

**FIGHT ALZHEIMER'S  
SAVE AUSTRALIA**  
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**ADEQUACY OF EXISTING RESIDENTIAL  
CARE ARRANGEMENTS AVAILABLE FOR  
YOUNG PEOPLE WITH SEVERE  
PHYSICAL, MENTAL OR INTELLECTUAL  
DISABILITIES IN AUSTRALIA**

**Senate Inquiry**

**February 2015**

**ALZHEIMER'S AUSTRALIA**

## Executive Summary

Alzheimer's Australia welcomes the opportunity to provide a submission to the Senate Standing Committee on Community Affairs on the adequacy of existing residential care arrangements available for young people with severe physical, mental or intellectual disabilities in Australia.

Alzheimer's Australia is the peak body providing support and advocacy for people with dementia and their families and carers in Australia. Dementia is the third leading cause of death in Australia overall and second for women, and will have an increasing impact on the health system due to population ageing. Currently there are more than 342,800 Australians with dementia and this figure is expected to increase to almost 900,000 by 2050<sup>1</sup>.

There are 25,100 Australians with dementia who are under the age of 65. This number is expected to increase to 36,800 by 2050<sup>2</sup>. There are many causes of younger onset dementia, with the most common being Alzheimer's disease, stroke and frontotemporal dementia.

Dementia is a progressive neurological condition, and as the symptoms become more severe it often becomes difficult to continue to care for the person at home. Unfortunately people with dementia and their families face the difficult issue of a lack of appropriate services to cater for the needs of younger onset dementia. Often aged care facilities will be reluctant to take on clients who may have significant behavioural symptoms and are still very mobile.

As of June 2013, there were 1901 people with younger onset dementia in residential aged care in Australia. Residential aged care services are usually an inappropriate environment for supporting a person with younger onset dementia who is often more physically fit and has different interests and social needs than an older cohort. The majority of people living in residential aged care facilities are over the age of 80, which often limits opportunities for appropriate activities and/or social interactions for young residents. Inappropriate care and lack of social engagement can lead to poor quality of life and increased behavioural and psychological symptoms of dementia due to unmet needs.

Access to appropriate community supports needs to be considered as part of this Inquiry, as often if supports are available in the community, people with dementia can avoid placement in residential care for longer. Unfortunately, for people with younger onset dementia there are difficulties in getting access to age appropriate supports in the community as well.

The Commonwealth Government currently funds the Younger Onset of Key Dementia Program (YODKWP) (contract ends 30 June 2016) which provides essential supports to people with dementia and their families and has worked to build capacity in the community sector to provide services to this group of clients. There is every indication that this program will be subsumed under the NDIS. This is an ill-informed approach that is not reflective of the desires of consumers, carers or experts in this area and will lead to significant gaps in services for people with younger onset dementia in the community. It is likely that this decision will lead to people seeking access to residential care services earlier at a significant cost to Government.

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<sup>1</sup> Australian Institute of Health and Welfare (2012). Dementia in Australia. Cat. no. AGE 70. Canberra: AIHW.

<sup>2</sup> *ibid.*

## Recommendations

1. The Government reduce the current numbers of younger people with dementia living in permanent residential aged care facilities by 50% to 950 by 2020.
2. The Government should establish specialised residential care facilities to provide care and support for younger people with dementia who require residential aged care.
3. The Australian Government continue to block fund the YODKWP outside of the NDIS which is ill-equipped to respond to the needs of people with younger onset dementia.
4. A review of the adequacy of respite facilities for people with younger onset dementia be carried out as a matter of urgency.
5. Alzheimer's Australia reiterates its call for Federal and State Governments to work together to develop and implement specialised community neurobehavioural units which provide specialised mental health services for people with dementia who have severe behavioural or psychological symptoms through matching residential care and mental health funding and services.
6. The Government ensure that the roll-out of the NDIS leads to better services and supports for people with dementia and does not remove important existing services such as the younger onset dementia key worker program.

**a) the estimated number and distribution of young people in care in the aged care system in Australia, and the number of young people who require care but are not currently receiving care;**

It is estimated that there are approximately 25,100 Australians with younger onset dementia<sup>3</sup>. This represents approximately 8% of the total number of people with dementia<sup>4</sup>. Aboriginal and Torres Strait Islander people are over represented in this group as they experience dementia at a rate 3 to 5 times higher than the general Australian population and often with symptoms starting at younger ages<sup>5</sup>.

According to AIHW statistics, on 30 June 2013, the total number of permanent residential aged care clients under the age of 65 was 6,209. Approximately 30% of these residents (1,901) have a diagnosis of dementia. This number is probably an underestimate of the total number of people with dementia under the age of 65 in residential aged care due to issues around diagnosis<sup>6</sup>. There was some variance across jurisdictions with NT having a significantly larger proportion of residents under the age of 65, with 12% of all aged care residents being under 65<sup>7</sup>.

These numbers suggest that approximately 8% of people with younger onset dementia are currently living in residential aged care, with the majority residing within the community. This likely reflects both a desire by families to keep younger people at home for as long as possible as well as the lack of adequate arrangements in residential aged care to support this group.

People with younger onset dementia require specialised care and support. Data from AIHW illustrates that care needs of younger people in residential care are on average higher than older residents (Figure 1). Overall, the proportion of permanent residents under 65 assessed who required high-level care in the behaviour domain of the ACFI at 30 June 2013 was 88% - this compares with 81% for all people 65+ assessed<sup>8</sup>.

