

**PRESIDENT'S WELCOME
ALZHEIMER'S AUSTRALIA 14TH NATIONAL CONFERENCE**

BRISBANE CONVENTION & EXHIBITION CENTRE

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As president of Alzheimer's Australia I am delighted to have the opportunity to welcome you all to the 14th national Alzheimer's Australia conference.

I have been told that Alzheimer's Australia conferences are remarkable in many ways. In particular they are characterised by a great deal of energy, fun, hard work and commitment.

I know that you come to this conference with a list of the workshops and talks you are eager to attend. I also know that much of the learning over the next few days will occur through informal chats in the hallways and over morning tea as you share the experiences, ideas and unique perspectives that each of you bring to the meeting.

It's my hope that you all will leave this conference with renewed energy, optimism and some new ideas about how to contribute to improving the quality of life of people with dementia.

I've only been in this role for a few months – although I've had experience of the work of Alzheimer's Australia as a member of the new advisory board since 2008 and also as a new Alzheimer's ambassador – but in the short time I've been president I have been impressed with the level of activity and the amount of work that has been carried out by the organisation.

I've already been asked many times why I took on the position of president. I suspect the reasons are not very different from those that bring you here today.

- We understand the effect dementia has on the individual and their families and friends.
- We've experienced – like I have – the journey of dementia with someone we care about – in my case, my father
- And we know the tears, the laughter and the mixed emotions that are part of it.

We also know that much, much more needs to be done to tackle dementia in Australia.

The theme of this conference “take a different view” is a challenging one and perhaps, an urgent reminder to all of us of the need to spread an understanding of dementia and, at the same time, to ask the general community to also “take a different view”.

As a professional communicator I find myself puzzled by dementia; puzzled by the disease itself and the whirlwind that can hit a family when someone receives a diagnosis; but puzzled too by the response of the community to dementia.

There are 269,000 Australians with dementia. By 2050 this number will have risen to almost one million. Alzheimer’s Australia has been raising awareness for many years as well as providing information about dementia and risk reduction.

The media has been extremely helpful in covering the issues and I thank them for it. We value their support but there is so much more to be done.

I want to put three questions to you.

- Firstly, is the message getting through?
- Secondly, why isn’t there greater resonance with the issue of dementia at a community and political level?
- And finally what exactly do we have to do to achieve “a different view”?

Recent Alzheimer’s Australia market research shows that most Australians underestimate how many people have dementia; many are unaware of the medications that are available 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.

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.

I would think there are few Australians who have not been touched by dementia. So why isn't there a greater resonance with the issue of dementia at a community and political level?

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.

As a result of ageism, dementia isn't considered to be much of a priority; it's a poor cousin to other diseases that affect people at younger ages.

Yet the care and cost of dementia is putting significant pressures on the community, the family and the government's health and welfare budget – and will continue to do so at an alarmingly increasing pace.

Why have we got the message while so many others seem to turn a deaf ear to our warnings?

Maybe our voice is just not loud enough. Do you think that could be it?

Perhaps mental health has shown us the way by shouting their important messages from the roof tops.

We certainly haven't succeeded in translating fear into action as cancer has done...

Can you believe there is no culture within the commonwealth department of health and ageing that recognises the need to tackle dementia across the whole department? Consequently there has been no action in the last decade on issues of primary care, timely diagnosis, preventive health and improving hospital care for people with dementia.

So what do we need to do to achieve “a different view”?

It is now six years since the former liberal government implemented the dementia initiative and so doing recognised dementia as a health priority. It was a landmark decision in recognising the needs of people with dementia.

But there are no guarantees in political life – and we forget that at our peril

As many of you would know there were no new measures for dementia in the recent budget – nor have there been in the life of the current Labor government.

The health reforms have passed dementia by.

And although the transformational approach of the productivity commission in their *caring for older Australians* draft report may have a number of benefits for people with dementia, it was disappointing that the commission failed to acknowledge dementia as the core business of aged care.

I hope that in the final report, dementia is not featured as just another chronic disease such as diabetes, but rather as a fundamental issue for aged care.

