

OUR FAMILY MADE A PROMISE ...

in the last days of my mothers life we promised her to do all we could to make it possible to deal with Alzheimer's, either through research dollars, donations of time and energy or in assisting other care givers. To date we have done this and we will continue. My father accepted a position on the National Alzheimer's research board in Australia, As a family, we have donated time to tell our mothers story, created a multimedia cd for caregivers, made donations to the nursing home our mother was at and financial donations to research funds. We do this willingly, with the knowledge that every single cent we can gain will help other families in the future and in time we hope rid the world of Alzheimer's. In my opinion, no single person deserves to end their life without the dignity and self esteem that this disease steals away.

HERE IS MY MOTHER'S STORY ...

I hope it provides you some strength to continue your role as a caregiver

Alzheimer's – From the perspective of a caregiver

by David Bull - www.caregiver4caregivers.com

Caring for a person with Alzheimer's disease at home is a difficult task and can become overwhelming at times. Each day brings new challenges as the caregiver copes with changing levels of ability and new patterns of behavior. Alzheimer's disease is not a normal part of aging. It is a devastating disorder of the brain's nerve cells that impairs memory, thinking, and behavior and leads ultimately, to death. It is a disease that no one should have to deal with either as a caregiver or a sufferer.

From a caregivers perspective, watching a person you love disintegrate slowly before your eyes is a traumatic experience I wish no one went through. The impact of Alzheimer's on individuals, families and the health care system makes the disease one the nation's greatest medical, social and fiscal challenges.

Statistics on Alzheimer's are shocking:

- An estimated 4.5 million Americans have Alzheimer's disease.
- Research suggests that by 2050, the number of Americans with Alzheimer's could range from 11.3 million to 16 million
 - Finding a treatment that could delay onset by five years could reduce the number of individuals with Alzheimer's disease by nearly 50 percent after 50 years.
- 1 in 10 Americans said that they had a family member with Alzheimer's
- 1 in 3 knew someone with the disease.
- National direct and indirect annual costs of caring for individuals with Alzheimer's disease are at least \$100 billion
- Alzheimer's disease costs American business \$61 billion a year
 - Of that figure, \$24.6 billion covers Alzheimer health care
 - \$36.5 billion covers costs related to caregivers of individuals with Alzheimer's, including lost productivity, absenteeism and worker replacement.
- 7 out of 10 people with Alzheimer's disease live at home,
 - Almost 75% of their care is provided by family and friends.

- The remainder is “paid’ care costing an average of \$12,500 per year which families pay almost all of that out of pocket.
- Half of all nursing home residents have Alzheimer’s disease or a dementia related disorder. The average cost for nursing home care is \$42,000 per year but can exceed \$70,000 per year in some areas of the country.

My own experience with Alzheimer’s is in Australia, but the situation is much the same both as a care-giver and I can only assume as a sufferer. I played the role of caregiver for 16 years - 4 with Grandmother, and then 12 with my mother who I watched disintegrate into a physical and mental wreck during the years prior to her death 5 days before Christmas in 2001.

Alzheimer’s is not a high profile disease that attracts funding. In my father's words, *"Unfortunately, Alzheimer's isn't 'sexy' in today's world. Breast cancer and child leukemia, for example are, so they attract research funding much more easily (add prostate cancer to the 'Non sexy" list)".* The burden of caring for the victims of Alzheimer’s falls on the families. In my family’s case, this financial burden fell on my father. Nursing homes are expensive and my ‘retired’ father had to pay over \$2,000 per month after tax for my mother’s care. This on top of the normal day to day expenses and any medical needs she had.

He was fortunate in that despite reaching retirement age in 1987 he continued to work. Others are not so fortunate and have to dissipate their retirement fund – if they have any! He enjoyed working but because of my mother's illness my parents weren't able to enjoy the typical retirement lifestyle. When asked to speak on behalf of caregivers at the National convention in Canberra my father stated “I worked since I was 17, paid all my taxes, become a self-funded retiree but felt I was being financially penalized because my wife had the misfortune to contract Alzheimer’s disease.”

My mother was considered by many who knew her as a strong-willed and giving woman. She was a working journalist from age 17, as a professional student completed a Diploma of Journalism, Bachelor of Arts, Diploma of Education, Masters Degree with Honors, and had begun her PhD, had a lifetime interest in classical music and theatre. Her father was John Hickling and the topic of her master thesis due to his involvement in the early days of radio plays which explained her interest in radio drama during radio's heyday. During her career she was also editor on early editions of the Macquarie Dictionary.

