



**Alzheimer's
Australia**
Living with dementia

**Submission to the Productivity Commission Inquiry:
Caring for Older Australians**

23rd of July 2010

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EXECUTIVE SUMMARY

Over 60 per cent of people with dementia live in the community many with no support from funded programs. The majority of individuals in residential aged care experience some form of cognitive impairment and it is one of the most common triggers for entry into residential aged care. Dementia can no longer be considered an issue effecting a small population of older adults in aged care but must be seen as part of the core business of aged care provision. Therefore, effective reform of aged care cannot occur without a focus on the needs of individuals with dementia. Dementia should be centre stage in reforming aged care because:

- Dementia is the largest cause of disability burden in older people.
- There are currently over 250,000 people with dementia and the numbers are projected to increase to 565,000 by 2030 and almost a million by 2050.
- In 2008, over \$5 billion was spent on health and residential care for people with dementia and dementia will become the third largest area of health expenditure by 2030 and the largest by 2060.
- Dementia is the third largest cause of death.

The social cost of dementia on Australian families is enormous.

- It is estimated that dementia impacts on the lives of a million Australians who provide support for people with dementia in one way or another – from helping with shopping to 24-hour care. ⁱ
- Family carers may be the only source of care for many people with dementia – around 37% of people with dementia received no formal care in 2008. ⁱⁱ
- The cost of replacing family carers with paid carers in 2008 is estimated at \$5.5 billion per annum. ⁱⁱⁱ

In order to address the needs of individuals with dementia and their family carers, any aged care strategy must include:

- Reforms to the aged care system to create a high quality, equitable and sustainable system that provides greater consumer choice and high quality community and residential care.
- A focus on improving the quality of dementia care including providing adequate support for individuals with behavioural symptoms of dementia and their carers, adequate funding for community-based dementia care services, training for aged care staff, high quality end of life care and providing services to special groups with dementia such as individuals from culturally and linguistically diverse backgrounds, Indigenous and rural populations.
- Improvement in the health outcomes for people with dementia through making the primary care and acute care systems more responsive to the needs of people with dementia.
- Investment in research into the cause and prevention of dementia and dementia risk reduction programs
- A plan to build on the work accomplished by the Dementia initiative to ensure a coordinated approach to addressing the dementia epidemic.

Aged Care

From a consumer perspective, the aged care system will respond better to needs and provide more choice if the reforms are driven by:

- The recognition that the allocation of care places will need to be increased beyond those provided for in the current allocation formula if they are to respond to the ageing of the population and the growth in the prevalence of dementia.
- Planning for adequate funding of aged care places including an evaluation of current subsidy arrangements as well as a consideration of increasing the private contribution to aged care costs when individuals are able to pay.
- The recognition of need for increased trained staff in residential care and adjustment of staffing ratios to reflect the increasing number of high care residents.
- Increased consumer choice through providing consumer directed care in residential aged care, community services and respite care.
- The separation of care and accommodation funding with an approach based on funding people rather than aged care places.
- Adequate funding of community care to enable individuals to stay in the community for longer
- Funding for specialized dementia respite services

Quality Dementia care

In relation to dementia care, there are a number of specific proposals for consideration that would enhance the choices available to people with dementia and the quality of their care. These include:

- Funding for knowledge translation activities that result in research evidence being translated into better practice.
- A behavioural supplement across all aged care packages to recognise the extra cost and care involved in supporting those who exhibit the Behavioural and Psychological Symptoms of Dementia (BPSD). Dedicated funding and allocated residential places for those who have severe psychiatric and behavioural issues.
- A commitment to expand the Dementia Behavioural Management Advisory Service to address the management of BPSD.
- Inclusion of quality of dementia care indicators in the Aged Care Accreditation and Standards process for dementia-trained staff in residential and community care settings
- A commitment by Government to expand components of the National Dementia Support Program and to link funding for the program to growth in numbers of people with dementia.
- A commitment to expanding dementia training for aged care assessment teams and other aged care staff.
- Improvement in the quality of end of life care through access to advanced care planning and palliative care

Special populations

Action is needed to ensure that mainstream services respond to the needs of all Australians irrespective of age, gender, education, ethnicity, sexual orientation, location and class. Individuals from regional and remote areas, CALD backgrounds, and individuals who are gay and lesbian face special challenges when confronting dementia and may face difficulties in accessing mainstream dementia services. Programs that embrace the concepts of person centred care should be funded in a way that ensures that service providers are able to respond to the needs of those whose care and support may entail extra costs e.g. translation, assessment etc. In addition, strategies could be pursued that involve enriching the infrastructure for service provision, providing adequate dementia care in regional and rural areas and supporting ethno-specific services.

Individuals with younger onset dementia face a separate set of issues. Following decisions taken by COAG in 2008 responsibility for services for this group lies with the disability services. Disability services are not adequately funded for this responsibility nor do they have expertise in dementia care. To ensure a seamless delivery of services, individuals who have not previously received support from the disability services should receive age appropriate care services through the aged care system. Individuals with a disability who develop younger onset dementia should be provided care within the disability framework with access to other agencies as necessary for assistance in the provision of dementia care.

Healthcare

Achieving better health outcomes for individuals with dementia is key to reducing the burden on the aged care system. Unfortunately, the issue of dementia was not addressed in the COAG health reform process, nor was there mention of dementia in the 2010 Budget. Individuals with dementia should be a priority in the reform of the health care system. Additional funding which focuses on better outcomes for people with dementia is needed. Specifically, the quality of primary care and acute care for people with dementia needs to be addressed.

Knowing that an individual has dementia is the first step in providing care and management of the disease. Unfortunately, diagnosis is often delayed. As a first step to address these concerns, Alzheimer's Australia have proposed that there should be a meeting of stakeholders to identify barriers to timely diagnosis of dementia by professional stakeholders with a view to identifying the action needed to improve diagnosis and management of dementia.

It is also important that hospitals are made less dangerous places for people with dementia. A small minority of patients may have dementia as their primary diagnosis yet perhaps 30-40% of patients may have some form of cognitive impairment. It is often the case that staff are not aware of an individual has cognitive impairment with the consequence that appropriate support is not provided. People aged 70 plus entering acute care need to be assessed so that doctors and staff know that an individual has cognitive impairment or dementia and can then provide appropriate care and support. Individuals with dementia need to be recognised as such

throughout their stay so that they are provided with appropriate care. There is a need too, for staff to be trained and Dementia Coordinators to be funded if acute care for people with dementia is to improve.

