing with them who you are talking to and explaining what you will be discussing. At least that includes the person in the conversation. People living with dementia say that one of their biggest frustrations is when carers or health professionals do not include them and talk about them as if they are not there or do not involve them in the conversation when they can in fact be involved.

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Another frustration can be when a carer or health professional talks to their relative rather than with them.

## HOW TO HELP FAMILIES

The more families know and understand about dementia, the better. And supporting them is essential because of the complex disease trajectory. When people are informed about dementia, they may become more resilient to some of the more confronting aspects of the disease. For example, if their loved one becomes aggressive or says hurtful things, it can remove a lot of the angst if they understand the disease process and why the person talks or behaves the way they do.

One of the concerns families may experience is guilt that they are no longer able to care for their loved one. It is important to acknowledge that people often improve when they go into aged care due to having others they can interact with, whereas they may have been socially isolated at home. Families need to be listened to and supported through their transition of placing a loved one into care.

Staff can refer families and carers to Dementia Australia for support and education to ensure they understand what is happening and for strategies on how to continue to play a caring role for their loved one.

## WHAT WE CAN LEARN FROM COVID-19

The first thing to acknowledge is that residential aged care homes are not hospitals. It is reasonable to expect a high level of infection control, but you cannot expect the same level of clinical care that is achievable in a hospital.

That said, aged care homes and families have a deeper focus on infection-control practices, how to implement them and how to keep residents, employees, and visitors safe.

Another meaningful learning is social isolation can occur in aged care homes as well as in the community. For people living with dementia, too little stimulus can be harmful, as can too much. Physical distancing, restrictions and lockdown measures implemented in response to the COVID-19 pandemic have had adverse effects on the physical, cognitive, social, and mental wellbeing of people living with dementia, as well as those providing care, particularly family carers. Social interaction is very important for people living with dementia.

There are many examples of creative ways aged care homes, including Catholic Healthcare's Residential Aged Care Homes, have managed to maintain social connections of their residents throughout the pandemic. It is important we learn from these examples and continue to provide opportunities for social connections despite the challenges.

It is also unprecedented that the entire workforce in some aged care homes had to be substituted. Not only did people miss out on family visits, the carers who knew and understood them were also no longer there.

Something else to keep in mind is that 70 per cent of people with dementia live in the community. But during the peak of the pandemic, Catholic Healthcare's Home Care services introduced new protocols, on-line resources and communication with clients to reassure them that they would be safely cared and supported.

We need to take COVID-19 on as a learning experience to ensure that some of the challenges that occurred never occur again.

## Tips from a person living with dementia

Christine Bryden AM was diagnosed with dementia at the age of 46 and is the author of *Who will I be when I die?* – the first book written by an Australian with dementia.

Here are Christine's seven tips for communicating with a person with dementia:

1. Give us time to speak, wait for us to search around that untidy heap on the floor of the brain for the word we want to use. Try not to finish our sentences. Just listen, and do not let us feel embarrassed if we lose the thread of what we say.
2. Do not rush us into something because we cannot think or speak fast enough to let you know whether we agree. Try to give us time to respond – to let you know whether we really want to do it.
3. When you want to talk to us, think of some way to do this without questions that can alarm us or make us feel uncomfortable. If we have forgotten something special that happened recently, do not assume it was not special for us too. Just give us a gentle prompt – we may just be momentarily blank.
4. Do not try too hard though to help us remember something that just happened. If it never registered, we are never going to be able to recall it.
5. Avoid background noise if you can. If the TV is on, mute it first.
6. If children are underfoot, remember we will get tired very easily and find it very hard to concentrate on talking and listening as well. Maybe one child at a time and without background noise would be best.
7. Maybe earplugs for a visit to shopping centres, or other noisy places.

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**Dementia Australia offers support, information, education and counselling. Contact the National Dementia Helpline on 1800 100 500, or visit our website at [dementia.org.au](http://dementia.org.au). For language assistance phone the Translating and Interpreting Service on 131 450.**

Catholic Healthcare is a trusted, leading not-for-profit provider of residential aged care, home care, retirement living and healthcare reaching across the east coast of Australia.

We have a strong and proud history of providing care and support to people of all faiths, backgrounds and ethnicities, for more than 26 years. Catholic Healthcare operates 42 residential aged care homes, 12 retirement living communities, two healthcare services and provides services to around 4,000 persons in the community.

We are passionate about enriching our clients' lives and offer services to nurture the body, mind and spirit.

Our person-centred, holistic approach focuses on the client's wellbeing with a continuum of care that is tailored, flexible and covers every stage of life's journey. We have expertise caring for residents living with dementia with dedicated memory support units in our Homes, respite care, and dementia care specialists supporting Home Care clients and their carers.



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