

**Speech Notes for Dementia Conference
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Many thanks for the invitation to open this Congress.

It is a valuable opportunity early in the New Year to remind ourselves why dementia is the major chronic disease of the 21st century and the action that is required to improve the lives of the nearly 1 million Australians currently affected.

I should first like to set out some of the basic facts and demographics. Then I will address three questions. **SLIDE 2**

First, why is it despite the evidence of the dementia epidemic that dementia is not embraced as a major chronic disease alongside other chronic diseases?

Second, what are consumer priorities in addressing the dementia epidemic in the 2010 budget for the five years 2010-2014?

Third, what are the means of implementing those priorities?

THE DEMENTIA EPIDEMIC

As an organisation, Alzheimer's Australia has thought very carefully about whether the word 'epidemic' is appropriate. Some might consider it alarmist.

We have reached the view over the years that both the evidence and, the neglect of dementia as a serious chronic health disease in health policy, justify strong language.

As you are well aware, the shape of our population is set to dramatically change as baby boomers age. And that baby boomer bulge in the Australian population means that the coming decade will see an acceleration of the impacts of ageing on dementia prevalence greater than seen in Australian history. Indeed, by 2020 there will be 75,000 baby boomers with dementia.

The fact is that ageing is the greatest risk factor for dementia as this chart **SLIDE 3** clearly shows. The estimated dementia prevalence rates double approximately every five years from 65 onwards. And there is increasing evidence that the rates go on climbing inexorably into older age.

There can be no excuse now for policy makers, the community and the political level not being aware of the dimensions of the dementia epidemic. In summary they are: **SLIDE 4**

- The number of Australians with dementia will double to 592,000 by 2030 and nearly double again to over 1.1 million Australians by 2050.

- The number of new cases will reach 187,000 in 2030 and 385,000 in 2050.
- The ageing of the population and changing family structures will lead to a higher demand on community and residential care services.
- Australia will face a shortage of more than 150,000 paid and unpaid carers for those with dementia within a generation. **SLIDE 5**
- The current cost of dementia care is estimated at \$5.4 billion per annum.
- 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. **SLIDE 6**
- Dementia is already the single largest cause of disability in older Australians (aged 65 or older) and is responsible for one year in every six years of disability burden for this group.
- The cost of replacing all family carers with paid carers is estimated at \$5.5 billion per annum.
- Dementia is the fourth most common cause of death after heart disease, stroke and lung cancer.

The Dementia Initiative **SLIDE 7** announced in the 2005 Budget was a landmark decision for people living with dementia. Funding of \$320 million was provided to support the introduction of Extended Aged Care at Home (Dementia) packages, and to expand training initiatives, investment in dementia care research and funding for services through Alzheimer's Australia's National Dementia Support Program.

But we should keep in mind that the Dementia Initiative was a political decision. It was not born of an interest in addressing dementia by those concerned with public health policy in the Department of Health and Ageing. To the contrary, it seems that the last thing they wanted was another health priority.

Given the linkages between different chronic diseases, one can well understand the logic of not wanting more health priority areas. But if that is to be the logic, then the onus is on those same public health experts to address the serious implications of growing dementia prevalence and incidence within the approach to systemic reform of health system. And there is no evidence of that in the final report of the National Health and Hospital Reform Commission, the Report to support Australia's First National Primary Health Care Strategy or the Report of the Preventative Health Task Force.

The political, administrative and policy reality is that dementia has been regarded traditionally as an issue for aged care. The positive has been increased dementia support through aged care programs. In fact some 63% of people in residential care have at least one diagnosis of dementia, based on the first set of the Aged Care Funding Instrument figures.

The negative has been the failure to take action on dementia by those responsible for health policy particularly in primary care, acute care, risk reduction and research investment.

The release of the **2010 Intergenerational Report** has brought a welcome focus on health issues and the ageing of the population. Cognitive impairment and dementia should be front of mind in health policy because they contribute significantly to morbidity and health care costs in the last few years of life, make management of other conditions more difficult and reduce the quality of life of Australians.

The starting point for policy makers in acting on the IGR and the recommendations of the National Health and Hospital Commission should be an assessment of the impact of diseases on the Australian population to better inform health and research priorities.

IS DEMENTIA A CHRONIC HEALTH DISEASE?

The answer is a resounding yes by any academic or clinical definition. So let me repeat the first question. Why is it that in Australia despite the evidence of the dementia epidemic that dementia is not embraced as an important chronic disease alongside other chronic diseases like diabetes, cardiovascular disease and arthritis?

