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SUBMISSION TO THE
AUSTRALIAN HUMAN RIGHTS
COMMISSION

NATIONAL CONSULTATION
PAPER
SHAPING OUR FUTURE:
DISCUSSIONS
ON DISABILITY RIGHTS

FEBRUARY 2017

EXECUTIVE SUMMARY

Alzheimer's Australia welcomes the opportunity to provide a submission to the Australian Human Rights Commission's National Consultation Paper, *Shaping our future: discussions on disability rights*.

Alzheimer's Australia is the peak body providing support and advocacy for people living with dementia, their families and carers in Australia. Dementia is the second leading cause of death in Australia and will have an increasing impact on the health system due to population ageing. It has been estimated that there are now more than 353,800 Australians living with dementia and over a million people involved in their care; and that by 2050 there will be nearly 900,000 people living with dementia.¹ Each week there are 1,800 new cases of dementia in Australia and it is predicted that these rates will increase to 7,400 new cases each week by 2050.²

A common misconception is that people diagnosed with dementia are older and live in residential aged care. The reality is that 70% of people with dementia are living in the community at the time of diagnosis.³ Statistics also reveal that dementia is the single greatest cause of disability in older Australians (aged 65 years or older) and the fourth leading cause of disability burden overall.⁴ However, a statistical focus on the prevalence of dementia in the over 65s creates an impression that dementia is 'an older person's disease' or a disease connected with ageing. Younger onset dementia can develop before the age of 65, even as young as 35 years of age. In 2015, approximately 25,100 people in Australia were living with younger onset dementia.⁵

An Australian National Population survey found that 44% of people believe that people diagnosed with dementia are discriminated against or treated unfairly. 22% indicated that they would feel uncomfortable spending time with someone who had dementia.⁶ Lack of awareness of dementia in the community can lead to discrimination, stigma and social isolation. This often results in people living with dementia becoming disengaged from workforce and community participation long before the condition requires them to.^{7,8}

A diagnosis of dementia should not lead to discrimination or deprive any Australian of being valued as an individual. The opportunities to contribute and pursue quality of life in the community through paid employment or volunteering opportunities are as important to people living with dementia as they are to all Australians.

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

² Access Economics (2009) *Keeping Dementia Front of Mind: Incidence and Prevalence 2009-2050*. Report for Alzheimer's Australia.

³ AIHW, *Dementia in Australia*.

⁴ AIHW, *Dementia in Australia*; Access Economics, *Keeping Dementia Front of Mind*.

⁵ AIHW, *Dementia in Australia*.

⁶ Phillipson L, Magee C, Jones S and Skladzien E (2012) *Exploring dementia and stigma beliefs. A pilot study of Australian Adults aged 40 to 65 years*. Paper 28. Alzheimer's Australia.

⁷ Mocellin R, Scholes A and Velakoulis D (2013) *Quality Dementia Care: Understanding younger onset dementia*. Alzheimer's Australia.

⁸ Alzheimer's Australia (2013) *Dementia Friendly Societies: The way forward*. Paper 31. Alzheimer's Australia.

BACKGROUND: DEMENTIA IN AUSTRALIA

Dementia is a complex chronic condition caused by one or more of a large number of illnesses affecting the brain. It is a terminal condition, which affects people's abilities and memories.⁹ Dementia is cloaked in stigma and misunderstanding,¹⁰ it isolates people with dementia and their carers from social networks¹¹ and it carries significant social and economic consequences.¹²

The care and support of people living with dementia is one of the largest healthcare challenges facing Australia. It is estimated that there are now more than 353,000 Australians living with dementia and over a million people involved in their care; by 2050 there will be nearly 900,000 people living with dementia.¹³ Each week there are 1,800 new cases of dementia in Australia and this is expected to increase to 7,400 new cases each week by 2050.¹⁴

Dementia has an enormous impact on the health and aged care system, with the cost of dementia to these sectors calculated to be at least \$4.9 billion per annum.¹⁵ Dementia also has a profound social impact. People living with dementia experience stigma and social isolation,¹⁶ and family carers often find it difficult to balance work, life and caring responsibilities.¹⁷

Many of us will be diagnosed with dementia over the years ahead or will have loved ones faced with the diagnosis. As our population ages and as more of us survive the diseases of mid-life, more of us – both in terms of raw numbers and as a proportion of the population – will experience dementia. The Framingham Study has found that for those of us who reach the age of 65 without having developed dementia, the risk we have of developing dementia in our remaining lifespan is 20% for women and 17% for men¹⁸. The higher lifetime risk for women is mainly due to women's longer life expectancy.

