

Wednesday 11 May 2016

Media Release

Younger people with dementia still slipping through the cracks

People with dementia under the age of 65 are in danger of missing out on essential services and support as they continue to be caught up in gaps between the disability and aged care sectors.

New research, released today by Alzheimer's Australia NSW, has found that people with younger onset dementia – that is with the onset of the symptoms of dementia under the age of 65 – have, for many years, fallen through the cracks of the disability and aged care systems, with both sectors seeing the other as being better placed to respond.

Despite significant policy reform in both the aged care and disability sectors, including the introduction of the National Disability Insurance Scheme (NDIS), the research has found that this is still the case, which means they are facing difficulties in accessing appropriate services.

There are an estimated 25,000 people with younger onset dementia in Australia and they face very different challenges to those diagnosed with dementia over the age of 65. Many are often still in the workforce, still raising children and financially supporting families and still paying off mortgages.

Alzheimer's Australia NSW CEO The Hon. John Watkins AM said while there had been some great examples of good will, flexibility and a willingness to help people with younger onset dementia in the disability sector, the division of disability and aged care eligibility at 65 years of age has, nevertheless, caused immense frustration for some.

"While this is a useful distinction for government and policy makers, it has, unintentionally, created a significant issue for many people with younger onset dementia in getting access to the services and support they need," Mr Watkins said.

"Currently, only people who are over the age of 65 can easily access services offered through the aged care sector, and people with younger onset dementia have felt excluded from this sector.

"This means that people under the age of 65 who have a diagnosis of dementia are funnelled through to the disability sector. The introduction of the NDIS held out great hope for this group.

"But limited knowledge and understanding of younger onset dementia in both the disability and aged care sectors, has caused a range of issues for people with younger onset dementia, including:

- a lack of responsiveness of the assessment process making it difficult to access needed support;
- a lack of knowledge of younger onset dementia among NDIA and Ageing Disability and Home Care (ADHC) staff;
- limited availability of appropriate long-term accommodation options for people with younger onset dementia;
- and lack of knowledge among clients about the availability of the NDIS for people with younger onset dementia."

Mr Watkins said that by its very nature, it is a complex system and there are no easy solutions.

"And some of our clients have had some great experiences accessing services through the NDIS," he said.

ALZHEIMER'S AND DEMENTIA AUSTRALIA AND HOPE

FIGHTDEMENTIA.ORG.AU

“With the help of their Younger Onset Dementia Key Worker, they have been able to access appropriate support in a timely manner.

“But we want these experiences to be the norm, not the exception. At the end of the day, no matter what age you are when you get dementia, you still have right to access appropriate services and support in a timely manner.

“We have found the Younger Onset Dementia Key Workers essential in helping people with younger onset dementia, their families and carers navigate this complex system, in helping them to know where to go to get help and helping them advocate for their needs.

“The Younger Onset Dementia Key Worker Program must be rolled into the NDIS to help people with younger onset dementia navigate the system, advocate for their needs and, ultimately, get the help, services and support they need.”

The new research, contained in the discussion paper *Younger Onset Dementia: Still Slipping Through the Cracks*, also recommends education of NDIS support planners in younger onset dementia, to increase their understanding of the condition and its progression to better serve people with younger onset dementia.

For Robyn and Mark Jenkins, having a Younger Onset Dementia Key Worker has been crucial in helping them navigate the system following Mark's diagnosis of younger onset dementia.

“The Key Worker explains the things that are happening when there is just so much stress and information overload that the person with dementia or the person providing support feel overwhelmed and unable to fathom what to do,” Mrs Jenkins said.

“Our Key Worker visited and listened, but also had practical solutions for us and was able to help navigate some services we needed. It is because of the Key Worker that we were advised of the *Living With Dementia* program and now have peer support, have found Dementia Cafes for ongoing social support and been advised of the range of other support services we can access.

“The Key Worker is like a lighthouse in the midst of the storm - an absolute lifesaver.”

A full copy of *Younger Onset Dementia: Still Slipping Through the Cracks*, including recommendations, can be found at <https://nsw.fightdementia.org.au/nsw/research>.

Alzheimer's Australia NSW is the charity for people with dementia and their families and carers. As the peak body, it provides advocacy, support services, education and information. An estimated 353,800 people have dementia in Australia. This number is projected to reach more than half a million by 2030.

National Dementia Helpline: 1800 100 500

An interpreter service is available

(The National Dementia Helpline is an Australian Government Initiative)

Dementia is a National Health Priority Area



@AlzheimersNSW

www.fightdementia.org.au

-Ends-

Media enquiries:

Sarah Price, General Manager - Media

Ph: (02) 8875 4635, Mobile: 0403 072 140

Matt Frilingos

Media and Communications Advisor

Ph: (02) 8875 4624, Mobile: 0417 880 949

Notes to media

When writing or talking about dementia, please provide your audience with the number for our National Dementia Helpline 1800 100 500 - a telephone information and support service available across Australia.