

**Dementia: managing not to forget  
Opening address**

**Australian and New Zealand Society  
of Geriatric Medicine (ANZSGM)  
Annual Scientific Meeting**

**Hilton Hotel,  
Sydney**

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It gives me great pleasure to be asked to deliver this opening address and to welcome everyone attending this important conference and to wish you well in your deliberations over the next couple of days.

I appreciate the opportunity of speaking at this scientific meeting which will look at so many aspects of dementia from prevention, early symptoms and diagnosis, current and emerging treatments to managing advanced disease, all issues that greatly concern the people I represent as national president of a consumer organisation like Alzheimer's Australia.

When I talk about consumers I mean people with dementia and their family carers who are understandably apprehensive about what the future holds for them.

I've been president of Alzheimer's Australia for just over 12 months – and what an extraordinary year it has been. It has included the launch of our fight dementia campaign which we created to inform the Australian community about dementia and the need for action; successfully rebranding our organisation; meeting with politicians of all political persuasions in Canberra as well as prime minister Gillard last December – she incidentally gave me and Alzheimer's Australia's hard-working CEO, Glenn Rees, a most sympathetic hearing and we were able to tell her a few things about dementia that she didn't know and was most interested to learn about.

Glenn and I also had several meetings with Mark Butler, the Minister for Mental Health and Ageing. He offered us little hope in terms of government monetary support for dementia but urged us to keep raising our voices – and those of our consumers.

Never let it be said that I don't take good advice when I get it. I have raised my voice about the need for better funding and of having a national strategy to tackle dementia at every opportunity – not just here in Sydney which is my home town – but every capital city of our country – including Darwin which I visited in March this year. As many of you would be aware, the prevalence of dementia may be for four to five times higher in indigenous communities.

Glenn Rees has been equally active – as have our affiliated organisations throughout Australia.

We have tried not to miss any chance afforded to us – we even incorporated Valentine's Day into our campaign encouraging supporters to send Valentine's Day messages to politicians in Canberra including the Prime Minister, the Treasurer, the Finance Minister and their opposition counterparts...with the message: 'what would you do if your loved one couldn't remember you?' Thousands of our Valentine's Day messages reached Parliament House.

Opposition Leader Tony Abbot tweeted his response:  
'Appreciate the many cards from [@alzheimersaus](#) about the need for more funding into causes of dementia. A timely reminder of a great cause.'

I tweeted him back:

On behalf of the 1.5 million Australians affected by dementia thank you for your support Tony.'

What an incredibly useful form of communication twitter can be. I've had a terrific time being able to engage with my tweeps, a word, which for those of you who are new to twitter, describes other people who tweet. Twitter has been invaluable in getting out messages about our cause.

We launched our Fight Dementia Campaign with a march on Parliament House in Canberra on October 13 last year. It was an unforgettable and moving event with 500 family carers and people with dementia from across Australia taking part.

For many of the marchers – including me – it was the first time they had taken part in a protest march.

It represented a turning point in the life of Alzheimer's Australia and signalled the recognition by our consumers of the vital need for them to tell their stories. It is personal stories, not facts and figures, that will bring about a better understanding in the community of the social and economic impacts of dementia.

Our march generated an audience of 7.6 million people through both traditional and social media. Now that's what I call effective communication!

The aim of our Fight Dementia Campaign was to get a commitment from the federal government in the May 2012 Federal Budget (which is due to be delivered next Tuesday) to implement a \$500 million action plan over five years to beat dementia.

In spite of the effectiveness of our campaign we still had no reason to think the government would act positively on budget day.

Then came word that the government was going to release its aged care reform package before the May 8 budget, to prevent it being overshadowed by community reaction to the anticipated spending cuts that will be required to enable the government to return the budget to surplus.

On April 20, Prime Minister Gillard, and Minister Butler announced a \$270 million commitment to tackle dementia. Were we pleased? We certainly were!

This funding will address many of the key priorities in the Fight Dementia Campaign, particularly timely diagnosis; improving the quality of dementia care and acute care services; and providing support for people with younger onset dementia.

In the last 5 years we have seen the health and hospital reforms, primary care reforms, preventive health reforms come and go without a whisper about dementia.

And the 2011 budget saw the termination of the *dementia initiative* and our hopes that dementia would become a health priority.

We had no reason to be optimistic apart from the strength of our case.

Now we can applaud the government for listening and its decision to take a recommendation to the next meeting of commonwealth, state and territory health ministers, that dementia be added to the list of eight national health priorities, which already includes diseases such as cancer, cardiovascular disease, and diabetes. This is not before time.