Even though the total numbers of people with younger onset dementia within residential care are relatively small, this reflects a significant number of consumers who are living within a care environment that in most cases is not age appropriate and often in a situation where care staff struggle to meet the needs of the person with dementia. This can lead to an exacerbation of symptoms and poor quality of life. It is essential that other residential care options be developed for people with younger onset dementia.

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<sup>3</sup> ibid

<sup>4</sup> It should be noted that these figures are based on analysis of international prevalence data which has been applied to Australian demographics.

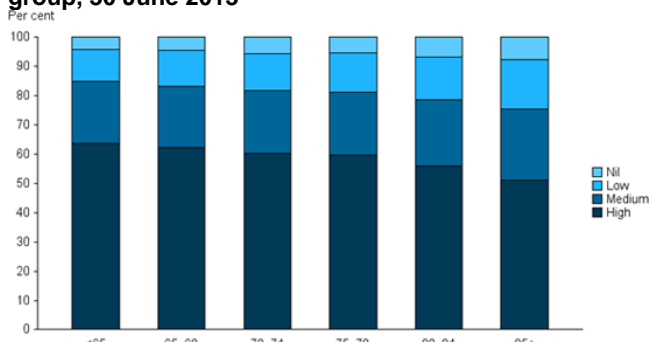
<sup>5</sup> Alzheimer's Australia (2014).. Aboriginal and Torres Strait Islander People and Dementia: A Review of the Research. Canberra: AA

<sup>6</sup> Australian Institute of Health and Welfare (2014). Residential aged care and aged care packages in the community 2012–13. Canberra: AIHW

<sup>7</sup> ibid.

<sup>8</sup> ibid.

**Figure 1: Permanent aged care residents, care needs within the behaviour domain of ACFI, by age group, 30 June 2013**



Source: AIHW Residential aged care and aged care packages in the community 2012-13

**1. Recommendation: The Government reduce the current numbers of younger people with dementia living in permanent residential aged care facilities by 50% to 950 by 2020.**

**2. Recommendation: The Government should establish specialised residential care facilities to provide care and support for younger people with dementia who require residential aged care.**

**b) short- and long-term trends in relation to the number of young people being cared for within the aged care system;**

The total number of younger people within residential aged care has remained relatively stable over the last 10 years<sup>9</sup>. It is unclear if the proportion of residents with younger onset dementia has also remained stable during that period of time.

The total numbers of people with younger onset dementia is expected to increase to 36,800 by 2050<sup>10</sup>. If the relative rate of placement in residential aged care remained stable, you could reasonably expect that there will be approximately 2,800 people with younger onset dementia within residential aged care by 2050, representing an increase of 47%.

**c) the health and support pathways available to young people with complex needs;**

Access to appropriate supports in the community, including respite, community care and key workers, is essential to delaying entry into residential care. It is only recently that specialised community services have started to be developed for people with younger onset dementia, previously it was expected that they should be able to fit into mainstream services either through disability or the aged care system<sup>11</sup>. Yet there is now a risk that essential services which have recently been developed to support younger people will soon be dismantled. Specific areas of concern are reviewed below.

<sup>9</sup> Young People in Nursing Homes National Alliance. Statistics – Estimated numbers of young people in nursing homes [Internet] (2012). <http://www.ypinh.org.au/statistics>

<sup>10</sup> AIHW op. cit.

<sup>11</sup> Op. Cit Brown 2012.

*Younger onset of Dementia Key Worker Program (YODKWP):*

In 2013, Alzheimer's Australia received funding from the then Department of Health and Ageing (now Department of Social Services) to develop the YODKWP, with funding secured through to 2016. This program provides a key point of contact for the person with dementia and their family throughout the dementia journey linking them into services and supports.

For decades, consumers have been calling for a program that provides this type of individualised, proactive, person-centred support. This approach is particularly important for this group of clients who in the past had often been shuffled between the disability and aged care systems. For the first time, people with younger onset dementia now have advocates to assist them in navigating this complex service environment. The YODKWP program provides expert information and advice from the initial point of contact and works alongside the client to develop a comprehensive strategy which optimises the client's engagement with support services and care options throughout their journey with dementia.

In addition to providing support directly to people with younger onset dementia and their family and carers, the key workers work with the acute, aged care, disability and community care sectors to improve their understanding of the issues facing those living with younger onset dementia and strengthen their capacity to provide services to this group. To date, the YODKWP has assisted thousands of people with younger onset dementia and their families navigate the health system and is proving its potential to improve the quality of life of people living with dementia and their families, as well as building capacity in the service sector.

***YODKWP Case Study from Victoria:***

A key worker in Victoria supported a person and his family to accept a recent diagnosis of Fronto-Temporal Dementia. The man was supported by the YODKW to disclose his diagnosis to his employer and receive entitlements when he decided he was no longer able to work. The key worker worked with the football club of which the client was a long standing member to support his ongoing involvement in the club.

The key worker also provided support to the client's teenage children, including working with the school to ensure supports were put in place. This has been done while linking the family into a number of other services and assisting with complex behavioural and psychological symptoms that needed extra support. This client's wife has commented that she does not know that she would have coped had it not been for the support from the YODKWP.

