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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

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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. In 2009 I was to find my birth mother only to find she also was in the late stages of Alzheimer's and passed away before I got the chance to meet her back in Australia.

Alzheimer's is not a high profile disease that attracts funding. 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 he 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 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 found it easier eventually to just frequent shops that were aware of my mother's condition. 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.

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

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the Christmas after her passing even more difficult because to them my mother had passed away several months earlier (not at Christmas).

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.



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