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**SUBMISSION TO THE
PRODUCTIVITY COMMISSION**

**REFORMS TO HUMAN SERVICES
(STAGE 2)**

FEBRUARY 2017

EXECUTIVE SUMMARY

Alzheimer's Australia is pleased to provide a submission in response to the Productivity Commission's December 2016 Issues Paper, *Reforms to Human Services*.

As noted in the Issues Paper, the human services sector plays a vital role in the wellbeing of the Australian population, but it is facing significant challenges due to the increasing demand associated with an ageing population, the impact of new technologies, and new and more complex service supply and demand. Alzheimer's Australia supports the objective of the Productivity Commission Inquiry to find innovative ways to improve outcomes for users of human services. However, Alzheimer's Australia also cautions that any moves to introduce greater competition, contestability and informed user choice must be accompanied by strong government stewardship that will ensure equity of access to high quality, cost-effective services, and the protection of all consumers, including vulnerable and disadvantaged groups with complex needs.

In considering the relevance of this Inquiry to the more than 410,000 Australians living with dementia and the more than 1.2 million people involved in their care, Alzheimer's Australia's submission focuses on the role that increased competition, contestability and improved user choice in the human services sector could play and the safeguards that will be needed to ensure a high quality of service with improved outcomes.

The conclusion drawn by our submission is that, to ensure the best outcomes, the following principles must underpin any reforms which introduce greater competition, contestability and user choice in human services:

- There must be a high level of government stewardship and a robust framework of consumer protections to ensure access and quality are maintained and improved, particularly for vulnerable users, including people living with dementia, their families and carers. This will require mechanisms such as mandatory quality standards and accreditation for all services providing publicly funded care; regulation of fees and charges; regulation of consumer information and marketing; powerful complaint mechanisms; and strong penalties for providers who fail to meet requirements.
- There must be a high level of consumer information and engagement to ensure genuine, informed user choice. This should include consumer co-design of services; comprehensive information to allow users to compare and choose between services and providers; and consumer engagement in service feedback and quality assurance processes.
- Commissioning of all human services must be based on principles of universal access to health care, equity and inclusion. Funding decisions and payment mechanisms need to reward the provision of appropriate services to consumers with complex needs, rather than providing perverse incentives to deliver services to those whose needs are more easily met.

- High quality outcomes for the populations dependent on human services must be balanced with affordability. It is essential that outcomes for consumers are at the centre of the provision of human services and that these outcomes are measurable, transparent and based on cost-effectiveness rather than simply on price.
- With the potential entry to the market of new providers, mechanisms are needed to ensure that all providers have appropriate expertise to understand the needs of their clients and are demonstrably committed to meeting those needs. It is important that protections are in place to ensure that smaller, niche providers, including specialised not-for-profit services, have the opportunity to participate in a diverse marketplace alongside larger public and private providers.
- Consistent administrative, regulatory, accreditation and reporting requirements must be applied to all providers whose services are publicly funded.
- Reforms to introduce greater competition, contestability and user choice in human services must be accompanied by increased investment in specific areas, including consumer health literacy and engagement, education and training of human service sector staff, and quality assurance infrastructure.
- Reforms to introduce greater competition, contestability and user choice must also be accompanied by increased overall resourcing to meet the increasing human service needs of our ageing population. While there may be some opportunities for greater efficiencies, the proposed reforms cannot be seen as a substitute for adequate resourcing and investment. The inevitable result of under-investment will be a contraction in service availability and quality, resulting in poorer outcomes for consumers.

Alzheimer's Australia also offers the following recommendations in relation to the six priority areas considered in the inquiry:

- **Social housing:** Providers of social housing, whether government or private, should be required and supported to offer dementia-friendly accommodation. The provision of social housing should not be undertaken in isolation from other human services. Initiatives are needed to support partnerships and collaborations between the social housing sector and other social and health services in order to improve access to appropriate, co-ordinated and seamless services that build individual capacity.
- **Public hospitals:** All endorsed providers of hospital services should be required to be accredited under the National Quality and Safety Health Service Standards. Dementia should be identified and managed through the hospital admission and discharge processes. Families and carers should be enabled to be actively involved in the care and support of a person living with dementia, while staff should be trained to more effectively communicate with and care for a patient with dementia. Physical environments should be made more dementia-friendly and alternatives to psychotropic medications should be used wherever possible. The Dementia Care in

Hospitals Program, which has been shown to improve care, should be adopted widely in acute care hospitals throughout Australia.