Prevention

It has been estimated that if the onset of Alzheimer's disease could be delayed by five years, it would reduce the numbers of those with Alzheimer's disease by half (between 2000 and 2040) with significant savings to the health and care system.^{iv} In order to move towards the goal of prevention, we need adequate investment in research into the causes of dementia, and support for preventative health initiatives.

The level of funding for dementia research in Australia is very low relative to other chronic diseases in terms of prevalence, cost to the healthcare system and disability burden. The average annual research funding for chronic illness in Australia between 2002-2007 was \$130 million for cancer research, \$90 million for research on cardiovascular disease, \$40 million for research on diabetes. Dementia receives only \$12.8 million.

Similarly, dementia risk reduction has not been included in any of the Government's preventative health activity. Yet there is evidence that the risk of dementia might be reduced through changes in behaviour and lifestyle. It is time that a connection was made in preventative programs directed at physical health with brain health. Dementia is linked to cardiovascular disease, diabetes, obesity and smoking.

Support should be provided for the national rollout of Alzheimer's Australia's **Mind Your Mind**® Program to both promote awareness of dementia and that people may be able to reduce their risk through physical activity, mental activity and social activity as well as by keeping their cholesterol and blood pressure levels under control.

Dementia Initiative

The Dementia Initiative - Making Dementia a National Health Priority was announced in the 2005 Budget with an additional \$320 million funding over five years and has received bipartisan support. This funding has been used to support high care community packages, expanded training initiatives, funding for dementia care research through the three Dementia Collaborative Research Centres, quality of care initiatives and funding of the National Dementia Support Program administered by Alzheimer's Australia.

The Initiative has been evaluated but not yet published. It shows that the Dementia Initiative has been effective, a judgement with which Alzheimer's Australia would agree. There are important gaps in the Initiative particularly in respect of awareness, primary care, acute care, risk reduction, dementia research into the cause and prevention of dementia and knowledge translation.

There are concerns that funding for key elements of the Initiative (e.g. the National Dementia Support Program) need to grow in line with the increasing numbers of

people with dementia if the supply of services is to meet demand and to promote innovation. The government should build on what has been accomplished by the Dementia Initiative in order to develop a coordinated approach to addressing the dementia epidemic and improving the quality of care.

RECOMMENDATIONS

Aged Care

1. The allocation formula for aged care places must take into account the increase in older segments of the population as well as growing prevalence of dementia. (p. 14)
2. Increases in aged care infrastructure in regional and remote areas in order to ensure adequate care in these areas (p. 14)
3. Aged care subsidies need to be independently reviewed at regular intervals in order to ensure that they provide sufficient funding to support high quality care and are appropriately indexed to cover rising costs in the future. (p. 15)
4. A longer term review is necessary into funding for aged care to develop a model of mixed public and private funding that ensures sustainability as well as equity in access. (p. 15)
5. The review of age care subsidies (recommendation 3) should be supported by regular monitoring of the care staffing profile in residential aged care (pg. 15).
6. Adopt consumer directed care in aged care services. (p. 16)
7. Separation of care and accommodation funding so that individuals have the choice to mix different care and accommodation options (p. 16)
8. Increased funding for community care services to enable individuals to stay in the community for longer (p. 17)
9. Graduated care packages to fill gap between CACP and EACH packages with behavioural supplements to recognise the extra costs associated with dementia. (p. 17)
10. Expansion of Consumer Directed Care respite places to ensure the flexibility needed to meet the individual circumstances of the individual with dementia and the family carer. (p. 18)
11. Prioritising dementia care places in the provision of services through the National Respite for Carers Program (p. 19)

Quality Dementia Care

12. Funding for activities that bridge the evidence-practice gap in dementia care that results in research evidence being translated into better practice through the Alzheimer's Australia Quality Dementia Care Initiative. (p. 21)
13. Behavioural supplement across all aged care packages to recognise the extra cost and care involved in supporting individuals with behavioural and psychological symptoms of dementia. (p. 21)
14. Allocation of dementia specific care places that provide accommodation and care for those with behavioural and psychological symptoms of dementia (p. 21)
15. Expansion of the Dementia Behavioural Management Advisory Service (p. 21)
16. A dementia focus in the review of Aged Care Standards, accreditation processes and development of quality indicators in order to provide

- consumers with more information about the quality of dementia care of individual providers (p. 22)
17. Increase in consumer consultation throughout the accreditation process including providing consumers with accessible information about the accreditation findings. (p. 22)
 18. Funding for the National Dementia Support program should be linked to the growth in the numbers of people with dementia (p. 22)
 19. Enhance the capacity of National Dementia Support Program to promote innovative community based dementia care projects (p. 22)
 20. Dementia specific training for all members of Aged Care Assessment Teams to ensure that individuals assessed for residential care are provided with the most appropriate care options (p. 23)
 21. Additional funding for dementia specific workforce training to expand on training that is currently supported by the Dementia Initiative. (p. 23)
 22. Improve access to information and support for advance care planning for people with dementia and their carers. (p. 24)
 23. Improved access to palliative care and pain management in aged care for people with dementia. (p.24)
 24. A specific funding allocation for promotion of access to dementia services by special populations that experience difficulty in aged care programs (p. 25)
 25. Providing care for Younger Onset Dementia within the aged care system for individuals who have not previously received support from disability services (p. 25)
 26. For individuals with a disability who develop younger onset dementia, providing care within the disability framework to avoid disruption in services (p. 25)

Health Care

27. As part of the Commonwealth Government's Primary Care Reforms implement an incentive, education and training package, including case detection, for primary care professionals across Australia to achieve timely detection and diagnosis in general practice (p. 26)
28. Cognitive assessment of individuals aged 70+ entering acute care (p. 27)
29. Funding for Acute Care staff dementia training and dementia coordinators (p. 27)
30. Introduction of the Cognitive Impairment Symbol in hospitals (p. 27)

Prevention

31. An increase in funding for Dementia Research into the cause and prevention of dementia with the objective of establishing a research funding target of 1% of the care costs of dementia. (p. 28)
32. Expand the funding for dementia care research through the Dementia Collaborative Research centres and Dementia Grants (p. 28)
33. Support for national rollout of **Mind Your Mind**® public health dementia risk reduction program of Alzheimer's Australia (p. 29)

34. Inclusion of dementia in Commonwealth preventative health campaigns for diseases linked to dementia e.g. cardiovascular, stroke, diabetes, obesity, smoking, alcohol (p. 29)

Dementia Initiative

35. Build on the platform established by the Dementia Initiative on the basis of the proposals in this submission – for example in respect of Dementia Behavioural Management Advisory Services, the National Dementia Support Program, research, knowledge translation to address the evidence practice gap (p. 31).

