

MAKING DEMENTIA A NATIONAL HEALTH PRIORITY THE AUSTRALIAN STORY

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I should like to thank ADI for the invitation to be at this seminar. I have the advantage of drawing some of our discussion together and the challenge of avoiding repetition. I hope the Australian story can show how the elements of advocacy come together.

In his 2004 Federal Election launch, the Australian Prime Minister, John Howard, included a commitment to make Dementia a National Health Priority if re elected. Shortly after the launch, Senator Marise Payne – one of the convenors of the Parliamentary Friends of Dementia – telephoned me to ask for my reaction. I said that I was over the moon and asked the obvious questions. How did this happen? And why now? Senator Payne's response was "Nothing sudden. It's like water dripping on a stone."

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I would like you to keep that image of water dripping on a stone in your minds when you reflect on what you need to do in dementia advocacy. Like water dripping on a stone, good ideas will get through in the end - but it may take sustained effort over a long time. The quality and integrity of advocacy do make a vital difference.

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It is clear that our situations are very different in the scale and complexity of the problems we face but that we have a lot to learn from one another. In confronting the consequences of an ageing population in Australian for some decades the barriers that have needed to be addressed to improve the quality of life for people living with dementia have included:

- Lack of awareness and understanding of dementia
- The social isolation and stigma that attaches to dementia
- Lack of resources like funding and services
- Competing health priorities
- Inevitable part of ageing
- The absence of a truly national voice
- Inadequate economic and social analysis

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Faced with these barriers, advocacy is about one thing - and that is credibility. And credibility in advocacy comes from four things in my experience;

- National Unity
- Being the dementia experts – the brand of Alzheimer's Australia is to be "the dementia experts with compassion".
- Developing the intellectual capital necessary to make the argument

- Sustained effort and clear direction.

National unity does not come easily - even for the committed! The strength of Alzheimer's Australia is now national unity but it was not always the case. Alzheimer's organisations were formed in each state and territory in the 1980s and a national body followed by 1990. Personalities and poor governance ensured that by 1999 there was no effective National Office and that is where I would like to start the Australian Story.

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Since 2001, our advocacy has been built on and marked by a number of landmark publications. Many have been released during our awareness weeks and World Alzheimer's Day in September.

Sept 2001	<i>Dementia a Major Health Problem</i>
May 2003	<i>Dementia Epidemic: Economic Impact and Positive Solutions for Australia</i> <ul style="list-style-type: none"> – Funded by pharmaceutical companies – Authored by the top economic consultants in Australia – Language is everything – the title of the Report was no accident – More than stating a problem – Emphasise there are solutions
July 2004	<i>Dementia Manifesto</i> – a well-presented document of 6 pages that displays at a glance what we are advocating for.
Sept 2004	<i>Dementia Research: A Vision for Australia</i> – setting out in layman's language where dementia research is at and the strategies that are being pursued.
Sep 2004	<i>Delaying the Onset of Alzheimer's Disease: Projections and Issues</i> – using modeling developed in the USA to demonstrate how even a few years delay in the onset of Alzheimer's disease may result in significant savings to public health budgets.
Mar 2005	<i>Dementia Estimates and Projections: Australian States and Territories</i> – updating statistics with revised population and prevalence figures and earlier diagnosis
Sept 2005	<i>Dementia: Can it be prevented?</i> <i>Mind your Mind</i> – a new focus with the message that dementia is of concern to all ages.
Oct 2005	<i>National Consumer Summit Communiqué</i> – promoting self advocacy, building on the opportunity of dementia being made a National Health Priority for consumers to have their say and reinforcing the brand of Alzheimer's Australia as a grass roots community organization that politicians should listen to.

All our stakeholders owned those publications, the texts were commented upon by all and we had common agreed media messages to convey. And we ensured Ministers and others were briefed in advance of publication.

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So how have we measured the effectiveness of advocacy? We know through market research conducted through Newspoll that there is a greater understanding of dementia and recognition of the brand of Alzheimer's Australia. We have secured Dementia as a National Health Priority in Australia. There is a political and government acceptance of our role as the peak national body speaking on behalf of people with dementia and their families and carers and we have representation on all national advisory bodies. We have secured strong support for our advocacy from other peak bodies and professional bodies. Lastly, the test for stakeholders is funding and the sense that things are getting better slowly.

