

Mum, my mother, Neil's mother passed away 8 years ago. Her passing was a blessed relief for her. She had been diagnosed with dementia several years earlier and after 15 years of confusion, bewilderment, frustration, torment and unbearable distress brought about by the inexorable impact of her dementia - she was, at long last, at peace.

The vow my family then took was to work as hard as we could to ensure that other families did not have to go through what we experienced.

Let me tell you about the scourge of this disease.

- o 330,000+ Australians have currently been diagnosed with dementia – more than 1,700 cases are being diagnosed each week.
- o The risk of dementia at the age of 65+ is 1 in 15. At the age of 85+ it is 1 in 4.
- o Nearly 1 million Australians care for someone with dementia.
- o Dementia is the number one disability in this country.

- o Alzheimer's disease is the cause of over 70% of all dementia.
- o In economic terms, in every year, dementia costs the economy \$6 billion in health care and loss in productivity.

On these statistics, it seems inevitable that every family in this country will at some stage experience the torment and distress of a loved one being overtaken by dementia.

This assessment, taken together with the personal experience of my brothers and myself, gives cause to our complete commitment to the ongoing research and translation into effective care in relation to this insidious disease. And that involves not only a dedication to assisting those who have the responsibility for caring for loved ones living with dementia, but also concentrating our energies into assisting research into finding a method for early detection, prevention and even a cure for this debilitating disease.

As President of Alzheimer's Australia I am committed to lead the organisation with a focus on three priorities.

Firstly, we must ensure that the investment in dementia research is not only increased but used effectively into the detection, prevention and cure of the disease.

There is much already being being done but while so ever as the disease afflicts so many there is so much more needs to be done to find a cure.

The AIBL Study of Ageing is but the beginning of the process.

The study, now into its 8th year, is helping researchers develop techniques that can be used to objectively monitor Alzheimer's disease progression and to develop hypotheses about diet and lifestyle factors that might delay the onset of this disease.

Successful completion of this work may enable the design and conduct of extensive cohort studies that could lead to clinically proven preventative strategies for Alzheimer's disease.

For it is becoming clear that early intervention is the key - the earlier we can identify the disease commencing, the greater the potential to take action to reduce the risk, slow

its advance or even halt it in its tracks before it has done its irreversible damage.

In the last budget, the Federal government allocated \$200m towards research into the causes of dementia, its early detection, prevention and cure. These research funds, are to be administered by a National Dementia Research Institute under the oversight of the National Health and Medical Research Council. This allocation of research funding effectively doubles the financial commitment to this area of research over a five year period.

The priority is to be able to identify those most at risk of dementia and to have medical interventions that will delay the progression of this terrible affliction. In addition, we also need to build capacity in dementia research and attract the brightest of the emerging researchers into dementia research and to get research evidence into practice.

Alzheimer's Australia is working closely with the NHMRC, the Federal and State governments and major philanthropists, to bring about genuine collaboration amongst the research clinicians in this area, both in

Australia and internationally - in an endeavour to ensure that scarce research funds are applied to their most productive uses.

There should be no doubt as to the commitment of the Federal government in this context. I was so pleased that in his 2014 Budget night speech, Treasurer Joe Hockey referred to dementia and Alzheimer's disease as one of the three most important areas of research that should be the focus of the government's proposed Medical Research Future Fund. The importance of establishing that Fund and resourcing it as a matter of national priority, cannot be overstated. This is not just another hope or aspiration – it is a social and economic imperative.

Secondly, I have a personal commitment to reduce the stigma and social isolation that attaches to a diagnosis of dementia. In the case of our mother, people started withdrawing from her life due to her diagnosis and progression of her symptoms.

It is saddening to think that this was what our mother endured during her the latter part of her life living with dementia and even worse to know that family carers and

people with dementia report experiencing this type of discrimination every day.

So our second priority is to foster dementia friendly communities and organisations in which people with dementia are encouraged to engage in social activities, to access services in the way that we will have a right to expect and to continue their lives for as long as possible in the community.

That means training staff in how to communicate with people with cognitive impairment. It means encouraging people with dementia to become volunteers, to establish buddy systems that enable them to continue their social activities and ensuring that staff are confident in communicating with people with dementia.

Which brings me to the staff and volunteers who are Alzheimer's Australia.

They provide vital services across Australia to support people with dementia, their families and carers throughout the course of the illness. They conduct information sessions and practical education programs, provide professional counselling and individual support, and they

increase community awareness about living with dementia. The National Dementia Helpline - 1800 100 500 - is a practical telephone information and support service that is staffed by experienced advisors.

My brothers and I turned to Alzheimer's Australia for guidance and counselling when Mum was first diagnosed. They met with us and advised and counselled us on the challenges we would face, the heart breaks we would suffer and above all how to deal with our anguish as we saw our mother progress through the inexorable stages of dementia – confusion, bewilderment, aggression, distress, failure to recognise her own children, and finally inability to communicate or carry out the most basic bodily functions.

I recall how often we referred back to the practical advice and counsel of Alzheimers Australia through the most difficult stages of Mum's illness.

The third priority is to work for improved access to quality dementia care. This has been the long term objective of family carers since Alzheimer's organisations were established in the early 1980s.

We need to establish a higher priority for dementia friendly respite care that flexibly meets the needs of both the person with dementia for the social engagement and the family carer for a break.

We need an expansion of home care services that enable the family carer to continue caring for the person with dementia longer in the community if that is their choice. Remember that over sixty per cent of people with dementia live in the community.

