

Living with Alzheimer's Disease

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It is estimated that 420,600 Canadians over 65 have Alzheimer's disease and related dementias, and 280,000 have Alzheimer's disease. The number of people in Canada with dementia is expected to grow by the year 2031 to over 3/4 million people due to the aging population. It could become even more widespread, over the next 30 years, as Canada's 10 million baby boomers turn 65 and head straight into the age of highest risk for Alzheimer's disease [1].

Currently 5.3 million Americans have the disease, by the year 2050 it is estimated that between 11 and 15 million will have the disease. 1 in 8 Americans over the age of 65 have the disease, which is nearly 10% of all grandparents in the United States. Almost half of Americans over the age of 85 have Alzheimer's disease or another form of dementia [2].

In Trinidad & Tobago in 2010 it was estimated that 5,000 people suffer from the disease. It is estimated 35.6 million people worldwide will be living with dementia in 2010. This figure is expected to practically double every 20 years, to 65.7 million in 2030, and 115.4 million in 2050. Much of the increase is clearly attributable to increases in the numbers of people with dementia in low and middle income countries [2].

According to Glen Smith [3]; Only 5 to 10 percent of people with Alzheimer's disease develop symptoms before the age of 65. The development of early-onset Alzheimer's is known to develop between ages 30 and 40, but it is very uncommon. It is more common to see someone in his or her 50s who has the disease. It often runs in families. Many people with early-onset Alzheimer's have a parent or grandparent who also developed Alzheimer's at a younger age. A significant proportion of early-onset Alzheimer's is linked to three genes [3].

These three genes are different from the APOE gene—the gene that can increase your risk of Alzheimer's in general. But you can have the APOE gene and never develop Alzheimer's. Conversely, you can have Alzheimer's and not have the APOE gene. The genetic path of inheritance is much stronger in early-onset Alzheimer's. If you have one of those three genes, it would be very unusual for you not to develop Alzheimer's before age 65 [4].

Alzheimer's disease is the most common form of dementia, which is a group of disorders that impairs mental functioning. Dementia literally means the loss of memory or thinking. Currently Alzheimer's disease is progressive and irreversible. In the brain, there are abnormal changes that occur that deteriorate over time and ultimately impede with brain function. Memory loss is one of the initial symptoms, intellectual, thinking abilities referred to as cognitive functions follow along with personality changes and behavior [4].

Alzheimer's disease is a progressive disease and it typically advances in stages. When Alzheimer's disease is advanced, those affected become

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completely dependent on others for every aspect of care. The length of time that one can have the disease varies; an individual can have the disease from five to twenty years. The most common cause of death due to Alzheimer's disease is some sort of infection [4].

In Alzheimer patients the loss of cognitive function is by disease-associated changes in the brain. Usually through MRI, the brain shows a formation of plaques which look like tiny brillo-pads in the spaces between the nerve cells. The plaques contain a brain protein called beta amyloid. The other protein in the brain, tau, within the nerve cells collapses making it appear as though it is a twisted piece of thread inside the nerve cells. Through the course of the disease, nerve cells in the brain continue to shrink and die as the disease progresses. As nerve cells continue to die, the brain itself shrinks and wrinkles along its surface and thus becomes smoother [4].

There is a plethora of information on the subject of Alzheimer's disease on the internet, or through Alzheimer societies or nursing homes etc. There is scientific research, neurologists that study the brain and atrophy of the brain however there is very little information on how to live with the disease and there is sound logic on why there is little to no information concerning that topic. There is no article or information that can offer anyone solace in dealing with a disease that follows no structure and literally returns a full grown adult into a fetus.

I have been a caregiver to my mother for the last 15 years of the disease, she has never gone to a facility. My home has been turned into a somewhat care institution. My mother developed the disease at age 57. She was a registered nurse, who did not get to retire from her 40 year career. My father passed away suddenly a year after her diagnosis and therefore her care became part of my life at the age of 31. I was immediately propelled into the sandwich generation, unarmed and uninformed. If I paid close attention to the developments of my son, I would understand now after 15 years going through the end stages of the disease, which it is in exact reverse.

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" (Table 1).

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 counseling/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 1: Progressive Decline in Alzheimer's Disease (Staging)

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.

