

## SPEECH NOTES

### THE SOCIAL AND ECONOMIC IMPACT OF DEMENTIA ON AN AGEING POPULATION

Thank you for the invitation to speak to the 6<sup>th</sup> Annual Australia's Ageing Population Summit.

Alzheimer's Australia takes the view that the social and economic impact of dementia will make it *the* major chronic health disease of the 21<sup>st</sup> century.

I emphasise chronic disease because dementia is a long-term condition for which there are presently few treatments and no cure. Like cancer, cardiovascular disease or diabetes, it is also a disease that affects a large number of older Australians.

Australia was the first country in 2005 to acknowledge the economic and social impact of dementia and to begin the process of planning for the epidemic. Through the Dementia Initiative, the government provided additional funding for high care community packages, expanded training opportunities, dementia care research and services through programs administered by Alzheimer's Australia.

Unfortunately, dementia is still not regarded as a chronic disease.

One of the challenges we face is that, dementia is still considered by many to be a natural part of ageing.

In fact the symptoms of dementia are caused by pathological changes in the brain that can affect people from their early 20s and most older people will never develop dementia. Like any other chronic disease, dementia must be tackled within a public health framework that addresses best practice management, timely diagnosis, risk reduction and research.

The main point I want to make is that we need to take the opportunity we have now to make a seismic shift in health policy that will enable us to combat dementia by treating it as we would any other chronic health disease.

I will make the case by providing evidence on the economic and social impacts of dementia. Then, I would like to address the challenges that dementia presents to the health and aged care systems, before touching briefly on the importance of dementia research. First, however, let me give a brief overview of dementia itself.

#### **Dementia**

Dementia is the term used to describe a large group of conditions that result in progressive decline in cognition. These include declining memory, reasoning, communications skills and the capacity to carry out activities of daily living.

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, diabetes, Parkinson's Disease, alcohol, HIV Aids, drug abuse and intellectual disabilities such as Down Syndrome.

At some stage of the illness, most individuals with dementia are likely to develop Behavioural and Psychological Symptoms of Dementia such as depression, psychosis, aggression and wandering. The extent of these symptoms will vary with the individual, but are likely to complicate care for the individual and 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 much better understanding of the changes that occur in the brain as dementia progresses.

### **Economic Impact**

Much of the work of Alzheimer's Australia over the past decade has been to document the economic impact of dementia through reports commissioned from Access Economics.

These reports tell us about the extent of the dementia epidemic:

- There are over 250,000 Australians with dementia and over 1300 new cases every week.
- By 2030 there will be over 560,000 people with dementia and by 2050 almost 1 million.
- Dementia is the third largest cause of death after heart disease and stroke.
- Dementia is already the single largest cause of disability in Australians aged 65 and over, and is responsible for one in every six years of disability burden for this group.

We also have estimates of the economic impact of dementia:

- The cost of dementia care was estimated at \$5.4 billion per annum in 2008.
- 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.
- By the 2060s, 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.
- The opportunity cost of lost productivity born by individuals, business and government was estimated at \$881 million in 2008.

These reports bring into context the size of the issues we are facing. There is every prospect that the figures have been understated because they have not taken into account the progression of dementia earlier in our lives. Specifically, the evidence suggests that dementia may develop decades before a diagnosis. The social and economic impact of improved diagnosis and screening in the future remains unclear.

The economic impact of the rapidly increasing number of Australians who need dementia services in the future can be seen in workforce projections. It has been

estimated, for example, that by 2029, Australia will need 150,000 more carers – 94,000 family carers and 54,000 formal carers - for people with dementia than in 2008. This is equivalent to a 76% increase in the workforce.

## **Social Impact**

Sadly, dementia is a social condition as well as a medical one. Dementia has a profound impact, not only on the life of the person with dementia, but on the lives of those around them: spouses, partners, families, and friends.

For those from CALD and Indigenous populations, the social consequences can be especially difficult.

To give you an idea of the extent of the social impact of dementia:

- 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.
- 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.
- The cost of replacing family carers with paid carers in 2008 was estimated at \$5.5 billion per annum.

Caring for a person with dementia is particularly challenging. The progressive degeneration of the person's cognitive capacity inevitably results in a reduced ability to communicate and to undertake daily activities. Dementia is also often associated with Behavioural and Psychological Symptoms of dementia that can be difficult to respond to.

As a consequence, there are often serious social and health impacts for family carers.

Social impacts may include a reduction in work hours or loss of employment, loss of relationships, time with friends and families and social activities, or the need to relocate or change living arrangements in order to provide care.

Health impacts include depression, anxiety, stress, physical problems and sleep disruption. Additional stresses can occur if the family carer is older and in failing health themselves.

For the person with dementia, diagnosis attracts stigma, social isolation and personal discrimination. Despite the fact dementia is now talked about much more openly in the media, there is little evidence in the anecdotes of people with dementia and their family carers that the social pressures have in decreased.

