

On April 27, 2017, I shared with the Pilot Club at a Program Meeting, my family's story of our collective battle with mom's Alzheimer's Disease. A little over a year after that, in May 2018, we lost our mom to the disease through a fatal fall. Since that time, we have shared our journey with others on a similar path. I hope that this account helps someone as they encounter the uncharted waters of this deadly disease. Following is the talk I shared with our Club.....

I've been looking forward to sharing information about Alzheimer's Disease with you, so thanks for giving me this opportunity! First off, I do not have a medical background. I'm speaking about Alzheimer's Disease from the perspective of a daughter dealing with the disease for the past twelve years. For over a decade, I've made "learning ways to fight Alzheimer's disease" my passion, and I love it that the Pilot Club supports brain health. It's about survival for my mother, myself, my sister, and my daughters, and really..... all of us!

Here's a brief summary of what I'm going to focus on today. I'd like to share a bit about what Alzheimer's Disease IS, what are the chances of having it, healthy brain tips to decrease your chances of

memory loss, a summary of my mother's struggles, my political work in the area of Alzheimer's Disease, and finally the tips from the Alzheimer's Summit, which is a compilation of lectures from healthcare professional across the world. Susan Grandgeorge is truly the expert here and she's going to help me out when we get to that point. I think that it would be great for her to give an additional program talk, because there is so much to cover.

The exciting take away today is that even though there is not a "cure", per se, for Alzheimer's Disease, there is a plethora of things that we can do to keep our brains healthy to avoid memory loss.

What is Alzheimer's Disease? It's a slow fatal disease of the brain affecting 1 in ten people over 65. No one is immune to it. Its progression is very gradual. It's the result of two abnormal protein fragments known as plaques and tangles, coming together, and killing healthy brain cells.

The first area affected is the hippocampus where memories are formed (by ear). Slowly, over time, the plaques and tangles destroy the hippocampus which decimates a person's ability to form new memories. That's why with Alzheimer's the first symptom is usually

short-term memory loss. As it spreads through different parts of the brain, it kills cells wherever it goes. The different stages of the disease progression are a result of its movement through various parts of the brain.

Next it moves to where language is formed and affects the person's ability to recall words and speak fluently. (just up from the hippocampus)

Then, when it moves to the frontal lobe, where logical thoughts are formed, it destroys the ability to understand concepts, solve problems, and to make plans.

From there it moves to the part of the brain that controls emotions, leaving the person out of control with their moods and feelings (hairline).

The backwards movement continues to the top of the head, which is the area of the brain where we make sense of our surroundings, including hearing, seeing, and smells. This damage creates havoc, and often hallucinations occur.

The disease then progresses to the back of the brain where our oldest and most cherished memories are stored.

Near the end, the area of the brain controlling balance and coordination is affected. (back of head)

The last and final area affected is the person's ability to swallow, breathe and for their heart to function, resulting in death. (brain stem). This cycle typically takes about 8-10 years to progress.

Let's talk a bit about **Risk Factors** for Alzheimer's Disease.

There are certain risk factors for the disease. Some of these risk factors are lifestyle related and so we have the ability control them by making changes. Life-style change is what I'm going to focus on a bit later today.

There are three Risk Factors that you can't change, which are age, family history, and gender. Regarding age, the older you are the higher your risk is for late-onset Alzheimer's disease. Late-onset Alzheimer's affects one in 10 people over the age of 65. For people 85 years old and older that risk jumps to one in four. If you have a direct relative, a parent or sibling, with Alzheimer's your chance of developing Alzheimer's is three times that of someone without any family history of the disease. Should both your parents have

Alzheimer's your risk is greater still. However, this does not mean that you will get Alzheimer's disease only that your risk is higher.

One form of early-onset Alzheimer's, called Familial Alzheimer's disease, is the result of an inherited genetic mutation in one of three genes. This form of Alzheimer's is extremely rare. It affects families across generations and starts when people are in their 30s and 40s. If a parent has one of these gene mutations, you have a 50% chance of developing this form of Alzheimer's disease.

Gender is also a risk factor for Alzheimer's. Women are twice as likely as men to get Alzheimer's. Even when statistics are adjusted to account for the fact that women live longer than men.

Scientists believe that menopause and the decline in estrogen play a role in Alzheimer's development in women. At mom's facility, there are 12 women and only 3 men in the Memory Care Unit.