SECTION 1 BACKGROUND

1.1 What is dementia?

Dementia is the term used to describe the symptoms of a large group of conditions that result in a progressive decline in cognition. These include decline in memory, reasoning, communication skills and the capacity to carry out activities of daily living. At some stage of the illness individuals are likely to develop behavioural and psychological symptoms, such as depression, psychosis, aggression and wandering. These symptoms may complicate care for the individual and the treatment of any other co-morbidities they may have.

The causes of dementia are not well understood, but research over the last 25 years has provided a better understanding of the changes in the brain as dementia progresses. The main types of dementia are Alzheimer's disease and vascular dementia, or a mixture of the two pathologies. Increased risk of dementia is associated with vascular disease, Parkinson's disease, Huntington's disease, obesity, diabetes, alcohol and drug abuse and intellectual disabilities such as Down Syndrome.

Dementia does not discriminate. It can affect anyone in society irrespective of age, gender, education, ethnicity and class.

1.2 Dementia: The Economic Impact

Dementia is both one of the most common and most disabling of all chronic health conditions. In summary:

- There are currently over 250,000 Australians with dementia with over 1300 new cases every week.^v
- By 2030 there will be 565,000 people with dementia and by 2050 almost a million.^{vi}
- The cost of dementia care in 2008 was estimated at \$5.4 billion per annum.^{vii}
- Dementia will become the third greatest source of health and residential aged care spending within two decades. These costs alone will be around 1% of GDP.^{viii}
- By 2060, spending on dementia is set to outstrip that of any other health condition. It is projected to be \$83 billion (in 2006-07 dollars), and will represent around 11% of the entire health and residential aged care sector spending.^{ix}
- The opportunity cost or lost productivity borne by individuals, business and government was estimated at \$881 million in 2008.^x
- Dementia is the fourth largest cause of death after heart disease, stroke and lung cancer.^{xi}
- Dementia is already the greatest single cause of disability in older Australians (aged 65 years or older) and is responsible for one year in every six of years of disability burden for this group.^{xii}

The economic impact of the rapid increase in the number of Australians who will have dementia and need services in the future can be seen in the workforce implications. It has been estimated that there will need to be an increase of over 150,000 carers for people with dementia in 2029 relative to 2008 – a 76% increase in the 2008 workforce. This shortage is likely to be made up of 58,000 paid dementia care staff and 94,000 family carers.^{xiii}

1.3 Dementia: Social Costs

Dementia is a social condition as well as a medical one. It can result in stigma, social isolation and discrimination. The social and economic impact on individuals and their families can be particularly difficult for individuals from culturally and linguistically diverse backgrounds, Indigenous population groups and gays and lesbians. There is also a need for recognition of the impact of dementia on younger people. Currently there are 15,000 Australians who develop this condition early in life (younger onset dementia) – sometimes in their teens, but with increasing frequency in their 30s and older.

Caring for a person with dementia is particularly challenging, with the progressive degeneration of the person's cognitive capacity and ability to undertake the activities of daily living. As a consequence, caring for a person with dementia has a negative impact on the health and wellbeing of family carers. Social impacts may include loss of work, friends and acquaintances and social activities. Health impacts can include depression, anxiety, stress, physical health impacts and sleep disruption. Additional stresses can occur if the family carer is older and in failing health themselves. Younger carers can also face difficulties if their working hours are reduced or if time with their immediate families is reduced due to their caring roles.

The social cost of dementia on Australian families is enormous.

- It is estimated that dementia impacts on the lives of a million Australians who provide support for people with dementia in one way or another – from helping with shopping to 24-hour care.^{xiv}
- Family carers may be the only source of care for many people with dementia – around 37% of people with dementia received no formal care in 2008.^{xv}
- The cost of replacing family carers with paid carers in 2008 is estimated at \$5.5 billion per annum.^{xvi}

SECTION 2 AGED CARE

Alzheimer's Australia has consistently advocated over the last ten years for fundamental changes in aged care to improve the quality of life and health of older people and people with dementia. The Productivity Commission Inquiry and the implementation of the National Health and Hospital Network provide an opportunity for those responsible for health policy to ensure the care needs of those with dementia are properly addressed in the aged care system. We welcome the opportunity to provide input into reform of the aged care system.

2.1 Planning

In order to provide sustainable high quality aged care into the future the Commonwealth must adequately plan for the rapid growth of individuals in the oldest age brackets and the related increase in need for aged care. The current aged care planning formula of 113 places per 1,000 individuals over the age of 70 does not take into account the projected increases in the oldest age groups over the next 30 years or the associated rates of chronic disease. This is particularly problematic as the age profile of aged care residents has been increasing over the past 10 years. In 1999, 49% of permanent aged care residents were over the age of 85. By 2008 this had increased to 55%^{xvii}. This trend is likely to continue as the Australian population continues to age. Over the next 30 years, the number of individuals in Australia over the age of 85 is expected to grow by 255% (compared to an expected growth of 115% for individuals 65+)^{xviii}. Planning of aged care places around the number of individuals over the age of 70 is inadequate.

Although it is important to plan for the approximate number of aged care places required into the future, the government needs to consider if planning formulas are the best way to *provide* aged care. Another option would be to provide aged care as an entitlement to all individuals who are assessed as needing aged care, much as hospital care is provided for those that require it.

Alzheimer's Australia commissioned from Access Economics the report ***Aged Care Places and Planning: 2010 and Beyond*** that presents an analysis of different scenarios for the supply of aged care places. This report has been provided to the Productivity Commission. The report concludes that an approach is needed that better reflects the requirements of those with the highest care needs including those with dementia. It proposes an alternative approach to planning the growth of aged care places on the basis of the growth rate of the population aged 85 years and over or the growth rate of dementia prevalence. Alzheimer's Australia agrees with that view.