- End-of-life care services: All providers of palliative care should be empowered to ensure that their services are dementia-friendly, that their staff are well educated and trained to honour advance care plans, and that families and carers are well supported throughout the palliative care and bereavement processes. Governments need to ensure that the community is well informed and educated about end-of-life care issues, including advance care planning; that consumers have comprehensive and appropriate information about their choices with regard to palliative care; that safeguards are in place to protect vulnerable people; and that palliative care services are well integrated with other health and human services.
- Public dental services: People living with dementia should be able to access high quality, appropriate dental care from all oral health providers in both the public and private sectors. To protect the interests of people living with dementia and other vulnerable groups, any move to open up public dental services to greater competition and contestability must be accompanied by strong government stewardship to ensure all service providers meet the same rigorous regulatory, reporting and quality assurance requirements (that is, accreditation under the National Quality and Safety Health Service Standards); that measures are in place to prevent cherry-picking or, over-servicing; and equivalent cost-effectiveness and value for money is practiced by all providers.
- Government-commissioned family and community services: The reform processes underway in relation to dementia services should be continued and completed. In relation to generalist family and community services accessed by people with dementia and their carers, education and training of service staff and inclusion of people with dementia and their carers in service co-design processes is needed to make services more accessible and dementia-friendly. Dementia should be identified amongst the inclusion principles underpinning commissioning and quality assurance processes. The costs associated with tendering and contract management must not be allowed to reduce the resources available for service delivery; and provision of valuable specialist services to vulnerable groups must remain viable. Consideration should be given to longer contracts for grant-based services, a greater focus on integration of services, and a greater focus on program outcomes.
- Services in remote Indigenous communities: Dementia is a significant yet under-recognised issue for remote Aboriginal communities. Dementia incidence in the Aboriginal population is among the highest in the world, and human services provision in remote Aboriginal communities needs to be inclusive of the needs of people living with dementia and their carers. Specific aspects that need consideration include preventative health activities to reduce the incidence of dementia; timely diagnosis to identify people with dementia; improved access to services for people living with dementia, their families and carers in remote Indigenous communities; and education and training to build the capacity of service providers to better understand and meet the needs of people impacted by dementia in these communities.

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 that affects people's abilities and memories.¹ It is surrounded by stigma and misunderstanding,² isolates people living with dementia, their families and carers from social networks,³ and carries significant social and economic consequences.⁴

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 410,000 Australians living with dementia and over a million people involved in their care; by 2050 there will be nearly 900,000 people living with dementia⁵. 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 2050.⁶

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 \$14 billion per annum.⁷ Dementia also has a profound social impact. People with dementia experience stigma and social isolation,⁸ and family carers often find it difficult to balance work, life and caring responsibilities⁹.

Many of us will be diagnosed with dementia over the years ahead, or have loved ones faced with a 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 men¹⁰. The higher lifetime risk for women is mainly due to women's longer life expectancy.

Given the high and ever-increasing prevalence of dementia, and its correlation with age, it is critical that inclusive, well-targeted, and specialised human services are available to people living with dementia, their families and carers.

¹ Mitchell, S et al. (2009). The clinical course of advanced dementia. *The New England Journal of Medicine*, 361, 1529-38.

² George D. (2010). Overcoming the 'Social Death' of dementia through language. *The Lancet*, 376, 586-7

³ 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.

⁴ Australian Institute of Health and Welfare (2012) *Dementia in Australia*.

⁵ Australian Institute of Health and Welfare (2012) *Dementia in Australia*.

⁶ Access Economics (2009) *Keeping Dementia Front of Mind: Incidence and Prevalence 2009-2050*. Report for Alzheimer's Australia.

⁷ Brown M, Hansnata E, La HA for Alzheimer's Australia (forthcoming) *Economic cost of dementia in Australia, 2016-2056*. NATSEM.

⁸ Alzheimer's Australia (2014) *Living with Dementia in the Community: Challenges and Opportunities*

⁹ 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.

¹⁰ Sehadi 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 (USA) 2013 *Alzheimer's Disease Facts and Figures* p 19. www.alz.org/downloads/facts_figures_2013.pdf

THE FRAMEWORK FOR ASSESSING REFORMS

Applicability of the principles of competition and contestability in human services for people with dementia and their carers

The concepts of competition, contestability, and informed user choice are complex and can be difficult to put into practice in the case of human service provision for people living with dementia. Where there is a strong and informed consumer voice, and where service supply exceeds demand, competition can indeed drive service innovation. However, the reality for populations with highly complex needs, including people living with dementia, is that there is often a lack of providers, a lack of specialised, appropriate care and services, low levels of information about quality, and a lack of real service choice.

People living with dementia, their families and carers are among the most vulnerable consumers in Australia. Because dementia involves progressive cognitive decline, people with the disease become increasingly less able to make informed choices about the services and programmes they can and wish to access. A significant proportion of people living with dementia are older and frail, and are usually dealing with other health conditions in addition to dementia. They are highly vulnerable to abuse of their rights and it is inherently difficult for them to complain about poor service quality or lack of appropriate service. Carers of people living with dementia are also often under strain because of their caring responsibilities and many are themselves elderly and have their own multiple health conditions to manage.

As a result of these factors, there are potential dangers associated with increasing competition and contestability in service provision to people living with dementia, their families and carers. A drive towards more commercially driven market principles, for instance, may reduce costs and/or increase profitability for providers of human services but it could also introduce perverse incentives to reduce services to the most needy and hard-to-reach people. Any moves towards greater competition and contestability must therefore address access and equity for this most vulnerable population.

In addition, the delivery of some services and programs to this group of consumers requires a high level of specialised knowledge and a highly targeted approach. Alzheimer's Australia is concerned about the current inability of many mainstream providers to deliver appropriate services to people living with dementia. Specialist services such as dementia specific advocacy, information and support are critical. Such services require specialist staff and organisational experience, expertise, and commitment. A generic approach to the delivery of services and programmes to people living with dementia, their families and carers and the indiscriminate introduction of competition and contestability would be likely to result in service failure and a lack of service access.

