

Senate Select Committee on Health
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Re: Submission to the Senate Select Committee on Health

Alzheimer's Australia welcomes the opportunity to provide a submission to the Select Committee on Health on health policy, administration and expenditure.

Alzheimer's Australia is the peak body providing support and advocacy for people with dementia and their families and carers in Australia. Dementia is the third leading cause of death in Australia, and will likely have an increasing impact on the health system due to the current demographic shift in the Australian population. The population aged 65 years and over is projected to increase from over 3 million currently to almost 5.8 million in 2031.¹ As a result of population ageing, we are also facing a rapid increase in the number of people who have dementia. Currently there are more than 320,000 Australians with dementia and this figure is expected to increase to almost 900,000 by 2050².

Changes to the health system may impact people with dementia in a number of different ways from the point of diagnosis to treatment and care until the end of life. Our concerns as they relate to the relevant terms of reference of this inquiry are below.

a) The impact of reduced Commonwealth funding for hospital and other health services provided by state and territory governments, in particular, the impact on elective surgery and emergency department waiting times, hospital bed numbers, other hospital related care and cost shifting

One in every four people with dementia require hospital services each year and up to 50% of all patients admitted to hospital have some degree of cognitive impairment. Yet people with dementia experience worse clinical outcomes including longer stays in hospital and higher mortality, as well as a higher likelihood for readmission compared to people without dementia at a high cost to the health care system³.

There is clearly a need to improve care for people with dementia in hospital and funding cuts create a risk that people with dementia will have even greater difficulty in accessing timely and appropriate care. With good care, the costs of dementia care in hospital may be the same but the outcomes for people with dementia would be improved leading to a more efficient use of health care spending.

Alzheimer's Australia believes there should be a coordinated national approach to improving dementia care in hospitals that focuses on:

- Better identification of cognitive impairment in hospitals
- Training for all staff including how to communicate with a person with dementia and how to respond to behavioural and psychological symptoms
- More extensive and systematic involvement of carers as partners in the health care of

¹ ABS (2013). 3222.0 Population Projections, Australia (2012) to 2101

² AIHW (2012). Dementia in Australia

³ Australian Commission on Safety and Quality in Health Care (2013) Evidence for the safety and quality issues associated with the care of patients with cognitive impairment in acute care settings: a rapid review.

- people with dementia
- Creation of appropriate physical hospital environments to reduce confusion and distress of people with dementia

b) The impact of additional costs on access to affordable healthcare and the sustainability of Medicare.

Alzheimer's Australia acknowledges the need to put in place measures to ensure the health system is sustainable into the future. The GP co-payment is a measure that needs to be carefully considered including the potential impact on people who have chronic diseases, including dementia. Access to timely and appropriate primary health care services is essential to the proper management and support of people with dementia, and the first step in accessing appropriate ongoing care and support. The financial impact of the co-payment on people with chronic diseases as well as the impact on seeking needed supports and access to assessment should be carefully considered.

Alzheimer's Australia recommends that the GP co-payment not apply to people within residential care as there are already significant issues around access to GP services within aged care. Access to GPs can be affected by GPs existing high workloads, time required to visit residential aged care facilities, and the high acuity level and complexity of treatment needed for residents with complex health needs⁴. This in turn can lead to an increased level of unnecessary admission or re-admission into acute care for residential care recipients. Evidence shows that the majority of residents would prefer to continue to receive care in the residential care facility where possible rather than be admitted to hospital, a choice which may be adversely impacted should the co-payment further restrict access to GPs in residential care.

c) The impact of reduced Commonwealth funding for health promotion, prevention and early intervention.