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Specifically the major outcomes of our advocacy have been

June 2000	New funding for Alzheimer's Australia to provide national training for carers and care workers, living with memory loss programs, a National Dementia Behaviour Advisory Service and base funding for the National Body
May 2005	Dementia made an Australia Government Health Priority with \$320 million over 5 years for education and other initiatives.
	Increased funding for Alzheimer's Australia National Programs.
	A recognition that dementia impacts on every part of the health and care system

The key to our success in advocating for Dementia as National Health Priority in Australia has I believe been in developing intellectual capital. The main body of this effort has in the economic and social analysis that has provided to Government and others a clear understanding of the economic and social impact of dementia. But there have been other publications too on Consumer Focus, Quality Dementia Care and Legal Planning and Dementia and others are in the pipeline on Dementia and Palliative Care and Dementia and Assessment.

We use the same figures again and again and the media never seems to tire of them.

- The current total cost of dementia in Australia is \$6 billion.
- The direct health care costs will double within a decade.
- There are over 200,000 people with dementia now and that this number will rise to over 730,000 by 2050 unless effective medical interventions are found.
- Dementia will be the number one source of disability burden by 2016.
- Dementia impacts on a million Australian lives.

Our strategy for nearly five years has been to advocate for dementia as a national health priority and to provide the data to back that up. A simple message and powerful facts are what advocacy is about. We have got good media and Government attention because our case has been factually based

and supported by the powerful stories of people with dementia, their families and carers.

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Governments in Australia are economic rationalists hence the emphasis on costs and benefits. In the 1980s and 1990s there was a much greater emphasis in Australia on advocacy within a social justice framework and rights based issues.

I should emphasise that it is not just analysis that the Government and the wider community want. It is no use having a problem and no answers. There is no cure but it is critical have positive solutions – through arguing for better services and support, medications and research. The simple question that politicians will always ask in some form is what do you want? – And they will give you only a few minutes to explain!

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I have emphasised intellectual capital and unity as the keys to our advocacy in Australia. But there is no magic bullet - many other elements have contributed to our credibility as national advocates and I will run very quickly through these.

SLIDE 11 Services

Clients want services that help them support their loved ones. Providing services makes Alzheimer's Australia credible because we can demonstrate our expertise. But remember the services of Alzheimer's Australia are a minor part of the overall service effort. Advocacy is about ensuring a focus on dementia across all parts of the health care system – primary care, acute care, community care, long term residential care and medications. And increasingly it is about prevention.

An intractable question for all those engaged in advocacy is the **balance** of the effort put into providing services and into advocacy and awareness. If resources are very scarce should the effort go into helping a few or the advocating for the many and long-term goals. And will the few be the educated and relatively well off or will there be an effort to reach out to disadvantaged groups.

SLIDE 12 Intelligent Lobbying

We are credible with Government because we present analysis and information and do not spring surprises on them in the media. A strategy is developed for every document - briefing Ministers in advance, getting the Minister on occasions to circulate our documents and support them, having the Minister at launches.

SLIDE 13 National and unified voice

It was the eight member bodies of Alzheimer's Australia that committed funds to re-activate the national office in 2000. I was recruited in March 2000 and the sole employee for the first 18 months. Alzheimer's Australia is a national peak body with representation in every part of the country and able to speak

with one voice. The roles of the national and body and its member organizations are different and complementary. My role is not to run programs or to interfere in the running of programs by others but to promote awareness of dementia and to advocate for improved access to services and investment in research.

We have promoted national unity by outsourcing to individual state members national functions – Victoria coordinate national resources for all members; management of the national website is outsourced to a state; South Australia manage our programs for non English speaking people and Indigenous people; NSW manage our public relations and Victoria manage our Mind your Mind campaign directed at making people aware that they maybe able to reduce their risk of dementia.

