

Dying with Alzheimer's Disease

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In 2000 my mother was diagnosed with Alzheimer's disease at the age of 57, I was 30 years old with a newborn which propelled me immediately into the sandwich generation.

There are nearly 44 million individuals that have Alzheimer's disease or related dementia and only 1 in 4 individuals that have Alzheimer's disease have been diagnosed. Alzheimer's disease and dementia is most common in Western Europe with North America very close behind. The least predominant place where Alzheimer's is present is Sub-Saharan Africa, which is an interesting fact that should probably be further researched on the reasons behind why that is. Alzheimer's disease and other dementias are the top origin for disabilities in later life [1].

The cost of caring for individuals with Alzheimer's disease in the United States is estimated to be \$236 billion in 2016. The global cost of Alzheimer's and related dementias is estimated to be equivalent to 1% of the entire world's gross domestic product, this should be a huge revelation. The cumulative cost of care by payer for American aged 65 and older with Alzheimer's disease and other dementias are \$113 billion with Medicare, Medicaid costs are \$41 billion, out of pocket is \$44 billion and other is \$29 billion [1].

In the United Kingdom, there are 850,000 individuals with dementia, that number is predicted to rise to over 1 million by 2025. It is predicted that one individual develops dementia every 3 seconds. There are 40,000 individuals under the age of 65 with dementia in the UK. Unpaid carers supporting someone with dementia save the economy 11 billion pounds per year. Dementia is one of the main causes of disability later in life, ahead of cancer, cardiovascular disease, and stroke [2].

A product of Alzheimer's disease and other related dementia is caregiving. Caregiving and Caregiver has been recently added to the dictionary as it only has now been recognized that this is also going to be a huge concern. There were many years that I would write the word caregiver and the red squiggly line would appear and separate the word or ask me if I meant something else. The diagnosis for the disease is horrible for the individual however the diagnosis is not individualistic, the diagnosis happens to the family members or rather the person who decides to take on the role of caregiving. I became part of the diagnosis, when my mother was diagnosed with this disease, I was diagnosed with this disease, because I became the primary caregiver of this disease. 16 years later, I am still living with the diagnosis.

In the United States, more than 40% of family caregivers report that emotional stress of their role is very high. 74% of caregivers are concerned about their own health being a caregiver. More than 15 million Americans provide unpaid care for individuals with Alzheimer's disease and other dementias [1]. Due to the fact that I was much younger when my mother was first diagnosed, I was overly ambitious therefore I continued to work full-time and pursue academic studies. I cannot fathom how I did this with also raising my son and dealing with the multitude of issues that arose daily while living with the disease. For catharsis, I wrote a book entitled Alzheimer's – what they forget to tell you, a personal journey. It started out as a journal and then I began researching many of the resources that I found out along the way.

The disease is supposed to go through stages, however my mother was diagnosed with Atypical Alzheimer's disease and did not follow the prescribed stages.

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

Table: Progressive Decline in Alzheimer's Disease (Staging).

My mother is in stage 4 according to this chart. The sad part of this illness is that 16 years later, I feel that there is no advancement. My mother is in palliative care in my home and this part of the journey has been as rough as the initial part. I am unsure why this is, with the amount of research and information surrounding the disease at this point. I struggle with my own resilience and trying to be a mother to my son, who has lived with the disease all his life. My son does not know the sound of his grandmother's voice, does not know her personality and does not know the joy of what a grandmother is. As stated earlier, this disease is not individualistic at all. It has been stated that it is the long goodbye, it is not a long goodbye, it is just long. I will not be able to say goodbye to my mother, as she cannot tell me last anecdotes, or words of wisdom or even utter the words goodbye.

In the last few weeks, I have had to plan my mother's funeral arrangements speak to speech pathologists as her swallowing becomes compromised and read facial expressions to see if she is in pain. I go through a line of questioning about the same things every time a nurse comes to the house. I wonder why it is not easier to make a chart and just go by that. I know will now have to create a chart, just so that I do not have to speak about my mother's illness all the time. This is supposed to be the end, it is supposed to be easier, if not smooth. The professionals say to me, talk to her, as her hearing is the last to go. Where is the dignity when you are speaking about what will happen to her, right in front of her and speaking about pressure sores and her continence or lack there-of?

The dignity is removed I believe when a person is bed-ridden and it seems odd to me. I am still advocating for my mother 16 years later. I cannot understand this. This disease has no awareness, yet it is prevalent worldwide. Many people think it is simply forgetting. "oh, is that when they remember the past but not present?" "No, it is when they forget how to speak, walk swallow." The picture where there is a brain and there is a giant eraser comes to mind. The financial burden on the caregiver and the person with the disease is prohibitive. There is no financial relief from the government, funds are being cut for actual in home care, until it effects you, I believe people are removed from it.

I hear that people feel so guilty for having to put their loved one in a nursing home, due to the inability to care for them at home or the financial concern. My advice is you do what you must do, it is a catch 22 either way and there is no right answer for this horrible illness. The stigma attached to the disease and the immediate result of a diagnosis, such as perhaps job loss, insurance coverage, and a plenitude of other things that transpire, would leave me to believe that many dementias are not reported. My journey continues, until my mother decides that she can no longer live in the shell that she now calls a body. At 75 pounds and very limited food intake due to compromised swallowing, morphine, we wait until she decides to concede to this illness.

Bibliography

1. "Alzheimer facts". Alzheimer's Association (2016).
2. "Facts for the Media". *Alzheimer Society of Great Britain* (2016).

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