Let me now comment on the challenges that dementia presents to making the health and aged care systems more effective in their responses to the needs of people with dementia.

## Health System

From a consumer perspective, I can say without fear of contradiction, that there are grave concerns about the capacity of the primary and acute care systems to meet the needs of people with dementia.

Nor is there any sign of those at the bureaucratic or political level making a commitment to the reforms that are necessary to improve the availability and quality of healthcare care for people with dementia.

The problems with dementia in the healthcare system start at the level of primary care.

Research commissioned by Alzheimer's Australia indicates that over 90% of 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 identifying dementia and are unlikely to provide appropriate referral to specialists and support services.

Both in Australia and overseas, there is mounting evidence that many people with dementia receive no formal diagnosis at any time in their lives. For those who do get a diagnosis, the gap between first symptoms and diagnosis can range from 10 – 32 months.

The barriers to early diagnosis of dementia and diagnostic disclosure in primary care include:

- Stigma and negative attitudes to dementia care.
- Reluctance of some individuals to seek medical assistance.
- Difficulties in differentiating normal ageing from dementia.
- GPs lack of confidence and training and risk of misdiagnosis.
- The paucity of specialist diagnostic services, especially in rural areas.
- Limited time and lack of recognised time efficient screening tool.
- A perceived lack of need to determine a specific diagnosis.
- A perception that the patient cannot comprehend or cope with the diagnosis.
- Risk of damaging the doctor/patient relationship.

From a consumer perspective, a diagnosis of dementia can be both devastating, and immensely relieving.

In either case, it is very important that a diagnosis is made at a point in time where the person with dementia and their family carers can do something about it: getting legal and financial affairs in order, exploring options for medical and non-medical treatment of symptoms, putting in place arrangements for future care, or enjoying activities that may not be possible later in the course of the disease.

We have proposed that within the Government's commitment to reform primary care there should be a review that would:

- Assess the evidence base regarding timely diagnosis and ongoing management of dementia: and,
- Develop proposals for improving diagnosis and dementia management within primary care.

Acute care is also problematic, and remains a dangerous setting for people with dementia – even more so if dementia has not been formally diagnosed. In Australian hospitals up to 50% of all patients admitted may have some degree of cognitive impairment, yet very few are identified as such, or have care plans that differ from patients without cognitive impairment. As just one example of the extent of this problem, impaired mental status is the most commonly identified factor in patients who fall while in hospital.

Delirium and dementia are also associated with increased length of stay in hospital, decreased mobility and poor prognosis. The effect of the hospital stay is often very detrimental to a person with dementia and its impact is felt well after discharge.

In April, 2006, Australian Health Ministers endorsed the National Action Framework on Dementia 2006 – 2010. The purpose of this framework was to simplify and co-ordinate care and support systems for people with dementia. But there is not much evidence that it has resulted in systemic change in acute care.

In particular, there is evidence, guidelines and strategies are needed to:

- Minimise unnecessary hospital admissions for people with dementia.
- Promote an understanding of how to communicate with people with cognitive impairment and their carers.
- Improve hospital practice through better assessment of cognitive status and admission.
- Improve access to specialist dementia programs.
- Include dementia care standards in hospital and accreditation processes.

These strategies and guidelines have not been implemented systematically, and consequently, the outcomes specified in the Framework have not been achieved.

## **Aged Care**

Dementia is core business for the aged care system.

In residential aged care, most residents experience some degree of cognitive impairment, and as many as 60% may have dementia; diagnosed or otherwise. Dementia is also one of the most common triggers for entry into residential aged care.

The scale of the issue is no less significant in the community care setting. Some 60% of people with dementia live at home or with family members, and there is a growing recognition of the need to better resource community based services to enable people with dementia to have the choice of living at home longer.

In August this year, Alzheimer's Australia released a report commissioned from Access Economics entitled ***Caring Places*** that formed part of our submission to the Productivity Commission Inquiry into Care for Older Australians.

The report concludes that the system currently used for planning aged care places is in urgent need of revision because of the ageing population, changing preferences for community and residential care, and the increased demand for services associated with the growth in prevalence of dementia.

In writing this report, Access Economics modelled the shortfall in aged care places that could be expected if the current planning system – based on the projected number of individuals aged 70 and over – were to remain unchanged.

Looking just at the increased demand that could be expected from the projected growth in the population aged 85 and over, where the biggest demand for aged care services lies, the shortfall would be:

- 13,800 places in 2030;
- nearly 150,000 places by 2040; and
- over 275,000 in 2050.

To capture what this means in crude terms, the supply of community and residential aged care places will have to double from the annual average of 8,500 places a year over the last five years to 17,000 places per annum every year until 2050.

The economic challenge in aged care goes beyond the number of places to the mix of community and residential care older people might choose if they were allowed choice. Past and present policy has favoured residential care even though the policy objective is to enable older people to remain in their own homes for as long as possible.

