Speech Notes for ACSA Conference
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DEMENTIA: FACING THE EPIDEMIC

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It has been my privilege for over 25 years to be associated with ACSA in one way or another.

Partnership between consumer organisations and service providers has never been more important in the interests of achieving much needed change in aged care.

Equally there is the mountainous challenge of persuading those in charge of health policy that dementia is a health issue as well as an aged care one.

We have a lot in common.

A recognition that dementia is an important driver of the growth of aged care services.

A common commitment to person centred care and to flexibly meeting the needs of older people and their family carers.

A recognition that workforce issues have an importance far beyond the priority they are given in current policy and funding settings.

In advocacy you have to make your own luck. We took the view earlier this year that we needed new intellectual capital to reignite political and community interest in dementia. We could not wait for Government reviews to provide the answers.
We released on 1 September a report commissioned from Access Economics ***Front of Mind*** that sets out the harsh reality of the prevalence and incidence figures for dementia to the middle of this century – over 1.13 million people with dementia and 385,000 new cases during 2050.

Next week we will be releasing ***Dementia: Facing the Epidemic*** that will contain the vision of Alzheimer's Australia for a world class dementia care system. **SLIDE 2**

Today I would like to give you a preview of the vision we have and to seek your support in advocating for it at the political level in the 2010 budget and as necessary beyond 2010.

We believe that Australia needs a new vision and increased Australian Government commitment to build the world class dementia care system needed to face the dementia epidemic.

In summary, we believe that an additional investment of $1 billion over five years is required to address the epidemic in Australia with an emphasis on encouraging community awareness and positive lifestyle choices, dramatically improving dementia

care practice and outcomes, promoting equitable access to support services and supporting cutting edge research.

We recognise that the 2010 budget will be particularly difficult. Nonetheless, the additional funding requested of $200 million per annum over five years is small relative to the current and projected economic and social costs of dementia and the real benefits of taking action now to plan targeted and effective growth in the necessary dementia services and research activity.

Australians need a genuinely national approach that recognises that dementia impacts on all parts of the health and care system - primary care, early intervention, acute care, medication management, community care, residential care and palliative care.

Let me explain why by talking about: **SLIDE 3**

- First, the evidence base for seeking urgent government action on dementia.
- Second, providing you with the view of Alzheimer's Australia on the outcomes achieved to date through the Dementia Initiative - Making Dementia a National Health Priority.
- Third, the proposals that we are making to establish a world class dementia care system in Australia.

The Evidence

As an organisation, we have 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 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 4** 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 into old age.

The evidence for concern is best summarised in some very disturbing numbers: **SLIDE 5**

- The number of Australians with dementia in Australia will double to 592,000 by 2030 and nearly double again to over 1.1 million Australians by 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 6**
- 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 7**
- 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 of 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 risk of dementia may be reduced by lifestyle and healthy behaviours, but 49% of Australians do not know this.

The Dementia Initiative - Making Dementia a National Health Priority

SLIDE 8 In the 2005 budget Australia became the first country in the world to make dementia a National Health Priority. Australia has led the way in acknowledging the economic and social impact of dementia.

The 2005 Budget provided $320 million over 5 years for three measures:

1. Initiatives to support dementia care, research and innovation, improved care and early intervention.
2. The introduction of Extended Aged Care at Home (Dementia) packages.
3. Training to care for people with dementia.

Importantly, the Dementia Initiative has received bipartisan support including for the continuation of the existing funding beyond 2009.

SLIDE 9 An independent evaluation has been commissioned by the Australian Government but is not yet publicly available.

We consulted our key consumer groups about the real outcomes of the Initiative, as well as what gaps needed to be addressed. To this end, our National Consumer Advisory Committee held a joint meeting with members of the National Cross Cultural Dementia Network and the National Aboriginal and Torres Strait Islander Dementia Advisory Group before the National Conference last June.

From a consumer perspective, the Dementia Initiative has achieved much of its promise and shown positive returns on the investment made by the Australian Government. 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, which many of you provide.
- Increased community engagement through community grants and the awareness and community education activities through improved funding for the National Dementia Support Program (NDSP) 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 NH&MRC 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 NDSP.

We believe that significant progress has been made and the core elements of the Dementia Initiative should be continued with the current level of committed funding of over $120 million per annum.

However, the Dementia Initiative falls short of the action that we believe is necessary to fully face the dementia epidemic. The current Initiative has not delivered on a public awareness campaign or in respect of primary care and early intervention which we believe are necessary. And there are other areas such as cutting edge research into the cause and prevention of dementia, acute care, prevention and more equitable access to services for special groups that need additional funding.

Priorities for 2010 – 2014.

There are two major challenges to maximising the strategic opportunities in planning the next stage of the Dementia Initiative. **SLIDE 10**

First, it must be genuinely national in its impact across the country's health and care system. The National Dementia Action Framework agreed by Health Ministers in May 2006 provides an excellent focus for identifying the priorities that need to be addressed.

Although individual State and Territory jurisdictions have taken some action, there has been little evidence of systematic change and sharing of the experiences of different States in changing practice.

Second, at the national level, there needs to be a recognition that dementia is a real health issue as well as an aged care one. You all know that but not everyone involved in health planning and policy does. At present, although significant sums are spent on dementia care through the aged care system, there remains inadequate recognition that dementia impacts on all parts of the health and care system –

including primary care, early intervention, acute care, medication management, community care, residential care and palliative care.

This is important because dementia usually presents with other co morbidities. US data indicate that among older people with dementia, 30% also have coronary artery disease, 28% have congestive heart failure, 21% diabetes and 17% chronic obstructive pulmonary disease.

