

BLUE CROSS EXTRAVAGANZA

**MELBOURNE PARK FUNCTION CENTRE
MELBOURNE**

12.00PM – 3.00PM

THURSDAY 2 OCTOBER 2014

**GRAEME SAMUEL AC
PRESIDENT
ALZHEIMER'S AUSTRALIA**

Many thanks for the invitation to speak to you today - to speak about my own family's experience with dementia and the priorities I have for my time as President of Alzheimer's Australia

My father died suddenly 24 years ago. I still recall that, during the weeks following his death, our mother, his widow, was our rock. My brothers and I leant on her; she was the glue that held our distraught family together.

She was the person we always relied on, could always turn to. And yet barely two years after losing our father, we began to notice that something wasn't quite right. She started to become overwhelmed by matters that she had formerly taken in her stride. She began repeating herself and forgetting to complete everyday tasks.

At first we thought she was suffering from a broken heart, and it was her continuing despair and sense of loss over the passing of her husband. To make matters worse, this was followed by the loss of her dearest friend.

When we managed to convince her to go to the doctor, they advised that she had most likely suffered a series of minor strokes that had caused the changes in behaviour.

But ultimately, specialist testing confirmed what we feared most – that she had entered the early stages of dementia, most probably vascular dementia.

We knew that the symptoms would only get worse and that she would need more support than ever. Caring for our mother was borne by my two brothers – Ian and Neil. They assisted with every facet of the disease, her inability to cope with usual tasks meant hands on assistance, the increasingly frequent accidents, getting lost and making phone calls in the middle of the night to check whether it was time to get up for breakfast, were all things that we were prepared for.

Perhaps what we were less prepared for were the tears and frustration, increasing isolation and reluctance to leave her apartment, difficulties in dealing with her grandchildren.

We all dealt with the frustration of her friends who had difficulty in coping with her behaviour and gradually deserted her. A lifetime of friendship did not store up enough reserves of care and compassion to help carry her through her tough journey.

The cancellation of her driver's licence further isolated her from her normal daily activities of shopping and visiting her grandchildren.

Unfortunately, this is not an uncommon story to hear when someone receives a diagnosis of Alzheimer's disease or dementia.

We all recall with sadness when she went to the annual reunion of Dad's extended family. These were people she had known for more than 40 years. She bravely addressed everyone as "darling" – she clearly could not remember any of their names.

We provided her with carers at home and debated for hours on end, about when she should be transferred to a care facility. At first she was involved in these discussions, and as the disease progressed we continued to have more vigorous conversations amongst ourselves.

Was the debate about her needs, or was it about the consciences of us, her children? It would be a lie if I said that some of us did not seek to delay her transfer to an aged care facility until she was no longer aware of what was happening to her.

Whether we believed it would be an easier adjustment for her, or easier for us as her carers is debatable. But the worst day for us was possibly the day we finally made the decision to place our mother into an aged care facility.

Ultimately she took up residence in the MECWA Sir Donald Trescowthick Centre in Prahran and then finally in the MECWA Noel Miller Centre in Malvern. But my brother, Neil, will never forget his mother's words to him as she entered the Trescowthick Centre for the first time – "Neil, there will be a death in the family, and it will be on your hands!"

Ian, who had retired from active law practice several years earlier, would visit Mum every weekday, helping to feed her and just to chat. At first she would ask why he wasn't at work, and he would say he was on long service leave - she never noticed that he carried with him an oxygen tank to help his breathing.

There were a few, very few, light moments.

Neil would invoke the disciplinary authority of Mum's long deceased Grandma Slonim to encourage her to eat her meals – "Shirley (she would have been confused if he had addressed her as Mum), if you don't eat I will call Grandma Slonim."

That worked a treat until one day she responded with – “What are you going to do, go out to Springvale cemetery to speak to her?”

Mum passed away 7 years ago. After 15 years of confusion, bewilderment, frustration, torment and unbearable distress - she was, at long last, at peace.

The vow my family took was to work as hard as we could to ensure that other families did not have to go through what we experienced. I am confident that the experience with my mother has given me invaluable insights into the small things that matter in caring for people with dementia.

As President of Alzheimer’s Australia I believe that means I have to work hard on three priorities.

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

The Government’s commitment to provide \$200 million over five years for dementia research through the National Dementia and Research Council is a wonderful initiative after years of under-investment in dementia research.

This amount will effectively double the funding for dementia research over the next five years.

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. Dare we hope for a cure? In addition, we also need to build capacity in dementia research and attract the brightest of the emerging researchers and get research evidence turned into practice.

Secondly, I have a personal commitment to reduce the stigma and social isolation that attaches to a diagnosis of dementia. As I mentioned in the case of my 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 my mother endured during her lifetime living with dementia and even worse to know that family carers and people with dementia report experiencing this type of discrimination every day.

So my 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.

Alzheimer's Australia's Fight Dementia Campaign "Creating a Dementia-Friendly Australia" is front and centre of our advocacy in encouraging Australians and organisations such as banks, retail and Centrelink to become dementia friendly.

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.

Thirdly, I will work for improved access to quality dementia care. There is a huge agenda to address in improving the quality of life and care for people with dementia in residential and community 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.

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. The increasing number of people living with dementia only gives urgency to Alzheimer's Australia's call for zero tolerance for poor quality care.

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.