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SUBMISSION TO THE JOINT STANDING COMMITTEE ON THE NATIONAL DISABILITY INSURANCE SCHEME

INQUIRY INTO ACCOMMODATION FOR PEOPLE WITH DISABILITY

March 2016

Joint Standing Committee on the National Disability Insurance Scheme - Accommodation for people with disabilities and the NDIS

Alzheimer's Australia NSW appreciates the opportunity to contribute to this inquiry into accommodation for people with disabilities and the National Disability Insurance Scheme (NDIS). Alzheimer's Australia NSW is the peak body for people with dementia and their carers in NSW. We provide advocacy, support services, education and information. Our organisational mission is to minimise the incidence and impact of dementia through leadership, innovation and partnerships - in advocacy, policy, education, services and research.

In summary, the key points of this submission are:

- Tightening the pathway to ACAT assessment via My Aged Care has made it increasingly difficult for people with younger onset dementia as a primary diagnosis to access residential aged care - the only long term accommodation and care model currently available to them. At some point in their life, the majority of people with dementia require this level of support.
- While NSW Ageing, Disability and Home Care (ADHC) currently provides accommodation options for people with a lifelong disability with a secondary diagnosis of dementia, there are no dedicated accommodation options available to people with a primary diagnosis of younger onset dementia.
- The lack of NDIS capital funding for the establishment of specialist housing for people with younger onset dementia suggests that the lack of appropriate accommodation will remain unresolved for the foreseeable future.

DEMENTIA IN AUSTRALIA

There are currently more than 353,800 Australians living with dementia. Without a major medical breakthrough this figure is expected to increase to almost 900,000 by 2050.[1] There are an estimated 1.2 million people in Australia caring for someone with dementia. The Australian Institute of Health and Welfare (AIHW) reported in 2011 that 30 per cent of people with dementia lived in residential aged care with the remaining 70 per cent living in the community.[2]

Dementia is the term used to describe the symptoms of a large group of illnesses which cause a progressive decline in a person's functioning including loss of memory, intellect, rationality, social skills and physical functioning. There are a number of types of dementia including Alzheimer's disease, vascular dementia, and fronto temporal dementia. Dementia is a progressive neurological disability and is

[1] Australian Institute of Health and Welfare (2012) *Dementia in Australia*
[2] Australian Institute of Health and Welfare (2012) *Dementia in Australia*

the third leading cause of disability burden in Australia.[3] Dementia is the 2nd leading cause of death in Australia and there is no cure.[4]

While dementia is often a person's primary diagnosis, dementia as a comorbidity of other diseases and disabilities such as Huntington's disease, Multiple Sclerosis (MS), Motor Neuron Disease (MND), Parkinson's disease, acquired brain injury, intellectual disability including Down syndrome, physical disability, as well as alcoholism is more common in people with younger onset dementia. This dual diagnosis can be a major driving factor in the rapid decline experienced by people with younger onset dementia. In addition to this, there is a greater proportional presentation of rapidly declining and debilitating dementias, such as vascular dementia, fronto temporal dementia and dementia with Lewy bodies, in younger people than in the older population.[5]

YOUNGER ONSET DEMENTIA IN AUSTRALIA

Younger onset dementia is the onset of symptoms under the age of 65 years which can include people as young as 30. It is estimated that there are currently 25,100 people in Australia living with younger onset dementia with this number expected to increase to 36,800 by 2050.[6] According to AIHW statistics, approximately 30% of people aged under 65 in residential aged care have a diagnosis of dementia. Situations such as this have great potential to lead to the exacerbation of behavioural and psychological symptoms of dementia and significantly reduce quality of life – for all the people in the aged care facility.

The needs of people with younger onset dementia vary to those diagnosed with dementia after the age of 65. Due to the life stage at onset, people with younger onset dementia require significantly more support services, in particular early intervention support, community participation and community engagement, family and relationship support, respite support, and also financial, legal, and employment support – services not offered to people with younger onset dementia in the accommodation models currently available to them.