Given the scale of dementia, it is significant to note that the United Nations Convention of Rights of the Persons with Disabilities, which was adopted in 2006, includes people with Dementia, as covered by the definition listed in Article 1:

⁹ Mitchell, S et al. (2009) 'The clinical course of advanced dementia'. *The New England Journal of Medicine*, 361: 1529-38.

¹⁰ George, D (2010) 'Overcoming the "Social Death" of dementia through language'. *The Lancet*, 376: 586-87.

¹¹ Blay, S and Peluso, E (2010) 'Public stigma: The community's tolerance of Alzheimer's disease'. *American Journal of Geriatric Psychiatry*, 18(2): 163-71.

¹² AIHW, *Dementia in Australia*.

¹³ AIHW, *Dementia in Australia*.

¹⁴ Access Economics, *Keeping Dementia Front of Mind*.

¹⁵ AIHW, *Dementia in Australia*.

¹⁶ Alzheimer's Australia (2014) *Living with Dementia in the Community: Challenges and Opportunities*.

¹⁷ Brooks D, Ross C, Beattie E (2015) *Caring for Someone with Dementia: the economic, social and health impacts of caring and evidence-based support for carers*. Report for Alzheimer's Australia.

¹⁸ Sehadri S, Belser A, Kelly-Hayes M, Kase CS, Au R, Kannel WB et al. (2006) 'The lifetime risk of stroke: Estimates from the Framingham Study'. *Stroke*, 37(2): 345-50; cited in Alzheimer's Association (2013) *Alzheimer's disease: Facts and Figures*, p 19. www.alz.org/downloads/facts_figures_2013.pdf.

“Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.”

The Articles listed under the Convention of Rights also provide detailed guidance on the important areas of everyday life for people with disabilities.

These include:

- Right to life;
- Accessibility at all levels;
- Equal Recognition Before the law;
- Freedom from torture, cruel, inhuman or degrading treatment, exploitation, violence and abuse;
- Living independently and participation in the community;
- Respect for home and family;
- Health;
- Rehabilitation;
- Employment;
- Adequate standard of living and social protection; and
- Participation in political and public life, cultural life, recreation, leisure and sport.

Alzheimer’s Australia is also concerned about the violation of human rights of older people in residential aged care, who are among the most vulnerable in our society.¹⁹ This risk is due to a host of factors including cognitive impairment and dementia, depression, immobility, limited support and contact with the outside world and difficulties in accessing the appropriate channels through which to raise complaints, as well as fear of victimisation for doing so.²⁰ The provision of quality aged care and support in a suitable environment is a central human right.²¹ The United Nations Principles of Older Persons states:²²

14. Older persons should be able to enjoy human rights and fundamental freedoms when residing in any shelter, care or treatment facility, including full respect for their dignity, beliefs, needs and privacy and for the right to make decisions about their care and the quality of their lives.

Consumers are often not aware of their legal rights with regard to complex issues such as use of restraint and antipsychotic medications, assaults perpetrated by other residents and access to appropriate end of life care.

Given the high and ever-increasing prevalence of dementia, its correlation with age and the extreme vulnerability of people living with dementia, it is therefore critical that issues affecting people with dementia have a high priority in the current Human Rights

¹⁹ Barnett, M and Hayes, R (2010) ‘Not seen and not heard: protecting elder human rights in aged care’. *University of Western Sydney Law Review*, 14. Retrieved from <http://www.questia.com/library/journal/1G1-262691573/not-seen-and-not-heard-protecting-elder-human-rights>.

²⁰ Barnett and Hayes, ‘Not seen and not heard’.

²¹ Australian Human Rights Commission (2012) *International Covenant on Economic, Social & Cultural Rights 1976*.

²² United Nations Committee on Economic, Social and Cultural Rights (2000) General Comment No. 14: The right to the highest attainable standard of health, UN Doc E/C.12/2000/4 (General Comments). Retrieved from http://www.nesri.org/sites/default/files/Right_to_health_Comment_14.pdf.

Commission's consultation on Disability Rights and that the Rights guaranteed under the UN convention and principles are upheld.