As the case study above highlights, a significant and distinguishing feature of the YODKWP is providing support to families and carers of the person with younger onset dementia. This is essential as a diagnosis of dementia can have a major impact on employment, finances and family relationships. Research also tells us that the carer burden is significantly higher among carers of individuals with younger onset dementia<sup>12</sup>.

*"Keep in mind with two little children trying to come to terms that 'dad' isn't the same. The stress of all the behavioural changes and just trying to run the household and finances, we were all under immense stress. There were many times where I felt that our whole family was going to go under with no help around."* (Carer of person with YOD)

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<sup>12</sup> Op. Cit RANZCP 2013.

As the Senate Community Affairs References Committee notes in its report, *Care and Management of Younger and Older Australians living with Dementia and Behavioural and Psychiatric Symptoms of Dementia (BPSD)*, neither the disability- nor aged-care sectors appear to be appropriately equipped to respond to the needs of people with younger onset dementia. The Senate report also noted that the disability sector does not have the expertise to care for people with younger onset dementia.

Programs like YODKWP are essential in bridging the various gaps between the needs of people living with dementia, their families and carers, and the existing framework of limited supports and services.

*“When I was first diagnosed with semantic dementia about 6 years ago it was devastating for me for about one week, then I thought that it may not be as daunting an experience as I first thought. I decided not to get angry but to get focused. I had this condition for the rest of my life so I might as well live with it to the best of my ability, albeit that there were going to be changes and challenges ahead.... I can't imagine where I would be today without the assistance of expertise offered by the likes of Alzheimer's Australia SA and other allied health professionals.”* (YODKWP Client from SA)

Despite the excellent progress of the YODKWP both in improving quality of life for clients but also in assisting in developing appropriate services in the sector, there is every indication that this program will be subsumed under the NDIS. This is an ill-informed approach that is not reflective of the desires of consumers, carers or experts in this area. This will lead to a range of gaps in services and supports for people with younger onset dementia and will likely lead to people entering residential aged care services prematurely at a significant cost to Government.

By moving the YODKWP into the NDIS, key features of the program will be lost including:

- early intervention/support for clients prior to eligibility for NDIS
- capacity building in the service sector
- advocacy
- support for family and carers
- assistance in getting access to a diagnosis.

Further discussion of the services and supports that will be lost if this program is brought into the NDIS is included under section g).

**3. Recommendation: The Australian Government continue to block fund the YODKWP outside of the NDIS which is ill-equipped to respond to the needs of people with younger onset dementia.**

*Access to Diagnosis:*

People with younger onset dementia have difficulty getting access to a timely diagnosis. Dementia is relatively rare for people under the age of 65 and therefore doctors need to rule out a range of other conditions before considering a diagnosis of dementia. The average time between first symptoms of dementia and an accurate diagnosis is 3.1 years for people over the age of 65<sup>13</sup>. The delay for younger people is often significantly longer, with one

<sup>13</sup> Speechly, C. (2008). The pathway to dementia diagnosis. Medical Journal of Australia, 189,487-9.

study indicating that the duration between symptom onset and the diagnosis of younger onset dementia exceeded that of later onset dementia by an average of 1.6 years<sup>14</sup>. Often the initial symptoms of younger onset dementia can be mistaken for symptoms of mental illness and may result in misdiagnosis and inappropriate treatments. This adds to the stress for people with younger onset dementia and their families.

Key workers have played an important role in assisting some people with younger onset dementia to get access to an appropriate diagnosis including through linking clients to appropriate specialists and providing support throughout the process.

*Respite:*

Respite provides an important break for the carer as well as an opportunity for social engagement for the person with dementia. Often for carers who maintain employment, respite can be an essential service<sup>15</sup>. Unfortunately there is a lack of age appropriate respite options for people with younger onset dementia and often respite services will turn people away once they have developed behavioural symptoms<sup>16</sup>. This puts enormous strain on the carer and can lead to social isolation for the person with dementia.

In addition to concerns about appropriate service models, access to care is also a concern. Carers report that there is not enough availability of residential respite beds which leads to long waiting periods. One carer in South Australia (SA) reported that she has to wait 8 months to get access to residential respite, a common issue for people with high care needs. Often significant delays in access to respite can lead to early placement in residential aged care.

*"I care for my mother, who has younger onset dementia. Respite took her for one day, and now they refuse to take her; too much hard work...all she did was wander."* Carer of person with YOD

There are examples where younger onset dementia specific respite services have been successfully developed and have had a positive impact on clients, but unfortunately these are the exception and are often due to the development work of key workers. If the YODKWP is defunded, these types of innovative solutions will be less likely to be developed.

For example, in Western Australia (WA), there is a pilot program that offers younger onset dementia specific residential respite services which was developed collaboratively by Alzheimer's Australia WA YODKWP, the Independent Living Centre of WA and Juniper (an aged care provider).

In the Australian Capital Territory (ACT), the YODKWP has developed a social engagement program where people with younger onset dementia volunteer at Greening Australia. This innovative approach provides respite for the carer while also providing opportunities for meaningful engagement for the person with dementia.

As the Senate Community Affairs References Committee noted in its report, *Care and Management of Younger and Older Australians living with Dementia and Behavioural and*

<sup>14</sup> van Vliet D. et al (2013). Time to diagnosis in young-onset dementia as compared with late-onset dementia. *Psychol Med.* 2013 Feb;43(2):423-32. doi: 10.1017/S0033291712001122. Epub 2012 May 28

<sup>15</sup> Op. Cit. Brown 2012.