SLIDE 14 Champions

It says a lot about the nature of dementia and the mystery and stigma that have surrounded the condition for centuries that in Australia only been one high profile public figure to date has disclosed their diagnosis. And that was Hazel Hawke – the wife of former Australian Prime Minister Bob Hawke. And it is only in the last 5 years that people with dementia have been active advocates for themselves and for Alzheimer's Australia. We are fortunate in Australia to have a Prime Minister and Minister for Ageing who have championed our cause

SLIDE 15 Partnerships

These are a few of the many organisations with whom we partner. Most are politically much better positioned than Alzheimer's Australia. Doctors have been immensely supportive, as have the nurses and all parts of the aged care sector. The formation of Parliamentary Friends of Dementia in the National Parliament is significant because

- It is bipartisan and jointly convened by a member of the Government and the Opposition.
- It provides access to political advice on handling issues
- It creates awareness of dementia though regular meetings and circulation of publications
- It hosted the National Consumer Summit at Parliament House.
- Promotes access to Ministers, Shadow Ministers and party committees.

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Probably 30-40 organisations are involved in our advocacy in one way or another. Remember our national body is small – 8 staff. While partnerships at the national level are important our state and territory members have service partnerships with other agencies and relationships with professional bodies.

SLIDE 17 Self-advocacy

Much of the emotional and political power of our advocacy is in the stories of the people with dementia and their family carers. Consumers, both people with dementia and family carers, play their part up front in all our media events, launches and the opening of conferences. In political terms, the thing

that makes a community organisation special is the integrity of its consumer focus. The hardest thing to do for bureaucrats like myself and perhaps for doctors is to stand back and let consumers determine the philosophy, priorities and action that govern the organisation. Our recent National Consumer Summit at Parliament House had significant media and political outcomes because it was driven by people with dementia and family carers and resulted in an agreed communiqué setting out their priorities and preferred action.

SLIDE 18 Communication Strategy

We do most of our own media work – to do otherwise is too expensive. And you have to determine your own messages and deliver them in your own way. The quality of communications will depend on the quality of your information and having a clear and agreed view of what you want. The recipe to disaster is to think an agency can do it all for you.

For a relatively small investment in intellectual capital we have been able to generate millions of dollars worth of media coverage – possibly \$7-8 million Australian. It is the nearest thing I have discovered to alchemists gold – the secret of turning base metal into gold.

The emphasis on intellectual capital means that the national website has a critical role in promulgating our facts and figures.

We now have Dementia Awareness Month every year to convey a nationally consistent message. Our messages are primarily directed to families and carers letting them know they are not alone and services can help. In recent years we have campaigned to get the message out that life does not stop for the person after a diagnosis of dementia or for their families and carers. We seek to inform the community about the early signs of dementia and how an early diagnosis can be of benefit. And now there is an emphasis on prevention with the clear message that all ages should be concerned about dementia and having a healthy brain.

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I believe that we can apply some of the fundamentals of the experience we have had in Australia in advocacy to the Asia Pacific region. This is not entirely unselfish on our part - we share a common interest in getting dementia onto regional and international agendas. For that reason at the Asia Pacific meeting of Alzheimer's Disease International last May, the 14 member countries agreed to develop a short readable report of about 20 pages on the impact of dementia across the region – from India to the Philippines.

We have not decided finally what to call it but possibly Dementia: The New Tsunami. It will be in five parts

1. What is dementia
2. The prevalence of dementia now and tomorrow
3. The economic and social impact of dementia
4. Cost effective interventions

5. Recommendations

I should acknowledge that the funding for the project has come from the Tsao foundation and also Alzheimer's Disease International. The Report has been commissioned from Access Economics in Australia.

Our objective is to lay the basis for advocacy across the Asia Pacific region – with Governments, the World Health Organisation and aid agencies. It may be possible at the next regional meeting in April to arrange media training to build the skills of those who have less experience of the media. Australia, in partnership with Singapore and South Korea, is excited to drive this project. We expect to launch the report on World Alzheimer's Day 2006 although, of course, we expect to have the final report by next June to brief key stakeholders on it in advance.

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We know that the Asia Pacific region, more than any other, will experience the impact of the dementia epidemic. I hope this report, like the ones commissioned in Australia, will be a significant tool in a process which will - like water dripping on a stone - eventually result in a greater understanding of dementia and the need for enlightened Governments to come to terms with what is, on the basis of any economic analysis, is a serious threat to public health and care world wide.

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Through this report and in other ways, I hope we can work together to get dementia on the political map across all countries in our region in the interests of our parents, our children and ourselves.

Thank you

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