

Mr Mathew Crawshaw  
Committee Secretary  
Community Affairs Reference Committee  
Parliament House  
Canberra ACT 2600

Dear Mathew,

**Re: Inquiry into the Care and Management of Younger and Older  
Australians Living with Dementia and Behavioural and Psychiatric  
Symptoms of Dementia (BPSD)**

I am writing to provide some additional information regarding assessment for people with younger onset dementia as a follow up to the recent public hearing on 14 February where Dr Ken Baker and Ms Phillipa Angley from National Disability Services spoke to the Committee.

As discussed at the hearing, people with younger onset dementia often have difficulty getting access to appropriate services and supports and can find themselves lost between the gaps of the disability and aged care systems. Issues around access to assessment will become even more important as NDIS is rolled out, as we have recently been informed by the NDIS that people with dementia will be required to have a formal diagnosis before they can access support through NDIS. For many this will mean significant delays in getting access to much needed services.

Evidence suggests that on average people with dementia experience a delay of 3.1 years between first noticing symptoms and receiving a diagnosis. For people with younger onset dementia this delay may be even longer.

As discussed at the public hearing, one of the challenges relating to assessment is access to ACATs. We have recently canvassed our Younger Onset Dementia Key Workers and understand that there are jurisdictional variations in access to assessment. From the reports we have received, there is particular difficulty in access for people with

younger onset dementia in Queensland, Victoria and South Australia. Before an ACAT can assess a person under 65 in these states they require a letter from the state disability services stating that there is no suitable disability supports for this person. Obtaining this letter can be a complicated, lengthy process.

Even when appropriate documentation has been secured, people with younger onset dementia can still face difficulty getting assessed. Key workers reported examples where disability departments refuse to action the letter because they think dementia is included under aged care regardless of age. There have also been situations where, even with a disability services' letter, ACAT teams have refused to conduct an assessment because the individual is under 65 and therefore they believe the individual should only receive disability services.

Initially the NDIS were going to base decisions about support on functional assessment without a requirement for a diagnosis. We understand that may become even more time critical.

These issues highlight the urgent need to address the difficult interface between disability and aged care and access to appropriate assessment for people with dementia of all ages.

I hope the Committee finds this information useful and I look forward to reading the final report of the Committee on 19 March.

Yours sincerely,

Glenn Rees  
CEO, Alzheimer's Australia

26 February 2014