

Holly's Story:

Alzheimer's first crept into my family's life with my Mother. Back in early 2000's, repeating her stories, losing her keys, asking the same questions, reading the newspaper over and over again and not retaining much, etc. Well there was no mental health care back then for forgetfulness and this was written off as a sign of old age. Well these symptoms were kept under wraps with people outside the family and my Father took care of her, one could say, covered up for her.

It was called Dementia back then, no one wanted to use the "A" word and there was no definitive test to diagnose Alzheimer's even if we wanted to test her out. My mom slowly declined over the next 15 years. At one point my Father's health started to fail with colon cancer and he put up the white flag. He could no longer care for my Mom, to the degree he was, and take care of his own symptoms. At one point she kicked him out of the bed they had shared for 61 years, not knowing who he was, saying her parents were upstairs and would be furious with her to find this strange man in her bed. He was so hurt and frustrated with her and in dire need of his own sleep recovering from surgery.

The parents "were upstairs alot"....one time at midnight with 6" of snow on the ground, my Mom had her flannel nightgown on, put on her winter coat and hat, grabbed her purse and tried to head out the front door to go to class. Thank God we caught her and had to put a child proof lock on the door. By now we had 24/7 live-in help and my sisters and I (3 of us) were rotating, visits home to Pittsburgh (4 hrs away) to help oversee and care for them both. Thank God our jobs allowed for teleworking and one sister is a grandmother and not working, and 2 hrs away for emergencies. Dad refused to move into assisted living, he did do a tour, we honored his decision and got the full time live in healthcare worker, we respected his decision to stay in his home.

Dad passed away 7/26/2014, we moved my mom in with my Sister Beth in Ohio, she thought they were going out for ice cream. We sadly, sold their house of 52 years. Mom did not even realize Dad had passed away even though we had her with us in the room in the hospital, when we had to turn off the ventilator. She still "waited for him to come home from the church", my Father was a brilliant concert organist and Chancellor of the Music Dept at Pitt University (47 yrs).

The Alzheimers association helped us greatly with advice, go along with it, trying to argue that he is not coming home and had passed away would make her relive that horrible news time and time again. A white lie but a passionate lie. Mom passed away soon thereafter on a quick decline. There was a mass in her lung that got the best of her, maybe a blessing by that time so she could be with Dad and shed this horrible disease. Only at this hospice stage did a doctor finally diagnose her with Alzheimers via an MRI which proved her brain had shrunk. It was not determined through an autopsy. My Mother's sister, Aunt Edee, had the exact same symptoms and decline minus the lung tumor. This is why we suspected genetic ties.

So my story, given my Mom's and my Aunt's situation, and the availability of blood tests now to prove genetic predisposition to this disease, I did my research and decided to ask my PCP doctor to do a blood test specifically to test the APOe gene to see if I have the predisposition. This was in 2016-ish. He asked if I really wanted to do this, why I wanted to see these results, that if it is positive, there was really nothing he or anyone could give me to cure it. My reasoning, I wanted to know what the future may hold and if it was positive, I would utilize every tool in my arsenal to fight it- lifestyle, diet, etc. It would also allow me to prepare for it, prepare my family and ask for their support.

I am not married, I have no children to take care of me, just siblings that are all older, and run the same

risks as I do, nieces and nephews I would need to lean on heavily if they pre-deceased me. Do I need long term health care, will they even cover Alzheimers? And get my will drafted to cover my health care wishes. This is the responsible thing to do, right?

I also know without a diagnosis, you cannot even get Healthcare help and support to treat it much less insurance coverage. this news has also fueled my intention to help fight for a cure through philanthropy, participate in events, share my story with others, get helpful hints and advice to live a high quality of life, to know that I am not the only one with this serious disease. He liked my reasoning and put the order in.

Well, it came back APOe 4/4. Ergh!!! the worst rating anyone can get. This means I have the highest level of genetic disposition from both my Mother AND Father!! Where did that come from on Dad's side?? Well go to learn my Father's Mother was under care for 5 years with dementia, probably Alzheimers, while I was a young child.

I have extremely mild cognitive issues, is it old age? I have a 42 year successful career behind me starting in technology sales and ending as a Director of Strategic Alliances for a multi billion dollar software company called Ultimate Software, now UKG. I decided to retire early in December '22 given the recent acquisition of Ultimate that destroyed the people first culture Ultimate Software had. The new investment owners put a huge amount of stress on their 55+ employees to take a one time offer, retirement package and leave. By choice, 200 employees like me took it.

The good news is this leaves me with more time to do the things I want to do. I always worked out since I was a teenager so am very active, and I am a lifetime Weight Watcher so do already eat healthy for the most part. I discussed my situation with my new PCP and found a really good Memory care doctor. He tells me that with my test results, it is not a matter of IF I will get Alzheimers, it is a matter of when. Really shocking when I heard this. I thought I had a 30% chance of beating it. So I am at serious risk of developing Alzheimer's.

He also advised that catching this early at my stage, there was a drug coming out in Jan '23 that may help so I have been following along. I am extremely frustrated at Medicare for not covering it and dragging their feet to do so when it has been approved by the FDA. But yet Veterans can get it. Why should I be forced to take \$27k a yr. out of my retirement savings because my healthcare provider is waiting to see what Medicare is going to do to decide if they will cover these costs? I am a successful business woman and would be happy to use my talents to help this cause and get all of the Alzheimers drugs covered, so there can be a competitive pricing environment. If there are still reservations about the drugs, let's do more testing and make sure that is funded. These two drugs are all we have, and if it is not treated early, then there is no hope but to fall prey to this terrible disease.

I saw this article in the Washington Post as I was leaving my supermarket. I never buy papers really but felt compelled to read the article about Rebecca Chopp on the front page and this organization. It is because of this article that I joined and am writing you today. Please let me know how I can help and thank you for bringing us all together.

The face of Alzheimers today are successful professionals who are brilliant, smart and bring great value to our world. We deserve better. We deserve a fighting chance. I look forward to learning more.