Ad-hoc adjustments to the planning formula are not a solution as it is important to plan for the resources required to adequately fund aged care in the future. On current policy, community care packages and residential care places would need to grow by 436% by 2050 at a cost of \$60 billion. If care packages and residential care places were to grow in line with the growth of the number of people with dementia, the increase would need to be 618% growth at a cost of \$80 billion.^{xix}

Individuals with dementia and their family carers who live in rural and regional areas face particular challenges in accessing appropriate care. In 2009, some 97,000 (39%) of people with dementia lived outside the capital cities. There are around 520 new cases of dementia in these areas every week. Prevalence outside the capital cities will grow to 241,000 in 2030 and nearly 450,000 in 2050. The number of new cases per year will grow to 76,000 in 2030 and 153,000 in 2050.^{xx} There needs to be an increase in aged care infrastructure and services in order to address the increase in dementia prevalence in regional and remote areas in the next 40 years.

Recommendations

1. The allocation formula for aged care places must take into account the increase in older segments of the population as well as growing prevalence of dementia.
2. Increases in aged care infrastructure in regional and remote areas in order to ensure adequate care in these areas

2.2 Resourcing

The question is how to adequately resource the expected increase in demand for aged care over the next 30 years while ensuring quality of care, sustainability, and equity in access.

There is concern that the current levels of aged care subsidies do not cover the true cost of providing high quality care and are not appropriately indexed to rise with the true increase in cost of care. Current indexation based on the Commonwealth Own Purpose Outlays does not reflect true increases in aged care prices. Inadequate subsidies result in problems with recruiting and maintaining staff, as well as encouraging investment in aged care infrastructure. A recent Access Economics report has shown that current subsidies for accommodation are insufficient and discourage investment in residential care.^{xxi} There is a need for an independent review into the current level of subsidy, and also a periodic review to assess that subsidies have been properly indexed to increasing costs. This review should be done by an independent body, such as the new independent hospital pricing authority which has been established under the New National Health and Hospitals Network COAG agreement.

In addition to addressing the current adequacy of funding for aged care, the Government needs to consider how it will finance the expected growth in age care. In particular, the Government will have to reconsider how the costs of aged care are

shared between public and private resources. Currently, aged care in Australia is mostly publicly funded through subsidies or contributions financed indirectly from aged pension payments. In future, it may be necessary to increase the contributions of users who are able to pay. More older adults may have more capacity to pay than in the past due to increased retirement savings and wealth. There may also be an increase in demand for differentiated aged care which will also call into question the current funding model.

The report ***Aged Care Places and Planning: 2010 and Beyond*** has a discussion of a number of alternate funding models including long term care insurance and health and ageing savings accounts. More details of these options are in the report which has been provided to the Commission. The report concludes that a combination of a variety of private and public funding mechanisms will likely lead to increased efficiency and sustainability while maintaining equity.

Recommendations

- 3. Aged care subsidies need to be independently reviewed at intervals in order to ensure that they provide sufficient funding to support high quality care and are appropriately indexed to cover rising costs in the future.
- 4. A longer term review is necessary into funding for aged care to develop a model of mixed public and private funding that ensures sustainability as well as equity in access.

2.3 Staffing

With increasing numbers of individuals choosing to stay in the community as they age, there has been an increase in proportion of individuals in residential aged care who require high levels of care. Between 1998 and 2008, the proportion of permanent aged-care residents classified as high care rose from 58% to 70%. Despite an increase in high care patients and operational places, the number of registered and enrolled nurses working in aged care facilities has decreased significantly over the same period of time^{xxii}. This suggests that not only have nursing ratios not been increased to accommodate for an increase in patients with high needs, there are in fact fewer qualified nurses to care for increasing numbers of patients and a large proportion with high needs. This decrease in registered nurses has happened in the context of up-skilling of certificate 3 and 4 nursing staff. Although we commend the trend for increased training for staff in residential care, patients with high care needs require specialised care. It is important that there are enough registered nurses to provide the high level of care that is required.

Recommendation

- 5. The review of age care subsidies should be supported by regular monitoring of the care staffing profile in residential aged care

2.4 Increasing Consumer Choice/Flexibility

The quality of residential and community aged care is likely to be highest if it is driven by a person-centred care approach that incorporates a partnership between the person requiring care, service providers and the family carer.^{xxiii} This includes providing a flexible system that is responsive to changing needs and preferences. Alzheimer's Australia has advocated that this could be achieved through adopting the consumer directed care model so that it is the consumer, if they wish, who determines the services needed and how, when and where they will be provided.

The 1,200 trial CDC packages funded as part of the recent COAG agreements on the National Health and Hospital Network (NHHN) are a welcome first step towards providing real consumer choice in community care and shaping the underlying philosophy and model of care to services in the Australian environment (COAG, 2010). This program needs to be expanded to allow for wider access to consumer directed care.

In order to further support consumer choice the Commonwealth should base aged care planning on the amount of care required rather than on a set number of community care packages or residential care places. The Productivity Commission (2008) noted that the accommodation and living expense components of the residential care subsidy should be covered through the welfare system. The aged care system could then focus on subsidising the nursing and personal care component. In doing so the government could plan for the amount of care it expects would be required, and allow consumers to choose a flexible mix of care provided in the community and in a residential facility.

Although consumer directed care has not been systematically evaluated in Australia, overseas evidence suggests that the more responsive and flexible service responses that are made possible in consumer directed care models may benefit people from diverse backgrounds, who can then make better use of their own networks and ensure cultural appropriateness in the delivery of services.^{xxiv}

Recommendations
<ol style="list-style-type: none">6. Adopt consumer directed care in aged care services.7. Separation of care and accommodation funding so that individuals have the choice to mix different care and accommodation options

2.5 Community Care

Research indicates that 60% of people with dementia live in the community, of whom 37% receive no formal care.^{xxv} Family carers are a critical component of the dementia care 'workforce', providing the larger part of the care and support required for people with dementia. In the absence of family carers the Government would face a crisis in both finding and funding the necessary workers to care for people with dementia in the community. For many family carers the demanding task of providing

dementia care will only be sustainable with the support of community care services that respond to their needs and those of the person with dementia.

