

Alzheimer's -Where did it Begin

Dr. Caron Leid*

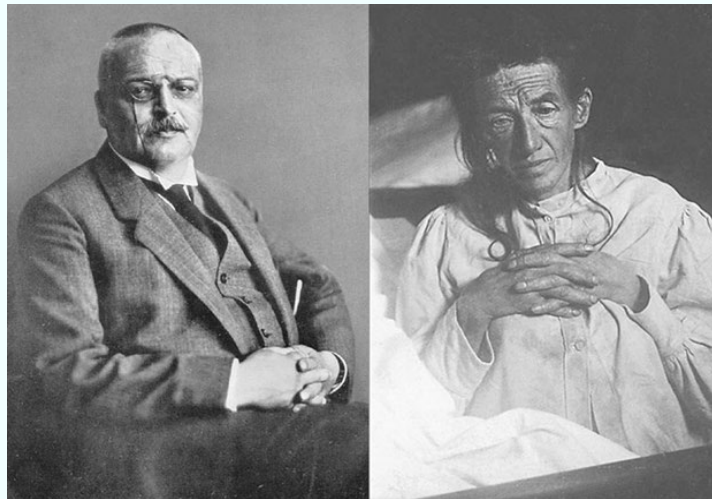
Alzheimer Researcher, Aspen University, USA

***Corresponding Author:** Dr. Caron Leid, Alzheimer Researcher, Aspen University, USA.

Received: November 20, 2017; **Published:** November 29, 2017

"Memory is the mother of all wisdom" Aeschylus 430 BC

A woman named Auguste Deter was taken into a medical asylum in Frankfurt, Germany in 1901. Auguste was 51 and was displaying odd behavioral symptoms including paranoia, progressive sleep and memory disturbance, aggression, and confusion. Her doctor was Alois, he watched over his patient but did not know how to assist or treat her. Auguste succumbed to her illness and passed away in 1906, Alois performed an autopsy and found bizarre lesions in Auguste's brain. Alois had never seen that type of atrophy of the brain in his career.

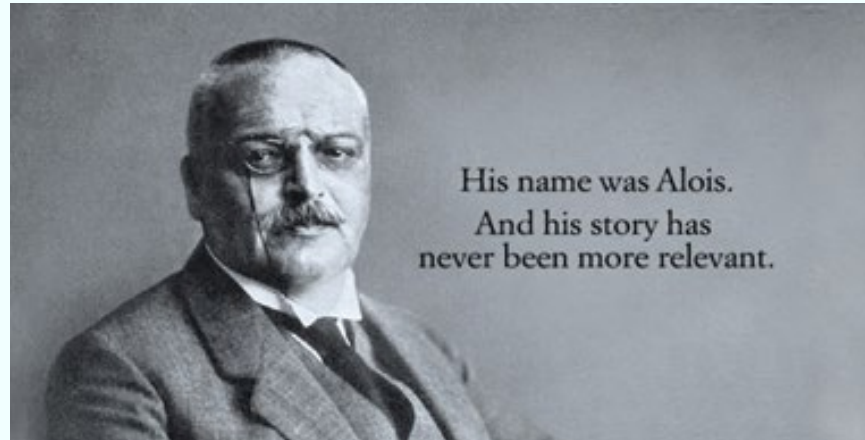


Alois

Auguste

That was well over 100 years ago, and even if Auguste was alive today, there is still no-one who can assist her. Auguste's doctor's last name was Alzheimer and Auguste Deter was the first patient documented with what we know now as Alzheimer's disease, named after Dr. Alois Alzheimer [1].

Citation: Dr. Caron Leid. "Alzheimer's -Where did it Begin". EC Neurology SI.01 (2017): 23-28.



Since the discovery of Alzheimer's disease, it affects over 40 million people globally and by the year 2050 it will affect over 150 million people. Think about those statistics, and probably look around, because that will include many of us. We are living longer, so the reality is that our chances of getting Alzheimer's disease will be close to one in two individuals developing it. Which means that you will probably spend your later years either suffering from Alzheimer's disease or helping a friend or loved one with Alzheimer's disease. Or in my case and even in the case of Auguste, being part of the sandwich generation, where you are balancing a career, newborn and looking after your sick parent with the disease [1].

We are quite aware of Alzheimer's disease care costs being exorbitant, In the United States it already costs over 200 billion dollars yearly. Today, it is the most expensive disease and costs are only projected to increase five times the amount by 2050 as the baby boomer generation ages. Alzheimer's is one of the biggest medical and social challenge of our generation and yet we have done nothing to address it. The average person doesn't even know what it is, how to pronounce it and how debilitating it is, until there is a diagnosis within their family. There is little understanding, awareness than any other disease because there is less time and money invested into it. Imagine over 100 years since the first diagnosis of the disease and yet, we are no further ahead in curing it. In the United States, the government spends 10 times more on cancer research than on Alzheimer's disease despite the evidence that Alzheimer's disease costs us more and causes the same amount of deaths each year as cancer [1].

It is estimated that 564,000 Canadians have Alzheimer's disease and related dementias. 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 is estimated that the cost to the health-care system and out-of-pocket expenses of dementia will be \$10.4 billion. There is a projected increase of this figure to \$16.6 Billion, a 60% increase by the year 2031 [2]. In Trinidad and Tobago in 2010 it was estimated that 5,000 people suffer from the disease. Much of the increase is clearly attributable to increases in the numbers of people with dementia in low and middle-income countries [3].