Without this kind of recognition, Australians are being short changed. They need, inter alia, awareness campaigns that show how the population risk of dementia might be reduced, timely and accurate diagnosis of memory and other cognitive concerns and investment in better policy, program and data development.

There are many possible explanations of why it has been so hard to get dementia on the national health agenda. **SLIDE 8**

Possibly there remains a misconception that dementia is a natural part of ageing. Yet we can be cautiously optimistic that impact of dementia, like any other chronic disease will be ameliorated and the onset of dementia will be delayed or prevented in time.

Could it be that ageism is alive and well? We know from market research that just over 1 in 2 Australians feel that people with dementia are unfairly treated or discriminated against because of their condition.

Possibly the lack of an effective medication to prevent or delay progression plays a part as many doctors like to be able to help their patients by curing their illnesses.

Possibly those responsible for health policy are unable to think beyond the major chronic diseases of the last century namely, cancer and heart disease. Research has identified treatment approaches which have supported the survival and ageing of the population which now underpins the growth of dementia within our older population.

Maybe a history of institutionalisation has blinded us to the fact that most people today with dementia live in the community and that life does not stop with a diagnosis of dementia?

You will have your own thoughts about why dementia is not on the mainstream health agenda. There is a long and potentially powerful list of factors that could be important drivers in shaping such negative political attitudes.

The issue is of immediate concern because the National and State and Territory Governments are about to embark on a program of ambitious reform in health and aged care.

SLIDE 9 Amazingly no priority is given in current health policy to reducing the prevalence and incidence of dementia.

This is the time to think about the ethics of a health care policy that does seek to reduce the number of new cases of dementia in the future. I suggest we not only have to communicate the facts of the dementia epidemic, as we have actively done over the last ten years, but to hammer home the necessity for a higher priority for dementia within health policy.

What Australians need is dementia risk reduction, timely diagnosis, less dangerous hospitals for people with dementia and increased investment in fundamental dementia research into cause and cure.

As part of that advocacy we need to seek an approach that not only provides support for people currently living with dementia, but has the objective of reducing the projected numbers of people with dementia.

While there are no studies proving that risk reduction prevents dementia there is strong evidence to support that risk reduction practices are important and are currently our only avenue for delaying onset and preventing the numbers of people with dementia growing.

There are many associations between dementia risk and lifestyle and health factors such as smoking, high blood pressure and physical activity. And while these programs still need more study the evidence of similar programs working in reducing heart disease and stroke points to potential success for dementia.

A greater effort is needed in raising awareness of risk reduction. If we are able to reduce the people with dementia by ten percent it will equate to over 100,000 fewer people with dementia in 2050. This would help lessen the economic pressures in the future from the health care industry.

The evidence points to the potential to prevent the growing numbers of people with dementia, but we can only do that with the appropriate resources for community education and the health system.

We need a policy approach that has these twin objectives. **SLIDE 10**

First, to provide quality dementia care for Australians from all cultures and of all ages, regardless of where they live

Second, to reduce the prevalence of dementia in the future.

PRIORITIES FOR 2010 – 2014.

So let me turn to my second question. What are consumer priorities in addressing the dementia epidemic in the 2010 budget for the five years 2010-2014?

Last year, Alzheimer's Australia released its Budget Submission *Dementia: facing the epidemic*. The submission reflects the four priorities identified by Alzheimer's Australia's consumer advisory network and sets out the action needed by the Australian Government to respond to this challenge. They are **SLIDE 11** to:

1. Increase public awareness of dementia.
2. Build infrastructure to reduce the prevalence and incidence of dementia and to achieve timely diagnosis.
3. Improve the quality of dementia care
4. Improve access to dementia services.

i) Increased Awareness and Reduced Stigma

SLIDE 12 The first proposal is a public information campaign.

In consulting with the Alzheimer's Australia National Consumer Advisory Committee and with the networks we have with those people from CALD and Indigenous communities we learnt that there is a strong belief that social inclusion and improvements in dementia care will only be achieved when the general population openly acknowledges dementia as a condition that does not need to be feared. They believe that greater community awareness has played a part in fostering more positive community attitudes to cancer and depression.

We need to adopt a positive approach to beating dementia as we have in respect of cancer and heart disease. We anticipate that in five to ten years time, it is possible that:

- Those population groups most at risk can be identified.
- There are medical interventions to delay the onset of dementia and slow the progression of dementia.
- There are more data to demonstrate that lifestyle choices including psychological well being and nutrition can delay the onset of dementia.

ii) Health Infrastructure

SLIDE 13 The second element of our proposal is for a greatly increased investment in health infrastructure to achieve three goals.

