

**A submission to the House Health and Ageing Committee inquiry into Dementia  
early diagnosis and intervention (FED)**

**My background & road to diagnosis**

I was a highly respected and sought after Public Accountant but about 2006 at 55 years of age, I was experiencing some unusual confusion problems and a reduced capacity to retain several financial situations in mind at a time. My GP suggested a discussion with a Neurologist who advised me it was probably simply that my memory and brain was overloaded and some items were simply 'dropping off' in a similar way to an over-loaded truck

Slowly more noticeable events occurred such as:

- I would be looking for an item and although it was right in front of me I could not recognize it.
- I was regularly extremely tired and I had lost a lot of my drive, I was no longer interested in owning my yacht and didn't really care about winning anymore.
- If there was more than one person talking near me or a lot of noise around, I could not follow conversations and would become confused.
- Early in 2010 when I was travelling from our home in [redacted] to my office in [redacted] where my accountancy business had been for over 20 years I became completely disoriented, confused and lost. I rang [redacted] (then partner and now my wife & carer) to ask her where I was supposed to be going and how to get there. It took a few minutes of jocular discussion to remind me I was simply going to work and that I was just 2 streets away from it.
- In May 2010, [redacted] and I had a 6 week European trip seriously disrupted by the Icelandic volcanic eruption and we were stranded in Dubai for 4 days without luggage. During this time it became apparent to [redacted] that my ability to 'see the whole picture' and draw logical & practical conclusions had significantly deteriorated.

It was obvious to both of us that there was more going on than the 2006 explanation indicated and I was again referred to the same Neurologist by my GP.

During July 2010 I had an EEG & MRI and a three hour assessment by a Clinical Neuropsychologist whose diagnosis of dementia probably Alzheimer's disease was confirmed by the Neurologist. Both these practitioners advised me to contact Alzheimer's Australia and they gave me pertinent information. The Neurologist offered me drugs which might slow the speed of deterioration but which are not a cure. I believe the human body and mind has its own powerful healing abilities which can be detrimentally affected by medications. I had bowel cancer in 2001 and following radical surgery was advised my life expectancy was less than 2 years. I declined the many drugs offered to me and proceeded to utilize meditation to 'get a handle' on the pain, along with exercise & diet to keep myself as fit & healthy as possible. To the great surprise of my doctors I am still here and still drug-free.

**Quality of life & independence**

By continuing to insist that what was happening inside my brain was definitely not usual I was diagnosed while still at a relatively early stage and therefore I have been able to have my say about our lifestyle decisions. But had the diagnosis been in 2006 when I first became aware of changes I would have had much greater capacity to make

decisions and therefore more choices from which to make them. I have done extensive research into the disease and its varying manifestation and it is apparent that with an earlier diagnosis and access to the Alzheimer's Association range of support and services I would not have found it necessary to sell my accounting practice. Even now, I am still able to perform some accountancy functions and it could have been reorganised to allow my continuing but in a different capacity. I would have retained my identity and continued to be financially independent.

### **Community awareness**

There is a major lack of knowledge about dementia in the community. I have been open about my diagnosis and while only a few folk have responded with open negativity the questions I am asked indicate the lack of basic familiarity and the apparent discomfort with the disease. It is as though I am suddenly someone who is dangerous or contagious or likely to behave in an unacceptable way.

My wife & I have personally addressed several local groups about my journey with Alzheimer's in order to help people in the community understand that the disease is individual in the way it progresses in the long term but a very enjoyable life is possible for those who work within the parameters laid down by how the disease affects them and who have the chance to plan their lives around the gradual impingements and limitations. Support for people with dementia to feel confident in sharing their experiences will help prove the disease is not the big bogey many perceive it to be. Continuing to engage with and listen to people with dementia and their carers about what will best help them in their individual situations and an expansion of the types of in-home and community support available will ensure more satisfactory lives for more people with dementia and their families while also showing the community at large that these people still have a lot to contribute.

The earlier the diagnosis and intervention occurs the greater the quality of life and the longer independence can be retained. Educating the community and providing support networks and services are the key ingredients to achieving these goals.

Submission by Robert

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