Although the cornerstone of Commonwealth policy is to enable older people to remain at home for as long as possible it is funding of residential care that continues to dominate. The consequence is that there are low numbers of EACH and EACH (D) packages available to support carers and as a consequence increase the likelihood of premature entry to residential care for some. In order to support informal carers the Commonwealth must adequately plan the number of community care places required in the future. Currently, like residential care, this planning is based on the expected number of people over the age of 70 and does not take into account the higher needs at older ages or current levels of unmet need.

According to the *Aged Care Places and Planning: 2010 and Beyond* report in order to meet demand expected due to growth in dementia prevalence there will need to be an additional capacity for 987,520 HACC clients, 45,157 CACPs, 5,591 EACH packages and 3,010 EACH-D packages by 2050 compared to current planning ratios. These estimates are based on the current split of services, which are unlikely to reflect choices older people would be make if free to do so.

There is also a need for greater continuity of aged care and flexibility in services. Carers often find themselves having difficulty transitioning between different types of care packages, and levels and forms of care and support. Difficulties can include the gap between CACP and EACH packages, withdrawal of service due to increasing care demands, lack of information about options and costs of higher level care, inflexibility of service provider policies and practices, and inadequate inter-agency and provider communication. Transitions may require extensive re-assessment of the consumer, have an impact on legal issues (e.g: Powers of Attorney) or mean that part-time employment for the carer cannot be sustained, creating additional financial stress. There is an opportunity to address this inflexibility and other issues through a national approach to funding.

Recommendations

- 8. Increased funding for community care services to enable individuals to stay in the community for longer
- 9. Graduated care packages to fill gap between CACP and EACH packages with behavioural supplements to recognise the extra costs associated with dementia.

2.6 Respite Care

Respite care is a crucial component of support for carers and can enable individuals with dementia to continue to live at home for as long as possible. Unfortunately, many family carers of individuals with dementia have difficulty accessing respite services that meet their needs. According to the ABS Survey of Disability, Ageing

and Carers in 2003, there were 10,000 individuals caring for someone with dementia who had an unmet need for respite care, compared to just 15,000 who had accessed respite. This means that for every three carers who have used respite, there are two dementia carers who need respite but have not used it. The differences between need for and use of respite on the part of dementia carers and all carers are striking. Dementia carers are:

- About half as likely to say that they had no need and had not used respite;
- 50% more likely than other carers to need and have used respite; and
- More than 10 times more likely than other carers to say they need respite but had not used it.^{xxvi}

In 2009 Alzheimer’s Australia released a publication, *Dementia and Respite Care: “More than just a short break”* which identifies a number of barriers to accessing respite and recommends major changes in the provision of respite care.

One of the main barriers to accessing respite services is a lack of flexibility and choice. This includes flexibility in when the respite is available, where the respite is provided, and what types of activities are included in the respite care. One means of promoting flexibility is by providing consumer directed care. Carers could be provided with a respite budget which they could use to purchase respite services that met their needs. The recent announcement of 200 consumer directed respite care packages is a first step towards providing consumers with greater flexibility and choice. This program needs to be expanded to allow for wider access to consumer directed respite care.

A reason advanced by carers for not utilising respite is a concern about the quality of care that will be provided to the person with dementia. Carers not only want a break from providing care but also want services that meet the needs of the person with dementia, including age and culturally appropriate social and community engagement. Activities provided in respite need to be appropriate for the varying needs of individuals with dementia. This requires staff that have been provided with dementia specific training, mentoring, and monitoring of care practices.

There is also a need for specialised dementia respite care. Family carers often report to AA that once the person with dementia develops any behavioural symptoms of dementia or becomes incontinent, they are no longer able to access much needed respite services. Service providers argue that there is not enough staff to adequately respond to the specialized needs of individuals with dementia. It is clear, therefore, that there is a need for specialist dementia respite care services that respond flexibly to the needs of both people with dementia and their family carers at any stage of the dementia journey.

Recommendations

- 10. Expansion of Consumer Directed Care respite places to ensure the flexibility needed to meet the individual circumstances of the individual with dementia and the family carer.

11. Prioritising dementia care places in the provision of services through the National Respite for Carers Program

SECTION 3 QUALITY DEMENTIA CARE

As there is currently no cure for dementia, it is important to focus on providing quality dementia care in order to support a high quality of life for individuals with dementia. The Dementia Initiative has helped to promote quality dementia care through increased and sustained resources for training, access to advice for family carers and residential care providers through the Dementia Behaviour Management Advisory Services, the Dementia Training Study Centres at the tertiary level and the funding for dementia care research through the three Dementia Collaborative Research Centres.

There is, however, still much work that needs to be done. A number of areas of dementia care need to be addressed including adequate support for individuals with behavioural symptoms of dementia and their carers, adequate funding for community-based dementia care services, training for aged care staff, and providing services to special groups with dementia.

3.1 Improve the Quality of Dementia Care

There are a number of direct actions that can be taken to improve the quality of dementia care. These include increasing funding for knowledge translation, and increasing the support for individuals who experience Behavioural and Psychological Symptoms of Dementia (BPSD).

Dementia care will be of the highest quality when it is informed by research into best practice. Unfortunately, the uptake of evidence at the level of medical and biomedical research generally is inadequately carried through in medical practice, care and policy.^{xxvii} Some research suggests that it can take up to 17 years for basic medical research to be put in to practice. Alzheimer's Australia has established the Quality Dementia Care Initiative that aims to improve the quality of dementia care through addressing the gaps between what is known from research about best practice dementia care, and what is currently done. This is to be achieved through better collaboration between dementia care researchers, consumers and service providers, as well as funding innovative projects that address these evidence practice gaps. This initiative is funded by the Wicking trust and BUPA. The Commonwealth should provide support for activities which promote the uptake of research to improve the quality of dementia care in Australia.

Most individuals with dementia experience BPSD at sometime to some degree. These symptoms require additional services and support for the individuals and their family. Caring for individuals with these symptoms requires a higher level of care and is more costly. As a result, individuals with BPSD maybe refused respite care, or excluded from some residential care facilities. To address this issue there should be a behavioural supplement across all aged care packages to provide extra support for

the extra care required. Similarly, there should be specific aged care places for individuals with behavioural and psychological symptoms of dementia.

