

A Personal Essay

An Activity Professional's Perspective on Alzheimer's disease and its effect on Family

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"You cannot control the disease. You can only control your reaction to it."

~Liz Ayres

Prelude

All across the world, thousands of individuals are walking for a sole purpose during these hot, humid summer months. Alzheimer's disease has affected millions; moreover, family and friends are taking a proactive stand toward increased financial support and further research in the hope of finding a cure to end this dreadful disease. This writing is a personal reflection, specifically, how Alzheimer's stole one of my family members; my precious mother-in-law. She was and will always be known as "Graybee."

Facts I Wish I Had Really Taken Time to Know

Alzheimer's disease, AD, is a brain disorder that progressively destroys an individual's memory, ability to make decisions, judgments and performance of daily activities. A

person's behaviors change as the disease progresses from early to late stages. Incidents of irritability, anxious feelings, and suspiciousness of others are just a few of the behavior changes evidenced in many patients. The individual may also experience hallucinations and delusions depending on other factors related to the disease.

According to current research and on-going studies, Alzheimer's disease damages the brain long before any noticeable symptoms appear. As someone ages, the odds become greater and greater. It affects 20 to 30 percent of those who live into their mid-eighties, male and female alike, and it accounts for about half of the cases of dementia at any age. Seemingly, almost every family unit on our planet will be affected by Alzheimer's at some point in time. As of today, there is no 'cure' for Alzheimer's; however, the good news is that the quest in finding a cure to treat this disease is a hopeful work in progress even though methods found through research only have delaying effects. (William R. Shankle, MD, Board Certified Neurologist, 1997).

Midpoint: Further Research and Study

As Recreation/Activity Professionals, one of the most important education strategies that we can offer our residents is the continual promotion of living a healthy lifestyle; both cognitively and physically. Providing activities and programming that support active, healthy lifestyles helps our residents have the tools necessary to keep their minds and bodies running at optimal levels. According to Shankle, "If we wait until all of the answers to preventing AD are firmly established before we apply sage strategies, we will already be affected." (Shankle, 2000). The key to prevention is not waiting, but taking a proactive role in our residents' years before any of these symptoms occur. And, just as research indicates, preventative measures are critically important for a resident's healthy

lifestyle, especially with genetic makeup being an initial precursor with this specific disease. On a personal note, no matter what happens with any Alzheimer's patient, the Activity Professional must be sensitive to how family members are treated and involved throughout the disease process.

Added stress and pressure may, and usually does, create tension between loved ones. On a day-to-day basis, AD patients lose some aspect of their life. This, in itself, is a very painful happening for family because the patient is dying not by the body, but by the soul. Jeff Carroll, scientific researcher in the area of Huntington's disease noted, "Loss after loss. Eventually patients become dead before they are dead. The patient suffers through a limbo period, because *this is not life; nor is this death*. What is it?" (Carroll, 2011).

Family Story: Part I

As the son-in-law of a former Alzheimer's patient, I have lived through and experienced many consequences of this terrible disease. My wife's mother passed from this Earth at the age of eighty-one years old. People from all over these United States and Canada were praying fervently for our dear mother. It was their prayers, cards and faith that brought us through this unexpected life-journey. Four years prior to her passing, my mother-in-law demonstrated many of the 'classic' symptoms of Alzheimer's disease. In the beginning and early stages, she created somewhat believable stories that seemed most possible. I remember her telling my wife that our daughter went into her house, borrowed her baking sheets, and brought them back the next day. Now, if you knew my daughter, especially at that 'vibrant' age of sixteen, you would certainly know that baking was the furthest thing from her mind! Not only was my wife confused by Mom's conversation, but she was concerned about her health and well-being. My wife made an

appointment with our doctor for an examination, which included a brain scan. The doctor said that Mom may have had eight mini-strokes. In addition, the results from the brain scan indicated that she could be experiencing symptoms of Alzheimer's disease.

Not only was this a very scary thought, but in our naïve eyes, a death sentence on Mom's life; a death sentence that no one knew the exact date, time, or outcome. At this time in our lives, not one of us; my wife, daughter, nor I, knew anything about Alzheimer's disease. I had just retired from the field of public school education and was beginning my brand new 'second career path' as a Recreation/Activity Professional. My learning curve was about to start immediately.

Family Story: Part II

As the next few years progressed, my mother-in-law's symptoms increased in number and intensity. One of her 'believable' stories, that we now know was part of the disease process, was a strange woman entering her home and stealing things right from under her eyes. Mom insisted that this 'other woman' was stealing checks, money, and other valuable items. No matter how much we tried to reason with her, she refused to listen.

As research shows, comprehension during the late stages of Alzheimer's is unrecognizable. She no longer could think abstractly or understand when someone rationalized a situation. My wife had such a hard time understanding this process because as stated before, she was grieving the living. "Family members...feel sad, discouraged, and alone. They feel angry, guilty or hopeful." (Mace, 2000). Each of us continue to experience strong, vivid emotions regarding the passing of our beloved mother. She will forever be the matriarch of our family; an individual who lived her life to the fullest and inspired each of us to pass a bright burning torch to the next generation

filled with wisdom, hope, kindness and faith. Through of all this, I truly began to understand and realize what Alzheimer's disease was and how real it could be in someone's life.

Now, more than ever, I realized that the very moment I stepped onto any healthcare community floor, I must be ready; ready to serve and give back to each person living with Alzheimer's and Dementia. And, giving back to others is exactly what this writer needed to do; giving hope, joy, and taking time to listen and let others know that they are worth it all.

Postlude

One of my favorite Alzheimer's and Dementia 'go to' resources is Jolene Brackey's, ***Creating Moments of Joy***. If you could see my book, you would immediately notice the yellowing, wear and tear, and how the front and back covers barely hold its pages together! Brackey's chapter, ***Saying Goodbye***, is a fitting close to this personal essay: "Saying goodbye is never easy, but hopefully I can make it easier. When you are getting close to departing start to make comments that leave them with positive 'feeling.' Feelings of assurance. Feelings of self-worth. Feelings of being loved. Feelings they have loved you. Feelings that everything is OK for the moment." (Brackey, *Creating Moments of Joy*, 2007, p.268). Thank you, Jolene, for these insightful words. My family thanks you.

*"We remember their **Love** when they can no longer remember."*

~ Unknown