

Dementia is a national health priority
The Private Healthcare Australia Conference 2012

Park Hyatt hotel,
Melbourne

15th November 2012

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I'm delighted to be here today; to have the opportunity of talking to you about the passion and commitment needed to change social attitudes and our health and care system.

I'm talking on behalf of the thousands of Australians, both family carers and people with dementia, who have courageously told their stories over the last 30 years.

These are the people who have made possible some of the almost revolutionary changes we have seen in recent years in the policies and programs shaped to assist people with dementia and their family carers.

Australia has achieved this ahead of the rest of the world.

Many of you would be aware that in August this year the standing council of health ministers made dementia a National Health Priority Area.

I wonder what impact, if any, that headline or news item might have conveyed to you.

Those of you whose families, like mine, have been touched by dementia might perhaps have thought "not before time"...and then gone on to ponder what difference the decision would make to the daily lives of people struggling with dementia.

Some of you might have wondered why dementia had not been made a national health priority area before.

And perhaps for others, it probably just passed by as another piece of health news.

For me as a journalist every news item has a story and it is the human story of dementia that drives me in my role as the President of Alzheimer's Australia.

When I heard the news about dementia being made a National Health Priority Area, I couldn't help but think about the family carers who formed Alzheimer's organisations in Australia in the early 1980s to fight for services for people with dementia...what would they be feeling if they could see what their efforts have achieved.

What would it mean to them to see that dementia has been finally recognised as a health priority alongside cancer, diabetes and heart disease?

A journalist has the opportunity and the privilege to reflect on the changes that are taking place in society...and I often count my blessings in this regard.

It is only a short while, since the turn of this century actually, that people with dementia have been empowered to advocate for themselves, and to express their own views about the care and support that will best meet their needs.

It is almost 12 years since former Governor General Sir William Deane, accompanied by a number of people with dementia, officially opened the 2001 Alzheimer's Australia conference in Canberra.

The emotion generated on that occasion by men and women with dementia speaking out for themselves was yet another turning point in the history of our organisation.

Having cared for my own father, who had vascular dementia the second most common dementia after Alzheimer's disease – it accounts for 50 to 70 per cent of all cases – I know the tears and laughter that caring for a person with dementia can bring.

My father did so many things that were out of character as his disease progressed, but it never changed the essential person that I loved and knew. That person, my father, was a unique individual who shaped my life and my interest in journalism.

He was as journalist, editor and author and I followed in his footsteps.

I'll never forget the Christmas eve I took the kids up to have afternoon tea with dad 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! So we had afternoon tea in front of the fire on one of the hottest of summer days...it was a memorable Christmas eve.

My experience as a family carer is what has ignited my passion and interest in bringing together my love for journalism with being an advocate for causes I strongly believe in.

As a family carer I experienced all of the frustrations of having to tell staff in hospitals that my father had dementia only to find little understanding of what that meant or the care needed.

How little understanding there is of why a person with dementia might leave their food because they simply do not know it is there, or that it is for them...

... How confusing it is to be in an environment that is so strange and driven by the emergencies of the moment.

There's plenty of evidence that shows people with dementia stay in hospital longer and have worse health outcomes compared to people of the same age without dementia being treated for the same medical conditions.

Dad was in and out of hospital in the last 12 months of his life – (he was 10 days shy of his 90th birthday when he died) 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 once 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 can become confused, agitated and sometimes aggressive.

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

In the last week of his life, when he was admitted to a leading 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 do this themselves and can't afford to pay for carers?

Is Australia's health system prepared to let our most vulnerable people starve because of staffing constraints?

In so many ways our society still makes life so difficult for people with dementia and their families.

The journey starts with the horrible uncertainty of unexplained symptoms; the sudden difficulty doing things that once were second nature, disturbing forgetfulness, and changes in mood and behaviour.

While diagnosis can be a relief for some, the persistent and pervasive stigma and social isolation is felt by others.

