

Executive Summary

In 2008, there will be 227,000 people with dementia, and by 2050 over 730,000. In 2002, the total direct and indirect cost of dementia was estimated by Access Economics at nearly \$6 billion. The direct cost to the health care system was projected to nearly double by 2010 from \$3.2 billion in 2002. By mid century, dementia costs (direct and indirect) may exceed 3% of GDP, up from nearly 1% today.

Alzheimer's Australia welcomes the commitment of the Government to respond to the dementia epidemic by continuing funding to make dementia a National health Priority.

The then Shadow Minister for Health, Nicola Roxon MP, issued a press release on 18 September 2007 committing a future Rudd Government to providing ongoing support for the Dementia Initiative¹ beyond 2009. It indicated that this funding would include support for the "three University based Dementia Collaborative Research Centres, prevention and early intervention programs, improved care initiatives, and training for the health workforce".

The proposals contained in this submission are:

1. **The Dementia in Primary Care Project (Attachment A).** This project was commissioned by the Department of Health and Ageing as part of the Dementia Initiative. A report on the first stage was completed in June 2007.

Alzheimer's Australia proposes that action to implement the recommendations of the report should be taken as soon as possible as part of Labor's commitment to strengthen primary health services and to better care for those with chronic diseases. Improved diagnosis and management of dementia by GPs is perhaps the most sensitive and longstanding issue for consumers. Delays in diagnosis, insensitive communication of the diagnosis and failure to refer to specialist and support services are some of the issues. GPs need support in achieving the best management of dementia.

2. **Preventative Health Care and Dementia (Attachment B).** There is now good evidence to support the potential for reducing the risk of dementia through changes in lifestyle. On the basis of economic modelling it has been demonstrated that delaying the onset of dementia would result in very significant savings to the public health system.

Alzheimer's Australia welcomes the recognition in Nicola Roxon's press release of 18 September that "prevention of onset of dementia is a valuable goal. Extending the age of onset by five years will lessen the effect of dementia on our community and on the individuals affected". Alzheimer's Australia has developed **Mind your Mind**[®], a public education program designed to promote awareness of the lifestyle changes that may reduce the risk of dementia. It is

¹ The Helping Australians with dementia, and their carers - making dementia a National Health Priority initiative

proposed that the Australian Government should support the national roll out of **Mind your Mind**[®] (cost \$4million over 3 years).

3. **Community care (Attachment C)** is the cornerstone of the dementia care system, as it enables people with dementia to stay for as long as possible in their own homes. In recent years, the Home and Community Care Program (HACC) has been indexed at 6% real pa. This is welcome but it is not enough and an increase to 10% pa is proposed.

Alzheimer's Australia strongly supports the initiatives proposed by Labor in New Directions for Older Australians for improving the transition between hospital and care in the community and residential care. The concept is important as it is likely to benefit many older people with dementia assuming that the range of services necessary including rehabilitation are available to make transition back to residential care or the community possible. We strongly support implementation of the election commitment.

4. **Social Inclusion (Attachment D)** Three initiatives are proposed.

- (a) The 10,000 people under 65 years of age (sometimes as young as 35) who have **younger onset dementia** are particularly disadvantaged. Loss of employment, family difficulties and the physical, social and emotional issues that result from younger onset dementia make life very difficult for the individual with younger onset dementia and for their families and carers. There are no appropriate services for this group. It is proposed that \$10million should be provided over 3 years to develop services for people with younger onset dementia including appropriate day care and respite care and cluster accommodation in residential care facilities services through existing dementia care networks and services.
- (b) Alzheimer's Australia has a strong commitment to **special needs groups** including people from a culturally and linguistically diverse (CALD) background and Aboriginal and Torres Strait Islanders. Our approach is to promote awareness and access to services by establishing partnerships between Alzheimer's Australia and the organisations working with or representing the interests of special groups. \$700,000 is needed for the employment of staff by Alzheimer's Australia to extend, promote and support these partnerships.
- (c) **Advance planning** plays an important role in allowing people with dementia to plan for their future health care and financial needs against the time when they lose their capacity to make those decisions. The law not only has the potential of offering people with dementia the ability to make decisions about their future, but of protecting their financial, and medical choices. Unfortunately current legal provisions relating to enduring powers of attorney and advance care directives are complex and vary across the jurisdictions; terminologies are confusing and inconsistent and all too often the wishes of the person with dementia are not appropriately followed. Currently the opportunity of advance decision making is underutilised.

To ensure priority for this important work it is proposed that \$1 million should be allocated to set up a Government Task Force to develop and implement, in consultation with consumers, the recommendations on substitute decision making in the Report on “Older people and the law” of the House of the Representatives Standing Committee on Legal and Constitutional Affairs. The priorities are to:

- Develop an education campaign to inform the Australian community of the benefits, issues and processes involved with advance planning for their health, their money and their lives.
- Facilitate national consistency and mutual recognition in advance care planning legislation, including enduring powers of attorney, across the Australian jurisdictions so that the law and documentation are nationally consistent, user friendly and readily available.

Glenn Rees
National Executive Director

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