RESPONSE TO THE PROPOSED PRIORITY AREAS

The subsequent sections of our submission responds to the following Priority Areas as identified by the consultation:

- Employment
- Housing
- The criminal justice system
- Implementation of the National Disability Insurance Scheme (NDIS)
- Other issues

Employment

The decision by a person living with dementia to continue employment before and after a dementia diagnosis is complex.²³ They may have limited choices or the decision may be taken out of their hands if there is no support to transition into other employment roles. People with younger onset dementia, especially, may take early retirement for fear of stigma if they disclose their diagnosis to their employer.

Easier access to information and support for employers and employees is required, so that there is better understanding of safety and duty of care, the extent to which symptoms affect the person's ability to do their job, the pace at which symptoms are progressing and the type of supports that will assist someone to continue working for longer.

The benefits to general wellbeing and social engagement that work and volunteering provide for older adults has been widely documented.^{24,25} Employment can therefore be viewed not only as a primary function but as an important part of a person's self-identity. Loss of employment can result in feelings of dependency, disempowerment and reduced choice.²⁶ People with younger onset dementia often have a greater awareness of their dementia diagnosis, which has been associated with a greater risk of depression.²⁷ Actively engaging in the workforce, either in a paid or voluntary capacity, increases a person's self-esteem, self-worth and quality of life.

Employment can be viewed not only as a primary function but as an important part of a person's self-identity.

²³ Hodges J, McKinnon C, Kelso W, Mioshi E and Piguet O (2015) *Quality Dementia Care: Younger Onset Dementia A Practical Guide*. Alzheimer's Australia.

²⁴ Schwingel A, Niti M, Tang C, Ng T (2009) 'Continued work employment and volunteerism and mental well-being of older adults: Singapore longitudinal ageing studies'. *Age Ageing*, 38(5): 531-37.

²⁵ Morrow-Howell N, Hinterlong J, Rozario P and Tang F (2003) 'Effects of Volunteering on the Well-being of Older adults'. *Journal of Gerontology Series B: Psychological Sciences and Social Sciences*. 58(3): S137-45.

²⁶ AIHW, *Dementia in Australia*.

²⁷ Mocellin, Scholes and Velakoulis. *Quality Dementia Care*.

In the *Your experiences of living with dementia* survey undertaken by Alzheimer's Australia in 2015, people living with dementia identified sense of purpose, social interaction and keeping the brain active as key benefits of continued work and volunteering.²⁸ 45% of those surveyed were working at the time of their diagnosis and pleasingly, 69% indicated that they were supported to continue in their role. The experience of people living with dementia reported via the Alzheimer's Australia's survey indicates that some employers can and do support staff to continue working.

Alzheimer's Australia's work in awareness raising, supporting volunteering opportunities through project work and our operation of the Younger Onset Dementia Key Worker program provide learnings on how to maximise opportunities to reduce stigma and discrimination. They also show how people living with dementia can be supported to participate actively in the workforce and in community activities.

As detailed in our submission to the Commission's Willing to Work consultation, Alzheimer's Australia calls for individual, organisational, government and community action that:

- identifies, prevents and addresses discrimination against people with dementia;
- provides people with early-stage dementia with information that assists them in their workforce participation planning and decision-making;
- seeks to create dementia friendly environments, workplaces and communities; and
- invests in awareness raising about dementia and support for people with dementia to continue to contribute to the workforce and community.

The barriers that can be addressed through community, business and government investment and action include:

- awareness raising to reduce stigma;
- awareness and support for dementia friendly communities, dementia friendly organisations and dementia friendly design;
- capacity building within organisations and within the community to include and support people living with dementia in workforce, volunteering and community activities; and
- providing people living with dementia and their carers with accessible information and support to live as valued and contributing members of society.

²⁸ Survey research conducted by Alzheimer's Australia (2015) 'Your experiences of living with dementia'.

Housing

Quality in community and residential care

We know that most consumers want to stay at home and live in their community for as long as possible. This can positively influence their quality of life as well as being more cost effective for the community than formalised care settings. Where residential care is required, an appropriate balance between quality clinical care and psychosocial support can also deliver individual and societal benefits. It is therefore critical that both community and residential aged care services can offer quality care for people living with dementia.

Community-based aged care services (in conjunction with other services, including general practice and primary healthcare) need to deliver holistic care that enables people living with dementia to remain living at home for as long as possible, where this is the person's preference. This must include measures such as support for carers, support for social engagement, including volunteering, and access to flexible respite care, including overnight care.

In the case of residential care, the key to good care is ensuring access to meaningful social engagement, support to remain as independent as possible and a flexible approach to providing the best possible care for the individual resident.

