Submission No. 020
(Dementia)
Date: 29/04/2012

I wish to make a personal submission to the inquiry into dementia early diagnosis and intervention.

I have 10 years experience with being the carer for my husband, who was diagnosed with Alzheimer's 10 years ago at the age of 55. Our experience is from a Younger Onset point of view, which is critical to get a diagnosis as early and quickly as possible. I have cared for him at home right up until 2 weeks ago, when he entered a Nursing Home at 65 years of age.

We had a relatively smooth process for getting the diagnosis, but initially, believing he could not have Alzheimer's due to his young age, they were diagnosing depression. At the time, I worked in the medical field, so I had access to excellent advice on what tests and who to see, as I had bigger concerns than depression. Once we had the appropriate scans and tests, we were given a diagnosis of Alzheimer's . It took about 4 months from beginning to end. Once we were given confirmation of Alzheimer's, the Specialist immediately put my husband on medication to slow down the progression. We were told, due to his young age, life expectancy can be between 5-7years as Younger Onset can decline quicker. Another age expectancy we were given was 7-10 years. I very strongly believe, by being given a quick diagnosis, and then being put on medication immediately to slow down the progression, did actually give our family about 8 1/2 years to experience many wonderful moments and memories.

When you first receive a diagnosis of Younger Onset Alzheimer's, initially you think you may never experience things like seeing your children graduate, getting married, seeing your grandchildren, travelling and doing things you have always wanted to do, but slowing down the progression can give you time for these experiences, which I am so happy to say my husband got to experience them all.

We also looked at leading a healthy lifestyle with fitness, diet, relaxation and natural therapies to give it our absolute best shot, both conventionally and naturally.

Even though my husband would never get full-time employment in his field of work again, it did enable him to work part-time for two years in a Sports Shop, which gave him his confidence, self-esteem and well-being back. He felt like he was contributing. Time also enabled him to keep driving, he attended a woodwork depot where they made toys to raise funds for the Royal Flying Doctor Service. He went out on outings to so many interesting places such as Museums, Galleries, Gardens, Parks etc. which also enabled him to follow his big interest in Photography. In 2008 (6 years after diagnosis) he and three other men with YO Dementia won the "Every Generation Positive Ageing Award" for Photography. Imagine what this continued to do for his self-esteem and confidence. All of the above gave my husband his independence, quality of life and so much enjoyment. For the first 8 1/2 years after diagnosis we continued to experience a very happy and enjoyable life doing many, many things as a family.

Social isolation, boredom, loss of confidence, self-esteem and unhappiness are all known to contribute to depression.

From a Younger Onset point of view, it is imperative to get all legal documents in order as soon as possible when dementia is involved (younger families can often not have these in place). Financially, the impact of Younger Onset dementia is massive. There are young children involved and even older adults still living at home, there are mortgages and also loss of income/incomes. Getting the diagnosis quickly and slowing down the progression, gives families time and enables income/incomes still to be earnt. Also time to seek advice, and get all the complicated information for setting up finances, right up until the time for entry into Nursing Home care, which is so very, very complicated. Slowing down progression also delays the entry into a Nursing Home (most people want to stay at home), as long as you are able to access all the help and support you need to keep your loved one at home.

There needs to be a massive public media awareness program established for dementia. In 10 years, you do not regularly hear any media advertisements re dementia. When we look back re cancer, prostate cancer, depression, suicide, addictions, heart disease, stroke, diabetes etc. they are so regularly advertised and discussed, but not dementia. Quite often high profile people can make a huge contribution in connecting with the community. We love our sport in Australia, maybe this path is a good one.

We need to start with our young people in schools which will then progress to teenagers, then adulthood. Then continue the education into Universities etc, especially anyone who is going to follow a Medical career, Acute Services, Dentists, Physiotherapists, Nursing, Care Workers, Occupational Therapists, Podiatrists and so on. We need to create "DEMENTIA CHAMPIONS". The current training is not satisfactory.

GP's are usually the first contact families have and continue to have, so they require a lot more support and information in this field.

Personal Stories have a huge impact on the Community.

Ita Buttrose is the best thing that happened for dementia awareness, but there is such a long way to go.

So much comes back to funding, and it is the Politicians both State and Federal, who make the decisions re funding. I wish that every Politician could be touched in some way with becoming personally aware of every aspect of dementia. Taking time to understand all aspects of dementia, taking time to meet and speak with many families and people with dementia, take time to actually visit High Care dementia units in Nursing Homes to actually be touched by dementia.

I believe I was able to keep my husband at home for as long as I did, as I had so much support and advice. I obtained all this information right from the very beginning from Alzheimer's SA through Support Groups, "Living with Memory Loss Program", Counselling, Dementia Help Line, Dementia Behavioural Management Assessment Services (DBMAS), being on Committee's and remaining connected all along our journey. You need one entry point, which can also remain with you along your journey, or it can become so very, very confusing.

There is no cure for this horrific, insidious disease and we need all the help we can get.

Thank you,
Jenny