

Alzheimer's Disease- The Forgotten

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Opinion

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Introduction

It is flabbergasting to me, that with all the statistics that are being shared regarding the prevalence of the disease, individuals still do not know what it is. I am unsure on why this is still happening in 2016. Personally, I did not know what Alzheimer's disease was until my mother was diagnosed in 2000 and had to do research on my own on what the disease actually was and there was very little how you live with the disease. I had to find out both on my own. To reiterate the statistics, the prevalence of Alzheimer's disease is rising at a fast rate. In 2016 [1], 5.4 million Americans of various ages have Alzheimer's disease out that statistic, 5.2 million individuals are 65 and older. There are 200,000 individuals out of the 5.4 million Americans that have early onset Alzheimer's, which means they are under the age of 65 years of age.

Think about this statistic, it means that 1 in 9 people age 65 and older has Alzheimer's disease and even with that tangible fact, there is still a high amount of ignorance towards this disease and awareness is extremely limited [2].

It is estimated that by mid-century, someone will develop Alzheimer's disease every 33 seconds and that as the baby boomers rise in the coming years, this number will escalate to a projected 13.8 million unless there is a medical breakthrough to prevent or cure the disease. Presently 1 in 3 seniors dies of Alzheimer's or other forms of dementia. As hard as this disease is on the patient, it is even harder on the caregiver. In the United States it was estimated in 2015 that 15 million caregivers provided 18 billion of unpaid care to their loved one. The cost of Alzheimer's disease in 2016 in the United States was estimated at 236 billion [2].

The mortality rates are even more morbid, it is estimated that amongst people age 70, only 61 percent are expected to live to the age of 80 in comparison to

those individuals that do not have Alzheimer's disease. However, to use the term live should be changed completely to stipulate that with complete care. You do not really "live" with the disease, the disease "lives" with you, you house the disease and it takes over your complete functions. It is like a parasite that completely drains you of your former self and eventually wins. I know that description sounds cryptic; however it was only until this very moment that I came up with that analogy that completely describes exactly what I have witnessed over the last 16 years. Alzheimer's disease is among the top 10 causes of death that cannot be prevented or cured or slowed in America [3].

The average person does not know what Alzheimer's disease is, I have been asked on so many different occasions what it is. It is due to the fact that Alzheimer's disease affects your memory; actually that is typically only the first symptom of the disease. I knew there was something wrong with my mother, more than memory loss 16 years ago. It was not memory loss; it was the fact that her brain was not telling her how to follow instructions. Alzheimer's disease is a progressive, degenerative disease of the brain. Put that in perspective, your brain, that operates and regulates everything in your body and now there is plaque on your brain, which is abnormal clusters of protein build up between nerve cells. This plaque is quite visible with a MRI scan, where you can actually see atrophy of the brain. The messages that are being conveyed to the brain are not being received, that is exactly what Alzheimer's is. One day you know that you need keys to lock your door, and the next day, you don't even know what keys are, that is not memory loss.

Alzheimer's disease is the most common type of dementia, which is under the umbrella of neurodegenerative diseases. In 2010, there was an estimated 35.6 million people worldwide that were living with the disease, with that figure expecting to double in 20 years [4]. My mother was diagnosed with "atypical

Alzheimer's disease" which in laymen terms translates to "not typical" So although the chart below describes staging of Alzheimer's disease, my mother did not follow this prescribed list.

Dividing the course of Alzheimer's disease into stages is purely hypothetical and for convenience – to discuss and identify progression. Progression from one stage to another is not "neat and tidy". It is continuum with much overlap. Not all persons will experience all the above

symptoms. Although worsening with time is inevitable, the rate at which client's progress varies with the individual and two clients at same stage have somewhat different symptoms. In addition, clients at any stage exhibit symptoms unpredictably, with daily fluctuations and stable "plateaus".

Progressive Decline in Alzheimer's disease (Staging)

Stage	Characteristics	Interventions
1	"Forgetful" early stage - insidious / gradual - recent memory loss - time / space disorientation - mood swings - slower / withdrawal / denial - impaired judgment - subtle language dysfunction - continues to worsen	seek interested & helpful GP - obtain thorough medical assessment - family conferencing - seek counselling / education - obtain legal / financial advice - secure power of attorney - adjust lifestyle (retirement, driving) - initiate individual / group supports
2	"Confusion" early middle stage - obvious memory deficits - need for supervision in specialized activities - language / communication problems - anxiety / restlessness - problem behaviour becomes more severe - usually most difficult period for client	time for decisions / future planning - seek help in home - learn coping strategies - investigate day programs - examine placement possibilities - focus on safety / anxiety - compensate for deficits & maximize assets (client & family)
3	"Severe Dementia" stage - obviously disabled cognitively - full-time supervision needed - marked personality / behaviour problems - disorientation to person - communication very difficult - psychosis - physical disorders appear - can still reminisce	minimize stresses - seek more help from all sources (usually most difficult period for family) - focus on health - continue with support / education systems - step-up respite care - be prepared for placement
4	"Terminal" late stage - almost total loss of intelligence / physical functioning - few words spoken / understood - emaciation / susceptible to infection - death	usually requires placement - continue with all systems of support - death / autopsy arrangements - limit visits to institution as needed - rest / regroup