First, measures to reduce the prevalence and incidence of dementia through an increased investment in research into the cause and prevention of dementia.

The National Health and Medical Research Council currently spends about \$22 million on dementia research. Cancer attracts nearly \$160 million, cardiovascular disease around \$110 million and diabetes over \$60 million.

Sadly Australia is not alone in its neglect of dementia research. The UK report *Dementia 2010* earlier this month delivered a wake-up call for the UK and many other countries in the same situation. www.dementia2010.org/

The report found that in the UK “dementia costs twice as much as cancer, three times as much as heart disease and four times as much as stroke”. £590 million is spent on cancer research while dementia research only attracts £50 million. And “each dementia patient costs the British economy more than the average salary and five times more than the average cancer patient”.

The UK report reaches the same conclusion as we have done in our work in Australia namely that the economic burden of dementia is far greater than cancer and heart disease and that dementia research funding is grossly underfunded balance of expenditure does not in our view reflect the importance of dementia as a chronic disease in terms of its prevalence, disability burden, and health and care costs.

The Dementia Initiative has supported a welcome increase in dementia care research. We now seek a greater and urgent injection of investment in research in order to:

- Better understand the causes of dementia.
- Develop medical interventions that delay the onset of dementia.
- Identify those at most risk of developing dementia.
- Further develop the evidence base that shows that and how risk of dementia may be reduced.

SLIDE 14 Second, action is needed to improve access to early intervention through improvement in assessment, diagnosis and ongoing management. This is important both to assist the person with dementia to plan their care and finances and because there is the prospect of disease modifying drugs that delay progression.

Our market research shows that over 94% of Australians would go first to their GP if concerned about their memories. At the same time, there is ample evidence that many GPs have difficulty in identifying or addressing dementia through appropriate referral to specialists and support services.

In summary, the evidence is that:

- Currently only about one third of people with dementia receive a formal diagnosis at any time in their illness.
- The gap between first symptoms and diagnosis ranges between 10-32 months.
- Up to 90% of mild dementia cases go undetected in general practice.

There are no single or simple solutions to these complex issues. The approach we are proposing is to:

- Promote existing Australian Government support mechanisms that can be used to better support people with dementia and their families, such as the Medicare items available to support complex and chronic care.
- Ensure appropriate funding models are in place to reimburse health professionals for the additional time they spend with family carers and to enable the employment of practice nurses to support active management of patients with dementia including, as appropriate, undertaking regular assessments and community referral.
- Implement a dementia education and training package for primary health care professionals to increase early detection and diagnosis in general practice.
- Develop and implement updated national guidelines for dementia best practice for use by various professions.

These and other actions should be complemented by encouraging consumers to make advance care directives and for health professionals and the legal system to recognise them.

Lastly, health infrastructure is needed to support a public education campaign based on the Mind your Mind program developed by Alzheimer's Australia to promote awareness of the potential to reduce the risk of dementia through changes in lifestyle and behaviours. Our market research shows that 50% of Australians are currently unaware that they may be able to reduce their risk of dementia. Worse still those that are aware have little understanding of the links between dementia and cardiovascular disease, high blood pressure and high cholesterol levels.

iii) Measures to Strengthen Quality Dementia Care

We all share a common commitment to achieving quality dementia care.

SLIDE 15 Arguably we all know a good deal about what constitutes good dementia care. The challenge is to deliver it.

There would be agreement I think, that there is “no one size fits all” set of practices. Each individual has unique needs.

Alzheimer's Australia takes the view that the quality of dementia care is likely to be high if it is driven by a person centred care approach that incorporates a partnership between service providers, the person with dementia and the family carer, and a service environment characterised by strong leadership and supported by the adoption of best care practices.

We could probably agree too, on the need for flexible and responsive approaches to care services that are tailored to the needs of the individuals living with dementia.

So starting from the assumption that we do have a knowledge base, we propose that strengthening quality dementia care should be addressed in three ways to promote collaboration and knowledge translation.

First, there is a need to review and then build on the training initiatives that have been taken under the Dementia Initiative.

Second, there is evidence that the Dementia Behaviour Management Advisory Services are providing needed and useful advice on behaviour management to community and residential care staff.

Thirdly, there is the need for better knowledge translation. There is evidence that it takes many years for new research evidence to feed through into practice. The Dementia Behaviour Management Advisory Services play a part in that, but there needs to be a greater emphasis in our view on bringing together consumers, service providers and researchers to find ways of more quickly making optimal use of the available knowledge to improve dementia care.

Possible examples of areas where research outcomes have not been taken up as quickly as they might include pain management strategies, minimising the use of medical restraint and developments in palliative care.

