



The importance of dementia-enabling housing

A submission to the Consultation RIS: Proposal to include minimum accessibility standards for housing in the National Construction Code

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About Dementia Australia

Dementia Australia (formerly known as Alzheimer's Australia) is the peak, non-profit organisation for people with dementia and their families and carers. We represent the more than 459,000 Australians living with dementia and the estimated 1.6 million Australians involved in their care.

Dementia Australia works with people of all ages impacted by dementia, all governments, and other key stakeholders to ensure that people with all forms of dementia, their families and carers are appropriately supported – at work, at home (including residential aged care) or in their local community.

Our close engagement with individuals and communities means that we can advocate for those impacted by dementia and we are also well placed to provide input on policy matters, identify service gaps and draw on our expertise to collaborate with a wide range of stakeholders, including researchers, technology experts and providers.

In addition to advocating for the needs of people of all ages living with all types of dementia, and for their families and carers, Dementia Australia provides support services, education and information aimed at addressing the gaps in mainstream services.

Dementia Australia is a member of Alzheimer's Disease International, the umbrella organisation of dementia associations around the world.

Introduction

Dementia Australia welcomes the opportunity to provide a submission to the *Consultation RIS: Proposal to include minimum accessibility standards for housing in the National Construction Code*. Our submission shares the experiences of people living with dementia, their families and carers, outlines how appropriate housing can support people with dementia to remain living in their own home for as long possible, and identifies the challenges that currently exist.

We believe that a minimum accessibility standard for housing should be included in the new National Construction Code and that this standard should include dementia-enabling environment principles to ensure that future housing does not present a barrier to people living with dementia.

Dementia in Australia

Dementia is the term used to describe the symptoms of a large group of neurocognitive conditions which cause progressive decline in a person's functioning. Dementia is not just memory loss - symptoms can also include changes in speech, reasoning, visuospatial abilities, emotional responses, social skills and physical functioning. There are many types of dementia, including Alzheimer's disease, vascular dementia, frontotemporal dementia and Lewy body disease.

Dementia is one of the largest health and social challenges facing Australia and the world. It is estimated that there are more than 459,000 Australians living with dementia in 2020¹ and around 1.6 million people² involved in their care. Without a significant medical breakthrough, there will be almost 1.1 million people living with dementia by 2058.³

Dementia is not a natural part of ageing. Although it is more common in older people, it can affect people in their 40s, 50s and even their 30s.⁴ Younger onset dementia describes any form of dementia diagnosed in people under the age of 65. In 2020, there are an estimated 27,800 people with younger onset dementia. This number is expected to rise to almost 29,500 people by 2028 and more than 41,000 people by 2058.⁵

¹ Dementia Australia (2018) *Dementia Prevalence Data 2018-2058*, commissioned research undertaken by NATSEM, University of Canberra

² Based on Dementia Australia's analysis of the following publications – M.Kostas et al. (2017) *National Aged Care Workforce Census and Survey – The Aged Care Workforce, 2016*, Department of Health; Dementia Australia (2018) *Dementia Prevalence Data 2018–2058*, commissioned research undertaken by NATSEM, University of Canberra; Alzheimer's Disease International and Karolinska Institute (2018), *Global estimates of informal care*, Alzheimer's Disease International; Access Economics (2010) *Caring Places: planning for aged care and dementia 2010–2050*

³ Dementia Australia (2018) *Dementia Prevalence Data 2018-2058*, commissioned research undertaken by NATSEM, University of Canberra

⁴ There are also some rare forms of childhood dementia, including Sanfilippo Syndrome, Niemann Pick Type C Disease and others.

⁵ Dementia Australia (2018) *Dementia Prevalence Data 2018-2058*, commissioned research undertaken by NATSEM, University of Canberra

Dementia is a terminal condition and there is currently no cure. It is the leading cause of death of women in Australia, the second leading cause of death in this country and it is predicted to become the leading cause of death within the next five years.⁶

It is not widely understood that dementia is a progressive cognitive disability. It is the single greatest cause of disability in older Australians (those aged 65 and over) and the third leading cause of disability overall.⁷

Dementia-enabling environment principles

Accessibility guidelines rarely take into account the needs of people living with dementia. As one person with dementia told us,

“The designs are aimed for wheelchair users rather than anything else.”

Yet a built environment that supports people living with dementia is one that supports all people. Incorporating dementia-enabling principles into a minimum accessibility standard within the National Construction Code would enable people living with dementia to age in place, supporting them to remain in their own home for as long as possible.

A well-designed environment, built with the needs of people with impaired cognition in mind, will help people maintain their activities of daily living and independence. It also enables meaningful engagement for people living with dementia. A dementia-friendly or dementia-enabling environment is one that:

- promotes independence and supports wellbeing;
- has familiar surroundings;
- allows easy access and way-finding;
- supports meaningful tasks;
- supports participation in daily activities; and
- promotes safety, security and comfort.