Service providers providing care for individuals with dementia need extra support and training. The Dementia Behavioural Management Advisory service provides much needed clinical advice to community and residential service providers on the management of the behavioural and psychological symptoms of dementia. This service should be expanded in order to encourage non-pharmacological management of these symptoms.

Recommendations

- 12. Funding for activities that bridge the evidence-practice gap in dementia care that results in research evidence being translated into better practice through the Alzheimer’s Australia Quality Dementia Care Initiative.
- 13. Behavioural supplement across all aged care packages to recognise the extra cost and care involved in supporting individuals with behavioural and psychological symptoms of dementia.
- 14. Allocation of dementia specific care places that provide accommodation and care for those with behavioural and psychological symptoms of dementia.
- 15. Expansion of the Dementia Behavioural Management Advisory Service

3.2 A Dementia Focus in Aged Care Standards and Accreditation

The current accreditation process protects consumers against under-performing residential aged care services. The process does not assess the outcomes of care or provide adequate information about the quality of care in the facility, beyond its meeting of minimum standards. It should do so both in respect of clinical and social quality indicators. The quality of dementia care in residential facilities needs to be assessed and reported.

A dementia focus in the review of Aged Care Standards, accreditation processes and development of quality indicators could be utilised by consumers to make improved choices about what facilities provide the best dementia care and could also be used to focus on improving the quality of care in facilities that fall short. Currently consumers have no way of knowing what they should expect of ‘dementia units’ or ‘special units’.

There also needs to be greater involvement of consumers in the accreditation process. An ongoing problem is that many consumers avoid raising concerns due to fear of potential retribution. Consumers should be provided with the opportunity to give confidential input throughout the assessment process. The outcomes of the accreditation process should be provided to consumers in an accessible form which can inform their decisions about care.

Recommendations:

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| <p>16. A dementia focus in the review of Aged Care Standards, accreditation processes and development of quality indicators in order to provide consumers with more information about the quality of dementia care of individual providers</p> <p>17. Increase in consumer consultation throughout the accreditation process including providing consumers with accessible information about the accreditation findings.</p> |
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3.3 Support an Integrated Suite of Community Based Dementia Care Services

The National Dementia Support Program plays a unique role in providing support to people with dementia and their family carers through the provision of world class information resources, skilled dementia counselling, support groups, education and training for both carers and care workers, early intervention strategies such as Living With Memory Loss programs, and both centre-based and outreach support programs. This National Dementia Support Program also provides an essential, widely accessible entry point to services and support through the National Dementia Helpline, which is operated by Alzheimer's Australia in each State and Territory. As the number of individuals with dementia increases over the next 40 years to nearly a million, there will be a comparable increase in demand for dementia services. It is crucial that funding for the National Dementia Support Program is increased in line with this increase in demand.

Evaluations of the National Dementia Support Program (and its predecessor programs) have shown it to be cost effective in the provision of helpline and counselling assistance.^{xxviii} The program has also been assessed as being effective in the provision of carer education by assisting carers, for example, to better use respite care and at an earlier stage.^{xxix} It was also found to be effective in reducing stress for both the person with dementia and their carer by providing structured information and support through the Living with Memory Loss program.^{xxx}

Significant investment has been made by the Commonwealth Government in the National Dementia Support Program in recent years. The program is well established and supported by consumers.^{xxxi} The Program has contributed to innovations such as the development of nationally accredited training competencies and mobile respite services. By enhancing the capacity of the National Dementia Support Program, this existing successful program could be used to promote innovative community based dementia care projects.

Recommendations

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| <p>18. Funding for the National Dementia Support program should be linked to the growth in the numbers of people with dementia</p> <p>19. Enhance the capacity of National Dementia Support Program to promote innovative community based dementia care projects</p> |
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3.4 Training for Aged Care Professionals

An important emphasis of the Dementia Initiative to date has been on workforce training, including through the National Dementia Support Program, Dementia Care Essentials and the Dementia Training Study Centres. Alzheimer’s Australia strongly supports the continuation of this core activity, but also recognises the need to ‘raise the bar’ for Australia’s care workforce through access to higher-order professional development and training. Training is particularly important for Aged Care Assessment Teams who have a unique role in directing individuals into care packages and providing referrals to appropriate services. In addition, Alzheimer’s Australia proposes that funding for workforce training should be increased to:

- Provide ongoing “base level” Dementia Care Essentials training to maintain an acceptable level of care workforce skills, after reviewing for consistency, quality and minimum standards against new unit requirements.
- Extend Dementia Care Essentials training access to people who require refresher courses to provide regular reinforcement.
- Support sustainable ‘special needs’ dementia education and information programs in Indigenous and CALD communities.
- Implement programs to trial and evaluate the delivery of existing multimedia resources for dementia education through e-learning technologies, including online, video and teleconferencing approaches.
- Deliver Certificate IV and Diploma in Dementia Practice to promote access to higher order professional development and training, providing a sustainable career pathway for dementia specialists.
- Promote training to complement the Certificate IV and Diploma in areas of practice that are critical to the quality of life of people with dementia

Recommendations

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| <p>20. Dementia specific training for all members of Aged Care Assessment Teams to ensure that individuals assessed for residential care are provided with the most appropriate care options</p> <p>21. Additional funding for dementia specific workforce training to expand on training that is currently supported by the Dementia Initiative.</p> |
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3.5 End of Life Care

There is evidence to suggest that many people with dementia experience poor quality care at the end of their lives. Issues can include inadequate pain management, inappropriate hospitalisation or medical intervention, and a lack of timely and appropriate consultation (with the person with dementia or their family carers) over their choices regarding end of life care.^{xxxii} Furthermore, there is often a lack of appropriate emotional and informational support provided to family and family carers during end-stage dementia.

Timely advance care planning and high quality palliative care are the preferred methods for ensuring quality end-of-life care for people with dementia. Individuals in

the early stages of dementia should be supported and encouraged to participate in advance care planning to express their views about medical treatment and their preferences about end of life treatment. Each State and Territory has a different approach to documenting wishes in relation to future health care. Families need to be provided with sufficient information after an individual receives a diagnosis of dementia in order to take appropriate steps in advanced care planning.