The diagnosis is, after all, confirmation of an incurable, degenerative and ultimately terminal disease.

Many people of course live with the increasing uncertainty and trauma without ever being diagnosed at all.

You might well wonder how someone without a diagnosis will attract the support and care they need during what, in any circumstance, is a difficult journey.

Well, the answer is, they often don't. There is a dramatic contrast between the experiences of those people who have benefited from timely diagnosis and care services, and the overwhelming majority of those who are traumatised by poor diagnosis, lack of information, and care services that have little understanding of dementia.

It is a shocking reflection on our society that we still think in terms of restraining individuals with dementia with 'difficult' behaviours, either physically or through medical sedation.

It seems the negative attitudes and stereotypes of the mental institutions of the 19th century endure within the nicer-looking physical environments of today.

We have heard in recent months about the hidden reliance on anti-psychotic medications to control people with behavioural and psychological symptoms who, in most cases, simply need personalised care.

These medications were developed as a treatment for schizophrenia, and although they are not approved for people with dementia except as a last resort, Alzheimer's Australia is aware that they are used in up to 25 per cent of cases.

The shocking truth is that these drugs are dangerous. While around 20 per cent of people receiving them can expect to derive some benefit, the remaining 80 per cent can only expect to suffer the side-effects such as an increased risk of falls, stroke and death.

It is unacceptable that we as a society allow this practice which results in hundreds or even thousands of avoidable deaths each year to continue.

While I believe that there are real problems with the way antipsychotic medications are used among people with dementia, there are four drugs that have been developed to help alleviate the symptoms of Alzheimer's disease.

These drugs don't work for everybody, and they will only ever work for a limited amount of time but we do hear over and over again from consumers that these drugs can provide a lifeline which helps them to manage the symptoms of dementia and to stay longer at home.

You can imagine our concern therefore when earlier this year, the government announced a review of Medicare subsidies for these four medications.

It is already very difficult for people to qualify for these subsidies, and to remain eligible they have to demonstrate a substantial improvement in mental abilities within six months.

It will be for the pharmaceuticals benefits advisory committee to make a decision on the review but we will oppose any move to deny people with dementia the only medications that may help relieve symptoms.

Perhaps the saddest stories I hear as I meet with family carers are about the difficult decisions that need to be taken when someone moves into residential care.

After years of love, care and partnership, many people tell us that after a few weeks in a nursing home, the person they love becomes unrecognisable...often as a result

of being drugged with medications they don't need; dispirited by the lack of social engagement or communication with staff or other residents, and having to live in an environment that is not well designed or appropriate for people with dementia.

So you will appreciate why for me, the story that dementia has been made a National Health Priority Area, has some considerable significance in terms of achieving a sea change in attitudes.

I truly believe we have the opportunity to do this.

Since the implementation of the dementia initiative in 2005 Australia has shown leadership to the rest of the world in tackling dementia

This year's commitment from Prime Minister, Julia Gillard and the Minister for Mental Health and Ageing, Mark Butler, to tackle dementia as a priority issue within the government's *Living Longer. Living Better. Aged Care Reforms* goes further.

The government is to be applauded for its commitment to tackling dementia.

There are, as always, doubts about the adequacy of the funding, the speed of the reform process and whether in Australia's three-year cycle of elections long term sensible social reform can be sustained.

But for the moment we are optimistic and excited that the government has adopted a policy framework that takes a positive stance in confronting long-neglected issues in dementia.

One of the things I'm particularly pleased about is the \$4.5 million over three years that the government has committed through Alzheimer's Australia to a world first national dementia risk reduction program, *Your Brain Matters*.

We have the opportunity to tell Australians about the links between physical and brain health.

Did you know that one year of regular moderate physical exercise may be enough to offset two years worth of normal age-related shrinkage of the hippocampus, the part of the brain that is responsible for memory?

I was taught in high school that our brains are on an inevitable decline from our twenties.