Certainly there is a focus on dementia in the government's overall aged care reform package. There will be supplementary funding available to meet the extra costs of dementia care in both residential and community settings

The reforms hold out the promise of strengthening the community care system which will make it possible for people with dementia to stay at home longer. There will be more community care packages and more funding for respite care.

This will help avoid premature entry to residential care but we are concerned as to whether the growth in community services will be fast enough.

The reforms to empower consumers through adopting consumer directed care in all care packages will enable them to have more say over the services they need, when they need them and who delivers them.

The government's proposals address the key priorities in Alzheimer's Australia's Fight Dementia Campaign, particularly in respect of timely diagnosis, improved acute care services, improved support for younger people with dementia and an expansion of dementia behaviour advisory services.

The reforms will be reviewed at the end of five years although the government has rightly taken the view that the full impact of the reforms will take ten years to work their way through.

This is because the reforms are not just a question of funding but will change the way services are delivered.

There will continue to be frustrations for many thousands of people with dementia and their carers as the reforms work their way through.

Now, while it may appear we have won the battle, we have not won the war or ended our campaign.

We will continue to advocate for a national awareness program that promotes a better understanding of dementia.

We will not rest until we have secured an additional \$200 million for dementia research over 5 years.

We believe that an investment in telling Australians about the things they can do to possibly reduce their risk of dementia is worth while and low cost.

And of course we want to be sure the announced reforms are implemented well.

Alzheimer's Australia is particularly concerned about the very low level of investment in dementia research. This is an issue we will be pursuing vigorously through the Minister's review of Scientific and Medical Funding in Australia.

Compared with other chronic conditions, the level of funding for dementia research in Australia is unacceptably low.

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

For that same period the NHMRC 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.

As I tweeted in on April 11...

Gillard Gov shd follow UK Gov's example. British pm Cameron has announced doubling UK dementia research budget to 66 million pounds by 2015.

Prime Minister Cameron also 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 have been in collective denial."

Prime Minister Cameron said the issue should be treated as a national crisis – and he is so right... dementia is a national crisis here as well as in the UK and other countries around the world.

So why am I so passionate about the work of Alzheimer's Australia and our aim to beat dementia?

As the principal carer for my father who had vascular dementia I understand the effect dementia has on the individual and their families and friends. I know the tears, the laughter and the mixed emotions that are part of the dementia journey.

This experience has helped me to understand and appreciate what many families go through and the stress and strain that this disease brings to family life.

Dad's dementia was manageable most of the time, but upsetting because we didn't like to see dad this way. He'd always told us what to do. Now we were telling him what to do, but always tactfully so as not to upset him. These are difficult times for families trying to do the right thing by a parent.

Somehow we coped and dad was happy in the strange place he often inhabited and when he was back in the real world he seemed content. He liked to walk around his garden; he enjoyed his tucker and the occasional glass of red or a nip of scotch, and took to napping in the sunshine on his front veranda in the afternoon. All things considered, I think dad's last years on earth were pleasant and comfortable.

It didn't take me long to find out that our health system that is not designed to care for people with the dementia.

Dad was in and out of hospital in the last 12 months of his life –. Each time I had to explain to nursing staff the needs of someone with dementia and to ask them to make a special effort in communicating with him.

"Your father has been very difficult, quite unruly," a nurse told me crossly. It was as if the staff assumed he was being deliberately difficult. This happened every time he was in hospital.

I had to explain that when the routine of someone with dementia is interrupted they become confused, agitated and sometimes aggressive.

He was often cold too and again I had to explain to the nursing staff that elderly people do feel the cold and often need extra blankets.

In the last week of his life, when he was admitted to a private hospital in Sydney, and required help to eat, the hospital told me they didn't have anyone available to feed him his meals. Couldn't I arrange for his carers and family to come in and do that?

I was appalled. What kind of health system is it that can't properly feed our elderly citizens who are hospital patients? What happens to people whose families can't afford to pay for carers? Or who haven't got family members who can do the feeding.

Well I know what happens because I have seen it for myself...

A couple of my other older relatives (longevity runs in our family) were in nursing homes – one was in an Alzheimer's ward. I used to pop in to feed that particular relative on weekends and I could see for myself that some residents weren't helped and consequently left their food untouched. I used to tell myself there has to be a better way; I still tell myself that.

I have happy memories of more light-hearted times with dad. One Christmas Eve I took my kids to have afternoon tea with him at his home on Sydney's north shore. He was waiting for us in the lounge room, sitting before a blazing log fire.

