



## **Alzheimer's**

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Alice has Alzheimer's disease. This is her first realization that something is wrong. She is 50, brilliant, a successful cognitive psychology professor at Harvard. Alice is a fictional character created with remarkable authenticity and compelling interest by Lisa Genova in her 2007 book, *Still Alice*. Alice is fictional, but her story has similarity to the many adults living with dementia in the United States. Alice is unusual in that she has what is known as "early on-set," that is her signs of dementia began in her 40's and 50's. A minority of people with Alzheimer's experience their first symptoms early. This is considered the severe form of Alzheimer's and there are three inherited, genetic mutations that can cause it. The majority of people with Alzheimer's experience onset in their 70's. As of now, there is no clear inherited pattern for late onset Alzheimer's, although there is one known susceptibility gene for late on-set Alzheimer's.

November is National Alzheimer's Awareness Month, which is good, because many of us are confused by and afraid of the facts associated with Alzheimer's. Most of the information for this sermon was taken from the multi-part HBO Alzheimer's Project, which can still be viewed on HBO's website. If you want to learn more about the science, treatment, conditions, or care-giver experience, please click and view. I watched every segment, and the series is exceptional.

There are several different kinds of dementia (not all dementia is Alzheimer's) and they physically and cognitively manifest themselves in different ways. Warning signs of dementia include memory changes that disrupt life, difficulty completing familiar tasks, changes in mood or personality, confusion in time or place, trouble understanding visual images and spatial relationships, and new problems with words in speaking or writing. A neurologist is the person who can test an individual to

determine if he/she has mild cognitive impairment, Alzheimer's, vascular dementia, or other forms of dementia such as Lewy body dementia. If you have any questions about yourself or a loved one, visit a neurologist and get tested.

Alzheimer's was first "discovered" in 1906 when Dr. Alois Alzheimer discovered similar lesions inside the brains of women who had died from dementia. The current dominant theory on Alzheimer's suggests that amyloid plaques build up in the bodies of some people. These plaques (protein deposits) build up in (stick to) the brain and destroy neurons and kills synapses, which leads to dementia. According to this theory, some people either produce too many amyloids or flush them out too slowly. A possible future treatment might include medication that diminishes amyloids. And the genome project is quickly identifying all genes causing disease, which will allow drug manufactures figure out which genes to target with which medications to manage disease.

In addition, there appears to be a link between hypertension, high cholesterol, diabetes, obesity, and insulin resistance for people with all forms of dementia (there appears to be a link with inflammation and dementia). There is a category of dementia diagnosis known as "vascular dementia," so one suggestion for dementia prevention, which will work for some people, is to eat healthy and exercise.

There is, unfortunately, a genetic component to some, but not all, Alzheimer's, and there are tests that indicate if a person has some of the gene mutations that cause early on-set Alzheimer's. In the story, *Still Alice*, two of Alice's three adult children choose to be tested after learning about their mother's diagnosis. One of them, a daughter, has the early on-set gene, which means that she will acquire early on-set Alzheimer's like her mother. This daughter, who is undergoing fertility treatments, chooses to have her embryos tested for the Alzheimer's gene mutation prior to implantation. The more information we have, the better decisions we can make.

I want to emphasize the need for proper medical diagnosis. The general population has lots of misinformation about dementia and there are stereotypes. In addition, people unqualified to make diagnosis, at times, casually diagnose others. I recently spoke to a member here who believed he had Alzheimer's based on what another professional (not neurologist) had to say to him. I was deeply offended on behalf of this gentleman. Given what I had learned in all the HBO documentaries, I had and have serious doubts about the accuracy of the diagnosis. Please don't live in fear. Live in the freedom of choice, with accurate information. If you have questions, visit a qualified professional. Especially because the earlier you are diagnosed, the earlier you can receive medicine that slows the progression of dementia. There is currently

no cure for Alzheimer's, but medication, if given early enough, can slow the progression.

If you visit a neurologist or doctor for dementia, you should first be tested on other things, sleep deprivation, depression, stress, vascular health, potential stroke – all areas that, if problems develop, can cause memory loss without the memory loss being Alzheimer related. Once these things are ruled out, a neurologist can perform cognitive tests to determine if dementia is present. Mild cognitive impairment, incidental forgetfulness (lost keys or glasses), is not a significant problem. Fifteen percent of the population aged 70 – 90 has mild cognitive impairment. This impairment will not necessarily progress to other forms of dementia, including Alzheimer's, so it is important to get tested in order to find out what is going on.

