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Don't let people with younger onset dementia fall through the cracks in aged care

Dementia Australia welcomes the Royal Commission into Aged Care Quality and Safety's focus on younger people in residential care at the hearings in Melbourne this week.

More than 27,000 people are living with younger onset dementia¹, defined as any form of dementia diagnosed under the age of 65. This includes people in their 50s, 40s and even their 30s.

Dementia Australia CEO Maree McCabe said dementia is often associated with older people and there is a lack of understanding in the community and industry generally about younger onset dementia.

"Services to meet the specific needs of people with younger onset dementia are essential to enable them to live productive and fulfilling lives for as long as possible," Ms McCabe said.

"Whilst a dementia diagnosis is difficult for anyone to process, people with younger onset dementia are often in the midst of their career and family life which makes it a particularly confronting situation for them and their family."

Current data indicates that dementia is the most common condition to trigger younger people's entry to aged care.² Despite being younger at the age of diagnosis, the progression of dementia will inevitably result in individuals needing high levels of support. For many, this will result in entry to a residential aged care home due to the lack of other age-appropriate supports.

Access to community disability or aged care services, such as respite, social support and community care, are essential to enabling people with younger onset dementia to enjoy living at home, participate in every-day life and avoid premature entry to residential care.

At the moment people living with younger onset dementia enter residential aged care because of the lack of options available in the disability sector.

"People with younger onset dementia often fall between the gaps of disability services – that typically cater for younger people who may be cognitively able, and aged care services – which cater for older people with decreasing mobility," Ms McCabe said.

"Neither service is equipped to support the increasing needs of younger, and often physically able, people with dementia."

"It's important that people impacted by younger onset dementia are able to access support to enable them to navigate the system and understand what services are available and appropriate to their needs."

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Dementia Australia is the national peak body and charity for people, of all ages, living with all forms of dementia, their families and carers. It provides advocacy, support services, education and information. An estimated 447,000 people have dementia in Australia. This number is projected to reach almost 1.1 million by 2058. Dementia Australia is the new voice of Alzheimer's Australia. Dementia Australia's services are supported by the Australian Government.

National Dementia Helpline 1800 100 500
Interpreter service available

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

² Australian Institute of Health and Welfare. *Pathways of younger people entering permanent residential aged care*. Cat. no. AGE 89. Canberra: AIHW. 2019

(The National Dementia Helpline is an Australian Government Initiative)

Dementia is a National Health Priority Area

www.dementia.org.au

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When talking or writing about dementia please refer to [Dementia Language Guidelines](#).