<sup>16</sup> Howe A (2013). Alzheimer's Australia Respite Review: Policy Paper. Canberra: AA



*Psychiatric Symptoms of Dementia (BPSD)*, there continues to remain an urgent need of review of the adequacy of respite services for younger onset dementia patients.

**4. Recommendation: A review of the adequacy of respite facilities for people with younger onset dementia be carried out as a matter of urgency**

**d) the appropriateness of the aged care system for care of young people with serious and/or permanent mental or physical disabilities;**

The majority of people with younger onset dementia live within the community with support from informal and formal carers. But often as the disease progresses, higher levels of support are required. Unfortunately many families find that there are no good options when this point is reached. Residential aged care facilities are often inappropriate because they may not have adequate or appropriately trained staff to respond to the behavioural symptoms of the person with dementia or because they do not have the opportunities for social engagement that are needed for people with younger onset dementia. The majority of people living in residential aged care facilities are over the age of 80, which often limits opportunities for younger residents to engage in age appropriate activities and/or social interactions.

Research by Alzheimer's Australia found that "few (consumers) have reported finding anything appropriate to meet their needs and it's often left to the goodwill of providers to provide services. This may be at the end of a frustrating and long process (for the family carer and person with dementia), and so the younger person's dementia may have progressed markedly by that stage"<sup>17</sup>.

Often the lack of appropriate social engagement and care within the residential aged care environment leads to an exacerbation of behavioural and psychological symptoms of dementia. Staff often respond to these behaviours by requesting that psychotropic medications be prescribed. As a result, people with younger onset dementia can end up heavily medicated to manage their response to an inappropriate environment<sup>18</sup>.

A report by Alzheimer's Australia to the Australian Government in 2007 also noted that residential care facilities may be reluctant to offer long term support to younger people, due to their unique and sometimes complex and high care needs. To compound this, it is acknowledged that younger people are less able to fund alternative solutions, such as engaging private carers within the home<sup>19</sup>.

Younger people with dementia and their family carers are often reluctant to access services because of the fear of the person with dementia 'not fitting' traditional aged care services. This consequently negatively impacts on family carers due to the increased guilt that a carer may experience when they have to access services that they believe are not adequately meeting the needs of their family member. For example, carers conveyed their concerns about the lack of engaging and enjoyable activities in many community based services and residential facilities.

*"After enquiring at several nursing homes in our area it became apparent that finding a suitable facility for Kym was not going to be an easy task. Many of the people I spoke with told me that they were not willing to accept Kym as a resident as they were unable to*

<sup>17</sup> Op. Cit Alzheimer's Australia 2007.

<sup>18</sup> Peisah C, Skladzein E (2014). The Use of Restraints and Psychotropic Medications in People with Dementia. A report for Alzheimer's Australia. Canberra. AA.

<sup>19</sup> Ibid.

*provide him with the care required by people his age. Other nursing homes sat with me and told me the activities they had in place for their residents like bingo afternoons, movie days with reruns of the Sound of Music or Gone with the Wind and music from the 40s & 50s. There were many obstacles because of Kym's age and it seemed I kept hitting brick walls because we didn't tick the appropriate boxes. Not only did I have to face the fact my husband was terminally ill I had to fight the system to ensure Kym had the care he needed and deserved." (Carer of person with dementia, diagnosed at 41)*

Consultations with consumers also highlight some significant barriers that people with younger onset dementia and their families and carers currently encounter in residential aged care:

- rigid visiting hours
- younger people absconding from the facility regularly
- staff not appropriately trained in the needs of younger onset dementia
- over reliance on medication to manage behaviours of concern
- lack of regular assessments
- clinical environment<sup>20</sup>

There is a lack of nationally consistent standards for the provision of care for people with younger onset dementia within residential aged care facilities. Many aged care facilities willing to accept people under the age of 65 with a diagnosis of dementia lack the skills, knowledge and resources to provide them with an adequate level of support. Nationwide there are very few specialised facilities for younger onset dementia. One of the primary reasons for this is the lack of funding incentives to encourage the development of specialised younger onset dementia facilities.

#### **Case Study from Western Australia:**

Staff from Alzheimer's Australia WA Dementia Behaviour Management Advisory Service (DBMAS) and YODKWP received a referral from a metropolitan residential aged care facility for a woman with younger onset dementia. Prior to entering the facility, the resident enjoyed a variety of activities including: walking, sewing, gardening and listening to music. Since entering the facility the resident had become disorientated, physically aggressive, withdrawn and resistive to receiving assistance with daily tasks.

Upon conducting a visit to the facility, the DBMAS consultant and key worker discovered that the resident had limited social contact and that there was no one else of a similar age living in the facility – most of the other residents were aged 80 years and over. The facility had a small lifestyle department that was unable to provide 1:1 social interaction to residents. Most of the activity groups run by the lifestyle department were tailored toward a much older audience (e.g. bingo, reminiscence, general knowledge quizzes, etc.).

The DBMAS consultant and key worker made a range of recommendations to facility staff to help them meet the resident's needs, e.g. personalise the environment and employ adequate signage to assist the resident to locate her room, interaction strategies for staff, using interests such as music to facilitate engagement in daily tasks, facilitate previous occupations such as walking and sewing as able.