Many people confuse Alzheimer's disease and Dementia or consider that it's the same thing. Although Dementia and Alzheimer's are related, they are quite different. Dementia is a broad term for a set of symptoms including impaired thinking and memory. It is a term that is often concomitant with the cognitive decline of aging. However, issues other than Alzheimer's can cause dementia. Huntington's disease, Parkinson's disease and Creutzfeldt-Jakob disease can also cause dementia. The difference between Alzheimer's disease and Dementia is that Alzheimer's is not a reversible disease. Presently, it is degenerative and incurable, whereas some forms of dementia are actually temporary or reversible with drug interaction or vitamin supplements due to deficiency [6].

There are different types of dementia, vascular dementia, Lewy body dementia and frontal temporal dementia. Vascular dementia is the second most common form of dementia next to Alzheimer's disease; it takes place when blood flow to the brain becomes reduced. Cerebrovascular disease is the progressive variation in the blood vessels. The most common vascular change associated with age is the build-up of cholesterol and other matters in the blood vessel walls. When this occurs, it results in the thickening and hardening of the walls, as well as narrowing of the vessels, which can cause a reduction or even a complete discontinuing of blood flow to brain regions delivered by the affected artery. If this takes place precipitously, it will result in a stroke. Symptoms could range from weakness to incoordination to anomalous sensations, contingent on the location of the injury in the brain [7].

When a stroke occurs there could be a sudden loss of cognitive function (such as language, memory, complex visual processing or organizational skills). Strokes are typically diagnosed without difficulty with modern brain imaging techniques. The cognitive complications are typically poorest at the time of the stroke and progress over time. In these cases dementia would not be diagnoses but rather as a residual cognitive impairment from a stroke.

Vascular dementia is a term typically reserved for subtly progressive worsening of memory and other cognitive functions that is presumed to be due to the vascular disease within the brain. Although similar to the symptoms of Alzheimer's disease, the changes in the brain of vascular dementia patients are due to chronic reduced blood flow in the brain that eventually causes dementia. These two types of dementias-Alzheimer's disease and vascular dementia are difficult to distinguish from each other due to the similarity of symptoms [7].

The second most frequent cause of dementia in elderly adults is Lewy body dementias include dementia with Lewy bodies and Parkinson's disease with dementia. These progressive brain diseases are linked with abnormal clumps of a protein entitled alpha-synuclein. These clumps, called Lewy bodies, originate in nerve cells throughout the outer layer of the brain and deep inside the midbrain and brainstem. Patients with these diseases experience progressive cognitive degeneration. Common symptoms include problems with movement, visual hallucinations, and fluctuations in thinking skills or attention [5].

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. 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 [5].

Living with Alzheimer's disease is undefinable. It is a day to day struggle with what the disease will present. It is a constant reminder that deep inside your love one still exists, however the challenge of the disease and the immense amount of time it takes away any normalcy of life makes it difficult. The disease has very limited awareness, which also makes it difficult to understand and to emotionally assist the caregiver. This disease does not only affect the inflicted, it significantly affects the caregiver. The disease is so undignified and so much so for someone developing in their 50s, putting my mother into a nursing home was not even an option for me.

Once my mother was diagnosed with Alzheimer's disease she was sent for a CAT scan at the hospital. They also referred her to a neurologist. I remember that the neurologist checked her dexterity and was surprised that she had full dexterity as he said that was one of the first things that are usually weakened with Alzheimer's disease. This I presumed was due to the atypical nature of her disease. The neurologist advised that he would have to report her disease to the Ministry of Transportation to have her license suspended. My mother just found out that she had an incurable disease and now her independence was being taken away.

To assist my mother I spent time making cue cards for everyone she knew, such as their name, who their spouse was, how she knew them, their address, their children, and their phone number. This was what they suggested as she may forget who she was talking to on the phone. They also suggested encouraging all hobbies that she liked before. When she first came here, she was sewing things like pillowcases, mending socks, and so on. I was glad because it proved that her dexterity was still very much intact. I purchased a sewing machine because she always had a sewing machine, so I thought she would start to sew as before, but no luck. Obviously, that interest was no longer there. I thought she may go back to reading; however, she lost interest in reading as well.