My parents didn't quite make their 50th wedding anniversary (she passed away 1 month shy) and was the mother of five children of which I am the second oldest. She maintained her association with her school as the archivist and edited the school alumni magazine despite the family being moved regularly due to my father's career success. The church was an important part of her entire life. She was the Sunday school and youth group superintendent, church elder and archivist. From my father's point of view she was the woman behind his career success with a major international computer company, and became actively involved in the community everywhere we lived. She

was also one of the first females of the local Rotary Club holding several officer positions throughout the years.

Despite her devastation at the eventual diagnosis, in typical style, my mother tracked down and volunteered for drug trials at Concord Hospital aged and extended care and eventually joined the trial group for the drug now known and used as 'Exelon'. As a family we became disappointed at the length of it took to get the drug onto the medical benefits list (otherwise it was over \$200 per month denying many less fortunate people of some relief. However, do not believe the headlines of breakthroughs - getting a new drug onto the market is a long drawn out process. Headlines usually come at the rats and mice stage when developers are looking for funding to move forward and can still be well over ten years away, too long for the average sufferer currently.

But she became reluctant to tell others of her diagnosis because she had observed how sufferers had been treated with her own mother. Despite these fears, she did do a TV interview during the drug trial complete with poor lighting and disguised voice. The next day one person still demonstrated the mind set that existed of viewing the person as 'mentally deficient' by calling her out in a crowd "*Hey I saw you on TV last night saying you had Alzheimer's*". And the final straw was being basically ignored by a club she had been a member of for almost 15 years whose motto was "is it fair to all concerned? and is it the truth?. Her generational baggage equated 'demented' or 'mad' with Dementia. nevertheless, despite all this, when asked by Concord, she immediately agreed to will her brain for research (long before more recent high profile donors e.g. E.G. Whitlam) and then challenged my father to do the same (which he did) but as he points out to us "at present I'm still using it"

My father and I resorted to displaying a little card to shop assistants in order to avoid any situations. People tended to steer away and distance themselves, maybe through fear of the unknown but it was something that was always on her mind. This was indeed the case I experienced as well from various groups she was a part of and even more surprising her own church congregation. Nevertheless despite all this when asked by researchers, my mother readily agreed to donate her brain to further Alzheimer's research and this was long before the current high profile campaign.

My mother's battle with Alzheimer's was a gradual decline over a 9 to 10 year period no doubt helped by the trial medication program. She remained 'in denial' and did not like to be told she had Alzheimer's becoming very angry and tearful. The challenge my father and I faced as the caregiver was how to help my mother cope but retain her dignity and independence. My mother's battle was almost unique in that she lost her physical functions before her mental functions which meant that she was aware but couldn't do them, which frustrated her enormously.

Early on there were often heated exchanges like "*you're taking over*", "*I used to do all that*" and "*I managed everything while you were at work*" before my father and I became adept at creative solutions to excuse our activity and avoid the angst caused. Later we experienced stages like "*I want to go home*" and "*Where are we*" while we were sitting

watching TV at home, "*Its too loud*" and of course the hardest of all for me "*who are you?*". Of course there are the usual difficulties with repetitive questions, sleeping, bathing and complete confusion of her surroundings. This frustration often resulted in her making life difficult for herself and those around her and although very, very rarely violent, more than once, she tried to escape through windows or locked doors and eventually it was suggested to us that we reduce or stop the medication.

My mother was cared for by my father and I at home. Simple tasks she used to do became tasks we did, for example buying clothes or any shopping trip; we had to quietly communicate my mother's condition to salespeople without her knowing. This involved carrying a small business sized card that we discretely slipped to the shop attendant. We became very adept at finding creative reason to excuse our activities doing things at night when she was asleep or statements like "your wrist isn't better yet" to explain why we were there helping her in shower. We found it easier eventually to just frequent shops that were aware of my mother's condition. Travelling became difficult packing for two and hotels became even more difficult to deal with. She gradually lost the idea of how to use a knife and eventually a fork. We had to devise "*mom-friendly*" meals. By the time she reached the nursing home; she had to be fed by hand and only on pureed meals. Toileting became a problem as she became doubly incontinent. Incontinence pads were resented, protective pads/sheets required on beds, chairs and car seats. Any dignity or privacy was basically lost to her.