This is particularly true for priority population groups such as people with younger onset dementia, Aboriginal and Torres Strait Islander people, people from Culturally and Linguistically Diverse backgrounds, people living with dementia from LGBTI backgrounds, people living in rural or remote areas, or people with dementia who are homeless. It can often be more resource-intensive to deliver services to such highly vulnerable groups, and real competition is difficult to achieve, so pure market forces are likely to lead to "cherry

picking” where providers target their services to those whose needs are more easily and economically met.

The experience of Alzheimer’s Australia is that people living with dementia, their families and carers need seamless access to appropriate, well targeted services, preferably through a “one stop shop” approach. In a more competitive and contestable environment, there is a real risk of splintering of services across a multitude of providers, making it even harder to develop and disseminate appropriate referral pathways and adding to difficulties for consumers in navigating the service environment.

Access to appropriate, well targeted human services delivered by providers with specialist experience and expertise is far more cost effective, given that early intervention and access to holistic support services can reduce or delay the need for residential aged care services or costly crisis services.

Marketplace competition typically offers advantages to larger providers that can maximise economies of scale. It is important, however, that protections are in place to ensure that smaller, niche providers, including specialised not-for-profit services, have the opportunity to participate in a diverse marketplace alongside larger public and private providers. Otherwise there is a real risk of large generic providers dominating the market and squeezing out smaller specialist providers, which would actually lead to reduced choice for vulnerable consumers with specialist needs. Public and not-for-profit providers may need practical support to transition to a new competitive market; and in the commissioning arena consideration should be given to longer contracts for grant-based services to allow for continuity of care, service development and targeting of marginalised groups.

Successful delivery of human services to vulnerable groups with more complex needs is generally resource intensive and requires long-term investment. In the case of for-profit providers, market entry will only be attractive if there is sufficient economic return on investment, and the requirement to return a profit is likely to put pressure on service quality. This is a real concern given that people living with dementia, their families and carers are highly vulnerable and are not likely to be in a strong position to “shop around” for better quality and higher value services.

In a commissioning environment, it is also critical to ensure that similar administrative, regulatory, accreditation and reporting applies to all providers whose services are ultimately funded by government.

Applicability of the principle of user choice in human services for people with dementia and their carers

Alzheimer’s Australia is strongly supportive of the principle of user choice in human services. For people living with dementia, their families and carers, having a say in their everyday lives is a basic desire and underpins a sense of purpose and wellbeing. Many people living with dementia have expressed a desire to feel that they are participating in decision making regarding their care but also recognise that their ability to do so can be impacted by their diagnosis: capacity to make informed decisions may change from day to day or may decline rapidly.

It is well recognised that health literacy in Australia is generally low, and the service system is fragmented and not well understood by the public. People living with dementia, their families and carers, along with other vulnerable and marginalised groups in society, are likely to have even poorer health literacy, and diminished capacity to identify the services they need in a market-driven system. They are also likely to have difficulty in interpreting available data relating to service quality, and in using this effectively to make informed health care choices, even where service choice is actually available.

There are lessons to be learned from the introduction of Consumer Directed Care (CDC) across the aged care system. Alzheimer's Australia supports the broader intent of CDC, which is to provide consumers with greater control over their own health and wellbeing by allowing them to make choices about the types, frequency and delivery mechanisms of care and services they access. However, the full potential of CDC – including its benefits to the consumer – is yet to be fully realised. Alzheimer's Australia continues to receive feedback from consumers that the level of information provided through the My Aged Care website and by call centre staff is inadequate to support informed consumer choice; that service quality remains inconsistent; and that an increasing proportion of available funding is being taken up by service co-ordination and brokerage fees.

In addition, it is very difficult for consumers to ascertain the quality of aged care and that of other human services available to people living with dementia. This makes the desired move to a more market-driven system challenging, as informed choice is not possible without readily available, accurate information.

A central principle of CDC – and of user choice across the human services sector more broadly – should be to build an interactive communication process that supports consumers to fully understand the choices available to them and provides the information necessary to support informed decision-making. Consumers need user-friendly, accessible and objective information targeted to their needs, on the range of services available; how to compare and choose between providers; responsibilities of providers; and consumer rights including complaint mechanisms. As an example, key information consumers have identified that they need in comparing and choosing between providers in aged care includes the level of case management provided; fees and charges; service availability; hours of operation; the education and qualifications of staff; the provider's complaints process; and provision of specialised services.¹¹

Genuine user choice for people with dementia can be delivered only when consumers are enabled to be partners in the decision-making process. A comprehensive advocacy framework is a critical element to support the implementation informed user choice across the human services sector. It is vital to ensure consumers are supported, empowered and have their rights protected throughout the reform process. Investment in the education, training, and quality infrastructures is vital to support the genuine implementation of informed user choice, particularly where choice is more limited, including in rural and remote areas.

¹¹ Consumer input provided to Australian Government Consumer Focus Group with Alzheimer's Australia in March 2016, regarding Increasing Choice in Home Care proposals.

The importance of government stewardship

As noted above, in many cases a standardised competitive market approach is not appropriate in the delivery of health care and human services, particularly for vulnerable populations. Strong government stewardship and a robust framework of consumer protections will be required to accompany any reforms to introduce greater competition, contestability, and user choice to the human services sector.