But we now know that if we look after our brains, even in later life, we can actually grow new brain cells and promote connections between them.

There is also an emphasis in the *Living longer. Living Better.* package on empowering consumers to take decisions in partnership with service providers about the services that will best respond to their needs.

There is a greater emphasis too on the community care that is desperately needed if the political rhetoric of enabling people to stay at home longer is to be fully achieved.

By 2014, all community care packages will be offered with options for consumer directed care, where consumers can be real partners in care.

Living Longer. Living Better. also included \$268 million over five years in funding for dementia services, and these elements of the package break new ground.

There is, for example, a commitment to achieving timely diagnosis of dementia through training doctors and nurses.

There is also a commitment to making hospitals safer places by training hospital staff and having protocols in place to better recognise people with dementia and cognitive impairment.

There is recognition of the additional costs of dementia care, in both the community and residential care settings.

And, for the first time there is a commitment from the government to support younger people with dementia – those people who receive a diagnosis under the age of 65.

Funding for this group could not have come at a better time, with the Australian Institute of Health and Welfare releasing new figures just six weeks ago that put the number of Australians with younger onset dementia at 24,000 – a much higher figure than any of us anticipated.

The one element missing from the government's package is investment in dementia research, something that is significantly underfunded in Australia in comparison to other national health priority areas in relation to health and care costs, disability burden and prevalence.

In 2011-2012, the National Health and Medical Research Council's investment in dementia research was \$24m. Over the same period the NH&MRC provided \$159.2m for cancer research and \$92.4m for cardiovascular disease.

Australia has some of the world's leading scientists in the dementia field, yet their work receives only a small fraction of the research funding allocated to other health priority areas such as cancer or heart. In the past 10 years this gap has been growing, something that greatly concerns Alzheimer's Australia.

It appears the biggest problem is the lack of capacity within the sector to compete for limited funds. While research fields such as cancer and cardiovascular disease have been successful in attracting the best and brightest new scientists to their fields, this is a particular area where dementia is being left behind.

Over the past 10 years, there have been just 56 grants, scholarships and fellowships awarded to new dementia researchers through the NH&MRC.

In comparison, the number of grants for cancer, cardiovascular disease and diabetes are around 700, 500 and 250 respectively.

As part of Alzheimer's Australia's *Fight Dementia Campaign* we are seeking a new investment in research of \$200m over five years in the 2013-14 Federal Budget. This relatively modest amount would bring the total investment in dementia research through the NH&MRC up to just over \$60 million per annum or around one per cent of the costs of dementia in health and aged care.

This funding is needed to build capacity in dementia research by supporting emerging researchers and to establish a strategic fund to support major new dementia research projects.

It is vital that people are given hope and in my view it is through investment in dementia research that we can give do this; that we can give people the hope of working towards a world without dementia.

From an economic perspective, dementia already costs the Australian health system at least \$4.9 billion each year. It will become the third greater source of health and aged care expenditure within 20 years if we do not find ways to treat and prevent dementia.

We all have an interest in a dementia free life and let me take the opportunity to invite you all to become a Dementia Champion. You will take a minute to fill out the champion cards on your table so that you can add your voice to our important cause.

I think dementia research is at the cutting edge of medical science. Every day there seems to be some new insight into the working of the brain.

We now understand the importance of intervening earlier at the pre-symptomatic stage and there is some cautious optimism that within a few years we will be able to identify those at risk.

There is fascinating research... for example the research exploring the possibility of transplanting stem-cells into damaged areas of the brain as a way to offset age-related memory loss.

Recent years have, however, been marked by failures rather than successes in the development of new medications. Perhaps this is because the focus of clinical trials has been on patients in the later stages of dementia, when the brain is already badly damaged.

Whatever the reason, we need to work harder to understand the causes of dementia and the interplay of physical, environmental and genetic factors.

