

Consumers and researchers: fighting dementia together.

**International conference:
Research and Standardisation in Alzheimer's Disease Conference**

**Melbourne Brain Centre
Public lecture**

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It gives me great pleasure to be able to speak at this important conference. I am grateful to Professor Richard Head and the other distinguished members of the organising committee for inviting me to share this platform with our colleagues from the United States Alzheimer's Association.

What could be more appropriate than for the president of a consumer organisation to speak at the opening of an international scientific gathering which is focused on lifting the standards of research into the diagnosis and treatment of dementia.

I want to talk to you about the importance of partnership between consumers – and by consumers I include people with dementia and family carers – and dementia researchers.

I will talk about four issues this evening...

- Alzheimer's Australia and our Fight Dementia Campaign.
- The commitment we have to knowledge translation through the national quality dementia care initiative.
- The partnership that has developed between researchers and consumers through our consumer dementia research network.
- The opportunity to do more to communicate the excitement of world-wide dementia research as the cutting edge of medical science this century.

As many of you will know Alzheimer's Australia launched the Fight Dementia Campaign with a march on Parliament House in Canberra on 13 October last year.

It was a wonderfully moving event with 500 family carers and people with dementia from across Australia seeking a commitment from the federal government in the May 2012 Federal Budget to implement a \$500 million action plan over five years to beat dementia.

Our march generated an audience of 7.6 million through the media, both traditional and social media.

Importantly, it represented a turning point in the life of Alzheimer's Australia and recognition by our consumers that they have to tell their stories.

It is personal stories, not facts and figures that are key to promoting a better understanding in the community of the social and economic impacts of dementia.

Our campaign has two key policy objectives.

Firstly, to ensure that dementia is centre stage in the government's consideration of aged care reform and secondly, that those responsible for health policy do not leave dementia to aged care but recognise the need for action on lifting the standards for a timely diagnosis of dementia, making hospitals safer places for people with dementia, validating dementia risk strategies and increasing investment in research.

Dementia has to be tackled within a public health framework that recognises the importance of new standards of information, early diagnosis, support and care, risk reduction and research.

It is a disgrace that the health care reforms of the last four years have resulted in no recognition of the under diagnosis of dementia or of the years of uncertainty, doubt and fear that are lost before a diagnosis is made.

It is concerning too, that given the numbers of older people and those with cognitive impairment in our hospitals there has been no national recognition of the need to make hospitals safer places for people with dementia.

We recognise of course the economic imperatives that face the federal government... but \$500 million represents only about two per cent of the cost of dementia care, and we have made sure our campaign is carefully targeted on issues of greatest concern to consumers.

I should add that in the context of partnership between consumers and researchers that \$200 million of the \$500 million has been requested for investment in dementia research.

Notwithstanding the desperate need for better dementia services, Alzheimer's Australia recognises the need to beat dementia in the future through medical and scientific research, and the application of new knowledge.

Alzheimer's Australia CEO, Glenn Rees and I have visited many politicians, including the Prime Minister, to raise awareness of Australia's looming dementia epidemic. At one of our meetings with Mark Butler, the Minister for Mental Health & Ageing, he told us to keep raising our voices and telling the stories of people living with dementia.

Glenn and I have been doing exactly that and it seems that someone has been listening.

Last week it was announced that an inquiry into dementia that will focus on the benefits of early diagnosis and intervention for people with dementia and their carers will be conducted by the House of Representatives Standing Committee on health and ageing in Canberra.

I am encouraged by this development but I have learned when dealing with politicians never to count my chickens before they're hatched.

As a consumer organisation we are proud to have taken an important initiative in knowledge translation.

The J.O. And J.R. Wicking trust and Bupa Care Services provided \$3 million to enable Alzheimer's Australia to implement the national quality dementia care initiative.

The logic of the initiative is simple.

First, identify consumer priorities for improvement in dementia care; second, identify with the help of researchers what evidence exists to address those concerns; and then conduct a tender process to invite projects that translate the consumer concerns and the evidence base into the best standards of practice on a national scale.

This is truly ambitious. But the approach emphasises the belief we have in the importance of partnership between consumers, researchers and service providers if we are to achieve improvement in quality of care and quality of life for people with dementia and their family carers.

Three projects have already been approved and we expect a further five to be in place by the middle of this year.

I want to tell you a little more about the Consumer Dementia Research Network which is modelled in part on the approach developed by the UK Alzheimer's Society.

The network was established in September 2010 and has quickly developed as a diverse, passionate and talented group of twenty five people with dementia and family carers, who come from around Australia, from a diverse range of cultural, professional and geographic backgrounds.