Younger onset dementia, as a neurological disability, is not well understood in the disability sector, particularly in cases where it is the primary diagnosis. Alzheimer's Australia NSW believes that while this situation is improving with the increasing number of people with lifelong disabilities living longer with a much higher risk of developing dementia at an earlier age than the general population, the degree to which younger onset is understood is not yet satisfactory. In cases where a person with a lifelong disability develops dementia as a comorbid condition, the disability

[3] Australian Institute of Health and Welfare (2012) *Dementia in Australia*
[4] Australian Bureau of Statistics (2015) *Causes of Death, Australia, 2013:* Cat no. 3303.0
[5] NSW Department of Health (2010) The NSW Dementia Services Framework 2010-2015, NSW Dementia Policy Team, www.health.nsw.gov.au

[6] Australian Institute of Health and Welfare (2012) *Dementia in Australia*

provider often seeks support from the aged care sector to support them in the care and management of the dementia and increasing frailty. Alzheimer's Australia NSW believes further education is required throughout the disability sector, particularly for staff involved in the roll out of the NDIS, in order to better address this issue.

In recent years, there has also been a growing focus from a research, policy and practice perspective with the Dementia Collaborative Research Centre at UNSW and the Centre for Disability Studies at University of Sydney both conducting a series of studies with this cohort. Alzheimer's Australia NSW is also leading practice in this area through hosting conferences on the topic, delivering training to disability providers throughout NSW, and evaluating the move from institutional to community living for a group of older men with intellectual disability and dementia.

The Younger Onset Dementia Key Worker Program is a Commonwealth Government funded program that provides essential supports to people with dementia and their families including functions around information, linkages, and capacity building. The program provides assistance and linkages to people requiring support in maintaining or securing appropriate care, support, and housing, by staff with a thorough understanding of the progression of younger onset dementia. As this program transitions to the NDIS, it is essential that consideration be given to how the provision of this necessary specialist linkage service will be maintained.

ACCOMMODATION AND YOUNGER ONSET DEMENTIA

While efforts to improve dementia knowledge and understanding in the disability sector are on the rise, there are still concerns about how the accommodation needs of people with a primary diagnosis of younger onset dementia will be met in the future.

It is anticipated that the National Disability Insurance Scheme (NDIS) will provide funding for support and services for people with younger onset dementia in the community. While it is expected that the NDIS will provide supports around information, linkages, and capacity building for people with younger onset dementia through the Younger Onset Dementia Key Worker Program, it is clear that the NDIS has limited funding to provide housing and care for people with younger onset dementia. While those with younger onset dementia as a secondary diagnosis have the option of disability funded housing, there is no purpose built accommodation for people with younger onset dementia as a primary diagnosis. Without addressing the supply side of the equation, residential aged care will continue to remain as the only 'choice' for people with younger onset dementia aged between 30 and 65 whose care needs exceed what can be supported at home.

Providing adequate community based supports to people with younger onset dementia still living in the family home ensures that they will be given the opportunity to participate in the community and exercise choice and control. There are varying estimates as to the likelihood of admission into residential aged care for a person

with dementia. Approximately 60-90%[7] of people with dementia will enter a residential aged care facility when they reach a point where they require 24/7 support. Figure 1 below demonstrates the natural history of Alzheimer's disease. The combination of the statistic on likelihood of need for permanent care with the graphic representation of functional decline and need indicate clearly that long-term care options need to be available for people with younger onset dementia.