Access by all Australians to safe, secure, affordable, accessible and suitable housing will be a priority as the population ages. Estimates by the Australian Institute of Health and Welfare (AIHW) indicate that 30% of people with dementia lived in residential aged care in 2011, while 70% lived in the community.²⁹ Provision of comprehensive home-based aged care services and appropriate, high quality residential aged care are therefore both critical to meeting the needs of people living with dementia.

Alzheimer's Australia receives reports from consumers about physical, psychological, and sexual abuse, inappropriate use of restraints, unreported assaults and people in extreme pain at end-of-life not having access to palliative care.

According to the framework set by aged care reforms, dementia should be core business for aged care service providers. However, there is evidence that in some cases the needs of people living with dementia are not fully addressed through current mainstream aged care services. While many people receive good care, there are also reports to Alzheimer's Australia of physical, psychological, and sexual abuse, inappropriate use of restraints, unreported assaults and people in extreme pain at end-of-life not having access to palliative care.³⁰ International evidence suggests these concerns span both residential and community

²⁹ AIHW, *Dementia in Australia*.

³⁰ Alzheimer's Australia (2013) *Quality of residential aged care: The consumer perspective*. Paper 37. Alzheimer's Australia. p 4. https://fightdementia.org.au/sites/default/files/20131112_Paper_37_Quality_of_Residential_Aged_Care.pdf.

based services, though less research on abuse in the community in Australia has been undertaken.

Case study: Inadequate care in residential aged care

“My mother was diagnosed with Alzheimer’s around 50. Family members placed her in a ... complex for geriatrics: the youngest resident. Mum remained a resident of the complex for 9 years until her death in 2014. Mum’s first ward was a lock-in facility for dementia, with no stimulation or meaningful activities. The place smelt like shit and had a vibe of death; dingy and dim. She wandered the hallways all day, bored out of her brain. Mum was soon put into a wheel-chair and moved to a palliative care unit where she remained in bed for the next 5 or 6 years, in a dark room with the curtains permanently drawn and an old arm-chair covered in black mildew, which no-one ever dared sit on.

If Hell exists, this was it. The hallways echoed with moans and outcries from patients, begging nurses to come change them, crying from the humiliation of having to sit in their own muck and faeces for hours on end: “Help me! Please! Can anyone hear me? Please! This is no way to be!” It was horrifying. My mother’s hygiene was not attended to by staff and nurses treated her like an inconvenience and a lifeless corpse. They had no respect for her well-being and treated her without dignity.

On many occasions, staff spoke about my mother as if she were already dead. One nurse had the audacity to discuss DNR options with others, in front of my mother, as tears rolled down mum’s face – ignoring my mother’s stress and trauma at hearing this. Another time, when my mum was suffering terribly from aspiration pneumonia, a nurse took no regard when suctioning mum’s throat and said to me, “She’s got no fight left in her. It won’t be long now. When MY husband died...” and proceeded to tell me about her husband’s death, as my mother moaned and groaned in pain, coughing, spluttering and crying out in pain. I was so overcome by grief and trauma that I had no response but to bow my head and cry a waterfall of tears, silently with a deep pain in my chest. The undignifying and inhumane way that my mother was treated within this ‘care’ facility will last with me forever.”

People with dementia will always need access to mainstream support services. However, it is essential that they receive appropriate specialised care within those services. A focus on domains of wellbeing and person-centred care, and a proactive approach through education and culture change to better meet the needs of people with dementia, offer significant scope to improve wellbeing and reduce the need for medical intervention in relation to distress exhibited by a person with dementia.

An approach is needed that combines building capacity in mainstream services to provide quality care for people with dementia, along with the integration of specialist dementia services to support mainstream services where required. A recent analysis noted calls for cultural change in parts of the aged care sector so that dementia capability, including

behaviour management, is accepted as part of core business and an essential in-house capability, rather than a discrete expertise or specialty area.³¹

The same assessment can be made of home care services, which, in conjunction with general practice and primary healthcare, need to be able to deliver high quality support to people living with dementia in the community.

Consumers must also be empowered to make informed choices about the support and care they need and their rights must be respected. Person-centred care must be the basis upon which all health, disability and aged care services deliver care, including to people with dementia. Person-centred care means that people with dementia and their carers are valued; they are treated as individuals; the perspective of the person living with dementia informs our understanding; and the person's social environment reflects the fundamental importance of relationships in sustaining personhood.³²

Younger Onset Dementia and Housing

It is estimated that there are approximately 25,100 Australians living with younger onset dementia.³³ This represents approximately 8% of the total number of people with dementia.³⁴ 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.³⁵

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) had 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.³⁶ There was also some variance across jurisdictions, with the Northern Territory having a significantly larger proportion of residents under the age of 65: 12% of all aged care residents there were under 65.³⁷

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 cohort.