The setting of priorities within the context of the national quality dementia care initiative has been a major focus of their work, but it is only part of the future that we see for the network.

The network is also an important resource for researchers who have a genuine commitment to the involvement of consumers in dementia research.

Despite the rhetoric that accompanies consumer involvement in research it is clear, at least in an Australian context, that the rhetoric is mightier than the deed.

We believe that the new initiative taken by the National Health and Medical Research Council (NH&MRC) in establishing a partnership centre on cognitive decline in the elderly offers a major opportunity for the involvement of consumers.

The objective of the centre is to change systems and improve standards to better address social, medical and other issues in relation to cognitive decline.

Where better to start than by involving consumers in the priorities that determine the work program and, in the longer term, the development of projects and dissemination of results.

It can be only beneficial in terms of the politics of research funding, and dementia research in particular, for consumers to be involved in research as integral partners.

Such a partnership allows consumers to better understand what is involved in research, and to be active participants in the advocacy for research funding.

This leads me to the last theme that I want to address in relation to the partnership between consumers and researchers. My own background, passion and expertise is communications.

It seems to me that we have a long way to go in persuading the wider community and government that we can beat dementia through medical and scientific endeavour.

Regular headlines about the 'next new cure' for Alzheimer's disease are not working to inspire our excitement and imagination. Not least because we have been hearing the same thing for a long time!

We need to combat the myth that dementia is a natural part of ageing, and convince the world and the decision makers that dementia is the major chronic disease of the 21st century.

Convincing the community and the government that dementia is not a natural part of ageing; that it's caused by diseases of the brain and can strike at any age, might well be our biggest challenge.

We need to engage with people at an emotional level to deliver this message. Dementia is a disease that robs people of their memories.

Surely there can be nothing more personal and intimate to any one of us, than the love we have for those around us and the memories that make us who we are.

We have to get the message across to the wider community that the identification of those at risk of dementia is not far off, given developments in recent years that I'm sure will be amply discussed at this conference.

We need to explain simply the wide-ranging strategies that are being pursued in seeking to modify the disease process at the pre-symptomatic stage.

We have to work together to deliver the message that dementia, like any other condition, needs early intervention before too much damage is done to the brain.

But we need to do more than this to inspire hearts and minds.

Too few people realise the breakthroughs that you and your colleagues are making... are breakthroughs that will potentially allow Alzheimer's disease to be identified while people are in their 40s and 50s, many years before dementia symptoms appear. This will lead to new opportunities for early intervention and treatment.

The work you are doing is at the very forefront of human endeavour. It should be seen as exciting and as challenging as discovering the mysteries of the universe, or of landing a man on the moon.

Over the years Alzheimer's Australia has benefitted enormously from the support of eminent clinicians and researchers such as Henry Brodaty, David Ames, Colin Masters and Tony Jorm.

But we need even more power in our advocacy if we are to persuade the broader research community and government of the desperately inadequate funding that dementia research receives in Australia. The figures speak for themselves.

For the year 2011-2012 the government through the NH&MRC allocated \$24 million on dementia research...

For that same period the NH&MRC funded:

- \$159.2 million on cancer research;
- \$92.4 million on cardiovascular disease research;
- \$71.2 million on diabetes research; and
- \$53.6 million on mental health research.

Funding for dementia is approximately 1/6th of what was provided for cancer and 1/3rd of what was provided for diabetes research.

Australia is not alone in its poor support for dementia research. In America, Canada and the UK, dementia research funding is about a sixth or less of that invested in cancer.

But it looks like attitudes to dementia in the UK are undergoing a significant change. Yesterday British Prime Minister David Cameron announced that the dementia research budget would be doubled to sixty-six million pounds by 2015.

Prime Minister Cameron said: "dementia is simply a terrible disease. And it is a scandal that we as a country haven't kept pace with it.

"The level of diagnosis, understanding and awareness of dementia is shockingly low. It is as though we've been in collective denial."

Prime minister Cameron said the issue should be treated as a "national crisis." And he is so right.

Ladies and gentlemen, dementia is not going to go away and neither is the advocacy of Alzheimer's Australia.

But if we are to succeed in our advocacy we need a stronger partnership with the research and science community.

I believe this can come about if there is a greater willingness on the part of researchers to engage consumers in their work.

Consumers do not want to be researchers but they want to understand better the nature of research and to have a chance to influence priorities, particularly in areas such as early diagnosis, care and services.

We can do so much better working together in communication and getting the message across that dementia is not a hopeless case or a natural part of ageing, but that it, like other chronic diseases, can be beaten.

We have done it with cancer and heart disease. It's now time to adopt a new attitude to dementia. Consumers and researchers must fight dementia together....

... Together we can beat it.

Thank you.