Key areas where government stewardship will be vital include:

- Ensuring that high quality services are available to all Australians, particularly the most vulnerable groups with the most complex needs. Comprehensive and consistent quality assurance mechanisms are needed, including mandatory accreditation against appropriate quality standards for all endorsed service providers. In addition, providers must not be incentivised or permitted to provide services to only those whose needs can most easily and economically be met.
- Regulation of fees and charges, which will be vital to ensure an effective and cost-efficient system. The experience with the introduction of Consumer Directed Care in the aged care system has been that increasing proportions of consumers' funding packages have been diverted to care-coordination, brokerage, and management fees, leaving less available for the actual delivery of care. Government should act to mandate ceilings on such fees, and transparency to the consumer of all fees and charges.
- Ensuring that adequate, objective information is available to consumers to support informed choice of service providers, including publicly reported quality indicators. The marketing of human services should be regulated to prevent informed choice being compromised, particularly for vulnerable groups.
- Protecting consumer access to quality services in circumstances where there is limited service availability and little or no competition, for example in the delivery of human services to vulnerable populations in rural and remote areas.
- Embedding strong complaint mechanisms so that service quality is reinforced and encouraged.
- Introducing strong penalties to address circumstances where providers fail to meet requirements and thereby compromise the care provided to Australians in need.

Such measures will be essential to ensure that all Australians can indeed access timely, affordable, and high quality services, which are appropriate to their needs, and which are delivered in a cost-effective manner.

The importance of consumer engagement in service design and quality assurance

There must be a high level of consumer information and engagement to ensure genuine, informed user choice. Direct consumer feedback and input should be obtained through a range of formal and informal mechanisms. This should include consumer co-design of services, comprehensive information to allow users to compare and choose between services and providers, and consumer engagement in service feedback and quality assurance processes.

Consumers and carers should be involved in the development and implementation of initiatives to monitor and promote the delivery of quality human services for people with dementia, and other consumers of human services. This could include developing checklists and guides for consumers as well as a consumer-audit and feedback program.

SECTORS FOR REFORM

Social Housing

Access to appropriate and affordable housing is a major issue for many Australians, including many people living with dementia, their families and carers.

Estimates by the Australian Institute of Health and Welfare (AIHW) indicate that around 30% of people with dementia lived in residential aged care in 2011, while 70% lived in the community.¹² The majority of people living with dementia choose to live in the community for as long as possible, rather than entering residential care early. This can enhance their sense of independence and social connectedness, and also serves to alleviate pressure on the residential aged care system and on government budgets. The provision of affordable, appropriate, and secure housing for people living with dementia, taken in conjunction with support services to enable them to live successfully at home for as long as possible, is therefore vital.

There is also a need to develop comprehensive supports for people who are homeless/at risk of homelessness or socially and economically disadvantaged and who have a cognitive impairment. A significant proportion of the homeless population have cognitive impairment, including dementia, indicating high levels of unmet need for housing and support services. A recent literature review on homelessness and dementia in Australia¹³ notes that while there is limited research evidence, it is apparent that rates of cognitive impairment and dementia are higher in the homeless population than in the general population. Available research indicates that approximately 10% of younger homeless people (aged under 65) are likely to have cognitive impairment, while around two thirds of older homeless people were found in one study to be cognitively impaired. Many of these people have not been formally diagnosed and have little access to services and supports. Cognitive impairment is often co-

¹² Australian Institute of Health and Welfare (2012) *Dementia in Australia*.

¹³ Chenco C (2015). *Homelessness and Dementia in Australia: A Literature Review*, conducted on behalf of the Victoria and Tasmania Dementia Training Study Centre. <http://dtsc.com.au/download/dementia-and-homelessness-report/>

morbid with other conditions, including mental health problems, substance abuse issues, and physical health problems.

One of the major barriers to addressing homelessness amongst older persons is a lack of appropriate, affordable housing. Many of the problems experienced by the homeless population can only be effectively addressed in an environment of stable housing, as it is difficult to provide care and resources to people who are living on the streets.

People living with dementia, including those with younger onset dementia and those who are homeless or at risk of homelessness, need access to affordable and flexible housing options in the community, particularly in the form of social housing.

As noted by the Australian Housing and Urban Research Institute (AHURI),¹⁴ many people with disabilities are unable to access secure housing in the private market for a range of reasons, including but not limited to affordability. AHURI notes that social housing provides tenancies that are more secure and affordable.¹⁵

Alzheimer's Australia supports the contention that well-designed supply-side approaches are most likely to be effective in meeting the housing needs and preferences of people with disabilities, including people with dementia. Governments will need to continue to take a lead role in funding and co-ordinating the provision of appropriate social housing, but there is also a role for charitable organisations, philanthropic funds, superannuation funds, and corporates to participate in funding and delivering social housing, including through such mechanisms as, for example, social impact bonds. However, this should be seen as additional to, rather than as a substitute for, government leadership and funding.

The provision of social housing should not be undertaken in isolation from other human services. Initiatives are needed to support partnership and collaboration between the social housing sector, and the dementia, health, and aged care sectors, in order to improve access to appropriate, co-ordinated and seamless services for people with dementia and to link these people with dementia support services that build individual capacity. Similar principles are likely to apply to other vulnerable groups.