It was about 32 degrees outside. "Dad, what's with the fire?"

"I was cold," he said. Right! Dad was even wearing a sweater.

So on one of the hottest of summer days, we had afternoon tea in front of the fire. It was a truly memorable Christmas Eve.

You do have to laugh sometimes when you're caring for someone with dementia – if you didn't you wouldn't be able to cope.

People often mistakenly think that it doesn't matter what you do with people with dementia; they don't know what's happening anyway. Well many of them do know what's happening. Not all of the time but much more than people think as I am sure most of you would know.

Since becoming President of Alzheimer's Australia I've met many people who have been touched by dementia.

Late last year we undertook consultations with people with dementia and their family carers on how the health and aged care system could be changed to provide better services and support to people with dementia and their families.

I had the privilege of taking part in the first of these consultations at Parliament House, Canberra, following our Fight Dementia march.

The stories told at this meeting reminded me again of the urgent need to improve services and support and made all of us at Alzheimer's Australia even more passionate about our cause.

It was impossible not to be moved by the stories we heard; not to marvel at the courage it must have taken for people to get up and share them with us...to admit they were no longer in control of their minds – a fate I am sure none of us here today would wish to ever experience.

One woman was a former Head Mistress who, at only 57 years old, had been diagnosed with younger onset dementia. She is a tall, imposing woman who must have commanded great respect from her pupils...

The journey she was travelling was clearly traumatic, and was made even more difficult due to the lack of services for people with younger onset dementia.

I remember so clearly what she said about the impact of dementia on her life.

“I feel diminished as a person,” she said... “And diminished as a mother in the eyes of my children.”

In total, more than 1,000 people attended the consultations in different locations.

A number of common stories came up again and again:

- The struggle to get a diagnosis. Often people with the disease knew that something was wrong years before receiving a diagnosis but were told it was just depression or normal ageing.
- Others told of the steep decline people with dementia often experience after entry into residential care. Families felt that the facilities failed to assist the person in retaining their mental skills or mobility.
- A few family carers said they felt they'd failed the person they loved at the end of their life because staff would not observe the wishes of the person concerned.
- Some spoke of the difficulty of getting access to care in the community and the lack of respite that was flexible or appropriate for people with dementia.
- Other family carers reported that patients with dementia admitted to hospitals were left unfed or experienced falls because staff were unaware they had dementia.

Our report of those consultations was released on Easter Monday broke all our media records. An audience of 16 million worth \$2 million in advertising equivalent.

These stories show how urgently we need to increase the level of understanding and skills in dementia care across the health sector and the community and why Alzheimer's Australia will closely monitor the government's commitment to reform the system so that people with dementia and their family carers receive the best care possible – sooner rather than later.

Of course there were good stories too, of excellent care and where it had made so much difference to the lives of the family carers. We want these kinds of stories to become the norm – not the exception.

Alzheimer's Australia market research shows that most Australians underestimate how many people have dementia; many are unaware of the medications that are available; many do not know that younger people have dementia and only half of all Australians know that there are ways to reduce the risk for dementia – and many of them are unaware of the benefits of diet and exercise.

Yet at the same time millions of Australians have been personally touched by dementia... and also by the negative attitudes that exist in the community about the disease.

We need the wider Australian community to recognise the importance of making our society dementia friendly.

We need a society where:

- People with dementia are not discriminated against in the services they seek.
- People are not defined by their diagnosis but by the person they are.
- The diagnosis of dementia is not a passport of social isolation and stigma.
- We learn patience in communicating with people with dementia.

In caring for dad I learned that the social dimensions of the disease are at least as important as the medical.

It's not easy to come to grips caring for someone who is no longer the person you remember; whose different behaviour and emotions sometimes baffle you as to the best way to respond.

It's a sobering moment coping with someone you love who may have depression – something that often affected my father and made me feel incredibly sad.

There are times when you're caring for someone with dementia when you feel very much alone; when friends and even sometimes family members seem to fade away and stop visiting or calling. It's not because they don't care, but rather they don't quite know how to handle the reality of the situation.

In spite of our best efforts, so many people consider dementia as just a "normal" part of ageing. They have difficulty seeing the difference between the natural changes in memory that occur as people get older and the devastating experience of dementia.

Earlier this year I spoke at the International Research and Standardisation in Alzheimer's Disease conference at the Melbourne Brain Centre.

I told that audience that the advocacy of Alzheimer's Australia will not go away. We have determined our next goals and will be vigorously pursuing them.

But if we are to succeed in our advocacy we need a still 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 do 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. I am sure that by working together, we can beat it.

Thank you