To assist in the design of dementia-enabling environments, Professor Richard Fleming and Kirsty Bennett developed ten dementia-enabling environment principles. These principles are evidence-based and have been designed to maximise enablement and wellbeing for people living with dementia.

Principle 1: Unobtrusively reduce risks

Principle 2: Provide a human scale

Principle 3: Allow people to see and be seen

Principle 4: Reduce unhelpful stimulation

Principle 5: Optimise helpful stimulation

Principle 6: Support movement and engagement

⁶ Australian Bureau of Statistics (2018) *Causes of Death, Australia, 2017* (cat. no. 3303.0)

⁷ Australian Institute of Health and Welfare (2012) *Dementia in Australia*

Principle 7: Create a familiar space

Principle 8: Provide opportunities to be alone or with others

Principle 9: Provide links to the community

Principle 10: Respond to a vision for way of life

Further information about dementia enabling environment principles is available through Dementia Training Australia at <https://dta.com.au/resources/applying-the-key-design-principles/>

Dementia-enabling housing

“Our common goal is the person living with dementia maintains a good quality of life and confidence to maintain their independence for as long as possible. Small (and big) changes around our homes, wherever that may be will achieve this...One thing I have in the back of my mind, is that there aren't many purpose-built disability homes built let alone those which incorporate accessible dementia principles.” – Carer

Dementia-enabling environment principles are frequently incorporated into the construction or modification of residential aged care facilities. However, as people with dementia increasingly wish to remain in their own homes and avoid transitioning to residential aged care, the availability of dementia-enabling housing stock within the broader community is critical.

Housing that is dementia-enabling provides a safer and engaging environment for people living with dementia. It can facilitate participation in daily activities and foster independence. Dementia-enabling housing also supports carers, who can be reassured knowing their loved one is safe.

“It just makes you more independent. My wife goes to work knowing that I'm in a safe environment.” – Person living with dementia

Dementia-enabling housing is especially important for people with dementia who live alone. A home environment that supports their independence, while offering safeguards against risk, is essential. Assistive technology has a considerable role to play. For example, sensor lights and automated cut-off sensors for taps, gas and ovens.

“When you make modifications you need to think past current need and tailor it for future need. It's not going to get any better. Dementia is a progressive disease. So if you think you need it now, you probably need it twice as much in 12 months' time.” – Person living with dementia

Australia's existing housing stock is rarely dementia-enabling. Often, as dementia symptoms progress, people living with dementia, their families and carers are compelled to modify or renovate their home to ensure that it is fit for purpose. Significant changes to bathrooms and

kitchens are common - additions such as grab rails, altering shower recesses, and refitting tiles and floors to create contrast between walls, benches and household items.

“These modifications and adaptations mean that people with dementia can stay living in their familiar home environments with their carers. Routine and familiarity are so important. Every time a person with dementia moves to a new environment, it is a whole new world, a new ball game, new learning, new environment, hostile surroundings. It equates to being lost in the jungle.” – Carer

The following stories from carers of people living with dementia demonstrate the considerable adaptations people have made to create a more dementia enabling environment to support their loved one to remain living in their own home.

“I needed to add nightlights in the hallway to bathroom. Too many doors creates confusion and causes her to be very nervous walking through them. Small height changes between internal sleep-out is a hazard. Step out of house to verandah requires her to be assisted. The steps to and from the front of house to street becoming very difficult. The hob into the shower is a risk as it needs to be stepped over so have bought a shower transfer seat to overcome that. Transition from carpet to polished floors is confusing. Rugs are also a risk and have been mostly removed. Changed cast-iron bed to modern bed. Replaced low lounge with new one of suitable height. Added chair raisers to favourite chair. Installed internal stair lift. Bought shower transfer seat. Bought touch to turn on bed light. In progress to modify driveway to eliminate external steps and provide all weather cover to access vehicle.” – Carer

“I have had to modify the bedroom and ensuite. There are double doors overlooking the landscaping and open on to the verandah, so I had the bed moved to face the doors. I had to build a wardrobe as a bedhead as the ensuite is on the wall opposite the doors and obscured direct vision to the ensuite for privacy. On the bedhead I installed a push-button time switch for the electric blanket so there is no worry in turning it off; a projection clock which projects the time on the ceiling; a 50” TV mounted on the wall beside the doors; a two-way switch for the main light on the bedhead as well as the main door; and a bed which can be elevated to a sitting position. In the ensuite, I have installed a bidet but I installed it a little late, as she has trouble remembering how to operate it.” – Carer