<sup>20</sup> Lovell Foundation (2011). Consumer Forum Outcomes.  
[http://www.lovellfoundation.com.au/index.php?option=com\\_content&view=article&id=34:consumer-focus-group&catid=7:volunteers&Itemid=16](http://www.lovellfoundation.com.au/index.php?option=com_content&view=article&id=34:consumer-focus-group&catid=7:volunteers&Itemid=16)

Over the course of the next month, the facility tried various strategies but in the end decided that they did not have the skills, knowledge or amenities necessary to meet the needs of this resident. As a result, the resident was transferred to an alternate facility.

Current service and support provisions are inadequate and insufficient to meet consumer needs. In the booklet *Garry's Dream*<sup>21</sup>, Garry Lovell who was 48 years old when diagnosed with dementia, outlines what he and others with whom he has consulted with younger onset dementia want in a care facility where they can live when their dementia becomes advanced. They want a care facility where life can be as normal as possible. They want to continue to do every day activities such as cooking, gardening, and spending time with family. Importantly they also want to be cared for by staff who have specific training in responding to the issues of those with younger onset dementia.

However as the Senate Community Affairs References Committee into BPSD noted in its report<sup>22</sup>, the residential care model as it exists for dementia, even what is considered best practice, may not be suitable for younger onset dementia.

*"Even residential care services dedicated to younger people with dementia may not be appropriate for residents if they are based on existing models. Hammond Care began pioneering a 15-place (14 permanent beds and one respite) cottage for young people with dementia. However, this cottage model, based on our cottages for older people with dementia, is not suitable for people with very severe and persistent BPSD."*  
- Hammond Care, Inquiry into Care and management of younger and older Australians living with dementia and behavioural and psychiatric symptoms of dementia (BPSD)<sup>23</sup>.

A project proposal has recently been presented to the Commonwealth Government, which aims to develop an integrated support service for people with younger onset dementia - linking diagnostic services, person-centred in-home care and community support, community-based respite and residential care. This proposal is a collaborative effort by the Lovell Foundation, Alzheimer's Australia Victoria and Mercy Health & Aged Care (Mercy Health).<sup>24</sup>

**e) alternative systems of care available in federal, state and territory jurisdictions for young people with serious and/or permanent mental, physical or intellectual disabilities;**

There are a few service providers who are developing younger onset dementia specific facilities in Australia.

*Brightwater Group Facilities, WA*

Brightwater provides accommodation and support for people living with Huntington's disease, and a range of rehabilitation and residential accommodation for younger people with acquired disability.

<sup>21</sup> Lovell Foundation (2011). *Garry's Dream: Creating services for people with Younger Onset Dementia*. [http://www.lovellfoundation.com.au/lovell\\_booklet\\_210711.pdf](http://www.lovellfoundation.com.au/lovell_booklet_210711.pdf)

<sup>22</sup> Community Affairs References Committee (2014). *Care and management of younger and older Australians living with dementia and behavioural and psychiatric symptoms of dementia (BPSD)*. Canberra.

<sup>23</sup> Hammond Care Submission (2013). *Care and management of younger and older Australians living with dementia and behavioural and psychiatric symptoms of dementia (BPSD)*. Canberra.

<sup>24</sup> For more detail about this proposal please contact Mercy Health.

Brightwater has two facilities dedicated to meeting the needs of people with Huntington's disease; Ellison House in Carlisle and Kailis House in Belmont. Both facilities comprise a small number of private rooms (6 and 12 respectively). There are 2-3 houses; with each house containing separate, lounge, dining and kitchen areas. Residents are encouraged to maintain optimal independence and well-being for as long as possible, while having on-site support to assist when necessary. In addition, Brightwater facilities also provide palliative support for all residents as their disease progresses.

In order to meet the needs of people experiencing BPSD living in residential care, Brightwater Residential Aged Care Services have implemented a broad range of initiatives including:

- accommodation designed and built according to principles of good dementia design to enable people's freedom within a safe and secure environment that facilitates way-finding, meaningful engagement and interaction in the indoor and outdoor environments
- implementing a range of person-centred approaches that focus on understanding the individual needs and experiences of the person with dementia and creating a person-centred environment in diverse residential care settings.

In addition, there are other models of group care that are being explored outside the traditional aged care setting, some specific to the needs of younger people.

#### *Group Homes Australia, NSW*

Group Homes Australia is an organisation that has established aged care accommodation within suburban housing in northern Sydney without Government funding through the *Aged Care Act*. Its current operations are not set up for younger onset dementia as the focus has been on older people. This model would be ideal but is very expensive and beyond the reach of younger people who may not have accumulated assets (house, superannuation, or other assets) that can be used to fund their ongoing care and accommodation costs.

#### *Youngcare Apartments, Brisbane, Gold Coast and Sydney*

Youngcare's one-bedroom apartments at Coomera on the Gold Coast, and Sinnamon Park, Brisbane provide a superior quality of life and incorporate facilities including gym, spa and therapy equipment. The Auburn Apartments in Sydney, which are due to open in 2016, will also be based on the same one-bedroom model and will be run in conjunction with St Vincent's and Mater Health Services. The apartments at Albany Creek, Brisbane which are scheduled for construction will showcase a new two-bedroom design, providing each resident with the added flexibility of an additional guest room or study. Other planned constructions include Wooloowin Share House which aims to provide the classic young life experience of share house living for four residents, as well as appropriate care and support. Stage two will deliver four co-located family homes – an innovative model allowing families to live close by.