One of the HBO documentaries featured an elderly man who was concerned he had Alzheimer's because he was forgetting certain things. Through testing, the older gentleman with cognition problems learned that he had early on-set Lewy body dementia, which manifests differently from Alzheimer's. His problem was with cognition skills, not memory skills. In fact, I watched this segment sitting next to a 14 year old. As we watched the older gentleman go through the memory test, we realized that he had a better memory than either of us (truly, he remembered word lists better than either of us). His course of treatment and prognosis is different than someone with Alzheimer's. Do not assume all dementia is Alzheimer's.

With all this said, there are people in our congregation today, perhaps even myself, who will be diagnosed with Alzheimer's. One of our older members, now dead, was diagnosed with Alzheimer's. His grief stricken family watched as this gentle, intelligent, loving man became paranoid and threatening. As one of the HBO specialists noted "Alzheimer's is a disease that destroys the nerve cells that control features that give us our human qualities . . . It is a disease of our most human qualities; reason, how we think, contemplate, and use abstract thought." Someone else might develop Alzheimer's and become patient and silent, or silly, or like this former member, paranoid. Alzheimer's expresses itself differently in every person. What any of these developments have in common is that they are alterations of our human qualities. With Alzheimer's, the person you have known yourself to be, the person who others know you to be, disappears forever even while the body remains.

At one point in my notes on the HBO series I wrote in capital letters "SO DAMN DEPRESSING." And Alzheimer's, particularly early on-set, really is. There is no cure, diagnosis is often made late (many people don't know about the early on-set genetic link or can't imagine developing Alzheimer's so early so they don't get tested), and medications, if given too late, barely slow the disease. Most of us are still very

active in our 40's and 50's, some still raising children, most still working, most still planning on enjoying things like retirement years from now. The HBO documentary profiled one couple, Pat and Terry who were married for 34 years. Pat developed Alzheimer's when she was 53. Her husband remembers that in the 17<sup>th</sup> year of their marriage (when Pat was 53) something went wrong. Terry cared for his wife for nine years at home before she moved into a nursing facility. He remembers it as a "lonely, difficult existence." HBO estimates that there are 10 million Americans providing 8.5 billion hours of unpaid care to people with dementia, and currently 70% of people with dementia still live at home placing significant emotional and financial burdens on family members.

As I listened to Terry tell his story, I want to confess a thought I had "I hope that this is never me." A decade in isolation caring for someone who used to be your partner; tragic? I felt ashamed saying this, and I assume I would survive, as Terry did (he later happily remarried), but how awful. Many of you wrote to me about the pain of watching a loved one with Alzheimer's disappear. One of you wrote to me about your mother who suffered with Alzheimer's

I was so naïve. I didn't have a clue about how bad things would get. No one does who has never experienced the disease firsthand. My Mom's physical body finally died. But the person she was—her mind, personality, soul, wit, intelligence, emotions—died long before then . . . Alzheimer's is a horrible, degrading illness. It starts out sneaky . . . Initially Mom couldn't remember the day or the time. After a while she couldn't remember what she always ordered at her favorite restaurant . . . Then Mom forgot she needed to pull her pants down when using the toilet. Then, she forgot that she needed to pull them back up. Finally, she forgot to do anything and ended up in diapers.

Another person wrote to me "Some people said to me 'Eventually you will laugh about all the crazy behaviors.' I never did and I never will. To see a loved one drift further and further away is sadder than death . . . A way to cope is that you try to see that person no longer as your mother but as just a person you are responsible for looking after." The pain of Alzheimer really is the power of the disease to destroy our human qualities, and with them, the connection of our relationships.

Alzheimer's, and other serious forms of dementia, are actually this painful. What we can do is to help the care givers. Watch their loved one while the shower, or take a walk, or nap. And we can maintain relationships with both of them, the caregiver and the person with Alzheimer's. Isolation is one of the most painful parts of Alzheimer's. People are uncomfortable with someone who forgets names or gets lost, or walks into the wrong home, or as one of you wrote to me, comes downstairs with

shampoo in her dry hair, wearing her clothes from yesterday claiming that she took a shower. This happened to one son during a family Thanksgiving dinner. It's Thanksgiving and Mom is standing in yesterday's clothes with shampoo in her dry hair. Yes. If you are a guest there, it is not time to leave. It is time to say, "How can I help?"

Alzheimer's unpredictability is also a challenge. One of you wrote to me that your father sang "Take Me Out to the Ballgame" over and over again. Someone else wrote to me that your mother complimented your shirt 28 times during one car ride (and yes, this person counted the number of times this was said as he explains "To keep my own mind."). Someone else had a parent with Alzheimer's who began to sign up for every contest that came in the mail. The progression of Alzheimer's is also unpredictable in terms of time. Some people deteriorate quickly, others deteriorate some, plateau for a while (even years), deteriorate some more, plateau a long while, etc. The series of small losses along the way are painful and difficult for the person with Alzheimer's who is simultaneously forgetting things and behaving differently, and also realizing the changes and loss.

