

MARK BUTLER MP
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Thank you Ita and congratulations on your appointment as National President of Alzheimer's Australia.

Can I acknowledge the traditional owners of the land we now call Brisbane and acknowledge her Excellency, the Governor General. Thank you for your wonderful contribution to the opening of today's conference.

To Glenn Rees and Victoria Beedle for having us in Queensland and particularly to all of the delegates for taking time out from the things that you do day-to-day to come together and develop some ideas for the country to do better in the area of dementia.

It is really a pleasure to come and talk to you a little about how the challenge of dementia fits into our thinking, particularly about aged care and more broadly in the health reform agenda and what I describe as the ageing agenda.

It's often thought that we politicians only ever want to see purely positive media, but I was genuinely glad to see that already, before the conference even opened, Ita had got significant media coverage this morning over her contribution last night at the welcome ceremony.

We all have a shared challenge to lift the profile of dementia and grab the opportunities that are presented to us for change. Aged care reform is a very significant opportunity to do better than we currently do for families living with dementia. So, I was pleased to see the media this morning even though it got me up early this morning to scratch out some slightly different remarks to the ones I had originally intended making.

I want to start with some comments about ageing.

The King's College University in Britain released some research late last year which I think is really interesting. They surveyed over a thousand Australians with similar numbers in seven other countries. They asked a series of questions - among others they asked, "What are the two or three things that most concern you about your country?" Like most other nations, Australians nominated the economy and climate change at the top of their list. But uniquely, Australians nominated mental health as their third major concern and ageing as their fourth. 31 per cent of Australians nominated ageing - far and away a higher response than comparable countries with similar demographic profiles; 20 per cent in Britain with a higher median age than ours and only 7 per cent in the US with a very similar demographic profile to Australia.

So, something is happening in Australia to promote awareness, understanding and concern about the challenge of the ageing. I think that has a lot to do with the impact of the Intergenerational Reports that Treasury has published. The reports paint a dramatic picture of our fiscal capacity to deal with on average, a much older population with a different dependency ratio, as they call it - that is the number of people paying taxes relative to the number who are out of the workforce and rely on significant government services.

And I've said this a couple of times before but I am frankly sick of the approach that some economists particularly take to the question of ageing as if it is at best an inconvenience and

at worst a downright problem.

We need to find a much more positive frame about ageing.

It is only 100 years ago that Australians died on average in their 50s, and I don't want to go back to then.

We worked for a long period of time - medical researchers, public health experts and Australians changing their own lifestyles not to die in our 50s. We now pretty much as a matter of right are able to look forward after we've finished raising our families, after we've finished the peak years of our work, to some time to smell the roses, time to travel, time to spend with our grandchildren and then hand them back as soon as they get ratty; also time to do a little bit of study, part-time work and volunteering.

This is something that should be celebrated. It is one of the great achievements of humanity and deserves a much more positive frame.

It does have its challenges and Treasury focuses significantly on the fiscal element. There are also the challenges of diseases associated with ageing and the principal one among them, as you know, is dementia.

Dementia, in my view, is one of the two emerging epidemics in Australia - the other being diabetes. As her Excellency said, you know the prevalence data much better than me, and you know it's scary for us in terms of the increase in that prevalence over the course of the next 20 years.

Prevalence studies show that, if there are no significant inroads into the prevention and treatment of this condition, prevalence doubles or thereabouts over the next 20 years.

There must be three levels to our response - not just the Government's response, but our response as a community.

The first - her Excellency talked about already - is awareness and understanding. The second is research and prevention, and the third is treatment and care.

And I just want to say a few things about each of those three.

One of our greatest challenges in this area is for the community to develop a clearer understanding, as her Excellency said, of what dementia is and what it isn't. There is still an enormous level of mythology and stigma around this condition, not assisted by the fact that we essentially don't understand the cause of Alzheimer's in particular.

The role of Alzheimer's Australia here and the contribution they make to this cause is utterly critical. We need this country to strike a balance between normalising this condition as one of a number of major health conditions we face in this nation, while also reinforcing its gravity.

Normalisation requires human stories.

Ita referred last night, I understand, to the recent coverage of mental health. I think mental health is a wonderful example of the way in which human stories have over a relatively short period of time significantly reduced stigma, raised awareness and created a level of political momentum that you saw reflected in the results of last week's Budget.