My mother was diagnosed while doing her Phd and much time was consumed by friends and family as we her with research and interviews etc. She lost her lifetime journalist's typing skills and couldn't understand why. Over time my mother forgot where she would put her research notes, topics she had researched or where she had put the results frustrating the family for various reasons and fortunately eventually her interest in her Phd faded away. By far the greatest frustration she faced was being told she couldn't drive any more, the family constantly listened to "*They have taken away my independence!*" she never accepted the reasons and was difficult for the family to cope with her distress

In May of 2001, we placed her into a 'dementia specific' nursing home where she was free to roam around and had several activities she could do without being able to wander out of the home, due to locked doors and windows. All under the supervision of remarkably dedicated and underpaid nursing staff. She had reached a point beyond our care and where professional attention was required. She could barely recognize my father and didn't always recognize myself, my brothers or sisters, let alone her 5 grandchildren. This was a harrowing time for all of us and became the start of an extended grieving process. My father found it difficult to 'pluck up' the courage to take the step feeling that it was the beginning of the end and the real end of his 49 year marriage. He and/or a member of my family visited every night to be with her and assist the nurses where we could, but by July 2001, she couldn't walk, by September 2001, she could scarcely talk.

One of the really sad things was that she didn't get to enjoy her grandchildren, nor did they get to enjoy her. Her recognition of them, their age and the confusion about 'grandma's' condition, helped in the family making the conscious decision of not taking her grandchildren to the nursing home. This made the Christmas after her passing even more difficult because to them my mother had passed away several months earlier (not at Christmas).

Was my mother undergoing mental or physical torture as she struggled to talk to us? I'm sure she was but how could we really know? She couldn't tell us although at times we would hear her saying "*I don't want to live my life like this*", "*I'm Frightened*", "*I must persevere*".

What did we do once she placed in the nursing home? We visited her every night; helped feed her and others; watched and waited and hoped it would end soon for her sake. Reality is Day care and respite care spots are extremely difficult to get; nursing home beds hard and Dementia specific nursing home beds even harder, even if you are prepared to pay an accommodation bond of around \$100,000 in additions to monthly fees. Government funding restrictions severely limit the availability of professional care. Nursing homes are expensive, especially for self - funded retirees - at the time means testing meant that my father had to pay \$24,000 per year after tax for my mother's care (that's \$2000 a month) and the harder he worked, the more he had to pay. He often mentioned to us he liked to work but he and my mother were unable to enjoy what should of been the benefits of his career and success. At the National Convention during the 2001 Alzheimer's week my father spoke matter-of-factly saying "*at 73 years old i have worked since i was 17, paid all my taxes, become a self-funded retiree and responded to Prime Minister Howards call for older people to work on, but I can't help feeling other than I am being financially penalized because my wife had the misfortune to contract Alzheimer's*"

My father was fortunate, having had a successful career as an executive for an International technology company, and following a trail that my mother herself started by contacting Concord Hospital. But even then my father felt like he was involved in '*Hawking*' his wife around all the recommended nursing homes, again without her knowing.

The emotional burden on caregivers needs to be also addressed. Watching the person you love disintegrate before your eyes and slowly, trying to run the house and job but being careful to tread a delicate line between supporting without appearing to support, preserving the dignity and sense of purpose in someone's life, Personal social life gradually decreases or ceases to exist. are all burdens most caregiver's are only too happy to shoulder because that is what the person deserves ... in my case my mother

There is still no forecastable pattern to the disease in any one person. Geriatricians are unable to predict with any accuracy how quickly, widely or deeply any one sufferer will be affected. In my mother's case, she lost her physical abilities before her mental

capacity to understand. This of course created much anxiety and confusion for her and difficulties for us.

As a nation, and in my own country of Australia, funding is needed for more research to reduce the incidence of dementia and therefore reduce the number of sufferers and the resulting trauma of the caregivers. But until a solution is found there is a need for more support facilities for the caregivers – day care, respite care, and permanent care, less financial impact on caregivers, more professional caregivers with better pay, more community education on Alzheimer's on how caregivers access facilities and support systems. Finally, a need for more community education and understanding that dementia should not be considered a dirty word and is currently something that could affect you as a caregiver or a sufferer at some point in the future.

To those who know of caregivers that need some support ... Please remember the one thing we do know about Alzheimer's is that it isn't a communicable disease. It may be gene related but you can't catch it by talking to, or touching a sufferer. As a friend or acquaintance, make the effort to talk to your suffering friend answer the same question as many times as it is asked, Listen to the same comment or story as many times as you are told. Help them move around, but surreptitiously ... They need to feel that life is normal.

Finally ... PLEASE REMEMBER THAT ANYONE READING THIS COULD BE NEXT – EITHER AS A SUFFERER OR A CARER! I CAN ASSURE YOU THAT IT WILL BE A DEVASTATING EXPERIENCE FOR YOU IN EITHER ROLE.

David Bull

Former caregiver

Owner, Designer and Webmaster

www.caregiver4caregivers.com