Memories Slipping Away: My Grandmother and Dementia

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"Who is that?" My grandma asks as I come into view on the phone screen.

"That's Grace, your granddaughter," my mom says. "She's the tall one. Remember?"

"Hi Grandma!" I say leaning over the back of our couch to wave at the camera.

"Oh, hello," my grandma says with a hint of an Irish accent. I cannot tell if she remembers me.

My grandmother, Doris, was born in 1934 in rural Northern Ireland. At the time of her birth her father had to bike three and a half miles to alert the doctor, since they had no car or telephone. She spent the first couple months of her life in a drawer cushioned by blanket pieces.

As a kid she spent her time exploring the small farm that her family owned and played with dolls made of sticks. She attended school at a small schoolhouse down the road. There were only a couple rooms, so she learned alongside children of many different ages. As the Germans became a concern the students brought gas masks to school in fear of bombs. During her school years she fell in love with books and read veraciously. When she turned eleven, she was chosen to take a scholarship exam. She had one of the top scores in the country on this exam and was given a scholarship to grammar school. Because of this opportunity she was able to complete an accelerated medical school program and do her residency in the United States, where she met my grandfather.

Now, at eighty-seven, my grandma has dementia, and many of these memories would have been lost if she had not written them down.

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FIGURE 1: A page from the memories my grandma wrote down

My grandma has seen the world change drastically. She began her life with no electricity or car. As a child she lived through World War II. As an adult she was an anesthesiologist at Mass General Hospital and raised a family. Now she is living through the pandemic. However, dementia has taken many of these memories from her. She often forgets about the pandemic and wonders why we cannot visit more often, or why we have to wear masks around her. She even forgets that she is in her own home and will ask my grandfather to take her home.

"John," she will say looking over to my grandfather, "will you drive us home?"

"Oh yes, let me find my keys," my grandfather will respond, not remembering that his license was revoked years ago.

"You already are home," someone will say. She gets confused when the whole extended family is visiting because it is outside of her normal routine, and she thinks that she is at one of our houses. We have to find humor in these moments because without it watching their memories deteriorate would be too unbearable.

My grandma can no longer recall many of the details of her own life, but she routinely asks about her seven siblings.

"How is Lorry doing?" She will ask my mom. As we are sitting in the living room with her gathered around her wheelchair. A cup of fresh tea in her hand.

"He died years ago, you went to his funeral," my mom will respond.

"And Bea?" Grandma will ask.

"She's dead too, you're the last one."

Dementia means that my grandparents can no longer live independently. They have a team of home health aides who provide round the clock care. My aunt and her family have moved back into their house to provide additional care that is needed. My grandma needs help dressing and getting into her wheelchair. She no longer does any cooking or cleaning.

My cousin has been reading to our grandma, which is something she still enjoys, but it can also lead to confusion. She is known to say "we have to leave" or "let my people go" during conversation since she has been reading Bible stories. She will also talk at length about the

journey she and my cousin took across the Oregon Trail after he read Oregon Trail by Francis Parkman to her.

Hearing these things brings on a mix of emotions. It is hard to see that my grandma remembers so little about who she is, but she seems happy with these memories, and I am glad that she is happy remembering them even though they are not real.

She will also often repeat questions, forgetting that she had just asked.

During my little sister's eighth birthday party we had parked my grandma's wheelchair in the grass in her yard, so she could be a part of the celebration. My grandma asked me multiple times about how my sister's biological grandparents were so young. Whenever she noticed the baby in a playpen grandma would ask who she was, and I would re-explain that that is my sister's aunt, her grandparent's kid.

It can be hard to have the patience for such circular conversations, but I know that it must be harder for my grandmother to not be able to remember things like this.

Dementia is the reason my grandma has lost so much of herself. Dementia is a general term for an impaired ability to remember, think, and make decisions. More than 55 million people worldwide suffer from dementia ("Dementia". 2021). There are five common types of dementia: vascular dementia, Alzheimer's disease, Lewy body dementia, frontotemporal dementia, and mixed dementia. There are also reversable causes of dementia ("What is Dementia?", 2019). We do not know what type of dementia my grandma, though we do know it is probably not vascular dementia. It can be hard to determine the exact type of dementia patients have because the symptoms and brain changes of different dementias can overlap ("What is Dementia?", n.d.). My grandma probably has Alzheimer's because it is the most common type of dementia.