The philosophy is based on promotion of young people enjoying dignified and relevant lifestyles like any other young person. This model of service provision is designed to function as independent units with varied levels of care. On site in the Brisbane facility there is also a hydrotherapy pool, recreation facilities area; gymnasium; and massage room. There is also palliative care.

Youngcare also has a research partnership with Griffith University, aimed at pioneering a consultative and evidence based approach to the development of care and housing models for young people with disability.

There are also numerous other international examples of best practice systems of care for people living with younger onset dementia, which are detailed in Appendix A.

**f) the options, consequences and considerations of the de-institutionalisation of young people with serious and/or permanent mental, physical or intellectual disabilities;**

There is an urgent need to deinstitutionalise people with younger onset dementia who are forced into residential aged care due to a lack of appropriate options in the community. However for many people, as the disease progresses there will be a point where residential care services of some type will be required.

In addition, there is a cohort of younger onset dementia clients with co-morbid mental health issues that may need more specialised care and support, although institutionalisation is not an appropriate response. As on 30<sup>th</sup> June 2013, around 19% (1,198) of younger people in residential aged care had a diagnosis of dementia and mental illness. In addition, many people with dementia will experience severe behavioural symptoms of dementia that will require short-term intensive psychiatric support. It is thus important to consider an integrated service response when considering the needs of people with younger onset dementia. This response should include:

*1. Specialised Units*

The establishment of specialised high care dependency units which are designed to meet the needs of individuals with dementia and mental health conditions. These units have appropriately trained staff and access to specialised clinicians and work to stabilise the individual so that they can be returned to mainstream services.

*2. Access to appropriate specialist teams within Residential Aged Care*

A second strategy is to ensure that individuals who are receiving care in mainstream services have access to appropriate specialist mental health care as needed. The goal should be to provide the best quality of care and to involve an interdisciplinary team that has the appropriate qualifications to provide the psychiatric care required.

**5. Recommendation: Alzheimer's Australia reiterates its call for Federal and State Governments to work together as part of their commitment to dementia as a national health priority to develop and implement specialised community neurobehavioural units which provide specialised mental health services for people with dementia who have severe behavioural or psychological symptoms of dementia through matching residential care and mental health funding and services.**

**g) the impact of the introduction of the National Disability Insurance Scheme on the ability of young people in aged care facilities to find more appropriate accommodation;**

There are serious concerns around how the NDIS will meet the needs of people with younger onset dementia. Experience to date in the trial sites suggests that people with younger onset dementia have difficulty getting through the assessment process and those in the early stages of the disease are considered as not having a sufficient functional impairment to access services. There are also questions as to how NDIS supports will relate to aged care services and assist people who are already stranded between disability, aged care and community services.

The decision to gradually dismantle the key worker model to be incorporated into NDIS is not supported by consumers or experts. There are serious concerns about how the NDIS will respond to the needs of people with dementia. It is clear that the unique one-on-one service model underpinning the YODKWP, which is highly valued by consumers, will not be replicated by NDIS.

As the National Disability Services noted in their response to the Senate Inquiry into the care and management of younger and older individuals with BPSD, while there is potential for people with younger onset dementia to access better quality services under NDIS, it is not 'a given', especially for people with younger onset dementia experiencing the behavioural and psychiatric symptoms of dementia.

*"These people—as they become participants under the NDIS—will have greater choice over the services they could receive, but organisations may not want to provide services to this group (this is often the experience of families). The NDIS must give consideration to how it will encourage or support the existence of specialist services for people with very challenging behaviours. The aged care sector must do likewise"* <sup>25</sup>.

Without this holistic support, people with dementia and their family carers will find it difficult to navigate the service system and to get access to the support and information they require, compounding the issues faced by the person with dementia. Block funding of the YODKWP ensures that key workers can provide the services and supports early in the disease, and build capacity within the service sector and the community, ensuring that younger onset dementia clients are supported through all care settings, including residential aged care facilities.

The evidence in the trial sites to date suggests real concerns around how NDIS supports people with dementia.

For example, a study by PricewaterhouseCoopers and the Sumner Foundation estimated that by June 2016, there would be 145 people under 65 in residential aged care in the Hunter, 96 in the Barwon region and 74-79 in the ACT<sup>26</sup>. The report also estimates the cost of meeting the needs of younger people in residential aged care in 2015-16 to be nearly \$14 million in the ACT, \$20 million in the Barwon site, and almost \$29 million in the Hunter launch site. With 30% of all younger residential aged care residents estimated to be diagnosed with dementia, the younger onset dementia specific needs the NDIS will need to meet will be considerable. As the report notes, the NDIS will be unable to meet these needs

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<sup>25</sup> National Disability Services Submission (2012). Care and management of younger and older Australians living with dementia and behavioural and psychiatric symptoms of dementia (BPSD). Canberra.

<sup>26</sup> Winkler, D. et al. (2013). National Disability Insurance Scheme Launch Sites: Projection of the number of people in residential aged care. Sydney, NSW & Melbourne, Victoria: PwC and Sumner Foundation Ltd.

without a large injection of capital funding and a building plan and program<sup>27</sup>. It is important to note that the NDIS has been unable to provide alternative, more appropriate arrangements to residential aged care for these clients.

Alzheimer's Australia's experience in delivering support services in NDIS trial sites leads us to conclude that there is significant misalignment between service provision and support for people with younger onset dementia under the key worker model versus the NDIS. Transferring funding from this program to NDIS at this stage will leave people with younger onset dementia once again struggling to get access to assessments and the support that they require.