People living 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

³¹ KPMG (2015) *Analysis of dementia programmes funded by the Department of Social Services*.

³² Hughes J (2013) *Models of dementia care: Person-centred, palliative, and supportive*. Paper 35. Alzheimer's Australia. p 9.

³³ Hughes, *Models of dementia care*.

³⁴ It should be noted that these figures are based on analysis of international prevalence data, which has been applied to Australian demographics.

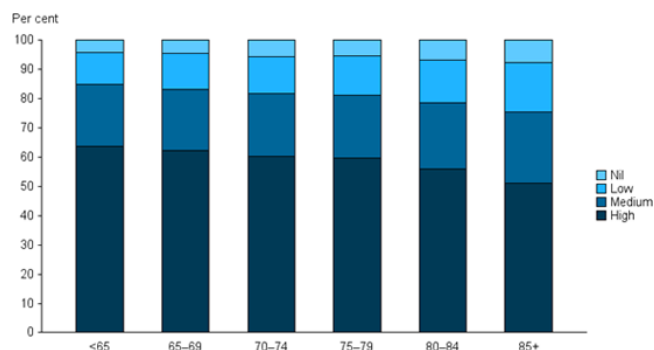
³⁵ Alzheimer's Australia (2014) *Aboriginal and Torres Strait Islander People and Dementia: A Review of the Research*.

³⁶ Australian Institute of Health and Welfare (2014) *Residential aged care and aged care packages in the community 2012–13*.

³⁷ AIHW, *Residential aged care and aged care packages in the community*.

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.³⁸

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

Even though the total number of people with younger onset dementia in residential care is relatively small, it nevertheless 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 therefore essential that other residential care options are developed for people with younger onset dementia.

The majority of people with younger onset dementia live in the community with support from informal and formal carers. Often as the disease progresses, higher levels of support are required. Unfortunately, many families find that there are few age-appropriate, high-quality options when this point is reached. Residential aged care facilities are often inappropriate because they may not have 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.”³⁹

³⁸ AIHW, *Residential aged care and aged care packages in the community*.

³⁹ Peisah C, Skladzein E (2014) *The Use of Restraints and Psychotropic Medications in People with Dementia*. A report for Alzheimer’s Australia.

People with younger onset dementia can end up heavily medicated to manage their response to an inappropriate environment

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. A common response to these reactions is the prescribing of psychotropic medications. As a result, people with younger onset dementia can end up heavily medicated to manage their response to an inappropriate environment.⁴⁰

A report by Alzheimer's Australia to the Australian Government in 2007 also noted that residential aged care facilities might be reluctant to offer long-term support to younger people due to their unique and sometimes complex and high care needs. To compound this, evidence suggests that younger people are less able to fund alternative solutions, such as engaging private carers within the home.⁴¹

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 impacts negatively on family carers due to the increased guilt they may experience when they have to access services they believe are not adequately meeting the needs of the person they care for. For example, carers have often conveyed their concerns to Alzheimer's Australia 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 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 but 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; and

⁴⁰ Peisah and Skladzein, *The Use of Restraints and Psychotropic Medications*.

⁴¹ Peisah and Skladzein, *The Use of Restraints and Psychotropic Medications*.

- clinically focused environment.⁴²

There are currently no 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.

Consumer Story: Lack of appropriate accommodation support

Due to carer burden and the impact of significant health and behavioural concerns, one consumer of the Younger Onset Dementia Key Worker Program (who is also a participant in the NDIS) has remained in hospital for approximately 4-5 months. A supported accommodation provider had been sourced with a request to have the environment audited and staff educated regarding the impact of dementia.

The case management agency had been meeting regularly with NDIA regarding funded support requirements. The plan was to transition the consumer in to the house 1-2 months before the other participants moved in to provide familiarity. A few days prior to the move from hospital, the NDIA refused to pay for 24-hour supports as the participant would be living in the property on his own for a few months and because the home modifications hadn't been completed prior to the move.

The family and case management agency have undergone a formal review, with the same outcome. The vacancy in the home has since been filled by another participant.

As at 30 June 2013, around 19% (1,198) of younger people in residential aged care had a diagnosis of dementia and mental illness. In addition, many younger people living with dementia will experience severe behavioural symptoms that 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.