Many individuals with dementia and their families want palliative care which focuses on relieving the symptoms experienced by the individual rather than trying to cure a condition or delay the progression of terminal disease, and provides emotional, informational and practical support to family and family carers. Research suggests that often individuals with dementia are unable to access desired palliative care^{xxxiii}.

Recommendations

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| <ul style="list-style-type: none">22. Improve access to information and support for advance care planning for people with dementia and their carers.23. Improved access to palliative care and pain management in aged care |
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3.6 Special Populations

Individuals from regional and remote areas, culturally and linguistically diverse backgrounds, individuals who are gay and lesbian and individuals who experience younger onset dementia face special challenges when confronting dementia. These groups make up a significant number of individuals who are facing dementia in Australia. In 2009, some 97,000 (39%) of people with dementia live outside the capital cities, approximately 35,000 (14%) of people with dementia do not speak English at home, and approximately 15,000 (6%) have been diagnosed with younger onset dementia.

Many of these groups have difficulty accessing services for a variety of reasons. For example, culturally and linguistically diverse and Indigenous population groups often have lower levels of awareness of dementia which results in later diagnosis and less access to support services. In part this lack of awareness is a result of differing health beliefs and perceptions about dementia but may also be attributable to the inequitable distribution of existing funding for dementia services. It is important to consider how to increase service delivery to these groups in a culturally sensitive and linguistically appropriate way. Individuals from rural and remote communities also have difficulty accessing services, and often pay high fees for community care workers to travel to their home. Many also find it difficult to access convenient respite care.

Individuals with Younger Onset Dementia face a separate set of issues. In 2008, COAG agreed that responsibility for this group should be included under the new

National Disability Agreement. As such, issues around providing care for Younger Onset Dementia must be addressed in both this Inquiry and also the Productivity Commission Inquiry into Disability Care and Support.

Alzheimer’s Australia has raised questions with the Minister for Ageing and the Parliamentary Secretary for Disabilities and Children’s Services that need to be addressed, including:

- How is the disability sector going to gain an understanding of the care and support needs of people living with dementia?
- What resources are available to develop services appropriate for people with younger onset dementia?
- What requirement is there on jurisdictions to include younger people with dementia within the current initiatives? (Alzheimer’s Australia, 2010).

There is a significant risk of younger people with dementia being shifted between disability and aged care services. When disability services are no longer able to meet a younger person’s needs due to the progression of dementia, the person and their family carers are required to navigate a second unfamiliar system. The progression of dementia in younger people can be quite rapid. The challenge is to develop a smooth and seamless service. One option might be to remove age limits for access to aged care services for those with dementia, and to ensure the services received are appropriate. For those with a disability ongoing support from their existing service to avoid disruption might be the preferable course with those services drawing on the dementia expertise of the aged care service providers as appropriate.

Recommendations

- 24. A specific funding allocation for promotion of access to dementia services by special populations that experience difficulty in aged care programs
- 25. Providing care for Younger Onset Dementia within the aged care system for individuals who have not previously received support from disability services
- 26. For individuals with a disability who develop younger onset dementia, providing care within the disability framework to avoid disruption in services

SECTION 4 HEALTH CARE

Achieving better health outcomes for individuals with dementia is key to reducing the burden on the aged care system. The first step in addressing the health care needs of individuals with dementia is to provide an accurate and timely diagnosis. Unfortunately there is much evidence to suggest that GP's have difficulty diagnosing dementia and may be reluctant to provide the diagnosis. It is also important that dementia is appropriately addressed in acute care. In many cases, individuals in acute care are not identified as having dementia and therefore do not receive appropriate care which may lead to an extended length of stay and a preventable admission to a residential facility.

4.1 Diagnosis

Research commissioned by Alzheimer's Australia indicates that over 90%^{xxxiv} of all Australians say they would be likely to visit their GP if concerned about their memory. At the same time, there is evidence that many GPs have difficulty in identifying and/or addressing dementia through appropriate referral to specialists and support services. Currently only about one-third of people with dementia receive a formal diagnosis at any time in their illness.^{xxxv}

Early diagnosis is key to providing individuals with dementia and their family appropriate support. The gap between first symptoms and diagnosis ranges between 10 and 32 months.^{xxxvi} Reducing this gap will:

- Provide the opportunity for people with dementia and their families and carers to make informed plans, including for their financial, legal and future care arrangements.
- Remove the uncertainty and trauma that comes with delays in the accurate diagnosis of dementia, particularly those with younger onset dementia.
- Assist with the targeting of support to those who need assistance within the health care system or are at risk of health complications.
- Allow carers to access support that can reduce their health risks and the associated costs for individuals and governments.

People with dementia and their families and carers are seriously concerned about the inability of the current primary care system to accurately diagnose/identify dementia in a timely way and to provide support and referral.

Recommendation

27. As part of the Commonwealth Government's Primary Care reforms implement an dementia incentive, education and training package, including case detection, for primary care professionals across Australia to achieve timely detection and diagnosis in general practice
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4.2 Acute Care

In Australian hospitals, up to 50 percent of all patients admitted have some degree of cognitive impairment. Acute care, however, remains a dangerous setting for people with dementia – and potentially more so for people whose dementia has not yet been formally diagnosed. It is difficult to provide adequate and effective care to treat other diseases when an individual has unrecognized cognitive impairment. Even if diagnosed, the diagnosis and its implications may not be set out clearly in their hospital notes and staff may be unaware or unwilling to provide the additional attention required.

Delirium and dementia are associated with an increased length of stay in hospital, increased morbidity and poor prognosis. Cognitive impairment is also the most commonly identified factor in patients who fall while in hospital.^{xxxvii} The effect of a hospital stay is very often detrimental to a person with dementia and its impact is felt well after discharge. Given the risks associated with acute care it is important to minimize unnecessary hospital admissions for people with dementia including through encouraging advance care planning, making services available outside emergency departments and up-skilling staff in residential care.

Better outcomes for people with dementia in acute care, as well as less burden on hospital staff, can be achieved through cognitive assessment, awareness of cognitive impairment, and appropriate staff training. Individuals over the age of 70 should be screened for cognitive impairment upon admission to hospital. Individuals who are assessed as having a cognitive impairment should be recognized as such by staff throughout their stay so that they are provided with appropriate specialized care. This could be accomplished through the use of the symbol for cognitive impairment which is an approach recommended by people living with dementia. In addition to the use of the symbol, there needs to be increased training of both clinical and ancillary staff in dementia care.

