

## AIBL STUDY LAUNCH

My father, Ralph, died suddenly just 16 years ago. My brothers and I still recall that, during the weeks following his death, his shocked and devastated widow and our mother, Shirley, was the rock on whom the family leant – the glue that held a distraught family together.

And yet barely two years later, the family matriarch began to show signs that something was amiss. She started to become overwhelmed by matters that she had formerly taken in her stride. She began repeating herself and forgetting to complete every day tasks.

At first her four boys thought it was her continuing despair and sense of loss over the passing of her husband of more than 40 years, compounded by the subsequent loss of her dearest friend.

Then her doctors advised that her symptoms suggested that she had suffered a series of minor strokes – known as vascular dementia. But ultimately, specialist psycho geriatric testing confirmed what we feared most – that she had entered the early stages of dementia, probably suffering from Alzheimer's Disease, and that the disease would progress inexorably.

The primary burden for taking care of our mother was borne by my two brothers present here today – Ian and Neil. They identified and compensated for her every symptom – inability to cope with usual tasks, accidents, tears and frustration, increasing isolation and reluctance to leave her apartment, difficulties in dealing with her grandchildren, getting lost and making phone calls in the middle of the night to check whether it was time to get up for breakfast.

We all dealt with the frustration of her friends who had difficulty in coping with her behaviour and gradually ceased to be her companions.

And we recall with sadness her attendance at an annual reunion of Dad's extended family where 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, at first with her and then more vigorously amongst ourselves whether and when she should be transferred to a care facility.

Was the debate about her needs, or was it about the consciences of her children? Did some of us seek to delay her transfer to an aged care facility until she was no longer aware of what was happening to her, out of care for her or out of a belief that the adjustment would be easier on us as her carers?

Ultimately she took up residence in the MECWA Sir Donald Trescowthick Centre in Prahran and subsequently in the MECWA Noel Miller Centre in Malvern. But will my brother, Neil, ever 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 retired from active law practice several years ago, would visit Mum every week day, helping to feed her and just chatting. 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.

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

But having shared her torment and distress, her four sons cannot be at peace while ever the causes of their mother's demise remain unsolved and means of prevention and cure remain undiscovered.

I am sure that most here today will have viewed the recent ABC Four Corners program on Dementia.

- 200,000+ Australians have currently been diagnosed with dementia – more than 1,000 cases are being diagnosed each week.
- The risk of dementia at the age of 65+ is 1 in 15. At the age of 85+ it is 1 in 4.
- Nearly 1 million Australians care for someone with dementia.
- By 2015 dementia will be the number one disability in this country.
- And 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 program being launched today as a vital part of the ongoing research into this insidious disease.

As it has been explained, the AIBL Study of Ageing will involve recruiting 1,000 volunteers from a cross section of Australia's population. It is the largest study in the world.

- Participants, which will include 600 people from Victoria and 400 people from Western Australia, will be grouped into the following five categories: -

1. Normal individuals with no genetic predisposition to Alzheimer's disease,
2. Normal individuals carrying a gene variant that increases the risk of them developing Alzheimer's disease in later life,
3. Individuals concerned about their perceived decline in cognitive function;
4. Subjects with diagnosed mild cognitive impairment, and
5. Patients diagnosed with early stage Alzheimer's disease.

- The study will help researchers develop and confirm a set of diagnostic markers and psychometrics that can be used to objectively monitor disease progression and to develop hypotheses about diet and lifestyle factors that might delay the onset of this disease.
  
- Successful completion of this work will enable the design and conduct of extensive cohort studies that may lead to clinically proven preventative strategies for Alzheimer's disease.
  
- The cluster will bring together researchers from a variety of disciplines across Australia, linking leading-edge science on Alzheimer's disease with human population studies and data. It will integrate expertise in neuroimaging, biomarkers, psychometrics, and lifestyle interventions.

I will be a volunteer for this research. I encourage fellow Australians who may qualify, to also volunteer. You do so in the interests of the community at large. Indeed you do so in your own interests.