There are some risk factors that you can change. They include managing diabetes, high blood pressure, high cholesterol, obesity, smoking, depression, cognitive inactivity, and physical inactivity, to name a few. The Mayo Clinic info that I'll share in a minute will give you some specifics for making lifestyle changes.

Also, cardiovascular disease is linked with developing Alzheimer's disease in later life. A history of strokes doubles the risk of dementia as you age. Reducing your bad cholesterol along with lowering your blood pressure will protect your heart health and lower your risk for Alzheimer's.

Next, I'm going to share A Dozen Healthy Brain Tips to decrease your chance of memory Loss. This tip sheet is from the Mayo Clinic, and I will include it as an attachment in an email that I'll send to all of you. Mayo Clinic Recommendations follow:

- 1. Mental exercise is important. Keep reading, doing puzzles and learning something new.**
- 2. Moderate aerobic exercise is great. 50 minutes 3x a week of walking, bicycling, or any activity that gets your heart rate up.**
- 3. B-Complex vitamins 1x day.**
- 4. Vitamin C (500 mg per day)**
- 5. A handful of nuts per day, almonds, walnuts PECANS**
- 6. Fish 3 x per week ~ cold water fish is the best ~ salmon, halibut, mackerel**

7. Foods with curry spice including curcumin. I use a turmeric root every day in a berry smoothie that I make. You can buy it at Publix in the produce section
8. Foods high in antioxidants ~ berries, green tea, cacao powder.
9. The Mediterranean diet. It includes vegetables, fruit, olive oil, fish, with moderate intake of dairy, and low intake of meat and poultry.
10. Treating cardio risk factors such as high blood pressure, high cholesterol, diabetes and being overweight.
11. Socialization (Frequent time with family and friends. Like Pilot Club!
12. Quality sleep. Tell your doctor if you have loud snoring or episodes of stopping breathing or gasping. This results in the brain not getting enough oxygen, which over time, does damage.

Now I'd like to share a brief history on my mother's struggle with Alzheimer's, and how it correlates to what we learned earlier about how the plaques and tangles move through the brain, affecting different areas.

My mother's story starts about 12 years ago. I was living in Seattle and raising my family. I would talk to mom about once or twice a week. Mom and Dad were living in Palatka, and my sister Cindy and her husband John, were just down the road in Satsuma. During our phone conversations, Mom began to ask me the same questions over and over. At that time, I had no idea that Alzheimer's could be a possibility. She was around 75 years old and had been sharp as a tack. I mentioned it to my sister, Cindy, and she too noticed that mom had become a bit forgetful.

Over the next year or so, Mom's short-term memory began to fail. This matches up with what we learned about the hippocampus being affected first. She would buy multiple items from the grocery store, and she would forget if she had fed her beloved cats. My sister and I, along with my brother-in-law John, decided that we needed to talk to mom about the situation. I flew out from Seattle, and Cindy, John, Mom, and I went to the gazebo at Ravine Gardens to have a heart to heart. We wanted to do this away from Dad, because he was helping Mom to mask and downplay the problem. Mom's first reaction was to withdraw and become silent. After that, she was physically sick to her stomach, and after that, she was angry.

I returned to Seattle, and my sister set up an appointment with a neurologist in Palatka. The doctor was older than mom and informed my sister that mom had the brain of a teenager, and that Cindy needed to be more patient with her. Of course, this was not the case, but it gave mom enough ammunition to dig in her heels. Over the next five years, mom began a slow mental decline.

The next area of the brain effected is the area that controls language. We noticed that mom often had brain fog ~ calling objects, do-hicky, thingamajig, or thingy, increasingly often.

Then, as it moved to her frontal lobe, her logic was affected. Mom would accuse my Dad of having all night drinking party with the boys, when in reality Mom was forgetting to clean up the kitchen. She would be shocked that the kitchen was a mess each morning. Apparently she also forgot that Dad wasn't a drinker.

One day, Mom left to go to Publix in Palatka and ended up in Gainesville. Dad and Cindy were in a panic because she had been gone for three hours. When mom finally got home, she explained that she drove and drove looking for Publix. When she got to a big town, she decided to turn around..... then she drove and drove and drove

until things started to look familiar again. When Cindy asked why she didn't call home on her cell phone, mom was pissy and said, "Don't you think that I would have if I could have remembered how to use it!" That's when we had to take the car keys away from mom.