“I went to a talk about how to make your home dementia-friendly. The hand-outs and links were from the UK (this was a few years ago.) Following this, I had plans for the bathroom drawn up by an architect who specialised in disability design. I then did a lot of searching to find materials and equipment that were dementia-friendly and stylish. My partner and I had both been interested in housing design, and while style was no longer relevant to him, I was keen to continue enjoying our house. Finding attractive rails and flooring that met disability safety standards was a challenge. In our case, the new bathroom reduced stress. Previously, it had been a challenge to get the shower temperature right, and accessing the taps meant I had to move my partner. Also, getting him out of the shower had become difficult because he couldn't

step over the raised door slide on the floor. Safety was also increased. I noticed that he automatically reached for the new grab rails because they were positioned correctly.” – Former carer

“[Following a renovation] our bathroom is legally compliant to be suitable for those with a disability, e.g. raised care pan toilet; grab rails on reinforced walls (at toilet, in shower and at towel rail); non-slip floor tiles; reduced temperature of hot water to the legal compliance; heat lamp (because often older people and those with dementia are more sensitive to the cold); a light sensor, sensitive to movement; level flooring. Plus principles regarding dementia, e.g. contrasting coloured flushing buttons on the cistern to match contrast toilet seat; contrast vanity to the wall tiles, basin and cupboards; good lighting throughout bathroom, including over shower area; taps are individual small hot/cold lever-style suitable for someone who may have arthritis or upper body weakness...shower, basin and plan to have them in the kitchen too; plus a mirror which can later be covered by a ‘curtain’ if my husband’s symptoms require that. Plus basics, e.g. non-slip bath mat a specific colour towel for him which contrasts against the wall tiles, etc. The hand-basin is built so that, if necessary, a wheelchair for either of us can easily fit underneath, including the decision re: drain position and style. This year we hope to renovate our kitchen to support my husband who enjoys cooking, however he stopped doing this with me when he couldn’t see the gas flame and rationalised that, therefore, the stove was turned off. Over the years, there were numerous other incidents of different types with the gas stove and these were increasing in frequency and concerns, re safety. Also, he not only lost his confidence to continue cooking, he was losing his independence. Because of the safety issues, we changed from gas to an electric induction stove top a few years ago.” – Carer

Financial support to make modifications and/or undertake renovations is limited. Some people with younger onset dementia have been able to access funding through the National Disability Insurance Scheme (NDIS), and there is some capacity for home modifications in aged care home care packages, however this is underutilised⁸. Hence, adapting one’s own home to be dementia-enabling can be dependent on having significant income or savings to draw upon. There are further challenges for renters who rely on landlords to make or allow changes. If there was a regulation for new housing to be accessible and dementia-enabling, this would benefit many.

“Through the NDIS I had an occupational therapist come out and she’s organising to redo the bath with a grab rail and stuff like that, which will make it a little easier. That is a big issue because it’s very, very cramped. [Are the NDIS helping you with any other modifications in your home?] Well, they can’t because it’s a rental place. I have to get the owners to do it.” – Person living alone with dementia

If possible, some people make the decision to move to a home that is more dementia-enabling rather than modify or renovate. However, this is not an option for many and,

⁸ Stewart Brown (2020) *Home Care Provider Survey Analysis of Data Collected*, April 2020, Department of Health

indeed, unless the move happens during the earlier stages of dementia, a move from a familiar environment to a new home can exacerbate the symptoms of dementia, with the potential to hasten the progression of cognitive decline.

“We moved to what I consider to be a more dementia-friendly place and then I just put some measures in place.” – Carer

“It is most important for people living with dementia to stay in their own home, if they can, as everything is familiar and this supports their independence.” – Carer

Including dementia-enabling principles in a minimum accessibility standard for housing would help ensure that new housing stock is designed with the needs of people living with dementia in mind. It would go some way to limiting the need for expensive and disruptive modifications, renovations or moves in future, and assist people living with dementia, their families and carers to avoid additional challenges.

“If the house was dementia-friendly to move into, it would not be up to the occupier to arrange and they could be assured of a suitable safe environment. Having a suitable dementia-friendly place in which to live reduces stress and anxiety and risk of falls that can be made worse by poor lighting, inappropriate colour of walls and floors, clutter, rugs, steps, little rooms off rooms etc.” – Person living with dementia

“Home is where the heart is. When suffering cognitive loss we need routine, openness, familiarity and guidance.” – Carer

Conclusion

Dementia Australia hopes our submission assists the Australian Building Codes Board (ABCB) to understand the importance of dementia-enabling environment principles in housing design and the current challenges that people living with dementia, their families and carers face.

The increasing prevalence of dementia, as well as community and government desire for people to age in place and avoid residential aged care, means that future housing stock needs to include dementia-enabling features. Dementia-enabling features improve quality of life and support independence, function and participation.

“Change to current building codes to be more accessible and inclusive have been a goal for us for a few years...If accessible environments aren’t regulated, it rarely happens voluntarily.” Carer

A minimum accessibility standard for housing should be included in the new National Construction Code and this standard should include dementia enabling environment principles to ensure that housing does not present a barrier to people living with dementia to age in place in their own home in the future.