There is now evidence that approximately half of the cases of Alzheimer's disease worldwide are potentially attributed to risk factors such as diabetes, hypertension, obesity, smoking, depression, cognitive inactivity and physical inactivity. The evidence suggests that a healthy lifestyle can reduce the risk of developing dementia.⁵ There is compelling evidence that healthy, active and mentally stimulating lifestyles along with prevention or control of cardiovascular risk factors, are associated with better cognitive function and lower dementia risk.⁶

The Australian Government supported Alzheimer's Australia to develop the world's first publicly funded dementia risk reduction program (Your Brain Matters) that highlighted the links between body, brain and heart health and dementia. Prior to Your Brain Matters, survey findings showed that few people understood that cardiovascular health behaviours, like physical activity, healthy eating and non-smoking, could reduce dementia risk. The Government has also lead the way on other public health campaigns linked to prevention and early intervention, such as the tobacco plain packaging, that are vital to the impact of chronic disease on the health system into the future. Alzheimer's Australia believes

⁴ Effectiveness of Nurse Practitioners in residential aged care facilities. Best Practice: evidence-based information sheets for health professionals. Joanna Briggs Institute. 2010; 14(19):1-4

⁵ Barnes DE, Yaffe K. The projected effect of risk factor reduction on Alzheimer's disease prevalence. *Lancet Neurol*, 2011, 10(9):819-828

⁶ Farrow M, O'Connor E. Targeting brain, body and heart for cognitive health and dementia prevention. Alzheimer's Australia Paper 29. 2012, Alzheimer's Australia: Canberra

it is important to invest in targeted health promotion, prevention and early intervention strategies across all chronic diseases to ensure the public continue to be engaged and encouraged to think about the impact of lifestyle on their health and the interrelationships between chronic diseases, which in turn will reduce the impact of those diseases on the health system into the future.

d) The interaction between elements of the health system, including between aged care and health care.

Dementia has a major impact on all aspects of the Australian health and aged care system, with \$4.9 billion being the total direct health and aged care system expenditure on people with dementia in 2009-10. 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.

The impact of dementia on the health system was recognised in 2012 when dementia became a national health priority and the 2012 Aged Care Reforms announced \$41.5m over 5 years to support people with dementia across the health system and \$39.2m over 5 years to pilot new programs to improve dementia care in acute care. It is imperative that these initiatives are delivered on and appropriately targeted to lead to better care and support for people with dementia in both the primary and acute care settings.

In addition, the interaction of the health and aged care system for people with dementia is particularly problematic in relation to access to appropriate end of life care and the use of medications.

End of life care

People with dementia often have difficulty getting access to appropriate end of life care because dementia has characteristics that make it different from other terminal conditions and many health professionals do not consider dementia to be a terminal disease. Dementia has an unpredictable trajectory and there can be difficult issues around capacity, decision making and communication.

Lack of advance care planning or lack of knowledge about dementia can also lead to unnecessary hospital admissions at the end of life. Alzheimer's Australia believes that people with dementia should have access to appropriate, respectful end of life care in their home when needed and in the form needed, and that includes:

- A flexible model of care which enables healthcare workers to provide the right care at the right time to accommodate the changing needs of people with dementia as the disease progresses.
- Increased availability of palliative care services in the community and the expansion of training, knowledge and support in the community, and in areas such as aged care, acute care and primary care (particularly General Practitioners).
- Increased availability of information and support around planning end of life care during the early stages of dementia.
- Nationally consistent advance care planning legislation to reduce jurisdictional confusion and provide protection to health professionals and community members.
- Advance care plans linked to the Personally Controlled Electronic Health Record

Use of medications

About half of people in residential aged care facilities and up to 80% of those with dementia are receiving psychotropics. The clinical effectiveness of these medications in treating behavioural symptoms of dementia is modest at best with only approximately 1 in 5 people

who receive these medications having any clinical benefit. Psychotropics have a range of serious side effects and are associated with increased mortality for people with dementia.

Alzheimer's Australia has proposed a multifaceted approach to the use of medications for people with dementia through changes in both the health and aged care system, including:

- Training and education for aged care workers and ensuring appropriate skilled staff are provided care for people with complex needs.
- Targeted information for consumers around their legal rights with the health and aged care sector relating to consent and use of medications.
- Support to assist physicians and residential aged care facilities to ensure they are following clinical guidelines for prescribing and that the use of medications are time-limited and reviewed regularly with input from pharmacists, behaviour management experts, general practitioners and psychiatrists.