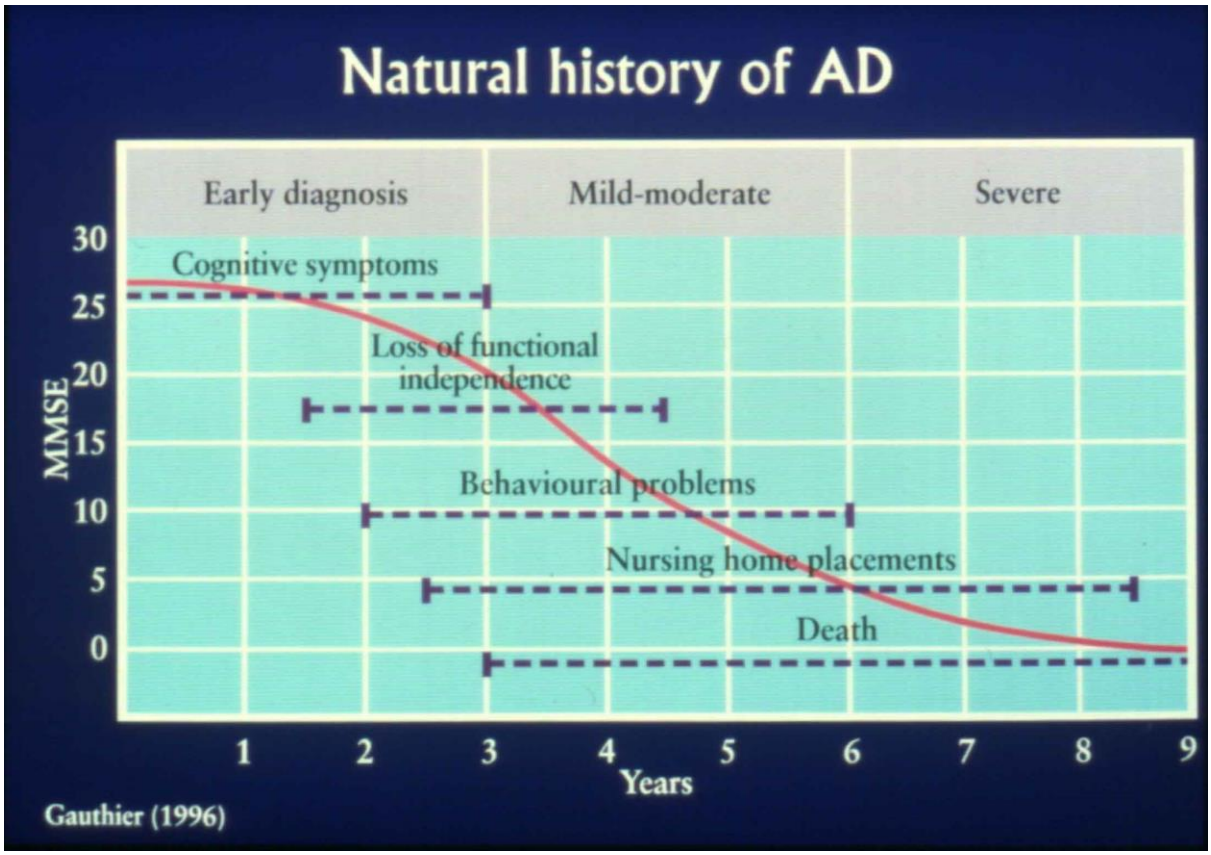

Figure 1 Natural History of Alzheimer's Disease[8]

Figure 1 suggests that during the natural cycle of Alzheimer's disease, the expression of behavioural problems and loss of functional independence after the two year mark often act as a driver for residential aged care placement. In the case of younger onset dementia, the progression from cognitive symptoms to loss of functional independence to behavioural problems is far more rapid, highlighting a need for long-term care much earlier in the course of the condition.

The rapid progression of a neurodegenerative condition such as younger onset dementia often places hefty demands on family carers to assist with personal care needs, increasing the risk of carer burn out, which is another factor contributing to

[7] Australian institute of Health and Welfare (2012) *Dementia in Residential Aged Care*
[8] Dr Serge Gauthier 2012 lecture series. Presented at NSW Parliament on Monday September 17 2012.

the earlier placement in long term care amongst people with younger onset dementia.

There are currently no existing long-term accommodation models that adequately address the dynamic needs of people with younger onset dementia as a primary diagnosis within the aged care or disability sectors. While residential aged care is less than ideal in servicing the social support needs of people with a primary diagnosis of younger onset dementia, it is the only option available to cater to their 24/7 personal care needs.

Residential Aged Care

Residential aged care is synonymous with a client base which is predominantly female, aged 85-90 and living in a very passive environment that "raised boredom to an art form"[9]. An environment such as this is less than ideal and definitely not suitable for people with younger onset dementia. Residential aged care facilities (RACFs) do not cater to the needs and wants of people to whom social support, engagement, and activity is of higher importance than personal care. As a result of their unmet needs, people with younger onset dementia placed in residential aged care facilities often exhibit aggression and other behaviours that staff and other residents along with their families find confronting, intimidating, and disruptive. We believe that as a result of this, placing people with younger onset dementia in residential aged care facilities is disruptive to other residents, and inadequate in servicing the needs of younger people such as the social support needed to maintain quality of life. It is also deleterious to the quality of life, safety and wellbeing of older residents.

However, in the current service environment, RACFs remain an important accommodation option for people with younger onset dementia and their carers as there are no other options available offering behaviour management and support, and coping with and providing for advanced dementia and palliation. While limited younger onset dementia specific wings in residential aged care facilities exist, access to these has been restricted by high demand, long waiting times, location and the difficulty in receiving an ACAT assessment for a person with dementia aged under 65 years of age.