Thus, there is an urgent need to deinstitutionalise people living with younger onset dementia who in the current environment may be forced into residential aged care or acute care due to a lack of appropriate options in the community.

⁴² 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

Criminal justice system

The ageing population in Australian prisons has grown at a faster rate than the general population. With about 12% of the prison population now aged over 65, there is also likely to be a rising number of people living with dementia in prisons.⁴³ There were nearly 30,000 people in Australian prisons in 2012, and taking into account prevalence rates in the general community, along with high risk factors and premature ageing of prisoners, Alzheimer's Australia estimates that dementia potentially affects at least 5% of prisoners over the age of 55.⁴⁴ Other estimates put the prevalence of dementia amongst prisoners as a whole at anywhere from 1% to 30% and it is highly likely that dementia in prisons is underdiagnosed.⁴⁵

Among this population are long-term offenders, including prisoners who have aged in the prison system and developed dementia; older first-time offenders, often people with fronto-temporal dementia who have disinhibition, loss of empathy, compulsive behaviours, and poor impulse control; and people with younger onset dementia.⁴⁶ Health assessments for older first-time offenders in particular should include assessments for cognitive impairment.⁴⁷

People living with dementia in prison, like people with dementia in other settings, will struggle with gradual loss of memory, functioning, co-ordination, health and sense of identity.⁴⁸ Research indicates that more than one in five prisoners aged over 55 need help with daily tasks. They often have multiple chronic diseases and rates of depression are high. The physical environment – stairs, bunks, long walks to cafeterias – are often unsuitable for older prisoners and prison staff are not trained to provide care and support to older prisoners with higher needs.⁴⁹

While specialist units for prisoners with dementia are costly, there are some advantages to the provision of specialised support for these prisoners. Units such as the Kevin Walker Unity for older prisoners in Long Bay protect prisoners from victimisation and facilitate access to specialist resources and care, as well as assisting with eventual reintegration into society.⁵⁰ Overseas, specific geriatric and special needs facilities have been designated within prisons such as Laurel Highlands in Central Pennsylvania and Singen, Germany, with benefits both in reducing victimisation of prisoners with dementia and in containing costs by concentrating specialist staff in one unit.⁵¹

Mainstreaming, if it includes amending facilities, training staff and educating other prisoners about dementia, also has potential to be beneficial. A positive example from the US is the Special Needs Program for Inmate-Patients with Dementia – California Men's Colony. In this

⁴³ Alzheimer's Australia NSW (2014) *Dementia in Prisons*. Discussion Paper 9. p 5.

⁴⁴ Alzheimer's Australia NSW, *Dementia in Prisons*, p 6.

⁴⁵ Cations M, Withall A, Ninaus N, Brown J, Butler T, Schofield P, Brodaty H (2016) *Dementia and the Ageing Prisoner*. Webinar presentation. University of NSW.

⁴⁶ Cations, Withall, Ninaus, Brown, Butler, Schofield, Brodaty, *Dementia and the Ageing Prisoner*.

⁴⁷ Alzheimer's Australia NSW, *Dementia in Prisons*, p 10.

⁴⁸ Alzheimer's Australia NSW, *Dementia in Prisons*, p 5.

⁴⁹ Cations, Withall, Ninaus, Brown, Butler, Schofield, Brodaty, *Dementia and the Ageing Prisoner*.

⁵⁰ Alzheimer's Australia NSW, *Dementia in Prisons*, p 15; Cations, Withall, Ninaus, Brown, Butler, Schofield, Brodaty, *Dementia and the Ageing Prisoner*.

⁵¹ Alzheimer's Australia NSW, *Dementia in Prisons*, p 11.

model, staff receive training and cognitively healthy offenders look after those with dementia, with an underlying philosophy that “socially inappropriate behaviour in dementia can be avoided and/or reduced by changes in both physical and social environments and activities.”⁵²

The needs of prisoners with dementia from special needs groups, including the disproportionately high numbers of Aboriginal and Torres Strait Islander prisoners, as well as female prisoners and people with younger onset dementia, require special consideration.⁵³

Alzheimer’s Australia believes that we need to question whether prison is the right place for people with dementia, both those who are first-time offenders (whose offending may have been triggered by their dementia) and people who have aged and developed dementia in the prison setting. Alternatives to prison should be considered, taking into account the needs of the person with dementia and the need to manage risks to the community.