The central question is what changes are needed in policy and services to achieve the balance of community care that might better respond to the choices older people might make to meet their needs to stay at home longer.

The issue of consumer sovereignty has become the key economic and social issue in aged care.

The Health and Hospital reform Commission adopted the theme of increased consumer choice in their final report, and the Productivity Commission have clearly indicated an intention to look at aged care from the perspective of the needs of older people in their Inquiry into the Care of Older People.

But in our highly regulated system Australia has limited experience of what choices older people might make to stay at home longer or what flexibility bureaucrats and service providers are prepared to allow them.

For 25 years in Australia the cornerstone of aged care policy has been the objective of enabling older people to stay at home longer. And the underpinning philosophy has been person centred care – to respond to the needs of the individual.

But the capacity of older people to make choices between different services and service providers will remain illusory unless:

- Firstly, there is a change in the balance of power between the consumer and the service provider, so the consumer is able, if they wish, to know what options and funding are available for them to take decisions on their care.
- Secondly, service providers have the flexibility within program structures and funding to respond to the expressed preferences of consumers.
- And finally, bureaucrats avoid imposing accountability and program guidelines to the extent that the concept of consumer choice is mangled and choice becomes a mirage.

There is at last discussion of consumer directed care and the separation of funding for accommodation and care. This promises to promote new models of care that might enable older people to access the mix of community and residential care that they both need and prefer.

In another 10 years we might have a better handle on the simple question - How much choice do consumers want to exercise and how much are service providers and bureaucrats prepared to allow?

## **Research**

Fear of cancer and heart disease translated in the last century to a huge community and Government investment in research to beat the problem. Fear of dementia has generated no such political or community response. The reasons for this are complex, but ageism and a sense of hopelessness in respect of dementia may account in large part for the lack of response.

The National Health and Medical Research Council currently spend about \$22 million on dementia research each year. In contrast, cancer attracts nearly \$160 million, cardiovascular disease around \$110 million and diabetes over \$60 million.

From any point of view, given the prevalence of dementia, the health and care costs, and the disability burden, research on dementia is grossly underfunded compared with all other major chronic diseases.

There is a need for increased parity and targeted funding to support basic research to:

- Better understand the causes of dementia.
- Develop medical interventions to delay its onset and progression.
- Build on the evidence base that shows the risk of dementia may be reduced through lifestyle changes;
- Identify those most at risk of developing dementia; and,
- Improve the quality of dementia care.

To illustrate the importance of this research, the benefits of even a short delay in the onset of dementia would be immeasurable. It has been estimated, for example, that if the onset of Alzheimer's disease could be delayed by 5 years, it would reduce the numbers of those with the disease by half.

Apart from the improved quality of life for hundreds of thousands of Australians and their families, this would result in significant savings to the health and care system.

And so I return to where I began, the importance of recognising dementia as a chronic health condition.

Clearly, the single most effective approach to managing any chronic diseases is prevention. However, dementia has yet to enter the lexicon of those responsible for health prevention programs. This is the case despite the evidence that dementia has direct links to cardio-vascular disease and diabetes.

In our most recent publication ***Towards a National Dementia Preventative Health Strategy*** Alzheimer's Australia has brought together the evidence for dementia risk reduction and advocated for

- The inclusion of dementia into existing health programs that combat heart disease, diabetes and obesity
- Urgent investment in research to find the cause of dementia and to delay the onset
- Funding to support the national rollout of the Alzheimer's Australia **Mind Your Mind**<sup>®</sup> program to promote awareness of dementia and risk reduction

In short the Australian Government must frame a public preventative health policy that recognises the link between lifestyle and the risk of developing chronic illness, including dementia. Australians should be informed that their lifestyle choices not only affect their physical health, but their brain health as well.

## **Conclusion**

The economic and social impact of dementia in an ageing population has been well documented.

The question is whether there is the political or community commitment to combat the dementia epidemic. In ***Dementia: Facing the Epidemic*** Alzheimer's Australia has set out a comprehensive plan to provide quality dementia care for all Australians and to reduce the prevalence of dementia in the future.

The scene has been set for change with the landmark decision in the 2005 Federal Budget to fund the Dementia Initiative - Making Dementia a National Health Priority with an additional \$320 million over 5 years.

This Initiative has received bipartisan support and although the funding was not increased in the 2010-11 Budget, it has been continued.

But no priority has been given in the Dementia Initiative to a communication strategy, primary care, acute care, dementia risk reduction or cutting edge dementia research.

To address the social and economic impacts of dementia, it will be necessary to ensure systemic change through health reforms, to recognise and address dementia as a chronic disease, to act on the report of the Productivity Commission Inquiry, and to continue to build on the positive outcomes already achieved through the Dementia Initiative.

Thank you.