There are many factors that can contribute to someone getting dementia. However, there is not a good understanding environmental and nongenetic risk factors for dementia because studies often have conflicting results. Women are more

likely to have Alzheimer's than men, which may in part be due to hormonal factors and estrogen. In men poor education can be a risk factor for Alzheimer's. Further studies are being done to see if this is education during childhood, or life-time acquisition of knowledge. Chemical exposure, and specifically aluminum exposure, may be a risk factor for Alzheimer's. Having an old or young mother is also a risk factor for dementia. (McCullagh, 2001). There is also evidence that in the UK the prevalence of dementia in African-Caribbean people is higher than that of White people. This suggests that ethnicity and race may be a risk factor for dementia. It is hypothesized that this is because there may be a difference in environmental risk factors between these two groups of people. (Adelman, 2011).

In the DSM-5 dementia is categorized as a Neurocognitive Disorder. This is further divided into major and minor Neurocognitive Disorders. The criteria for a minor Neurocognitive Disorder includes evidence of moderate cognitive decline, and neurocognitive decline in formal testing. However, the person is still able to function independently. Major Neurocognitive Disorder is characterized by evidence of significant cognitive decline, and the inability to live independently ("Diagnostic Criteria for Dementia", n.d.).

Dementia patients are also likely to have complications such as pneumonia, febrile problems. episodes. and eating These complications are frequent with advanced dementia and are associated with high six-month mortality rates. These patients also often have distressing symptoms such as labored breathing and pain. There are also likely to undergo burdensome intervention in the last three-months of life. It can be discouraging to think that these things might happen to my grandmother, but patients whose health care proxies understand the prognosis of dementia are less likely to undergo burdensome procedures at the end of their life (Mitchel et al, 2009). I hope that knowing this will help to prevent my grandma and others dementia having with from burdensome procedures at the end of their lives.

When someone has dementia betaamyloid proteins clump together to form plagues that collect between neurons. This disrupts the neurons' ability to function, as they can not send signals to other neurons, which can impact memory, behavior, and many other things. Additionally, a protein called tau will bind to itself forming tangles inside neurons. Normally tau binds to microtubules which are structures that help guide nutrients and other molecules from the cell body of the neuron to the axon and dendrites. When tau forms these tangles it blocks the neuron's transport system which makes communication between neurons harder. Also. neurons will be injured and die which breaks down the neural network and the neuron's ability to ("What communicate with other neurons Happens to the Brain in Alzheimer's Disease?", 2017).

There is currently no cure for Alzheimer's, but patients can do treatments that help alleviate symptoms. For example, there are some medications that can help Alzheimer's patients with memory and cognition ("Treatments", n.d.). To help my grandma we try to give her activities that will keep her brain stimulated. This could be reading a book to her, having her do a puzzle, or having her attend events at the senior center. This has become more challenging with the Covid-19 pandemic, as it is not very safe to take her places even though she is vaccinated.

Caring for a person with dementia can be difficult. Informal caregivers often experience burnout. Factors that are associated with caregiver burnout are extensive informal care provided by the caregiver, and a decreased quality of life for the caregiver. Reduced cognition, decreased quality of life, and severe neuropsychiatric symptoms and depression in the person with dementia are also associated with informal caregiver burnout (Lethin et al, 2018).

My aunt is an informal caregiver for my grandparents. She puts a lot of work into taking care of them, and it can be a stressful job. However, my family is lucky enough to be able to have home health aids go to my grandparents'

house every day to help my aunt take care of them. I can imagine that for families who do not have that privilege the burnout and stress that they experience must be much greater.

It can be hard watching my grandma live with this disease. There are many doctor's appointments and occasionally hospital visits, but the hardest part is seeing her loss of independence and cognitive skills. She now struggles with having a simple conversation which is a stark contrast to the doctor she used to be. I take comfort in the fact that she seems happy. She no longer has the stress of cooking and cleaning when family comes over. She loves having so many people there to take care of her. She is happy that she can live in her house with her husband instead of in a nursing home and her happiness is the most important thing.

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