Younger Onset Dementia Key Workers (YODKWs) report that the means tested nature of the aged care system alone is not ideal for this group as it often results in exorbitant costs to the family. YODKWs also report that the refundable accommodation deposit (RAD) for an individual with younger onset dementia and assets would come at such a high cost that without any other option, they would

[9] Cohen, B. (2015). 'Tackle Dementia or it will cripple us all', *The Australian,* January 15th, page 10

struggle. Consultations with YODKWs revealed that in some instances, couples legally separate in order to maintain the financial stability of the family while still trying to provide the person with younger onset dementia with the best possible care and quality of life.

Access to residential aged care for either permanent admission or respite can only be determined by Aged Care Assessment Teams (ACATs). The *ACAT Guidelines 2014* state that "people who are not aged are eligible for aged care services in some circumstances".[10] The loophole which allows a person with younger onset dementia to be assessed to access residential aged care is a statement on a form to the effect of "there is no permanent placement option available in the disability services system" provided directly to an ACAT. In the past, this statement was easily made as there was a high demand for disability accommodation in NSW, but no supply for people with younger onset dementia as a primary diagnosis. This often resulted in pursuing an inappropriate substitute such as residential aged care.

With the introduction of a new ACAT referral pathway in February 2016, the task of obtaining an ACAT assessment for a person aged under 65, has been made more difficult. My Aged Care is the gateway to ACAT referrals and our Key Workers and clients are reporting varying levels of responsiveness from both My Aged Care to people under 65 with some receiving a blanket denial of service and information followed by a redirection to the NSW FACS intake service.

As a result, people with younger onset dementia have no way of accessing long-term care should they need it. This is a real concern as this restricts entry to the one existing option for people with younger onset dementia. Without immediate increase in accommodation supply dedicated to people with dementia aged under 65, or the implementation of an exception policy in My Aged Care, people with a primary diagnosis of younger onset dementia will have no long-term accommodation option available to them.

Therefore, action to improve accommodation supply for people with YOD would need to address two social policy issues. An alternative accommodation model is needed to overcome the gaps identified in aged care, whilst drawing on the expertise that the sector has. At the same time, more contemporary models which can support ageing in place for younger people are evident in the disability system and could be looked to in order to identify a future solution.

Supported Accommodation

If a person with younger onset dementia has an intellectual disability, group home placement is possible because of the primary disability. However we need to acknowledge the potential limits to support and care expertise available in the disability sector as dementia progresses. Staff need to be equipped with the

[10] Department of Social Services (2014)

knowledge and skillsets to provide appropriate care and support to people with dementia.

Alzheimer's Australia NSW fears that despite recent focus and attention on people with younger onset dementia, *NSW Ageing, Disability and Home Care* (ADHC) has failed to make any inroads in resolving the accommodation and support needs of people with younger onset dementia despite investment from policies such as *Stronger Together I and II*, and the *Young People in Residential Aged Care* (YPIRAC) program.

In early 2016, Alzheimer's Australia NSW conducted consultations with members of the NSW Younger Onset Dementia Service Provider Network, an interagency group with 100 members comprising aged care and disability providers, health, mental health, allied health and academics which is facilitated by Alzheimer's Australia NSW. Members of the network were asked questions about the appropriateness, desirability, and feasibility of four different accommodation models. Survey results indicated that 88 per cent of respondents believe that residential aged care is inappropriate for people with younger onset dementia as it does not provide adequate social supports, is costly to young families not eligible for a concessional place, and does not provide an empowering environment. Meanwhile, 100 per cent of respondents indicated that a specialist supported accommodation model similar to disability group homes was the most appropriate and desirable option for people with younger onset dementia as a primary diagnosis.

Network members were also questioned about the staff ratios necessary to adequately meet the needs of people with younger onset dementia within the preferred specialist supported accommodation model. Following the responses of network members, Alzheimer's Australia NSW factored in the frequency and duration of staff visits ranging from personal care assistants, to allied health professionals. Based on these results and the current median pay for each of the roles, Alzheimer's Australia NSW calculated that staffing costs alone would amount to approximately $1.1 million per annum. Alzheimer's Australia NSW acknowledges that this is a desired model and may not be feasible to achieve in practice given the price limits set by Government funding models[11]. It is considerably more expensive than comparable disability group homes that have been funded by State Governments. However, it does give an indication to the Joint Standing Committee of the expense involved in delivering a model of care and accommodation that is deemed appropriate by experts working with people with younger onset dementia.

