

Submission to the Disability Care and Support Inquiry

The Younger Onset Dementia Association Inc (YODA Inc) was established in 2010 to inform people about younger onset dementia and to support those whose lives are affected by the disease. Many people assume that Alzheimer's disease and other causes of dementia only affect older people. In fact about 1 person in every 1000 with dementia is below the age of 65. While rare, it can affect people in their 30's and 40's.

Any dementia beginning before the age of 65 is known as younger onset. There are estimated to be approximately 15 000 Australians currently living with younger onset dementia but there are very few services to cater for their specific needs.

Younger onset dementia falls into a grey area in terms of funding and service supports - because the person is under 65, should they be supported by disability services or should they be supported through aged care services, giving that dementia is seen as an age-related illness?

This submission is to highlight the Association's concerns with the issue of eligibility. There is concern that people living with this illness will be excluded from the scheme as the terms of reference indicate that younger onset dementia may be seen as a disability that arises from "natural ageing", which is not the case. Statements in the eligibility section such as *"...certain conditions that are strongly related to ageing and that occur in people after middle age. For example, exclusions might apply to disability arising from dementia or Parkinson's disease in someone aged 60 years or more"* are of great concern to the Association and those living with younger onset dementia.

Younger onset dementia imposes many limitations on an individual's ability to function – in terms of mobility, self-care, communication, social engagement etc. Those affected are in a completely different life stage to those who develop dementia later in life. The types of dementia that affect younger people are often very different to those affecting aged persons, and these more unusual types of dementia come with a very different presentation of symptoms and functional disability.

- In the general population of dementia sufferers, the types of dementia are:-
70% Alzheimers, 25% vascular and 5% other dementias
- With younger onset, the prevalence of different types of dementia is:-
34% Alzheimers, 18% vascular, 12% Fronto-temporal, 10% alcohol related, 7% lewy body, 19% other causes

For example, Fronto Temporal Dementia has a severe impact on a person's ability to function due to the part of the brain that is affected. The frontal lobes are responsible for "executive control" - the ability to make decisions and exercise control over their actions. The "typical" presentation includes:-

- Loss of insight
- Loss of communication skills - impaired comprehension of word meaning, loss of "naming" skills etc
- Alterations in personality and behaviour – (unco-operative, belligerent)
- Confabulation
- Disinhibition
- Tactless/inappropriate comments
- Strange obsessions and rituals
- Poor planning and organisation
- Repetitive speech
- Decline in self care, grooming
- Determined wandering

From a carer:

"My husband, Peter was diagnosed at 54 with fronto-temporal dementia. He was a fairly fit, active, talkative person, a teacher and businessman, involved in education, life and family. Five years later, he is now sad and withdrawn and his erratic behavior and mood swings have made life at home very difficult. He is unable to communicate effectively and cannot perform even the simplest of tasks to care for himself. Even though medication has helped, he is compelled to walk all day and some of the night".

Additionally the Association has concerns with the statement that "The aged care system has developed strong capabilities for the management of such disabilities because of their high prevalence among the aged." This reflects a lack of knowledge, as in fact the current management options and service provision available to people with younger onset dementia is extremely limited, be it from the aged care sector or the disability sector.

From a carer:

"We have tried over the years to find programs, activities and services to occupy Peter and give him some social contact. We have found that Peter's level of dementia is too advanced for most community groups, even those which are dementia based. He is too young and fit for most aged care services, which offer supervised activities not suitable for his fitness level or which do not interest him".

From a Carer of a man with Lewy Body dementia:

"I took my husband to attend a dementia day care service which we had been referred to thinking he needed to have something meaningful to do during the day. As soon as we arrived I noticed that all the people at the centre were a lot older and frailer than my husband and I could sense that he was registering this which made me feel really uncomfortable. I left him at the Centre and encouraged him to get involved in the activities. One hour later, I was called by the Centre to say that my husband had tried to abscond. I took him home and we never went back to the Centre".

It is also not socially or physically appropriate to place fit and active people with dementia, who are in their 50's, into services with people who are frail and aged in their 80's, which is the scenario with most dementia services. Disability services have the level of flexibility required to be able to develop person centred plans to meet the very unique and individual needs of people with younger onset dementia.

The Younger Onset Dementia Association Inc therefore requests that the Inquiry looks very carefully at the question of eligibility. Once they gain an understanding of the specific needs of people with younger onset dementia, it will become apparent that the aged care sector is not best equipped to provide appropriate services to this group and that in fact the disability sector is the preferred option for a service provider.