A greater investment is needed in knowledge translation including through the National Quality Dementia Care Network being established by Alzheimer's Australia in partnership with the three Dementia Collaborative Research Centres, Bupa Care Services and the Wicking Trust.

iv) Measures to Improve Access to Dementia Services

SLIDE 16 We are putting forward **five** proposals to improve access to dementia services.

First, a dementia equity program that would ensure more equitable distribution of mainstream funding for dementia services to support all Australians from all cultures and of all ages no matter where they live.

Perhaps the strongest point that emerged from our consumer consultation was the feeling that "special groups" did not want to be marginalised as "special groups". Rather they want action that assists them to access culturally appropriate mainstream programs.

SLIDE 13 Second, there is a need to strengthen the support given to people living with dementia in the community through the National Dementia Support Program administered by Alzheimer's Australia. This Program plays a unique role in providing co-ordinated 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 the Living with Memory Loss Programs and both centre based and outreach support programs.

There is a need for these services to grow in line with the growth of people with dementia. The program should have components for innovation and

demonstration of new models of dementia care, for example in respect of restorative therapies, safe to walk technology and key worker support for those living alone or those with younger onset dementia.

Third, community care remains in our view the Cinderella of health and care funding both in terms of the need for a higher funding priority and the need for urgent reform.

We have advocated strongly for graduated community care packages, streamlined assessment processes and a removal of program boundaries that prevent a flexible and consistent response to the support needs of people living with dementia.

Consumers want an increase in the number of dementia specific care packages. There is a need to ensure that financial incentives are targeted to those who do have Behavioural and Psychological Symptoms of Dementia that require additional support.

Fourth, residential care is going to continue to be a vital part of the care system for people with dementia. There is a need both for mainstream services to be sensitive to the needs of people with dementia and for places to be available for those that have special dementia care needs.

The introduction of the Aged Care Funding Instrument incorporating a behavioural supplement was a welcome recognition of the special demands of dementia care and the requirement for additional funding.

But consumers do have concerns about the need for clearer guidance as to what constitutes dementia friendly care in mainstream services and what is meant by dementia specific places or dementia units.

There are areas of particular need that deserve highlighting, including the needs of those with both psychiatric and dementia issues, improving access to primary health care for those in residential care, and the need to include in the planning allocations dementia specific care places that provide accommodation and care for those with severe BPSD. For the consumer there is no way of knowing what such services can or should provide. Arguably there is a need to accredit dementia specific places.

Lastly, acute care remains a dangerous setting for people with dementia – and potentially more so for those whose dementia has not been formally diagnosed.

In Australian hospitals, up to 50% of all patients admitted have some degree of cognitive impairment. Impaired mental status is the most commonly identified factor in patients who fall while in hospitals.

While admissions are less commonly made for dementia, many people with dementia are admitted for treatment of other conditions.

There are a range of strategies that might achieve better outcomes for people with dementia as well as place fewer burdens on hospital staff and budgets.

THE NEXT STEPS

So what are the means to implement these priorities? **SLIDE 17** Alzheimer's Australia has proposed that \$1 billion be made available over 5 years in addition to the funding currently provided for the Dementia Initiative – about \$120 million per annum.

This funding could be made available through: **SLIDE 18**

1. The health reforms of the Federal Government in key areas such as primary care and prevention
2. The Dementia Initiative for example in respect of awareness, research into the cause and prevention of dementia, quality dementia care and services, including an equity element.
3. The renewal of the National Dementia Action Framework agreed by Australian Health Ministers to prioritise key areas for national action such as acute care.

From a consumer perspective we know the 2005-2009 Dementia Initiative has achieved many positive outcomes. We understand that the yet to be published evaluation reports that the Initiative has been effective and identifies that there are gaps to be addressed.

The time to address the Dementia Epidemic is now. **SLIDE 19**

As the UK National Dementia Strategy acknowledges

If we spend money now to improve the quality of life for people with dementia and their carers we will save money in the future as well as make things better for everyone concerned.

I look forward to hearing from the many speakers who follow me in the conference program about how a range of issues that currently exist across Australia can be addressed by successful approaches that, with funding, might be extended to support Australians affected by dementia in all jurisdictions. I particularly welcome the support of State and Territory Governments in addressing the Epidemic.

The 257,000 Australians with dementia and those who support them deserve a greater investment of resources in the next National Dementia Initiative to address new priorities and the service gaps and deficiencies that persist. And future generations have a right to expect that governments will take action today to reduce the scale of the dementia epidemic in coming decades.

So we know what to do. Thank you for your support.