Dementia is a fatal condition which decreases life expectancy, adversely impacts on an individual's ability to manage their own health and may affect the quality of health care provided. Dementia risk factors that may be managed within the broader health agenda include hypertension, cholesterol, cardiovascular disease and diabetes.

There is a need, in other words, to prioritise dementia in the health system as well as in aged care.

The delivery of better access to quality dementia care will depend on fundamental changes in the delivery of health care and in particular, on the Government's decisions in their response to the final report of the National Health and Hospital Reform Commission.

SLIDE 11 Alzheimer's Australia has welcomed the directions proposed by the Commission for greater choice for older Australians and the particular priority identified for mental health given the importance of depression among those living with dementia and the poor access to services for those with dementia and psychiatric conditions. There is a welcome emphasis too on addressing inequities, prevention and early intervention, strengthened primary care, end of life issues and research and knowledge translation. The Report is the only show in town to get much needed reform in aged care.

But – and this a very big but – this action in itself will not be enough to address the challenge of reducing the prevalence and impact of dementia or the current deficits in dementia care services when faced, as Australia is, with growing numbers of people with dementia. We know that many Australians with dementia do not have access now to quality dementia services in their location which meet their cultural and other needs.

On 21 September – World Alzheimer's day - Alzheimer's Australia will be putting forward a new vision for a world class dementia care system that will require additional measures and funding to: **SLIDE 12**

i) Increase public and professional awareness and reduce the stigma associated with the condition.
ii) Build health infrastructure to reduce the prevalence and incidence of dementia and to achieve early intervention.
iii) Improve the quality of dementia care.
iv) Improve access to dementia services.

Let me give you a preview of what we will be proposing.

i) Increased Awareness and Reduced Stigma

SLIDE 13 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. There is a belief that greater community awareness has played a part in fostering more positive community attitudes to cancer and depression.

But when it comes to dementia, old attitudes, compounded by the absence of disease modifying agents, die hard.

- The belief that dementia is a natural part of ageing.

- The lack of awareness that good quality dementia care can play a part in improving the quality of life of people living with dementia.

- The ignorance that is pervasive around the possibility of dementia risk reduction.

- And maybe there is an element of ageism.

The consequence is that there is no belief we can beat dementia as we have in respect of cancer and heart disease. In five to ten years time, it is possible to envisage a world where:

- 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 is more data to demonstrate that lifestyle choices including psychological well being and nutrition can delay the onset of dementia.

ii) Health Infrastructure

SLIDE 14 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.

This balance of expenditure does not in our view reflect the importance of dementia as a chronic health disease in terms of prevalence, disability burden and health and care costs.

The Dementia Initiative has seen 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 risk of dementia may be reduced.

SLIDE 15 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 that there is 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 16 Arguably we all know 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 both through Dementia Care Essentials and the Dementia Training Study Centres.

In particular, we see a need to increase investment in training to raise the bar for Australia’s care workforce through access to higher order professional development and training as well as the “base level” training available through Dementia Care Essentials.

There is a need to focus on some additional areas of practice that are critical to quality of life for people with dementia including cultural competence, pain management, palliative care and the recognition of depression and anxiety.

Second, there is evidence that after perhaps a slow start the Dementia Behaviour Management Advisory Services are providing needed and useful advice on behaviour management to community and residential care staff. Different models have emerged in different places and there is a need to draw on experience before further investment in this model.

But if there is to be an emphasis on knowledge translation then maybe – just maybe the Dementia Behaviour Management Advisory Services hold out the seed of something helpful in terms of better supporting community care staff and residential care staff in the difficult task of dementia care for those who have Behavioural and Psychological Symptoms of Dementia.

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.

An investment in knowledge translation through improved coordination and networking is a vital element of our proposed strategy.

iv) Measures to Improve Access to Dementia Services

SLIDE 17 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 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 mainstream programs. We propose to achieve this by

- Having a funding pool that can be used to provide better access to mainstream dementia services by those from CALD and Indigenous communities, regional Australia and those with younger onset dementia.
- Providing funding to promote partnerships between CALD and Indigenous organisations and Alzheimer's Australia to more effectively engage those communities.

SLIDE 18 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 in 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 a shared vision with ACSA for a world where there are graduated community care packages, streamlined assessment processes and a removal of inflexible 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. The jury is still out on whether that approach is working in the way that it should in promoting access to better quality dementia care for those in residential services.

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, better 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.

This is an area where one might have hoped for more action through the National Dementia Action Framework in terms of cooperation and sharing of information between the different jurisdictions on approaches which minimise unnecessary hospital admissions, promote family and carer support for those in hospitals, improve hospital practice through better recognition of cognitive impairment and result in a national approach to dementia care standards in acute care.

Conclusion

SLIDE 19 In conclusion there is solid evidence that the rising prevalence of dementia will have substantial implications for our health care system. As people live longer and longer there is a need to recognise in health policy an important epidemiological transition, with the emphasis changing strikingly from cardiovascular disease and cancer to the neurodegenerative diseases. There will be a massive gap in the supply of future dementia care services unless the opportunity is taken to plan now and to make the investment in research necessary to find therapeutic interventions to delay the onset and progression of dementia and identify those at most risk of developing dementia.

People with dementia will continue to be a significant client group within your aged care services. Please think about how you might support Alzheimer's Australia in securing the policy changes and funding that people with dementia and their family carers need and deserve.

By 2020, there will be 75,000 baby boomers with dementia unless there is a major medical breakthrough. The dementia epidemic will affect us all – both professionally and in our private lives. Please join us in our advocacy.