It would be tempting in a sermon this serious to offer you some false encouragement and suggest that is not that bad, but one of the problems with Alzheimer's disease is that we ignore its existence and reality, which makes it worse for everyone. We avoid telling our doctors if we have memory issues. We avoid telling people we have Alzheimer's. We avoid visiting long time friends with Alzheimer's. We avoid caregivers of Alzheimer's patients.

If we truly respect the inherent worth and dignity of everyone we need to admit to the reality of Alzheimer's and find out how we can be of help to our family, neighbors, and friends living with Alzheimer's. Cincinnati has an exceptional Alzheimer's Association Chapter which offers continual educational programs, and a regular list of communication tips for those working with Alzheimer's patients in their quarterly newspaper, *Cornerstone*. Even more important, they have a free help line anyone in the community can use to ask questions about Alzheimer's. I have called this number myself and spoken to a social worker and nurse who answered my questions about the progression of Alzheimer's and how to help members here living with the disease

One of the most difficult decisions families face is when to place a loved one in a nursing facility. One of you wrote to me and said that making this decision about a parent was the hardest thing you have ever done. In the HBO documentary one woman recounts that she and her husband promised one another that they would never put one another in a nursing home. Her response now is "Some vows you have to break." This woman patiently and regularly visits her husband. She feeds him and

files his nails. Every time she goes to visit she gets dressed up. She explains “He may say my name, put his arm around me and then it is all worth it . . . I’d like to say ‘Can you come out of there? I’m here. Why did you leave me by myself?’” One of you was diagnosed with PTSD (post traumatic stress disorder) after being the caretaker of a parent with Alzheimer’s for several years. There are support group for caretakers, and they can be a life-line.

Why did you leave me by myself? It’s not just caregivers who struggle. Children and grandchildren struggle as well. Alzheimer’s is painful for everyone involved. Seeing the commitment of some family members and caregivers is extraordinarily moving. I was reminded of “unending love.” She may have chosen to put her husband in a nursing home for his safety, but her love is unending. Another man, in his 30’s, cares for his father with Alzheimer’s. His father wanders, especially at night, showers at night, tries to walk out the door. In the two years he has been caring for his father, this man has gained 30 lbs and developed high blood pressure. When asked why he cares for his father he replies “He is my Dad.” Again, unending love.

Of course, not all family members are so functional. One of you wrote to me about a step-mother who was reluctant to acknowledge the disease, and then care for her husband. Very painful.

Those of you who wrote about some positive experiences with Alzheimer’s tended to have loved ones who were calm through the progression of the disease, and were at times, though different, enjoyable. One of you wrote to me “I know I am lucky she is alive and her demeanor has actually improved during the disease.” Someone else wrote

Mom’s Alzheimer’s gave her children and husband a chance to forgive and forget . . . After my dad died, mom went to a nursing home where she became the favorite of all the caretakers. She would burst into song when a word jogged her memory. She would talk about her childhood on a farm in Canada and carry on conversations in French . . . She would “dance” in her wheelchair. She complimented everyone who took care of her or served her food. If one of her children or grandchildren came in the room, she’d light up and say “You’re one of mine, right?” That’s all we needed . . . to know we were one of hers.

What I liked about the HBO documentary was that it was so real. At one point a woman with Alzheimer’s is interviewed. She says “Alzheimer’s just a part of my life ... I try not to dwell on it...Um...I don’t remember anymore.” Long silence. She can’t remember her thought. There it is, what is familiar and what fades away, for everyone.

This world is precious and real. Here is what is today, and it will change tomorrow. That is a guarantee. Make the most of this day. In a recent issue of Cornerstone the “Coping tips for Caregivers” had these suggestions for talking with a person with Alzheimer’s “Ask one question at a time, patiently wait for a response, avoid criticizing or correcting, avoid arguing, and focus on feelings, not facts. Sometimes the emotions being expressed are more important than what is being said ...learn to forgive yourself when things are not going according to your expectations, keep your sense of humor, and take pride in the care and comfort you give.”

Alzheimer’s is what it is. Denial will not change it. Love and medical care can help it. Support can make it bearable. But Alzheimer’s will be what it is. This is not a failure on the part of anyone, a care-giver or patient. Take care of yourself and your loved ones. Love what is good. Make time for what really matters to you. Care for those who need help. This is it. Amen.