Some of the significant issues we have encountered in transitioning to NDIS in trial sites such as Barwon, Hunter and the ACT are as detailed below. These issues highlight the inadequacy of NDIS to deal with the specific needs of people living with younger onset dementia.

#### *1. YODKWP Services are provided before people are eligible for NDIS*

An essential component of the YODKWP is that it provides support from the time of first having concerns to the end stages of dementia. This means that people are connected to services and supports before they enter the formal care system and are provided with ongoing support throughout their dementia journey. In some cases this happens when people are in the very early stages of the disease, before they have the level of functional impairment that is required for eligibility to NDIS.

This early-intervention approach is essential in supporting people to remain independent for as long as possible while enjoying a good quality of life and ensuring that people living with dementia do not enter residential care earlier than necessary<sup>28</sup> thus reducing avoidable Government expenditure.

#### *2. Challenges/Support with application/planning process*

People with younger onset dementia in the trial sites have indicated that they find the application process difficult and confusing with some consumers giving up because the process was too difficult. Key workers are helping people with younger onset dementia in the trial sites apply for the NDIS, prepare for planning meetings and ensure they have appropriate support to implement their NDIS plan to receive services. This support would not be funded through the NDIS, and if the YODKWP is dismantled, people with younger onset dementia would be forced to face the application process without support.

The administrative burden of enrolling into NDIS has also been a major barrier for our clients. Currently, the Evidence of Disability Form must be filled out by GP or specialist for each client. The completion of this form is dependent on the doctor having a thorough understanding of the functional capacity of the person with dementia. The Access Request Form must accompany the Evidence of Disability Form. Understanding the forms, and how to complete them is an area identified as a barrier to those with cognitive impairment. Key workers have needed to assist in this process, unless the person has a competent family member or supporter.

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<sup>27</sup> *ibid.*

<sup>28</sup> The Royal Australasian College of Physicians Submission (2012). House Standing Committee on Health and Ageing Inquiry into Dementia: Early Diagnosis and Intervention.

The key worker role has also been essential in assisting NDIA planners to develop a plan for a client with advancing dementia. NDIS planners, while eager to assist, have very limited knowledge of younger onset of dementia and Alzheimer's disease, and minimal information on what services a client with progressive functional decline may need. They also lack the capacity to estimate the number of hours of support and appropriate resourcing that would be required. Our key worker's experience has been that the NDIS plan would not have been suitable for the client's needs if key worker advocacy had not been available.

In our experience, there are also large variances in what is considered "reasonable and necessary". e.g. one person with younger onset dementia has been given horse riding lessons, while another person was not allowed bathroom aids. (Information from NDIS working group meetings).

There are also concerns about how the NDIS will respond to disabilities that are progressive and where function and needs change very rapidly.

*The rate of progression of dementia in younger onset dementia can be very rapid, and the current waiting periods through NDIS are a huge issue for key workers and clients of the YODKWP. In one unfortunate situation, a YODKWP client's condition deteriorated rapidly while he was waiting for appropriate support through NDIS. The client's application was in place as he deteriorated, however, he was hospitalised and needed permanent placement in that time and there was confusion around whether NDIS would support this as they don't have capacity to find permanent placement or whether it should be the aged care system. The feedback from the wife of this client is that NDIS had no understanding of YOD. The client died while waiting for placement.*

### 3. Core services of the YODKWP which NDIS currently does not support:

There are a range of services which the key workers currently provide which will be lost when the program is brought under the NDIS. These include:

#### a. Capacity development

A critical objective of the YODKWP is to provide sector support and capacity development to meet the specific and unique needs of each client. This could include:

- Addressing gaps in services (e.g. developing programs for social engagement)
- Building capacity in the local service sector to ensure appropriate services are available
- Networking with local GP's, geriatricians and other specialists to ensure that individuals with younger onset dementia are referred to the key worker soon after diagnosis
- Networking with key workers in other states and territories to share information, examples of best-practice and provide support.

These are services that the NDIS does not formally support in its current form.

#### b. Support for family and carers

Through the YODKWP, key workers act as a primary point of contact for people with younger onset dementia, their carers, families and friends. They support individuals and families to take an active role in their own health and wellbeing through the provision of



information, counselling, advice and advocacy. Key workers also assist individuals and their carers work together to develop goals and action plans, navigate the health system and engage with services appropriate to their own unique needs, i.e. younger-onset specific social clubs, respite, retreats, etc. Our experience has shown that in most instances, it is not just the individual who needs assistance but the family, friends and partners. With the NDIS currently not aimed at providing direct support to family and carers, this is another critical component of the YODKWP that risks being lost in transition.

### **c. Information**

Key workers have also supported clients transitioning into long term care and assisting to improve their quality of life by educating staff and improving social programs to meet the needs of younger people living with dementia, which are currently not in scope for the NDIS. Provision of timely information, advice, crisis prevention, referral and community development supports are vital supports that the block-funded YODKWP provides to meet client needs. There is a significant risk that these activities could disappear under the NDIS because these services cannot be purchased out of individual packages.

### **d. Assistance seeking diagnosis**

As detailed earlier in the submission, diagnosis of younger onset dementia can be a challenging part of the consumer's journey, and the support key workers provide in assisting clients getting a diagnosis would not be funded under the NDIS.