Providers of social housing, whether government or private entities, should also be required and supported to incorporate dementia-friendly principles. Many traditional landlord services have the potential to become dementia-friendly and enhance the quality of life of residents, often by creating a more generally customer-friendly approach which recognises and responds to individual needs and circumstances. Providers of social housing need to work to better understand the needs of residents, to improve housing design to meet their residents' needs, and to improve contact with residents, for example by providing user-friendly information to residents and delivering responsive maintenance and other building related services. Organisational cultures and systems need to be considered in any service redesign, as well as the need for providers to work working co-productively with residents and staff. In addition, social housing providers need to build collaborative partnerships with

¹⁴ Report of Joint Standing Committee on NDIS October 2015 Roundtable:
http://www.aph.gov.au/joint_ndis_accommodation

¹⁵ Report of Joint Standing Committee on NDIS October 2015 Roundtable:
http://www.aph.gov.au/joint_ndis_accommodation

other community based and statutory services, including those that specialise in providing dementia services.

Public Hospitals

As the prevalence of dementia increases in our community, it is critical that all hospitals and other health services are well equipped and motivated to provide safe, high quality care for people living with dementia as part of their core business.

People with cognitive impairments are high users of hospitals and other health care services. However, people living with dementia who are hospitalised experience worse clinical outcomes and longer lengths of stay as well as a higher likelihood of readmission compared to people without dementia. Not only is this detrimental to the patient with dementia but it also results in a high cost to the health care system. Many people living with dementia are not identified as having dementia on admission to hospital, and even where they are, hospital staff may lack dementia-specific education and training. There may also be a failure to involve and listen to carers. The result is that people with dementia may be labelled as “difficult” and may be over-medicated with antipsychotic drugs or physically restrained.¹⁶ There have also been reports of advance care plans made by people with dementia or their medical representatives not being respected in the acute hospital setting.

Better screening, detection, and care for people with cognitive impairment in the health care system can make a real difference. Alzheimer’s Australia supports moves at system level to improve care for people with dementia in the hospital system. Following advocacy by our organisation, safety and quality of care for people with cognitive impairment is now embedded throughout Version 2 of the National Safety and Quality Health Service Standards. These Standards are the basis for hospital and health service accreditation, and the transition to Version 2 is expected in the near future. Compliance with these standards should be required of all providers of hospital services.

There are also some very positive “on-the-ground” initiatives to improve dementia care in hospitals. The Dementia Care in Hospitals Project is a national project based on a model of care developed by Ballarat Health Services in conjunction with Alzheimer’s Australia Vic and people living with dementia, their families and carers. This approach is based on staff education and cultural change linked with an over-bed alert – a visual Cognitive Impairment Identifier – which alerts staff to memory and thinking difficulties such as dementia, delirium and cognitive impairment experienced by the patient. Hospitals which use the approach undertake extensive hospital-wide training on use of the identifier, and on the associated philosophy of care. The approach has been shown to improve staff and carer satisfaction with the care provided to people with dementia in acute care facilities. It has been implemented in over 20 hospitals across Victoria, and is now being rolled out and further evaluated in four states across Australia.^{17 18}

¹⁶ Alzheimer’s Australia (2014). *Dementia care in the acute hospital setting: Issues and strategies*. Paper 40.

<https://fightdementia.org.au/files/NATIONAL/documents/Alzheimers-Australia-Numbered-Publication-40.pdf>

¹⁷https://fightdementia.org.au/sites/default/files/08_Mark_Yates_The_Ballarat_Approach_The_Dementia_Care_in_Hospitals_Program.pdf

¹⁸ Alzheimer’s Australia (June 2014), Paper 40: *Dementia care in the acute hospital setting: Issues and strategies*, p 13.

Based on this successful program, and on other strategies identified through a 2014 Alzheimer's Australia symposium on dementia care in hospitals,¹⁹ we recommend that dementia should be identified and managed at hospital admission through to discharge. Families and carers should be enabled to be actively involved in the care and support of the person living with dementia and staff should be trained to more effectively communicate with and care for a person with dementia. Physical environments should be made more dementia-friendly and alternatives to psychotropic medications used wherever possible. The Dementia Care in Hospitals Program, which has been shown to improve care, should be adopted widely in acute care hospitals throughout Australia.

In any consideration of increased competition, contestability, and user choice in the delivery of public hospital services, it is critical that quality and safety of care can be assured for all consumers. Alzheimer's Australia therefore strongly advocates that any providers endorsed to deliver hospital services should be required to be fully accredited under the National Safety and Quality Health Service Standards.

End of Life Care

Being able to access appropriate care at the end of life is a critical factor in a more dignified death. This requires early planning and documentation of wishes, particularly for people who have progressive neurological diseases such as dementia. Appropriate discussions with clinicians and family members are also important in achieving end-of-life care that aligns with the consumer's wishes and goals. Coordination of care amongst various care teams such as health, community, residential and interdisciplinary care teams is needed, and care staff should have training in providing end-of-life care.

A number of factors currently contribute to poor access to quality end of life care for people with dementia. Firstly, there is a lack of understanding that dementia is a terminal illness, which leads to delays or inability to access palliative care services. There is also often poor understanding of the legal rights of people living in aged care, by both health professionals and family members. In addition, we still see a relatively low rate of advance care planning (a process undertaken by individuals, in consultation with their healthcare providers and significant others, to plan for medical decisions or treatments in advance) by people living with dementia, their families and carers, which means that there may be uncertainty about the person's wishes for end of life care; we also hear of care providers not adhering to end of life care wishes due to staffing issues or concerns about legal implications. Quality palliative care can be further hampered by poor identification and/or inappropriate treatment of pain for people who have difficulty communicating their discomfort.