There is a serious lack of awareness of the disease which affects the lack of resources, just like any other disease, there must be a cure for Alzheimer's disease. Alzheimer's disease has been mistaking confused with natural aging and we know now that is not the case. Therefore, it is important to understand the healthy brain and what triggers severe memory loss and mental abilities.

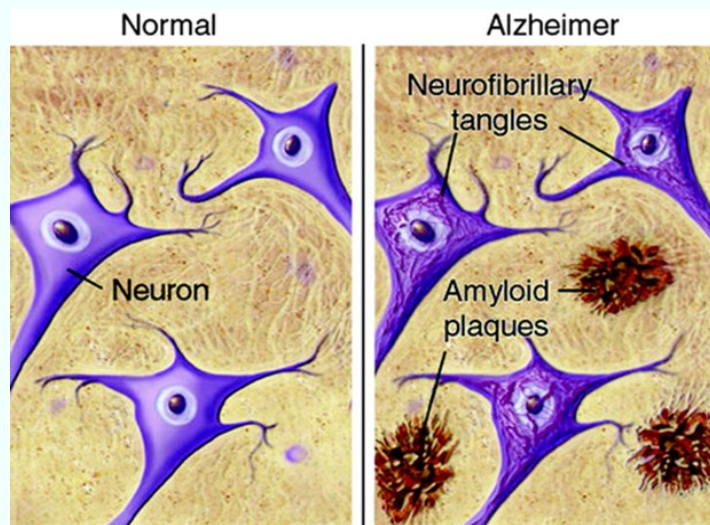
According to Glen Smith PhD; Only 5 to 10 percent of people with Alzheimer's disease develop symptoms before the age of 65. The development of early-onset Alzheimer's is known to develop between ages 30 and 40, but it is very uncommon. It is more common to see someone in his or her 50s who has the disease. 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 (Smith, 2012).

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 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 day to day 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.

My story.....

Marlene Leid

I have been a caregiver to my mother for the last 17 years and counting 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 17 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, individuals at any stage exhibit symptoms unpredictably, with daily fluctuations and stable "plateaus". This statement alone is a contradiction in terms, however it describes exactly the day in the life of a person suffering from Alzheimer's disease. I am sure there could easily be a corresponding chart for those that provide informal caregiving as well.

Progressive Decline in Alzheimer's Disease (Staging)

Stage	Characteristics	Interventions
1	"Forgetful" early stage <ul style="list-style-type: none"> • Insidious/gradual • Recent memory loss • Time/space disorientation • Mood swings • Slower/withdrawal/denial • Impaired judgment • Subtle language dysfunction • Continues to worsen 	<ul style="list-style-type: none"> • Seek interested and 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 <ul style="list-style-type: none"> • 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 	<ul style="list-style-type: none"> • 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 and maximize assets (client and family)
3	"Severe Dementia" stage <ul style="list-style-type: none"> • Obviously disabled cognitively • Full-time supervision needed • Marked personality/behaviour problems • Disorientation to person • Communication very difficult • Psychosis • Physical disorders appear • Can still reminisce 	<ul style="list-style-type: none"> • 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 <ul style="list-style-type: none"> • Almost total loss of intelligence/physical functioning • Few words spoken/understood • Emaciation/susceptible to infection • Death 	<ul style="list-style-type: none"> • 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 (National Institute on Aging, 2014).

Due to this reason, my mother's Alzheimer's was particularly difficult because she lost her speech and was unable to articulate anything comprehensible. Therefore, I can now identify that her progression of the disease mimicking reverse aging. I did not understand at the time and it is very hard to wrap your head around it, because you identify the person with the disease as they are in your life. At 30, I looked at my mother as my mentor, a nurse, the wise independent woman that I grew up with. She knew everything, she was wise beyond her years. She had lived in 4 countries, Trinidad W.I., England, Germany, Canada. She lived in countless cities, she drove in all the countries that she lived and standard cars as well as automatic. She taught herself German because she was a nurse there when my father was in the Royal Air-force.

My mom was a continuous learner, she worked at hospitals in so many different cities internationally. She left Trinidad at the age of 16 after her O'level exams and went to study nursing in England. When I even think of that, It amazes me.

Due to my father's job as an airport manager, besides residing in many countries, she travelled all over on many airport conferences that were held in every city all over the world. Japan, Brazil, Prague, Spain, China, Thailand, Singapore, just to name a few. And to think that the first thing to go was her speech. Many people think, oh is Alzheimer's when they remember things from the past? No, it's when parts of your brain die and shrink and then you slowly reverse, until you can no longer swallow and then you die. That is the sad reality. (Coles notes version of Alzheimer's disease, but it doesn't have to be). I can look back now, because at the time, navigating through the disease was so challenging. To put it in perspective, my son is 17 now, and at the time this was happening he was a toddler.

I have gained more knowledge now and I also have a different perspective being older now regarding the disease. As it robs, it replaces. I am a complete different person now because of it. It has dragged me through so many challenges, ups and downs, depression, compassion fatigue and resilience. The silver-lining is that my mom's story is helping others and if there is much consolation in that for me and to bring awareness about this horrible disease, including informal caregiving and the prohibitive costs and sacrifices that we make. Yes, I am part of the statistic. I am an informal caregiver.

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 [5].

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 inco-ordination to anomalous sensations, contingent on the location of the injury in the brain [6,7].

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