Dementia Supplement

Alzheimer's Australia welcomed the introduction of a dementia and severe behaviours supplement to try to address the higher care needs of individuals with behavioural and psychological symptoms of dementia and were disappointed by its termination in July 2014. It is critical that a new scheme is implemented as soon as possible to deliver the original objective of ensuring appropriate care for those with high care needs in residential care. Alzheimer's Australia supports the replacement scheme being linked to better care and support for people with severe BPSD, including monitoring the use of restraint and antipsychotic medications, as well as the capabilities of the residential aged care facility to provide dementia specific high care.

e) Improvements in the provision of health services, including Indigenous health;

The difficulties that people with dementia face in accessing the health system (appropriate assessment and diagnosis, dementia specific care in hospitals, access to specialist medical practitioners) are increased for both people with dementia in Aboriginal and Torres Strait Islander communities. We now know that the prevalence rates of dementia among both rural and urban Aboriginal and Torres Strait Islander people are three to four times higher than the mainstream population, yet the awareness and understanding of dementia among these people is low. Improvements in the provision of health services to these communities should include education programs about what dementia is and the risk factors for dementia and training for health workers in the administration of appropriate cognitive screening tools.

f) The better integration and coordination of Medicare services, including access to general practice, specialist medical practitioners, pharmaceuticals, optometry, diagnostic, dental and allied health services;

Early diagnosis of dementia, accurate assessment and access to appropriate interventions, care and support is a critical issue facing people living with dementia in Australia. It is an area with a multitude of problems that have been identified time and time again by consumers, researchers and health professionals alike that is exacerbated by a disjointed health system.

General Practice is the first point of contact for people with dementia, and the primary care system is responsible for the bulk of their ongoing medical management and care throughout the 5-15 years of the dementia journey. 94% of Australians indicate that they would see their General Practitioner if they were worried about their memory⁷, and appropriate assessment, referral and management of these individuals from the first point of contact is essential to

⁷ Market research conducted for Alzheimer's Australia by Newspoll. September, 2004.

achieve optimal health outcomes. However, many General Practitioner lack training and expertise in dementia which can lead to poor assessment and diagnosis.

There are clear benefits of early diagnosis and management of dementia, yet as many as two thirds of people with dementia live and die with the condition without ever being diagnosed⁸. Amongst the minority who do receive a diagnosis, the average time between first symptoms and diagnosis is 3.1 years⁹. As a consequence of non- and late-diagnosis, the majority of people with dementia and their families in Australia slip through the gaps and miss out on crucial opportunities for early intervention in the form of treatment, support, advance planning and understanding of their condition. Obtaining an early diagnosis of dementia is even more fraught for people with younger onset dementia; those from diverse cultural backgrounds and from Aboriginal and Torres Strait Islander communities¹⁰.

Health economics analyses also suggest savings to health and aged care budgets from early diagnosis and quality medical care¹¹.

Alzheimer's Australia would welcome the better integration and coordination of specialist medical practitioners if it lead to a reduction in the time between first noticing symptoms and diagnosis, access to specialised medical professionals such as psychogeriatricians, and increased access to medical specialists for people with dementia in residential care.

Thank you for the opportunity to provide a submission.

Sincerely,



Glenn Rees AM
CEO
Alzheimer's Australia
16 September 2014

8 Brodaty, H. (2005). Six reasons why diagnosis of dementia does not occur, and 10 reasons why it is important. Dementia Collaborative Research Centres. Available: www.dementia.unsw.edu.au

9 Speechly, C. (2008). The pathway to dementia diagnosis. *Medical Journal of Australia*, 189, 487-9

10 Storey, J., Rudas, J., Conforti, D., & Dickson, H. (2004). The Rowland Universal Dementia Assessment Scale (RUDAS): a multicultural cognitive assessment scale. *International Psychogeriatrics*, 16(1), 13-31.

11 World Alzheimer's Report. The Benefits of Early Diagnosis and Intervention. *Alzheimer's Disease International*, September, 2011.