My mother's first MRI revealed that her plaque was focused primarily in her frontal temporal lobe. The right and left frontal lobes at the front of the brain are involved in mood, social behavior, attention, judgment, planning and self-control. Damage can lead to reduced intellectual abilities and changes in personality, emotion and behavior. The right and left temporal lobes at the two sides of the brain are involved in processing what we hear and understanding what we hear and see. Damage may lead to difficulty distinguishing objects or understanding or articulating language [5].

Due to this reason, my mother's Alzheimer's was particularly difficult because she lost her speech and was unable to articulate anything comprehensible. This is why I can now identify that her progression of the disease mimicked reverse aging. She could no longer speak. Many people do not know what Alzheimer's disease is, as it has been misnamed as "Old-Timer's disease" for many years and as name suggests individuals assume that only elderly people can be diagnosed with it. Statistics show that around 5% of Alzheimer patients suffer from early onset disease. Although rare, one can develop Early Onset Alzheimer's disease between 30s-40s, however most early onset cases are people in their 50's.

At the time of my mother's diagnosis there was not much information on the disease, and the information was not easy to disseminate, unless you were a doctor. There was nothing on how to live with the disease and nothing medically for "atypical Alzheimer's disease", that is not following a prescribed list. The most similar to my mother's symptoms was Frontal temporal dementia. Frontotemporal dementia is a progressive, degenerative brain disease that slowly destroys the capability to act appropriately, relate to others, learn, reason, make decisions, communicate and perform daily activities. Frontal Temporal Dementia is the most common cause of dementia for people under the age of 60 and affects as many individuals as Alzheimer's disease in the 45-64 age groups [6]. It affects more men than women. As with other dementias, frontal temporal dementia can be mistaken for Alzheimer's disease, Parkinson's disease, depression, manic-depression, obsessive-compulsive disease or schizophrenia. (National Institute on Aging, 2014)

In December 2015, my mother had a bad seizure where she was unresponsive and had to be hospitalized. When she recovered, she lost the ability to chew solid foods. The doctor ran all the tests, and other than Alzheimer's disease, my mother is healthy, which the doctor attributed to her care she is receiving. It is a double edged sword, my mother is receiving exemplary care, however this is sustaining her semblance of a life. The psychology of that is extremely painful. I have to watch my mother slowly decline, and it is extremely slow. She is now in palliative care in the home, as she is exhibiting the end stages of the disease.

She is also on liquid morphine, but a low dose to assist her comfort. She is less than 80 pounds now. She is on a puree diet and is slowly and I do mean slowly, returning to a fetal position. There are palliative care nurses that assist her, personal support workers and a caregiver. The emotional toil that it is taking on me is not measurable as, my doctor is convinced that I am definitely suffering from post-traumatic stress disorder. I try to say good-bye to my mother on a daily basis, because I don't know when the day will come, but this doesn't make it any easier.

The caregiver role is so complex and yet it is the most undervalued job in the world. I have been a caregiver for 16 years, however my mother has battled this disease for 16 years, who is the braver person? That is an everyday debate. I look at her struggle to eat puree, and see that this is no quality of life, absolutely none. She is completely bedridden and has been for almost 2 years, when she lost the ability to walk. The brain is shutting down, piece by piece, like a light going out. The reality is now that either

she has a massive heart attack, she develops pneumonia, she forgets how to swallow and basically starves to death or she just doesn't wake up. I know what I am hoping for.

No one prepares you for this, and very little talk about is and there is No cure. This disease is not a long goodbye, because when you say goodbye to someone, there is closure, there is an understanding, a conversation. Just as the person is robbed, you also are robbed. This is not a long goodbye, it is like being in a coma, but you happen to have your eyes open and there is no life support. Alzheimer's disease is so savage, and it is so true, that unless you see it first hand, up close, it is difficult to understand. My mother was 57, did not get to retire as a registered nurse, did not get to enjoy her hard work, she got to deal with this illness for the last 16 years. This disease is a thief, it robs and continues to rob, every day there is something more.

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