

H2O HEALTH SUMMIT

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MELBOURNE

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Holistic Approaches to Health and Welfare from Alzheimer's Australia

Thank you for the opportunity to speak at this important conference. I should note at the outset that I am speaking here today in my capacity as incoming CEO of Alzheimer's Australia as well as a Board Member of the International Alliance for Patient Organisations. I also speak as a carer of someone with dementia.

I want to acknowledge the traditional owners of the land where we are meeting and pay my respects to their elders past and present.

Welcome other panellists

Let me begin this session by introducing you to Jan. Jan is a 76 year old woman living in a nursing home. Her family now visit once a week – it used to be more frequent and they used to take her out each weekend, but as she can no longer dress or toilet or feed herself, it has become too difficult. She is also losing her capacity to communicate. Jan has end stage dementia, the final phase of a long journey. Our challenge is to change Jan's journey and change the experiences of millions of people in our communities.

Over 330,000 Australians are living with dementia, and this number is expected to rise to almost 900,000 Australians by 2050. There is an estimated 44 million people worldwide with dementia and that number will increase to 135 million by 2050.

Jan's carers join 1.2 million other Australians looking after someone with dementia. Globally we are talking about over 100 million carers.

The rate of dementia diagnosis is increasing rapidly. Currently one new case is diagnosed in Australia every six minutes, by 2050 there will be one new case every 95 seconds – over 7400 new cases each week. The economic implications are massive.

In 2010, it was estimated dementia cost over \$600 billion, an expenditure which would make dementia the 18th largest country in the world. This figure is increasing precipitously.

So what can we do that might have made a difference in the lives of Jan and her carers?

Firstly we need to engage the health care system in providing better quality care, not just in aged care, but across the board from prevention and primary care right through the whole healthcare system. At the heart of this issue is supporting people with dementia and their carers to have choices about the care and support they receive. Too often we expect consumers to fit the services on offer. We need to build a more responsive health system that is about the experience of care, not just providing a clinical treatment.

Secondly we need to engage our communities. Dementia may be about deterioration in the function of the brain, but it is deterioration in the capacity of people to connect and belong that often has the biggest impact. We must accept that the way someone experiences dementia is partly determined by the way the community around them responds – from employers and shop keepers and banks and other businesses right through to families and friends. There is good evidence of the stigma associated with dementia. If we create dementia friendly communities, we can completely change the experiences of dementia for millions of people. And we can all make a contribution in our own small ways to improving the lives of people with dementia.

Thirdly we need to engage researchers around the world. Ideally we will find a cure for dementia in the not too distant future, but in the meantime, any advancement we can make in treatment and slowing the impact of the disease will have a real impact on millions of people. Thankfully some additional research funding has been made available in Australia, but there is so much to do and the more quality research, the better the chance of making a difference.

While focusing on what needs to be done to reduce the harm associated with dementia, it is important to remember that the majority of people will age without ever having dementia. Dementia is not a normal part of ageing, and should never be dismissed as inevitable.

It is also important to note that like other chronic diseases, there is now clear evidence that lifestyle factors can increase or decrease the risk of dementia. Research indicates that approximately half of the cases of Alzheimer's disease worldwide are potentially attributed to factors such as Diabetes, hypertension, obesity, smoking, depression, cognitive inactivity and physical inactivity. We may be able to have some impact on dementia in our own lives.

Jan's family first noticed her loss of cognitive capacity three years before she was diagnosed. Jan started to become more isolated, less engaged in her circle of friends, less able to go out and do things for herself. She started having trouble remembering things, filling in forms, managing accounts, managing her own appointments. She became anxious, not knowing what was wrong.

There were times when the family worried that people were taking advantage of Jan and a 'power of attorney' was appointed, her driving license was revoked. More and more support was needed to keep Jan in her home in the community. Some of the medication helped for a while, but then there would be periods of fairly rapid decline. It took eight years before Jan began a pattern of hospital admissions following various incidents, and then a place was found for her in a nursing home when she could no longer be sustained in the community.

Jan's journey is not unusual, and in so many ways, it is a journey that needs to change. From early diagnosis and intervention through to the care and support she received along the way, things could and should have been done better. Innovation for Jan would not just be about introducing one or two stops along the way, but about engagement across a broad range of domains, a broad range of people, a broad range of expertise and communities. This is not just about dollars or improving health systems, it is also about the way we live together, the way we support each other in our communities.

Alzheimer's Australia and others engaged in this space are pleased that innovation is starting to happen.

With your engagement and the engagement of others, we can all continue this work to change the journey and disrupt the concept that dementia is a predetermined experience.

Thank you.