My mother was taking Aricept which was approved for the treatment of mild to moderate Alzheimer's by the FDA in 1996, and for the treatment of severe Alzheimer's in 2006. Studies showed that it helped cognition and function including effects on memory and performing everyday tasks. Aricept is the number one prescribed Alzheimer's drug worldwide and is part of a class of medicines known as cholinesterase inhibitors. Aricept comes in two strengths, 5 mg and 10 mg. My mother was on 10 mg. Aricept is well tolerated but may not be for everyone. People at risk for stomach ulcers or who take certain other medicines should tell their doctors because serious stomach problems, such as bleeding, may get worse. Some people who take Aricept may experience fainting. Nausea, vomiting, diarrhea, bruising, restless sleep, muscle cramps and loss of appetite [8].

My mother was 130 pounds when she was first diagnosed. After being on Aricept, she had no appetite, would complain of headaches, and would not sleep well. She was still able to have a conversation. She still knew who we were, and I would not ask her to cook, just for fear of her forgetting and leaving the stove on. Everything else was okay; she just had to be reminded. When I had to go to work, I would wake her up and remind her to have a shower. I would put out her clothes, and she would walk to her friend's house every morning. She was able to remember to put on her shoes, lock the door, and walk to her friend's house. I would drop my son at the day care, go to work, pick up my son, and then pick up my mother at her friend's house.

When my father passed away 14 months after my mother's diagnosis, her disease immediately worsened. She could not walk to her friend's home and her behavior was changing. She was becoming aggressive and un-cooperative. I hired a live-in caregiver, as I worked full-time. To off-set the time off for the caregiver I also had to put her into an Adult day program offered by the Alzheimer's Society and made arrangements travel to and from the program. On these days, I would arrange Personal Support workers to come in to get her ready for the program and wait with her for the transportation. The Day Program lasted probably a year. The disease changed once again, she was no longer benefiting from the program and had a few incidences with other patients.

I then had to supplement personal support workers for the time that the live-in caregiver was off. In these stages of the disease my mom would always try to leave and needed constant monitoring. Her behaviour was very challenging; it would change from aggressive to apathetic. With each live-in caregiver came another care-plan that had to be molded to the current stage of the disease. About fifteen months after being diagnosed, my mother's incontinence commenced. She would have various mood swings, either crying or just being aggressive.

Due to the aggression my mother was prescribed Ran Risperidone. This medication falls into the group of medications known as antipsychotic agents. The medication is used to treat mental and emotional disorders such as schizophrenia and bipolar disorder. Risperidone is also used for the short-term treatment of behavioural struggles (such as verbal or physical aggression, suspiciousness, and agitation) in individuals with severe dementia of the Alzheimer type and there is a risk of harm to individuals or others. Medications like risperidone are thought to work by fixing the function of nerve pathways in specific areas of the brain [9].

The medication made her very subdued and extremely tired. She complained also that it gave her headaches. My mother was also prescribed Ebixa. Ebixa tablets contain the active ingredient memantine hydrochloride, which is a type of medicine called an NMDA receptor antagonist. It is used for treating Alzheimer's disease. There is increasing proof that memory loss and dementia in Alzheimer's disease are associated to malfunctioning of the signals that pass messages amongst the nerve cells in the brain. As with any medication there are side-effects. The medication did improve her daily functioning as there was a noticeable difference prior to her taking the medication and after. My mother was on this medication for approximately 6 years. When my mother could no longer walk and assist her daily functioning, there was no efficacy of the drug, therefore no requirement to take it [10].

As her brain was deteriorating, with evidence from MRI scans, my mother started to develop seizures. According to research, individuals who suffer from Alzheimer's disease also increase their risk of seizures, and it is estimated that 10-22% of people with AD develop unprovoked seizures at some point (the higher rates being associated with hereditary/early-onset, such as my mother. Due to the fact that little is currently understood about the nature of seizures that are linked to Alzheimer's disease and they are therefore difficult to identify. Additionally, it is

reported that more than half of the seizures experienced by people with Alzheimer's disease are non-convulsive, there is a possibility that they can easily go unrecognized [11].

The rise of Alzheimer's disease and related dementias are increasing exponentially, the impact it will have on health-care and families is catastrophic. Due to the fact that the most likely cause of death due to Alzheimer's disease is infection, the infection is listed on the death certificate, not the cause. Alzheimer deaths are not statistically reported properly, which causes Alzheimer Awareness to be majorly deficient. There is no cure, there are no remedies we are heading into an Alzheimer epidemic that worldwide we are not ready for.

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