The next area that the disease moves to is the part of the brain that controls emotions, leaving the person out of control with their moods and feelings (hairline). Mom often took out her anger and frustration on Dad. It was heartbreaking to see him cry when she had said something uncharacteristically cruel to him. The angry, emotional stage of Alzheimer's is not pretty, and often times dangerous for the person and the family.

The disease destroys the part of the brain that makes sense of things, causing hallucinations. (top of head). An example of this was when mom showed us a portal to **another world** through the guest room closet door when she was still living at home. She explained that this is where her Daddy goes to make moonshine every day. Her father passed away before I was born in 1954.

The disease progresses to the back of the brain where our oldest and most cherished memories are stored. Mom has been in this

stage for the past five years. As the disease attacks this part of her brain, she is slowly going back into time, regressing through her life. It was about five years ago that my sister Cindy called me when I was still living in Seattle and said that I should plan a visit soon while mom still remembered who I was. I thought that Cindy was exaggerating. She was not. During my visit, Mom asked me, "When you were growing up, did you get spanked?" To make my mom not feel guilty about spanking us, I said "No, I didn't get spanked as a child" At that point, mom swatted my arm and said, "I knew you weren't my child, because my child got spanked!" While it seemed funny at the time, the week continued to decline. The first time that a parent doesn't recognize you is devastating, but I had to quickly get over this.

After this trip, it wasn't long before Mom did not know who my Dad was. Cindy got a call from work from one of my parent's neighbors asking Cindy to come to mom and dad's house immediately.

Apparently, mom became alarmed that there was an intruder in the house, so she went to the neighbors for help. The neighbor came back with Mom and saw my poor Dad sitting in his wheelchair with his driver's license out and crying. We were now in crisis mode.

After several unsuccessful tries with in-home care, Cindy moved in

to care for my parents. After six weeks **Cindy** just about lost her mind. Mom had angry knife wielding outbursts at the **strangers** in her house, who happened to be my sister and my dad. At one point during this time, Mom told Dad that maybe she should just push his wheelchair in the neighbor's pool and do them both in. Cindy worked full-time and no longer felt safe leaving Mom and Dad alone at all. She researched facilities where mom and dad could reside together, Mom in a memory care unit, and Dad in adjoining assisted living..... where they could get the care they need. I flew out to help with the move which was the most heartbreaking day of my life.... It's still difficult to talk about , but it truly was the best for them.

Three years ago, after retiring from my job with the military, I relocated to help Cindy care for Mom and Dad. I moved into their house and soon discovered Mom's diary from the late 1940s. I transcribed it ~ 33 type written pages. When I'd visit Mom, I would read it to her, and she would tell me "the rest of the story". She was able to do this because in her mind, she was now a teenager, so these memories were vivid. On the last page of her diary, she wrote "Always remember the Summer of 1945". And that is exactly what she was doing.....

But, over time, as the disease progressed, she no longer remembers very much of her teen years. In her mind, she is now a child, often talking about her Mom and Daddy, and telling me on our visits that she has to get back to Miami soon because her parents will be worried. Many of her friends at Vintage Care in the memory care unit are in this stage. They believe that they are children in school. When I visit, I become part of their reality ~ I am at school with them. One of mom's friends, Miss Joyce, was worried last week that her mother wouldn't know where she was. I assured her that her mom had signed the permission slip and it was ok for her to be at the "slumber party". Miss Joyce relaxed and was happy. For the time being, you see in five minutes, she was worried again.

With the disease, near the end, the area of the brain controlling balance and coordination is affected. Over the past year, we have noticed that mom's gait is off, she lists to the right. Since her balance is off, she falls and runs into things on a regular basis. Mom doesn't really know who we are and she is childlike, but we love her and have wonderful visits. The angry outbursts have almost subsided, but she is still not allowed to have access to knives. She resides in a world where her closest living relatives are her parents.

She no longer remembers being married or having children.

Between my sister and I, she has visits from us every day and she is happy most days. Memory care residents are in various stages of the disease. The beauty is, they still have their personalities, and I can sit by the hour and talk to them. They are a gift to me, and I actually learn life lessons from them every day.

I know that the very last and final stage is next for Mom. She currently struggles with swallowing at times, and her ability to breathe and her heart to function, will be next. As I mentioned, the disease typically takes about 8-10 years to progress. We are in year 12, so we are on borrowed time. We have seen others go before her at the facilities that she's been in, so we know what's next. The saddest part for us is when we do lose her, we won't be losing our mother, we will be losing our child, and this breaks my heart.