Alzheimer's Australia and Palliative Care Australia have developed a joint position statement on palliative care and dementia. The statement highlights the challenges

¹⁹ Alzheimer's Australia (2014). *Dementia care in the acute hospital setting: Issues and strategies*. Paper 40. <https://fightdementia.org.au/files/NATIONAL/documents/Alzheimers-Australia-Numbered-Publication-40.pdf>

around access to end-of-life care for people with dementia and makes recommendations to improve access to care.²⁰

There is a need for awareness and education for both consumers and health professionals about dementia end-of-life care. This needs to include education on issues around capacity, legal rights, pain assessment and management in people who have difficulty with communication, and appropriate end-of-life care for people who have dementia. There is also a need for better understanding and uptake of advance care planning for people with dementia. Increased use of healthcare directives, relevant education for health professionals, and quality palliative care can help people with dementia to have better end-of-life care, and reduce grief and trauma for families.

Any reforms to introduce greater competition, contestability and user choice in palliative care services should support these basic tenets being met. Governments, as part of their stewardship responsibility, need to ensure that the community is well informed and educated about end-of-life care issues, including advance care planning; that consumers have comprehensive and appropriate information about their choices with regard to palliative care; and that safeguards are in place to protect vulnerable people, including those with dementia, to ensure that their wishes and choices are respected. All providers of palliative care should be required and supported to ensure that their services are dementia-friendly; that their staff are well educated and trained to honour advance care plans; and that carers are well supported throughout the palliative care and bereavement processes. It is also important that palliative care providers are required and supported to collaborate with other health care and human services, as integrated care is critical at end-of-life. It would be of concern if competition in the market hindered such collaboration.

Alzheimer's Australia supports the development of consumer resources and further effort in education and training for health professionals on advance care planning, advance care directives and other end-of-life care matters for people with dementia.

Alzheimer's Australia also calls for the further development of expertise and resources on grief and loss counselling for loved ones of people with dementia, and support for capacity building for service providers, particularly in the aged care sector.

Public Dental Services

Regular dental checks and the provision of oral health care are as important for people with dementia as they are for other people in the community. People living with dementia have specific needs in relation to dental care, and all personnel working in public and private dental health should have appropriate information, education and training to meet these needs.

In recognition of this, Alzheimer's Australia partnered in 2016 with the Australian Dental Association to produce *Partnership in Practising Care: Quality Dental Care for People with Dementia*, a series of six online Continuing Professional Development education modules designed to support dentists treating people living with dementia. The modules were jointly

²⁰ Palliative Care Australia and Alzheimer's Australia *Palliative Care and Dementia: Position Statement* Accessed 18 September 2015 at; https://fightdementia.org.au/sites/default/files/18122013_PCA_Alzheimer_position_statement.pdf

developed by dentists, medical practitioners and people living with dementia and their carers, to educate dentists and dental professionals on best practice care for people living with dementia. The education modules encourage dentists to continue treating people living with dementia, to focus treatment on preventative methods and have a strong emphasis on quality of life.²¹ The series tackles a range of issues including understanding dementia; the responsibility all health practitioners have to people living with dementia; the benefits of continuity of care; the simple yet effective non-clinical changes every practice can make to ensure that their patients with dementia continue to enjoy the highest quality of life; clinical issues including the risks of multi-morbidity, the clinical implications of using general anaesthesia and sedation, and the advantages of taking a multi-disciplinary approach to creating treatment plans; and the importance of good communication in every aspect of treating a person living with dementia from the initial phone call to the best appointment times and ensuring access to the practice is seamless and trouble-free.²²

Alzheimer's Australia believes that people living with dementia should be able to access quality dental care, based on the principles outlined in this education series, from all oral health providers in both the public and private sectors.

Alzheimer's Australia notes that several expert submissions to Stage One of this Inquiry raise serious questions about the value of opening public dental care to competition and contestability.²³ These concerns include:

- Public dental services being seriously under-resourced, as evidenced by lengthy waiting lists and the inability of the sector to service the whole eligible population – there is no evidence that competition without additional resourcing will significantly improve access or outcomes.
- Available evidence (e.g. from the use of publicly funded vouchers in the private dental system) indicating that the unit cost of providing services is higher in the private sector than in the public sector, raising concerns that the broader entry of private sector providers would be likely to result in fewer treatments being provided within the available quantum of public funding.
- The possibility that private providers could “cherry pick” those clients who are easiest and most profitable to provide services to, rather than more complex clients such as people living with dementia; that clients could be over-served, for example with overly frequent check-ups or unnecessary cosmetic dentistry, reducing the resources available for essential care; and that quality standards which apply to the public sector are not applied to the private sector (currently they do not apply).

²¹ <https://www.fightdementia.org.au/about-dementia/health-professionals/education-modules-for-dental-practitioners>

²² <http://www.ada.org.au/News-Media/News-and-Release/ADA-in-the-News/New-video-series-launched-to-help-dentists-treat-t>

²³ For example, submissions from the Australian Healthcare and Hospitals Association, Dental Health Services Victoria, Victorian Healthcare Association, Dr Martin Dooland AM, at: <http://www.pc.gov.au/inquiries/current/human-services/identifying-reform/submissions>

Alzheimer's Australia believes that to protect the interests of people living with dementia and other vulnerable groups, any move to open up public dental services to greater competition and contestability must be accompanied by strong government stewardship to ensure all service providers meet the same rigorous quality assurance requirements (that is, accreditation under the National Safety and Quality Health Service Standards), regulatory requirements, and reporting requirements; that measures are in place to prevent cherry-picking and over-servicing, and to ensure equivalent cost-effectiveness and value for money across all providers.