In summary, the integrated approach of the YODKWP in working with people from the point of diagnosis throughout the dementia journey and being linked in to the service sector is essential to supporting the person with younger onset dementia and their family and carers. While the NDIS can provide supports in some aspect, if particular functions are carved out, this would take away from the benefits of having a single point of contact which can provide specialist support throughout the dementia journey and link people to appropriate services and supports.

**6. Recommendation: The Government ensure that the roll-out of the NDIS leads to better services and supports for people with dementia and does not remove important existing services such as the YODKWP.**

## Conclusion

There are 25,100 Australians with dementia who are under the age of 65. This number is expected to increase to 36,800 by 2050<sup>29</sup>. People with younger onset dementia struggle to get access to appropriate care and support both within the community and in residential care. Historically, there has been a lack of clarity of the roles of the disability and aged care systems in providing support.

The Younger Onset Dementia Key Worker Program, which was established in 2013, has provided consumers for the first time with much needed specialist support and advocacy in getting access to appropriate services. This Program has also worked with the service sector in developing specialist programs and services such as innovative approaches to respite.

Unfortunately this Program is now at risk of being dismantled and incorporated into NDIS. For people with younger onset dementia and their families this would mean a loss of essential services and supports. The NDIS is ill-equipped to respond to the specialised needs of people with dementia. If the YODKWP is defunded it will result of a lack of support in the community, more people with younger onset dementia would face premature entry into residential care.

As of June 2013, there were 1901 people with younger onset dementia in residential aged care in Australia. Residential aged care services are usually an inappropriate environment for supporting a person with younger onset dementia who is often more physically fit and has different interests and social needs than an older cohort. Inappropriate care and lack of social engagement can lead to poor quality of life and increased behavioural and psychological symptoms of dementia due to unmet needs.

It is essential that Government continue to support the YODKWP as well as reviewing current arrangements for respite in the community. In addition, there is a need to ensure access to appropriate residential services through developing specialised facilities that can cater to the needs of younger people.

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<sup>29</sup> *ibid.*

## Appendix A

### Overview of international younger onset dementia residential care

Some international examples of best practice provision of residential aged care facilities for people living with younger onset dementia

#### **Florence Nightingale Centre for Specialised Care, Netherlands**

The Florence Nightingale Centre for Specialised Care in the Netherlands comprises a memory clinic, day program with 42 places, an outreach service to 100 people still residing in their homes and a 68 place residential care service, which includes a respite component. A day program creates opportunities for recreational groups, workshop for employment, social groups, and an individualised fitness program for each participant. Residents are given the choice to participate in any of the day program activities and families are encouraged to visit as much as possible. Florence also provides a 12 place Sheltered Living Unit for those who need support to live 'independently but not full time care'. There are two respite beds open at all times for emergency or planned stays.

An outreach service operates weekdays during business hours. It operates in accordance with a policy to stay involved with a person and their family for the entire episode of care. It provides in-home information, family counselling support, practical advice, and links with doctors and a physiotherapist. It introduces clients to the day program. The facility office is at the centre along with the manager (psychologist) and the memory clinic doctor for support. There is a strong belief in the need to engage clients in purposeful activity, fitness programs and brain training exercises, as well as the sharing by social activity. They are highly responsive to the varying needs of each individual and family.

The centre has a link to full-time geriatricians, physiotherapists, occupational therapists, music therapists, social workers, speech therapists, dieticians and psychologists. Care workers provide all assistance with ADLs. Nurses comprise a large proportion of the staff group with seven nurses for 35 patients, 2:7 in the day program and a higher staff ratio in older groups. All staff have specific training provided in-house with a learning exchange between disciplines. Volunteers are available for social engagement in meaningful daytime activities. Families are encouraged to maintain a relationship with their GP and in the latter stages of the condition, the geriatrician replaces the role of a GP.

#### **Ribblesdale Unit – Bupa, Bradford UK**

The Ribblesdale unit within the grounds of The Dales Nursing Home is a 12 bed unit designed for aged care residents and was converted for younger onset dementia use. The unit decor creates a low stimulation environment. Its co-location with the nursing home site enables laundry and meals to be prepared onsite and shared across all units. The staff ratio has been kept high - three staff throughout the day, and two overnight for the nine residents. Activities tend to happen on a 1:1 basis quite spontaneously through the day depending on the mood and needs of the residents.

### **Merevale Lodge, Fifth Lock Cottage and Coleshill Road, Atherstone UK**

There are three houses in this younger onset dementia service, staffed to a ratio of 1:3. Staff are trained by the managers of the facility. The houses have a supported community feel. There are few structured (institutionalised) routines. Positive Risk Assessments are completed for each resident in consultation with family which are part of care plans, encouraging residents to still engage in any activity that they can still do, even if there may be slight risk. Merevale House won the award for Outstanding Dementia Care Product for Innovation and also the award for Best Dementia Care Home in 2011 at the National Dementia Care Awards.

### **National Reference Centre for Young Alzheimer's Disease, France**

The National Reference Centre for Alzheimer patients is a clinical diagnostic centre (not unlike Royal Melbourne Neurological Unit) in the north of France. It drew its consumers together to give them an opportunity to let staff know what they wanted. The principal characteristics of this proposed residential service include:

- pleasant premises, which bear no resemblance to a hospital, which looks like a house visitors would feel good in,
- a human scale (12 residents),
- freedom to come and go,
- services that take account of each person's preferences,
- no imposed schedules and
- facilities that include residents' own space, including a living room and garden area.