And that has significantly been built on personal stories. It's hard to remember how difficult

and unusual it was for Jeff Kennett to talk as openly as he did about his experiences with depression only 10 years or so ago - since then there have been countless public figures talking very openly about their experience with mental illness, not only with depression but other types of mental illness; John Brogden and his attempt at suicide, Geoff Gallop's fight with depression, and Jessica Rowe's experience with post natal depression to name just a few. Many, many others as well, have done the same. Patrick McGorry, as former Australian of the Year gave all of those stories a shape and a profile that perhaps they had not had before. But the power of those personal stories I think is instructive for all other conditions facing similar challenges around awareness, understanding and stigma.

Now, every area is different and I don't suggest that the dementia sector should simply copy the handbook in mental health or breast cancer. But we must build on top of the scary graphs, the scary numbers that are increasingly well understood in Government about the prevalence of dementia. We must build on them with personal stories. I hear them all the time - there are hundreds in this room - but I don't think they are often heard more broadly in the public realm.

In Australia, I would suggest that the vast majority of the public only really know the Hawke family's story and perhaps a fictional account by Ruth Cracknell in *Mother and Son*.

Beyond that, for those who have not been touched personally by dementia, it remains quite an abstract and scary condition. And that needs to change.

The Government has a role in changing that obviously, but Alzheimer's Australia will continue to be essential to that challenge. I think your appointment of one of Australia's great communicators, Ita, as your President is a wonderful step in that direction. But it is going to be a significant body of work which all of us need to undertake.

The message of balance with normalisation, I think, is incredibly important. The lack of understanding in the community doesn't reflect the gravity of this condition. We need to reinforce that dementia is an incredibly serious, ultimately fatal condition. But we need to also deal with the misconception and the myth that life ends as soon as you are diagnosed.

There are a vast number of people with dementia who still live at home, who still lead lives in their community.

Normalisation and balance will see a decline in fear and stigma associated with dementia, which will improve our capacity to get timely diagnosis.

Alzheimer's Australia's work in this area is incredibly important. As Ita reported, one of my first jobs as the Minister for Ageing was to launch a number of tools aimed at families and at General Practitioners to assist them to make much more timely diagnosis than they currently do of dementia.

We know that an earlier diagnosis better places a person diagnosed with dementia and their family to access the support and treatment that they need.

As you know better than me, dementia used to be regarded as inevitable and inexorable. It's just one of those things that happen as you get old and there's nothing you can do about it. Then, we were encouraged to do crosswords or, more recently, Sudoku puzzles to stave it off.

Our understanding of this condition is far more layered now. We understand increasingly what causes it and how we might be able to delay or prevent it.

Our knowledge in this area is growing incredibly fast.

One of the other responsibilities I have as Minister is to oversee the National Health and Medical Research Council, the principal body for medical research in this country. There are a number of incredibly exciting frontiers of knowledge that I see every day – dementia is one of those frontiers. Our increasing knowledge about what might cause Alzheimer's is informed by the mapping of the human genome. Genomics and its sister field proteomics are incredibly rich fields of research and increased understanding. We have known for some time, as you know, that the risk factors for vascular dementia are the same as the risk factors for cancer and cardiovascular disease; the unholy trinity of cigarettes, booze and saturated fats. But increasingly we are coming to understand they are probably risk factors for Alzheimer's as well -the old adage of "healthy body, healthy mind" at play again.

There are a number of NHMRC projects under way that are trying to explore those ideas. For example, one is measuring the impact of dietary fats on the development of Alzheimer's; another is exploring new therapeutics to inhibit certain proteins that are thought to be active in the onset of Alzheimer's.

While we now spend much more as a nation than we did on medical research into dementia 10 years ago, I am conscious that we spend vastly less than on a range of other major health areas such as cancer, cardiovascular disease and diabetes.

Last week I announced a strategic review of medical research in this country. It's been 13 years since we had our last review, the Wills Review, which was intended to take us up to 2010. This is something the research sector has been calling for, for a significant period of time. And one of the things I'll be asking the people who conduct this review to focus on will be how we better align our research effort with those things we identify as our national health priorities.

It's also important we try and link the dementia challenge to the preventative health agenda. As you know, we have established the first ever preventative health agency and our increasing understanding of what causes dementia, particularly Alzheimer's, and how we might forestall it should ultimately become a part of the Preventative Health Agency's work. The ageing agenda, I think, should very much rest on the goal of healthy ageing, and dementia is central to that.

The third challenge, of course, is how we deliver good treatment, care and support to those who are living today with dementia and their families. The scale and the complexity of dementia means that the condition doesn't fit neatly into one of the health sectors; primary health, acute care or aged care. It touches all of them. We know that the challenge of people presenting to emergency departments with dementia is a huge one. We know that the challenge of getting GPs to better understand dementia and to be able to provide diagnosis and support is also significant. But, by and large, dementia has been treated, within the Commonwealth Government at least, as a part of aged care, and I want to talk briefly about our aged care reform process and how that might impact on the dementia challenge.