If people with dementia are detained in prison, measures need to be in place to ensure they receive appropriate cognitive assessment and access to appropriate treatment and support. Staff need to be appropriately trained and other prisoners educated about dementia and the needs of a person living with dementia. People living with dementia exiting the prison system need to be referred into appropriate accommodation and support programs.

The New South Wales Law Reform Commission has completed a review of the criminal law and procedure applying to people with cognitive and mental health impairments in the criminal justice system, including the issue of criminal responsibility and consequences.⁵⁴ Although the proposed reforms relate to New South Wales, the recommendations provide a good model for national reform.

Alzheimer’s Australia is involved in a number of initiatives to address the needs of people with dementia in the criminal justice system. For example, Alzheimer’s Australia Vic is involved in several initiatives to improve the responsiveness of the Victorian Police Force and Custody Officers to the needs of people with dementia. Education has also been provided to the Police Dog Squad, specifically to equip their search efforts when people with dementia become lost. The Victorian prison system offers a comprehensive medical service and has a range of mechanisms to identify and support vulnerable prisoners including those with cognitive impairment. Alzheimer’s Australia Vic provides resources and information sessions to raise awareness of dementia with prison and community correctional staff.

The Australian Senate Community Affairs References Committee recently conducted an Inquiry into the indefinite detention of people with cognitive and psychiatric impairment in Australia. Alzheimer’s Australia has made the following recommendations, which may also be of relevance to this consultation.

⁵² Cations, Withall, Ninaus, Brown, Butler, Schofield, Brodaty, *Dementia and the Ageing Prisoner*.

⁵³ Alzheimer’s Australia NSW, *Dementia in Prisons*, p 9.

⁵⁴ New South Wales Law Reform Commission (2013). *People with cognitive and mental health impairments in the criminal justice system: Criminal responsibility and consequences*. Report 138.

http://www.lawreform.justice.nsw.gov.au/Pages/lrc/lrc_completed_projects/lrc_peoplewithcognitiveandmentalhealthimpairmentsinthecriminaljusticesystem/lrc_peoplewithcognitiveandmentalhealthimpairmentsinthecriminaljusticesystem.aspx

- All detainees aged over 55, and any others who exhibit signs of cognitive impairment, should receive appropriate cognitive assessment as part of a comprehensive health assessment.
- When a person with dementia has committed an offence which requires a custodial sentence, alternatives to prison should be considered. Such alternatives should ensure appropriate care and support for the person with dementia, as well as ensuring community safety.
- For people with dementia who are detained in prison, programs are needed to provide access to appropriate treatment and support. Dementia-specific prison units should be implemented where possible, based on successful models in operation both in Australia and overseas. When this specialised support is not available appropriate support and protections must be in place for people with dementia living in mainstream prisons.
- Prison staff need to be appropriately trained about dementia and the needs of the person with dementia.
- People with dementia exiting the prison system need referral into appropriate accommodation and support programs and support in accessing these programs upon release.

Implementation of the National Disability Insurance Scheme (NDIS)

There are serious concerns around how the NDIS will meet the needs of people living with younger onset dementia. Experience to date in 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 not considered to have sufficient functional impairment to access services despite an obvious need for support. 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.

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.

The YODKWP was funded as part of the 2012 aged care reforms in recognition of the difficulties faced by people with younger onset dementia in getting access to appropriate care and support. People with younger onset dementia have for decades been caught between the disability and aged care systems with neither system having the funding nor knowledge to provide appropriate care. The YODKWP was the culmination of decades of advocacy by consumers and Alzheimer's Australia. It provides essential supports to people with younger onset dementia and their families as well as building capacity in the community sector to provide services to this group of clients.

There are serious concerns about how the NDIS will respond to the needs of people with dementia.

In 2016, the Government extended the contract to June 2018, after which the Program will transition into the NDIS. The transition of the funding of this program to NDIS will essentially mean that the holistic, early intervention approach of the program will be lost and the program will be dismantled. This outcome 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 and other crisis supports earlier at a significant cost to Government.

As the National Disability Services noted in their response to the Senate Inquiry into the care and management of younger and older individuals with Behavioural and Psychological Symptoms of Dementia (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."⁵⁵

Without this holistic support, people living with younger onset 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. Block funding of the YODKWP ensures that key workers can provide services and supports early in the disease and build capacity within the service sector and the community. This ensures that younger onset dementia clients are supported effectively through all care settings, including residential aged care facilities.