My mother's disease has made me become politically active. Two years ago, I became involved with the Alzheimer's Association of Central/North Florida. Once a year, we make a trip to the State Capital at Tallahassee to meet with our state representatives to share our stories and to gain their support for various bills affecting

Alz which are up for vote. We become the face and the voice for our loved ones so that they are not just a budgetary line item that can be crossed off or reduced. Our presence there has been very effective, supported by both political parties. Just yesterday, a bill was passed unanimously (115-0) in the house to fund a memory disorder clinic in Orlando. Next year, I hope to go to Washington DC with the group to talk to our members of congress about the disease. It's pretty cool when we go because they light up the capital building with purple light.

(Note from my updated preface above, in the end, it was a terrible fall that took my mother's life. She ran full speed into a wall at her facility and broke her neck. She would linger for nearly two weeks in hospice, on morphine, without food or water. My sister and I were with her that entire time until she took her last breath).

The last part of this presentation comes from information from the Alzheimer Summit, which is a compilation of lectures from healthcare professionals across the world. It will provide you with life style information to help you reduce your risk of having Alzheimer's Disease. I am so glad that I sat next to Susan a few

months ago at a Pilot Meeting because she truly is the expert on the disease. Susan gave me a thumb drive with many hours of information on Alzheimer's disease. I've incorporated much of it in the information that I've already shared with you. Now I want to provide you with some additional information that I found invaluable. As I mentioned, Alzheimer's Disease is the result of two abnormal protein fragments known as plaques and tangles, coming together, and killing healthy brain cells. Plaques alone will not do this. It takes the destructive comingling of the plaques AND the tangles to destroy the brain. What can we do to avoid this happening? I'd like to share some lifestyle changes recommended by the Summit that are in addition to the ones that I already covered from the Mayo Clinic recommendations above.

I learned that a key factor for the disease is Inflammation in the body, and there are many causes for this. Inflammation can be mitigated by an anti-inflammatory diet. Lots of fruits and vegetables, elimination of refined sugars and simple carbohydrates, and elimination of unhealthy fats. One fantastic thing you can do is to add virgin coconut oil to your diet daily. 3-6 tablespoons are the therapeutic amount recommended, and 3 tablespoons for

maintenance. I began doing this two months ago, and I feel so much more alert, and the brain fog that I experienced before has been lifted. Another huge take away from the summit was the benefit of elimination of metals from the body such as mercury and aluminum. The summit also discussed how toxins in our environment can wreak havoc on the body and the brain. I know about the lethality of this first hand. When I was in my 20s, I worked at AF Plant 44 outside of Tucson, Arizona in the middle of the desert. While I can't tell you about many details because of the classified nature of my job, I can tell you that missiles were made there, such as the Tomahawk cruise missile recently launched in the middle east. There are some very nasty chemicals there. I worked delivery schedules for the government back then, so I was on the manufacturing floor on a daily basis. I became very sick. My immune system was severely compromised. My doctor ran many tests on me, including ones for leukemia, lupus, and cancer. My face had sores all over it, and my gums were swollen up over my teeth in the back of my mouth. The doctor asked me what kind of work I did. When I told him, his response was that he believed that my job was drastically affecting my health. I immediately applied and was accepted for a different

government job in California. Shortly after the move, my condition improved, and I regained my health. After I left, 60 minutes did an expose piece about the AF facility and how people living near it were becoming very sick and dying as a result of water runoff from the toxic manufacturing process. You can google AF Plant 44, EPA superfund to read more about what happened there. I am convinced that if I had not moved, I would not be alive now. I share this to highlight just how dangerous toxins can be to our bodies.

In addition, I no longer use aluminum or metal cook wear. Metals can leach out of them and into our food during the cooking process. I've replaced all of my pots and pans with ceramic cook wear.

The last item I want to share with you is the importance of drinking lots of high-quality water. The Summit featured an hour segment on the value of drinking Fiji water. Fiji is a unique artesian water which contains naturally occurring electrolytes. It contains a substance called Silica, which actually bonds with unwanted metals in our body, and helps to eliminate them. Fiji water is not cheap, but the extra cost is worth it to me.

In conclusion, we shared a lot of information today. If any of it resonates with you, that is the part that you can use and take away to improve not only your health, but to reduce the risks of having this horrible disease.