Because if the reform of aged care is not accompanied by a funded comprehensive strategy to address dementia it will fail people who have the disease and their family carers.

We cannot and should not embrace reform without a comprehensive and funded strategy for dementia.

I suspect that over the next 12 months we will all need considerable energy if we are to succeed in putting dementia centre stage in the 2012 budget and beyond.

The government can be in no doubt about the passion Alzheimer's Australia has for the task that confronts our nation.

what we need now is a vision for dementia, one that recognises that dementia is not just a problem for older adults but a chronic disease that needs to be addressed through research, prevention, treatment and high quality care. It is a disease that develops decades before diagnosis.

A comprehensive strategy to tackle the dementia epidemic must include:

Multiple strategies to achieve better quality of life for people with dementia and their family carers.

These were set out by Alzheimer's Australia in *dementia: facing the epidemic* and I suggest we need to be more determined in telling government to act on it. We need to get government to listen.

It is essential to increase public awareness and reduce the stigma associated with dementia.

The disease raises so many issues that are sensitive and difficult to address; issues that often some people find it easier to discussing, but we do need to talk about such matters – they won't go away by not talking about them...

...and I'm thinking here about questions that relate to sexuality and dementia, providing person-centred services to people who may be gay or lesbian, or more recently in tackling end of life issues including euthanasia.

Alzheimer's Australia has made some truly positive steps forward in raising awareness and tackling such sensitive issues.

As well as continuing to do this we need to do more to persuade government to fund an awareness campaign in order to promote a greater understanding of dementia.

At the same time, we urgently need to improve the quality of care for individuals with dementia and their families. The productivity commission inquiry gives us a once in a generation chance to be involved in real reform of aged care.

Alzheimer's Australia has already put in a number of submissions to the commission. We look forward to working with the government as it considers how to positively implement these transformational reforms.

We can take some satisfaction that many of the major reforms in the productivity commission's draft report owe something to the advocacy of Alzheimer's Australia over a long period including:

- Strengthened assessment and information
- Giving a higher priority to community care including respite care
- Separating accommodation and care in the funding of residential services.
- A focus on consumer directed care

As we continue to press the urgency of our case lets not overlook the need for action in areas that fall outside of the traditional "aged care".

we need to advocate for timely diagnosis to ensure that individuals with dementia and their families can access the services and supports they need and to enable them to plan for the future.

We also need to make hospitals safer places for people with dementia. Dementia risk reduction must be implemented as a matter of some urgency.

And lastly, there is an overwhelming need for greater investment in research. Dementia remains the poor cousin in the research community. Given its increasing prevalence and its impact on every aspect of aged care I am at a loss to know why this is.

Without adequate funding it is difficult to imagine how we will reach our goals of gaining a better understanding of the causes of dementia and learning how to reduce

the risk of developing the disease. We need the most urgent action in the area of research.

I'm sure there are other issues you will want to bring to the table...over the next few days you will have an opportunity to see how we can fit these elements together and get closer to a new vision of dementia not only for ourselves but for the larger community.

And while we ask ourselves tough questions, it's also important to recognise how far we have come and how much Alzheimer's Australia has achieved over the last 30 years. We can be proud of that; but not complacent.

I hope you and the family carers who founded Alzheimer's organisations in the early 1980s are proud of what Alzheimer's Australia has achieved as a consumer organisation, in continually pressing for the choice and flexibility in service delivery and most importantly, support for people with dementia and their families... such as the living with memory loss program, the national dementia helpline and individual counselling services.

I know, without them many families would admit to finding it impossible to imagine how they would have found their way through the journey of dementia.

The issues I've touched on this evening are just a few of the many topics that will be covered at this conference. It's important for all of us to get the balance right between tackling these serious issues and having fun.

So I hope this conference will be successful in both provoking and stimulating thought and enabling you all to have a good time; to enjoy the company of others and come away from this meeting with new ideas, energy and new friends. Thank you all for being here.

Please join me in thanking Alzheimer's Australia Queensland and the team who have put this conference together for the fantastic effort they have made to make it all happen.

Now it's time for us to get started by looking up – for a completely different view....