Recommendations

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| <ol style="list-style-type: none">28. Cognitive assessment of individuals aged 70+ entering acute care29. Funding for Acute Care staff dementia training and dementia coordinators30. Introduction of the Cognitive Impairment Symbol in hospitals |
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SECTION 5 PREVENTION

The benefits of even a short delay in the onset of dementia will be substantial. It has been estimated that if the onset of Alzheimer's disease (50-70 per cent of all cases of dementia) could be delayed by five years, it would reduce the numbers of those with Alzheimer's disease by half (between 2000 and 2040) with significant savings to the health and care system.^{xxxviii} Further investment in research into the causes and prevention of dementia is key to reaching this goal. Increasing awareness of the current knowledge of potential risk factors of dementia through public health initiatives is also imperative.

5.1 Research

- Investment in dementia care research has increased in recent years, in part as a consequence of the Dementia Initiative. Nevertheless, dementia research in relation to health and care costs, disability burden and prevalence is underfunded in relation to other major chronic diseases. Based on average annual Australian research funding over 2002–2007, it has been estimated (2008)^{xxxix} that in comparison to other major diseases annual expenditure on dementia research was:
 - 50% of research funding for cancer relative to current disease burden.
 - 30% of research funding for cardio-vascular disease, relative to current direct cost of care.
 - 20% of research funding for cancer and diabetes, relative to current direct cost of care.
 - 5% of current research funding for cancer, relative to predicted direct cost of care in 2023.

The average annual research funding for chronic diseases in Australia between 2002-2007 was cancer at \$130 million, cardiovascular at \$90 million, diabetes at \$40 million. Dementia only received \$12.8 million^{xl}

Recommendations

31. An increase in funding for Dementia Research into the cause and prevention of dementia with the objective of establishing a research funding target of 1% of the care costs of dementia.
32. Expand the funding for dementia care research through the Dementia Collaborative Research centres and Dementia Grants

5.2 Public Health Initiatives

There is now good evidence to support the view that lifestyle changes may reduce the risk of dementia for some people. The evidence base is being further developed by the Dementia Collaborative Research Centre on Prevention, in which Alzheimer's Australia Vic is a partner.

Market research commissioned by Alzheimer’s Australia demonstrates that 50% of Australians are unaware that they may be able to reduce their risk of dementia. Among those who are aware that it is possible to reduce the risk of dementia, there is limited understanding of the full range of potentially positive changes in health habits. For example, even after prompting, around 40 percent did not agree that reducing blood pressure or high cholesterol would help.^{xii}

Alzheimer’s Australia has developed and successfully implemented the first stage of the **Mind Your Mind**® public education program which provides information on ways to reduce risk for dementia. This public education program needs to be extended to culturally and linguistically diverse and Indigenous populations, as well as to a broader geographic audience across Australia. The program aims to increase awareness of dementia risk reduction and an investment in this approach may contribute to reducing the numbers of those with dementia.

Information about the effects of a healthy lifestyle on brain health should also be included in existing government public health campaigns that address behaviours and diseases that are linked to dementia such as cardiovascular disease, diabetes, obesity and smoking.

Recommendations
33. Support for national rollout of Mind Your Mind ® public health dementia risk reduction program of Alzheimer’s Australia
34. Inclusion of dementia in Commonwealth preventative health campaigns for diseases linked to dementia e.g. cardiovascular, stroke, diabetes, obesity, smoking, alcohol

SECTION 6 DEMENTIA INITIATIVE

The decision in the 2005 Budget to make dementia a National Health Priority was a landmark decision not just in Australia but worldwide. Australia has led the way in acknowledging the economic and social impact of dementia and the need to plan for the epidemic. Other countries have since developed national strategies, following Australia's lead.^{xlii xliii}

From a consumer perspective, the Dementia Initiative has achieved much of its promise and has shown positive returns on the investment made by the Australian Government. While some significant areas like awareness and primary care have not been comprehensively addressed, it has provided:

- An opportunity to improve access to specialist dementia services and demonstrate the potential of greater choice for consumers through access to Extended Aged Care at Home (Dementia) packages in the community.
- Increased community engagement through community grants and sector development grants and the awareness and community education activities made possible through improved funding for the National Dementia Support Program administered by Alzheimer's Australia.
- Much needed funding increases in dementia care research through the three Dementia Collaborative Research Centres and dementia research grants, which have increased research capacity, promoted collaboration, attracted young researchers into the field of dementia care and positioned dementia researchers to apply for National Health and Medical Research Council grants and other major grants.
- An opportunity to improve the quality of dementia care through the Dementia Behaviour Management Advisory Services.
- Greater opportunities for workforce education and training through Dementia Care Essentials and the Dementia Training Study Centres.
- Better access to support for people with dementia and their family carers through targeted resources and improved funding through the National Dementia Support Program.

The 2010 Budget continued existing levels of funding for the Dementia Initiative.

However, the Dementia Initiative falls short of the action necessary to fully face the dementia epidemic in key areas that include public awareness, diagnosis and early intervention, acute care, prevention and equitable access to services for all Australians. There is also a need to better coordinate the elements of the Dementia Initiative and in particular the work of the Dementia Collaborative Research Centres and the Dementia Training Study Centres.

It was disappointing that no additional funding was provided for the Initiative in the 2010 budget both to recognise the increase in numbers of people with dementia and gaps in the current programs. Many of the actions proposed in this submission could be addressed through increases in funding for the initiative including:

- Expansion of funding under the National Dementia Support Program to meet increasing demands and service innovation
- Expansion of services through the Dementia Behaviour Management Advisory Services.
- Public awareness of activities to promote a better understanding of dementia and risk reduction in the community.
- Knowledge translation activities.

Recommendation

35. Build on the platform established by the Dementia Initiative on the basis of the proposals in this submission – for example in respect of awareness, Dementia Behavioural Management Advisory Services, the National Dementia Support Program, research, knowledge translation activities to address the evidence practice gap.

CONCLUSION

A new vision is needed to build a world class aged care system. Alzheimer's Australia advocates for a system with greater consumer choice and flexibility, higher quality of care, and a focus on prevention. Dementia is one of the most common triggers for entry into aged care, and the majority of aged care residents have some form of cognitive impairment.

Endnote

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