Commissioning Family and Community Services

In exploring the appropriateness of commissioned family and community services to people living with dementia, their families and carers we should consider two distinct groups of services: dementia-specific services and generalist services that are accessed by people living with dementia, their families and carers.

In relation to dementia-specific services, the Australian Government currently funds a range of dementia programmes and services covering systematic advocacy and awareness raising; support services and care for people affected by dementia; education and training (aged care and health professionals, carers and families); and research, pilots and scoping studies.²⁴ Some of the major service providers for these programs are Alzheimer's Australia, the Dementia Behaviour Management Advisory Services and the Commonwealth Carelink and Respite Centres.

An independent review of these programmes, published in September 2015, found that carers and consumers value the information and support services provided through Commonwealth-funded programmes. Family and carer education and training services were also well-received and are reported by participants to be beneficial in helping them provide better care. Workforce education and training services were generally considered to be beneficial, but greater national consistency and coordination was needed in this area. Unmet needs were identified within some consumer cohorts, including vulnerable and hard-to-reach populations. Many stakeholders advocated for a 'one stop shop' for dementia care to reduce system complexity for carers and consumers and to improve access and efficiency. Some duplications and gaps were identified, and opportunities were identified for potential consolidation of services and programmes. The majority of stakeholders support the development of an overarching national framework to guide dementia programme and service funding.²⁵

The Commonwealth and State/Territory Governments agreed in 2015 to a National Framework for Action on Dementia 2015-2019²⁶. The Australian Government announced significant changes to programmes and services to better support people with dementia and their family and carers from 1 October 2016. The changes are in line with the findings of the

²⁴https://www.dss.gov.au/sites/default/files/documents/11_2015/final_report_analysis_of_dementia_programmes_funded_by_dss_30sept2015.pdf

²⁵https://www.dss.gov.au/sites/default/files/documents/11_2015/final_report_analysis_of_dementia_programmes_funded_by_dss_30sept2015.pdf

²⁶ https://www.dss.gov.au/sites/default/files/documents/09_2015/national-framework-for-action-on-dementia-2015-2019.pdf

Analysis of Dementia Programmes report and advice from the November 2015 Ministerial Dementia Forum. The new national approach includes a single national provider for Dementia Behaviour Management Advisory Services, and a single national provider to deliver a streamlined dementia education programme. The Government has also indicated that it will develop an improved and consolidated suite of consumer support programmes for people with dementia, commencing July 2017. Thus there is already a significant reform and improvement process underway in relation to dementia services, and this process should be completed.

In relation to generalist family and community services accessed by people with dementia and their carers, there is limited data in this area, but there is an evident need for education and training of service staff to heighten awareness of dementia, how dementia can impact a client, and how the needs of people with dementia and their carers can be better met. Inclusion of people living with dementia, along with their families and carers in service co-design processes will also assist to make services more dementia-friendly. Dementia should be identified amongst the inclusion principles underpinning any commissioning and quality assurance processes.

In relation to commissioning of services, it is of concern that the introduction of competition and contestability could lead to greater costs associated with tendering and contract management for providers and governments, reducing the resources available for service delivery. There are also concerns that smaller not-for-profit providers who offer valuable specialist services to vulnerable groups may not survive in a market-driven environment. Strong government stewardship is required to ensure cost-effectiveness and optimal outcomes for consumers, and consideration should be given to longer contracts for grant-based services to allow for continuity of care, service development, and targeting of marginalised groups. Reforms should also aim to improve service integration from the user perspective, and to increase the focus of programs on outcomes rather than inputs, outputs, and processes.

The Commission has specifically requested information about cost-effective ways of helping users navigate the system of service delivery, with particular regard to users with complex needs who require access to multiple services. Alzheimer's Australia's Younger Onset Dementia Key Worker (YODKW) Program, currently being transitioned to the National Disability Insurance Scheme, is a critical initiative in meeting the needs of people with younger onset dementia, who often "fall through the cracks" between the aged care and disability services sectors. Under this program, the Key Worker acts as a primary point of contact for providing information, support, counselling, and advice; and links people with services that are appropriate to their individual needs. Eligibility includes being under 65 years on first contact to the program; and includes all forms of dementia, including a person with symptoms of dementia that have not yet been diagnosed. Key Workers co-ordinate service access across disability services, aged care services, and other services. As this program transitions to NDIS it is essential that consideration is given to how to continue to provide this important specialist linkage service, as mainstream, non-condition specific services will not meet the needs of people with younger onset dementia. Alzheimer's Australia commends this program to the Commission as a positive example of supporting users with complex needs to navigate the service system. It is important to note that the

success of the program lies in its specialist rather than generic approach, and it is likely that other user groups with complex needs will require similarly specialist approaches.

Human Services in Remote Indigenous Communities

The Commission has noted among its preliminary findings that culturally appropriate care, better co-ordinated service delivery, reduced fragmentation, greater community voice in service design and stable policy settings are important in the delivery of human services in remote Indigenous communities. Alzheimer's Australia supports this finding.