I've been working with the aged care sector now for almost 20 years. I've visited aged care facilities very regularly for all of that period and I've seen quite profound changes in the sector over that time. Firstly, community care did not exist in a formal way in the early 90s. But secondly, I've seen a huge increase in the frailty and complexity of residents in aged care facilities, and the most striking cause of that increase in frailty and complexity is the prevalence of dementia. When I started visiting aged care facilities, there was usually a lock-up dementia ward out the back, which was a pretty grim place. They're not perfect places now, perhaps, but we've come a long way in 20 years. Dementia is no longer a small part of the aged care facility; it's now right through the facility.

Last week, the AIHW released a review of the aged care funding instrument. The Australian Institute of Health and Welfare said that about 53 per cent of residents in aged care facilities now have been diagnosed with dementia. That figure is striking enough, but it is lower than the figure that many aged care providers report to me. I think Bupa reports about 70 per cent and some report higher. So the challenge of dementia and how we deal with it in aged care is utterly central to how we do aged care in the future.

The Productivity Commission will release its Final Report on aged care reform in June. Obviously, we're not going to pre-empt our responses to it, but our guiding principles in aged care reform are threefold: that older Australians should be able to access the care and support that they need when they need it - the question of timely access, calibrated access, is incredibly important. Secondly, that older Australians deserve greater choice and greater control over their care arrangements than the system currently provides them. A very clear message I hear time and time again is that the sector as it now operates is very "one size fits all" and is not really good at meeting individual needs and preferences. And the third, which may be the hardest, is how we develop funding arrangements for aged care that are fair and sustainable, not only for older Australians and their families, but also for taxpayers more broadly.

These are going to be the principles that I'll take to the reform process which will start from early July. I think that there also needs to be a strong focus on better links between aged care, restorative care and primary care, and dementia must be central to this. This is a wonderful opportunity for Alzheimer's Australia, and for other organisations working in the dementia field to really bring dementia to the front of the policy agenda.

Aged care reform is something the Prime Minister has committed to in this term of Government. It is something that will increasingly become a focus of the Government in the second half of the year and I really do encourage Alzheimer's Australia to make sure you are front and centre in the debate, sticking your hand up saying that aged care nowadays is largely about dementia care, and an aged care reform response which doesn't have at its heart a dementia response will not be a proper response.

I give that advice to get engaged, but I also give the commitment that I am passionate about dementia. I'm genuinely passionate about aged care reform and have been for a long time, and I'm passionate about the idea that we need a better, calibrated response to the challenge of dementia. So, I look forward to working with all of you, with Glenn and with Ita and the state organisations, during that discussion and the development of a response over coming months.

So, now for some good news. I am pleased now to ask Glenn and Paul Gregerson from Bupa to come and join me to announce the inaugural recipients of grants under the National Quality Dementia Care Initiative. This is an Initiative that has been funded jointly by Alzheimers Australia, by Bupa, and also by the Wicking Trust, a wonderful organisation set up by the Wickings to support the development of a better response to dementia.

There are two outstanding elements of this Initiative. The first is that it focuses on research that can be translated very quickly into practice. We have to make sure that our wonderful research in the country is translated as quickly as possible into getting better outcomes for patients, consumers and their families. So that's the first wonderful element of this initiative. The second is the involvement of consumers in the selection process. No one knows better whether or not these initiatives are going to meaningfully change their lives than consumers and their families themselves. There were 44 applicants in this round, judged against the potential of their project to improve the lives of those living with dementia. I'm told they were all outstanding applications, but there can only be one two winners. Each of them receive a

\$250,000 grant for their project.

The two projects selected in this round I'm very pleased to announce are firstly the "dementia enabling environment" project and, secondly, the "personalised care management strategies" project. The dementia enabling environment project will provide guidelines for the creation of dementia-friendly environments, including recommendation for the design of aged care homes. This project has been proposed by Alzheimers Australia WA and will engage architects, designers, aged care organisations and members of the community broadly to optimise environments for people living with dementia.

The second project awarded a grant under this initiative is personalised management care strategies, which is based upon the Montessori model – which you'll all be familiar with in the education field. This initiative is designed to reduce agitation and to promote engagement among aged care residents. It is led by Professor Daniel O'Connor from the Monash University and will teach family carers new ways to interact with their relatives once they enter a nursing home.

So congratulations. I'd like to invite representatives from both projects to come up and receive their certificates.

Congratulations again to the winners and thank you very much for giving me the opportunity to come and talk to you. I wish you all the best for the rest of your conference. Thank you.