

They Don't Remember, But We Will Never Forget

Dementia, forgetfulness is merely the first rain drop in an inevitable storm. Dementia is a term used to describe the deterioration of cognitive function, and its progression is often divided into four stages: Mild Cognitive Impairment, Mild Dementia, Moderate Dementia, and Severe Dementia (MacGill, 2017). Over the past several years, I have seen my grandma progress through these stages. There are many forms of dementia, but Alzheimer's is by far the most prevalent; 60-70% of dementia patients have Alzheimer's disease (World Health Organization, 2019). Additionally, while dementia may not be a normal part of aging, it is by no means uncommon. An estimated 50 million people worldwide have been diagnosed with dementia, and it is predicted that this number will rise to 85 million people by the year 2030 (World Health Organization, 2019). Many of us have seen the effects of dementia in our lives, and for those of us who have not yet, we likely will. Therefore, it is imperative that we understand its progression so that we may prepare ourselves emotionally and mentally, and so that together we can take steps to improve the lives of dementia patients and love them well as they have loved us.

Mild Cognitive Impairment is defined as general forgetfulness and is often a normal symptom of aging. Therefore, while not all people experiencing cognitive impairment will develop dementia, it can be an early indicator. As symptoms progress into mild dementia, patient's daily lives begin to be affected (World Health Organization, 2019). Patients may lose track of time and forget to do mundane tasks that they have performed hundreds of times, such as turning off the stove top or taking out the trash. Often, as was the case with my grandmother, symptoms in this early stage get overlooked. This stage also often involves one becoming disoriented and getting lost or turned around in familiar places. The road someone took to work for 30 years or the drive to the grocery store will no longer stir up recognition, and patients may find themselves unaware of their surroundings. This can be especially dangerous while driving and could put the driver and others on the road in jeopardy.

As dementia progresses into Moderate dementia, symptoms become more severe. The names of people and places, once familiar, begin to slip their mind, and they can no longer remember recent or upcoming

events. These could include doctors' appointments, children's or grandchildren's birthdays, or what day of the week it is. I can remember playing cards with my grandma during this stage, and she would concentrate her eyes on mine and my brother's face, trying to remember our names and becoming sad and frustrated by her inability to do so. One's ability to manage personal care also decreases drastically during this stage, and a person may need assistance completing simple tasks like brushing their teeth and hair or dressing themselves (World Health Organization, 2019). Additionally, patients often experience changes in personality that manifests as random bursts of anger, fearfulness, or agitation. During moments of mental clarity, they may not understand why certain freedoms have been taken away from them, like driving or living on their own, which can lead to greater agitation.

Over time, dementia will progress into its last stage known as Severe Dementia. Time and place become incomprehensible, and the person may be confused as to whether it is morning or night. This my grandmother experienced on several occasions. Additionally, communication becomes limited, and when there is communication, questions are often repeated several times, and the answer is forgotten just as often. The dementia patient may no longer recognize the faces of friends and loved ones, and difficulty walking progresses as cognitive processing declines. At this stage, one usually requires full-time care in order to ensure their safety.

There is currently no cure for dementia, but preventative measures can be taken to decrease risk. For example, maintaining a healthy diet, weight, and blood pressure and exercising daily are believed to decrease the risk of developing dementia. Additional risk factors include depression, smoking, excessive alcohol consumption, lack of education, social isolation, and cognitive inactivity (MacGill, 2017).

Along with knowing the risk factors, it is important to know methods for improving quality of life for those with dementia. One common suggestion is to establish a routine that gives structure to patients' lives. Engaging in conversation, or in light cleaning, laundry folding, or other purposeful activities is also suggested, for they instill a sense of meaningfulness (Bailey, 2019). Finally, it is suggested that dementia patients, especially women, have something to care for such as a doll or stuffed animal. This strategy

draws on the patient's desire to care for something, as many had cared for children or spouses throughout their lives, and it gives them something tangible to remain focused on. I can speak to the benefits that having a robotic dog had on my grandma's emotional health.

Anyone who has known someone with dementia can attest to the fact that dementia can take a severe emotional, financial, and physical toll on the patient's family and friends (World Health Organization, 2019). It can be stressful to discuss and manage the care of a person who can no longer care for themselves. Heightened stress leads to dissension among family members as they all seek to provide the best and struggle to identify what the best truly is. I believe that a family is truly blessed if they are able to go through these situations together and make it out with all relationships intact. The emotional and financial toll, as well as the time commitment necessary to care for someone with dementia, often leads families to seek outside support and resources. I want people to know that there is no shame in seeking help. Relying on resources such as assisted living facilities to tend to someone with dementia does not diminish the love you have for them. It simply means that you are aware of individual limitations and know that there are people more capable than yourself who can help.

Dementia was never something I thought about until it affected my family, but ever since it entered our lives, we have seen firsthand the burdens it places upon families. My Grandma was diagnosed with dementia several years ago, and it has been heart wrenching to watch the effect it has had on her and everyone close to her.