The proposed solution above does not address the costs of capital, nor who would fund this. There was an expectation amongst the Network members that the Government would provide this in accordance with the current practices in ADHC group homes.

[11] Varies by State and whether the service is Government or NGO operated, however, the average staffing costs in disability group homes would be in the range of $600-700k.

Currently there are no funding incentives for providers to develop younger onset dementia specific accommodation models. Alzheimer's Australia NSW anticipates that there will be a lack of funds within the NDIS for younger onset dementia specific accommodation. Therefore the accommodation and operational costs would not be met without a co-contribution from clients as happens in the residential aged care system. As previously noted, it is very difficult for most people with younger onset dementia to incur high costs for care and accommodation due to their life circumstances. It is therefore unlikely that the advent of the NDIS will drive service providers to develop appropriate accommodation for people with younger onset dementia as a primary diagnosis.

In addition to concerns regarding the accessibility to an ACAT assessment, members of the Younger Onset Dementia Service Provider network also highlighted disability accommodation waiting times and the limited availability of respite in the disability sector as issues affecting the availability of accommodation for people with younger onset dementia.

CASE STUDY 1: Issues with obtaining an ACAT assessment

A YOD Key Worker Program client's dementia has progressed to the stage where her current supports are not enough to meet her needs. The family carer is unable to provide additional supports as they are working full time and have two young children in school. The carer is at risk of burn out and the client's needs are no longer being adequately met at home. The family carer approached the Key Worker and made it known that the client will continue to decline if they did not receive a long-term accommodation placement. The Key Worker attempted to obtain an ACAT assessment from a local ACAT but was told that she must go through My Aged Care. The Key Worker was unsuccessful in attaining a referral and is currently in the process of dealing with ACAT directly to obtain an assessment.

CASE STUDY 2: Client with dementia as comorbidity

A 49 year old female YOD Key Worker Program client with Down's Syndrome and Alzheimer's Disease is currently living in a 'low care' group home owned by the NSW Department of Housing but provided by an NGO for people with 'low care disabilities'. The client lives with three other residents who she has lived with 25, 20, and 15 years respectively. Now that her dementia is progressing, the NGO is threatening to move her on the basis that she struggles to manage the stairs safely. An occupational therapist (OT) and cardiologist report supports the client's wish to stay in her current home and age in place, while the NGO still insists on moving her into a 'high care' facility where they believe she will be better off. The OT report suggests that the client's mobility issues are easily overcome with simple home modifications. Furthermore, the client's housemates are faced with the same issue of climbing the stairs, but have not been threatened with a move as they do not have a

diagnosis of dementia. Upon assessment, the 'high care' facility has been deemed inappropriate for the client, but the provider refuses to acknowledge this.

Concluding Statements

There are currently over 25,000 people in Australia living with younger onset dementia and this number is continuing to increase. As highlighted throughout this submission, accessing appropriate accommodation is an issue for people with younger onset dementia as a primary diagnosis as they often fall between the aged care sector and the disability sector. With the closing of the alternative ACAT pathway, there are currently no accessible or appropriate accommodation options for people with younger onset dementia as a primary diagnosis who require long-term care. The NDIS will not be committing any capital resources to house people with younger onset dementia as a primary diagnosis, raising further concerns for Alzheimer's Australia NSW as the State transitions to the NDIS.

Alzheimer's Australia NSW has concerns for people with younger onset dementia and their carers as NSW transitions to the NDIS in advance of the rest of Australia. As dementia is a degenerative condition, people's needs can escalate and change far more quickly than the minimum twelve month re-assessment timeframe currently in place in trial sites. As demonstrated in the case studies above, the housing and accommodation needs of people with younger onset dementia can change rapidly in 12 months, thus there is a need for flexibility in terms of NDIS re-assessment and planning for future accommodation needs.

Alzheimer's Australia NSW hopes that the issues raised in this submission will be of assistance to the Joint Standing Committee on the NDIS in the development of strategies by which specialised accommodation can become available for those with younger onset dementia as a primary diagnosis.