Until medical science comes up with better treatment we have to do all we can to tell Australians about how they can promote their brain health and possibly protect themselves against dementia.

That is why Alzheimer's Australia's new program *Your Brain Matters* is so crucial.

Over the last four years we have developed the intellectual capital for this program. We have invested considerable time and energy in drawing together the evidence base from research across the world that shows how environmental and lifestyle factors can reduce a person's risk of dementia.

The evidence confirms that by adopting a healthy lifestyle, we are more likely to live longer with a healthy brain.

Yet market research commissioned by Alzheimer's Australia shows that 50 per cent of Australians are unaware that they may be able to reduce their risk of dementia. Even among those who are aware there is something they can do to reduce risk, approximately 60 per cent are not aware of the potential benefits of reducing high blood pressure, cholesterol and avoiding head injuries.

Our aim is to encourage people, young and old, to embrace this program and take care of their brain just as seriously as they do the rest of their body.

To do this we have simplified the program to three key messages:

- Keeping your brain active matters. Regular mental activity and new learning builds up brain reserve that can help keep your brain functioning well.
- Being fit and healthy matters. This is something we all know, but what is unknown to many is that regular exercise helps to grow new brain cells and keep them alive.
- Looking after your heart matters. Keeping blood pressure, cholesterol, blood sugar and weight at healthy levels also plays a big part in brain health.

To ensure we reach the widest audience possible we believe it is essential that Alzheimer's Australia partner with organisations that have similar interests.

And this is where we need your help and experience in getting our message out across Australia. People need to be made aware that their physical and brain health are linked, and that by looking after one, they are looking after the other.

It is a no-brainer to develop preventive health programs in a way that gives people the double benefit of improving their physical and brain health into old age.

And it wouldn't require excessive funding to include brain health messages in preventative health campaigns that have already been developed for smoking, diabetes, heart and excessive alcohol consumption.

I would welcome the opportunity of exploring with you how we could get our messages out through your newsletters or other mediums.

Over the years, it has given me huge satisfaction to use my profile and experience in support of important social issues as varied as dementia, macular degeneration, arthritis and HIV/AIDS.

Macular degeneration, because my father had that disease too. It affects one in seven people over the age of 50. We have successfully raised awareness but we are still trying to get people to realise that if MD is in their family they have a 50 per cent risk of getting the disease.

Arthritis, because my daughter Kate was diagnosed with a rare form of juvenile arthritis when she was a teenager and I've been involved in the arthritis cause ever since.

HIV/AIDS because when I was Editor-in-Chief of the Daily & Sunday telegraphs in Sydney I returned a phone call from then Health Minister, Neal Blewett, who told me the government had a job they wanted me to do...

I am still actively involved in all of those causes but the one that occupies a great deal of my time is Alzheimer's disease and dementia.

In my opening remarks I said it was the human story of dementia that drives me in my role at Alzheimer's Australia. I've met many people with Alzheimer's and their carers since becoming president and I am constantly reminded how much we, as a society owe, to people who take on a carers role.

Last week I was at a reception at Government House in Sydney to mark the 30th anniversary of Alzheimer's Australia New South Wales.

Barry, a carer spoke about his wife Joan, who has Alzheimer's.

He spoke well and movingly about their life together; how everything had changed after her diagnosis.

'We used to talk about retirement and what we'd do, he said 'but retirement is never mentioned these days.'

'But look', he went on, 'what better thing could there be than looking after another fellow human being. It's a privilege to be able to do what I do....'

And indeed it is... and it's a privilege to be able to try to make a difference to others in community especially people with dementia.

There's no doubt in my mind that if we can succeed in the difficult task of raising community awareness and encouraging a change in people's behaviour, to get Australians to think positively about their physical and brain health, that we will have an increased chance of moving towards a world without dementia.

Yes it is an ambitious goal but one worth fighting for and with the help of my colleagues at Alzheimer's Australia I intend to do exactly that.

Thank you.