In this context, the Dementia Enabling Environment Project has taken dementia design and home modification programs to consumers, the residential aged care sector, undergraduate architecture schools, and to the Australian design standards committee in an effort to help care facilities and family carers provide living environments that give people with dementia the best opportunities for independence and wellbeing.

And lastly, we need quality residential care that is accessible to those with dementia including those who have severe behavioural and psychological symptoms of dementia.

Let me share with you some of the technological advances that are being made to assist both those living with dementia, their families and carers.

Maree briefly shared some highlights regarding some of the great work being carried out here in Victoria by Alzheimer's Australia Vic, harnessing and utilising technology in order to transform the way we support people living with dementia, their families and carers.

As National President of Alzheimer's Australia, I would like to share with you some of the achievements in this area from other States and Territories.

At its most basic level, technology allows us – as a federated organisation – to communicate effectively. Telephones, computers and the internet allow for us to share resources and ideas and means consumers across the country reap the benefits of work being conducted in other States and Territories.

During the last financial year a huge amount of work was put into redeveloping our website at a national and state level. It was a true collaboration between all States and Territories, with input received from a wide variety of

internal and external stakeholders. We should never underestimate the importance of our website. It is a resource used by all our stakeholders – people living with dementia, their families and carers; health care professionals; academics; students; media; people with concerns relating to dementia and interested members of the general public.

Nationally, our website receives an average of 108,000 visitors per month, with a projected 2014 total of 1.3 million.

- Website traffic has increased 17% from 2013 to 2014.
- Our aim was to create a website that is more accessible to the public, where information is easy to find and that will truly engage our broad cross section of audiences. It launched in September this year.

Alzheimer's Australia's national advertising awareness campaign, *There's a difference*, aims to show the difference between forgetting something once and forgetting it many times. It has now been translated for 13 different Culturally and Linguistically Diverse languages which were made broadly available through

YouTube in September. -

<https://www.youtube.com/playlist?list=PLAwhBH-4GO5gJ5cgfiZjSRifSDDOcbT-h>

Your Story Matters is a resource developed specifically for Aboriginal and Torres Strait Islander communities, presenting the messages of our national Your Brain Matters risk reduction program. There are three videos, which are all available online, as well as a booklet, poster and postcard. - <http://yourbrainmatters.org.au/your-story-matters>

Developed in South Australia as a national resource, *Is it Dementia?* is an educational, online and video resource which aims to increase awareness of the challenges experienced by people with dementia among frontline staff in the transport, emergency, services, banking, retail and correctional service sectors. - <http://isitdementia.com.au/>

BrainyApp - the world's first risk reduction app in the global fight against dementia - was developed in 2011 by Alzheimer's Australia in partnership with Bupa Health Foundation, to raise awareness of the risk factors for Alzheimer's disease and other types of dementia, and to help members of the public stay brain healthy. Since its

launch, it has been downloaded almost 338,400 times. - <http://www.yourbrainmatters.org.au/download-brainyapp-today-free>

This year saw the launch of *BrainyApp español*, the new Spanish version of *BrainyApp*. It is the first non-English translation of and, like its predecessor, is available for Apple and Android smartphones and tablets for free.

Looking to the future, we are excited about our plans to adapt the Virtual Dementia Experience technology, described earlier by Maree McCabe, to Oculus Rift. This will mean that, by utilising virtual reality headsets, we are able to make this unique technology accessible interstate and even globally.

We were delighted when Lifeview Residential Care became official corporate sponsors of Alzheimer's Australia Vic and, in particular, our Virtual Forest Project. Our partnership with Lifeview means this amazing, cutting-edge technology will be further developed to make a huge difference to the quality of life of people living with dementia, and will become available by late 2015.

The Virtual Forest Project is a sensory therapy application, designed to improve quality of life for people living with dementia, through the use of video game technology. The cutting-edge project will take a living room in an aged care home and transform it into an enchanted space that both stimulates the senses and engages through interactivity.

Future plans include the possibility of Telecare that is in-home monitoring, e-counselling, and other assistive technology to support people living with dementia, their families and carers. I have a vision of this facility here at Oak Street being connected to the homes of those living with dementia so that we can provide a monitoring service to assist family carers in taking care of their loved ones. If Neil and I think back to the experience of our mother, we wonder how much longer she could have stayed in the comfort and familiarity of her own home, if we could have ensured that her well being was receiving appropriate care and attention 24 hours each day.

Conclusion

My vision is for a dementia care system that focuses not just on care but on psychosocial and cultural needs as well. To achieve this we need well-thought out and coordinated plans that draw together the need for social

action, quality health and aged care, research and knowledge translation together.

There are only seven countries worldwide with a national plan in place to address dementia. They include Australia, Denmark, UK, France, Japan, Korea and the Netherlands. Countries such as India, China and the USA are currently developing national strategies for dementia.

My hope is that within future policy frameworks we will see greater innovation and more tailored services that can well support people with dementia to have a high quality of life and empower them to make choices about the support and services they receive.

As President of Alzheimer's Australia I look forward over the years to developing these priorities. I regard it as a privilege to have this opportunity and a wonderful way of building on the experience which my own family had in their journey with dementia with my mother.

So while Mum is at last at peace, having shared her torment and distress, her four sons will not be at peace whilst ever the causes of their mother's demise remain unsolved, the means of prevention and cure remain

undiscovered and the care for those living with dementia is capable of improvement to provide a better quality of life.

That is my commitment as President of Alzheimer's Australia.

Thank you.