However, evidence in the trial sites to date suggests that an NDIS alternative is not adequately meeting the needs of people living with younger onset dementia.

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.⁵⁶ 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 as having a diagnosis of 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 without a large injection of capital funding and a building plan and program.⁵⁷ It is important to note

⁵⁵ National Disability Services Submission (2012) *Care and management of younger and older Australians living with dementia and behavioural and psychiatric symptoms of dementia*.

⁵⁶ Winkler, D et al. (2013) *National Disability Insurance Scheme Launch Sites: Projection of the number of people in residential aged care*. Report by PwC and Sumner Foundation Ltd.

⁵⁷ Winkler et al., *National Disability Insurance Scheme Launch Sites*.

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. While the NDIS can provide some supports, 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.

Other Issues

Besides the priority areas the Commission is seeking feedback on, our consumers have also highlighted the following areas that should be considered in the scope of this consultation.

Abuse of People with Dementia

The very nature of dementia, as a degenerative disease that affects cognitive skills and decision-making ability, makes people with dementia vulnerable to human rights abuses

Elder abuse encompasses the more widely acknowledged forms of physical or financial abuse as well as more subtle forms of human rights abuses, such as chronic neglect or inappropriate use of physical and chemical restraints.

A recent report from the Australian Institute of Family Studies notes that although evidence about the prevalence of elder abuse in Australia is lacking, it is likely that between 2% and 10% of older Australians experience elder abuse in any given year, and the prevalence of neglect may be higher. The available evidence suggests that most elder abuse is intra-familial and intergenerational, with mothers most often being the subject of abuse by sons. The study found that financial abuse appears to be the most common form of abuse experienced by elderly people and that this is often accompanied by psychological abuse.⁵⁸

The degenerative nature of dementia and its effect on cognitive skills and decision-making ability makes people living with the condition vulnerable to human rights abuses. People living with dementia may be unable or unwilling to report abuse because they are often highly dependent for their care on those perpetrating the abuse, whether this be family members or professional carers.

⁵⁸ Kaspiew R, Carson R, Rhoades H (2016). *Elder abuse: Understanding issues, frameworks, and responses*. Research report No 35, Chapter 3. <https://aifs.gov.au/publications/elder-abuse>.

Research demonstrates that cognitive impairment and other forms of disability have a strong association with being vulnerable to elder abuse.⁵⁹ Some key settings and circumstances where abuse of people living with dementia commonly occurs includes:

- Abuse by families and carers: While most families are caring and supportive, there have been well-documented cases where people living with dementia have been inadequately cared for, restrained against their will, physically abused, emotionally abused, or financially exploited by family members. This can be a result of carers being under tremendous stress and not having access to the supports they require. In some cases, it is the result of longstanding family turmoil or an ongoing history of domestic violence, which can be exacerbated by the issue of dementia.
- Abuse in residential aged care: While many aged care facilities are striving to provide the best possible care, the human rights and dignity of vulnerable people living with dementia have not been upheld in some instances. The inappropriate use of physical and chemical restraint is widespread and there have been some cases of deliberate assault of residents by staff members.
- Abuse in the health system: Examples include doctors not telling a person of their diagnosis; hospitals using inappropriate methods of restraint; or the preferences of the person with dementia with regard to their end-of-life care (expressed by the person themselves if they have capacity, or through an Advance Care Directive, or by their legally-authorized substitute decision-maker, if they have lost capacity), not being respected and followed.
- Human rights abuses of people with dementia also occur in other settings and circumstances. Although they are not explored in depth in this submission, our consumers have highlighted the discrimination that exists in regards to income protection, life insurance policies and travel insurance. In particular:
 - Income protection denied to people living with dementia;
 - Rights of people living with dementia accessing superannuation and life insurance to receive full payment, which could assist in their well-being and care; and
 - High fees associated with obtaining travel insurance. Alzheimer's Australia recommends that dementia should be listed as a pre-existing condition, similarly to heart disease or cancer.

ABOUT ALZHEIMER'S 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 second leading cause of death in Australia, and there is no cure.⁶⁰ Our organisation advocates for the needs of people living with all types of dementia, and for their families and carers; and provides support services, education, and information. We are committed to achieving a dementia-

⁵⁹ Kaspiew, Carson, Rhoades, *Elder abuse*, p 8.

⁶⁰ Australian Bureau of Statistics (2015) *Causes of Death, Australia, 2013*. Cat no. 3303.0.

friendly Australia in which people living with dementia are respected, supported, empowered and engaged in community life.