My grandparents have been married for 62 years. Together they raised five beautiful children, who went on to have children of their own, who in turn had a few of their own. This upgraded their title from Grandparents to Great Grandparents. They once lived in a ranch style house in Ohio with a big backyard that saw many small feet running through the grass over the years. My brother and I used to spend happy summer days there catching butterflies in the dandelion-covered yard or building forts in the family room-turned-playroom. My grandma was loving beyond all measure, and she showed this love by spending

time with us and caring for us in a manner that only a grandma knows how. She was especially meticulous about keeping us well fed. Everyone knew that you never went hungry at grandma's house.

When my grandma first began showing signs of dementia, entering the stage of mild cognitive impairment, her symptoms went unnoticed. My grandpa had been diagnosed with multiple sclerosis at the age of 42, and he has had to use a walker which progressed to a wheelchair, for as long as I can remember. My grandma cared for him in that well-loved house and he cared for her. As the years passed, his body declined, but his mind was as sharp as ever. As a result, when my grandma started to forget simple daily things like turning off the stove, or where her keys were, nobody noticed because she had my grandpa. The pair worked in synchronized unity: my grandma acting as the body where my grandpa wasn't able, and he acting as the mind when hers fell short. However, as both of their illnesses progressed and my grandma declined towards mild and moderate dementia, it became clear that it wasn't safe for them to remain in their home.

In 2018, their house was sold, and my grandpa went to live in a nursing home while my grandma lived with my aunt as she did not yet need nor want to be in full time care. While my grandpa understood the need to move, my grandma could not understand why she was not allowed to live on her own. She didn't remember getting lost, or leaving on the oven, or forgetting to eat. She didn't remember that she had dementia even though her children repeatedly explained the disease to her. My mom would explain to her that dementia is an illness of the brain just like heart disease is an illness of the heart, and it meant that some aspects of life would need to change. My grandma could not grasp this, however, and she thought people were calling her crazy. In this middle stage, my grandma experienced a lot of confusion and anger.

Over the course of a year, we saw my grandma's mental state take a drastic decline. She went from knowing each of her grandchildren's birthdays and never forgetting to call and wish us well, to forgetting that she had grandchildren. I can remember one occasion when my mom called her mother and told her what each of her six children were doing with our lives. My grandma responded in devastated shock that she never knew my mom had six children. She said she was sorry she had missed us growing up. How

could she have missed all that? I listened as my mom assured her that she hadn't missed it. She had been there through every moment of our childhoods, and she was a wonderful grandmother. My mom assured her of her love for us and of ours for her. It was then that I realized that dementia is a thief. It steals precious moments meant to be cherished, and for those of us who do remember, our memories become tainted with sadness.

My grandma's symptoms continued to progress towards severe dementia. Some days she was agitated and asked to go home to live with her parents who had long ago passed away. Other days she sat on the couch petting her robotic dog my mom got her for Christmas after learning the benefits animals have for dementia patients. My grandma named the dog Cocoa, and during these moments she was content.

We began to notice that her symptoms became worse when she was tired. Occasionally she would get up in the night and get ready for the day as if it were morning, saying that her son would be there to pick her up soon. Her sense of location also continued to decline, as well as her ability to hold a logical conversation. It became clear that she needed professional care beyond what we could give her, so the difficult decision was made, and my grandma was moved into the Alzheimer's unit in the same nursing home as her husband.

Recently during our winter break, my mom, brother, and I drove to Ohio to visit them. As we walked into the unit, my grandma looked up meeting my mom's eyes and recognition lit her face. While she did not always know which one of her three daughters my mom was, she knew my mom to be her child, and the same contagious smile that had blessed us so many times spread across her face. We took her to lunch at what once was one of her favorite restaurants, though she no longer remembered the name of it. We took her bowling, which she used to enjoy and be quite good at, and she sat back grinning, as I sent ball after ball into the gutter. My grandma may not have remembered doing those things later that evening, but in that moment she was happy. I know that while she may not remember, we will be sure to never forget those moments together.

Too often people with dementia become invisible. They get overlooked because they no longer remember the events that shaped them. They get set on a couch and forgotten because the words they form no longer make sense. I know that it hurts to watch the generation who raised you and who cared for you as a child become so childlike themselves, but I implore everyone not to look away. The greatest gift you can give someone with dementia is to love them through it. Talk with them even when they can't respond and surround them with loved ones even when they don't know your name. Not only will this bring them joy in the moment, but it will give you time and memories with them to cherish with all your heart.

Bibliography

Bailey, D. (2019, May). *Improving Quality of Life For Dementia Patients*. Retrieved from Lakeside Manor: <https://lakesidemanor.org/quality-life-dementia-patients/>

MacGill, M. (2017). *Medical News Today*. Retrieved from Dementia: Symptoms, stages, and Types: <https://www.medicalnewstoday.com/articles/142214.php>

World Health Organization. (2019, September). Retrieved from Dementia: <https://www.who.int/news-room/fact-sheets/detail/dementia>