Dementia is a significant yet under-recognised issue for remote Aboriginal communities and needs to be taken into account in the provision of human services to these cohorts.

Dementia incidence in the Aboriginal population is among the highest in the world, and is associated with both age and head injury.²⁷

Alzheimer's Australia recommends that human services provision in remote Aboriginal communities is inclusive of the needs of people with dementia and their carers. Specific aspects that need consideration include:

- Preventative health activities: Given the high incidence of dementia in Indigenous communities, and given that research over the last decade has shown that up to a third of cases of Alzheimer's disease are potentially attributable to preventable risk factors,²⁸ it is recommended that service providers in remote Indigenous communities focus on preventative health activities that will help to reduce the incidence both of dementia and other non-communicable diseases.
- Timely diagnosis: In response to under-diagnosis and under-treatment of dementia in remote Australian Indigenous communities, a tailored screening tool called the KICA-Cog was developed with Indigenous health and aged care organisations to address the lack of a validated tool to assess cognition in older Indigenous Australians.²⁹ The new Australian clinical guidelines for dementia recommend use of the KICA-Cog for remote Indigenous Australians.³⁰ Alzheimer's Australia supports this recommendation and urges that service providers in remote Indigenous communities be educated on the use of the KICA-Cog.

²⁷ Smith K, Flicker L, Lautenschlager NT, Almeida OP, Atkinson D, Dwyer A, Lo Giudice D (2008). High prevalence of dementia and cognitive impairment in Indigenous Australians. *Neurology*, Nov 4; 71(19):1470-3; Lo Giudice D, Smith K, Fenner S, Hyde Z, Atkinson D, Skeaf L, Malay R, Flicker L (2015). Incidence and predictors of cognitive impairment and dementia in Aboriginal Australians: A follow-up study of 5 years. *Alzheimers Dement*, May 18. Pii: S1552-5260(15)00151-X.

²⁸ Barnes DE, Yaffe K. (2011) *The projected effect of risk factor reduction on Alzheimer's disease prevalence.*

²⁹ <https://www.perkins.org.au/wacha/our-research/indigenous/kica/>

³⁰ National Health and Medical Research Council (NHMRC) Cognitive Decline Partnership Centre, Guideline Adaptation Committee (February 2016). *Clinical practice guidelines and principles of care for people with dementia.*

http://sydney.edu.au/medicine/cdpc/documents/resources/LAVER_Dementia_Guidelines_recommendations_PRVW5.pdf

- Access to services: There is a real lack of service availability for people with dementia and their carers in remote Indigenous communities. This is a gap that should be urgently addressed through any reforms aiming to improve service delivery and outcomes for these communities.
- Education and capacity building: Providers of human services to remote Indigenous communities will require education and training to build their capacity to better understand and meet the needs of people with dementia and their carers in these communities.

CONCLUSION

Dementia is one of the major chronic diseases of this century. High quality, appropriate and targeted health and human services will continue to be crucial for people living with dementia, their families and carers, and demand will only continue to increase as the prevalence of dementia increases.

This submission has focused on the role that competition, contestability, and improved user choice could play, and the safeguards that will be needed, to ensure access to high quality services and improved outcomes for people with dementia and their carers who access the human services sector.

Key principles which have been identified in our submission, which must underpin any reforms which introduce greater competition, contestability and user choice in human services, include the need for:

- A high level of government stewardship and a robust framework of consumer protections to ensure access and quality are maintained and improved particularly for vulnerable users, such as people with dementia and their carers.
- A high level of consumer information and engagement to ensure genuine, informed user choice.
- Principles of universal access to health care, equity and inclusion, to underpin all commissioning processes and funding decisions.
- The best outcomes for the population needing human services to be achieved at the lowest cost.
- Protections to ensure that smaller, niche providers, including specialised not-for-profit services, have the opportunity to participate in a diverse marketplace.
- Consistent administrative, regulatory, accreditation and reporting requirements to be applied to all providers whose services are ultimately funded by government.

- Increased investment in specific areas including consumer health literacy and engagement, education and training of human service sector staff, and the quality assurance infrastructure.
- Adequate resourcing overall, to meet the increasing human service needs of our ageing population.

Our submission has also provided specific recommendations in relation to the six priority areas considered by the inquiry – social housing, public hospitals, end-of-life care, public dental services, government-commissioned family and community services, and services to remote Indigenous communities – that reflect the principles outlined above and seek to ensure access to quality services for people with dementia and their carers.

The issues raised and recommendations made in this submission, whilst framed with reference to people with dementia and their carers, are also largely applicable to other vulnerable groups with complex needs who access the health care and human services sector.

We trust that the matters raised in this submission will be of assistance to the Productivity Commission in considering future reform across human services in Australia.

ABOUT ALZHEIMER'S AUSTRALIA

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 there is no cure.³¹

Alzheimer's Australia represents and supports the more than 410,000 Australians living with dementia, and the more than one million family members and others involved in their care³². 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-friendly Australia where people with dementia are respected, supported, empowered, and engaged in community life.

³¹ Australian Bureau of Statistics (2015) *Causes of Death, Australia, 2013*: Cat no. 3303.0

³² Australian Institute of Health and Welfare (2012) *Dementia in Australia*.