

I read a story about a man who was caring for his wife. He shared "My wife does not recognize herself when she looks in the mirror. Sometimes she points 'at that woman' in the mirror and then accuses me of having an affair. At other times, she says, 'That's an ugly old woman.' I don't know what to say or do."

The emotional and physical toll is a reality for many people who are caring for a loved one who becomes ill. When the illness effects mental processing there can be an extra layer of challenge. This man's wife suffers from a form of dementia known as Alzheimer's disease.

Alzheimer's is the most common form of dementia and is characterized by an individual's problems with memory, thinking and behavior. The disease typically progresses slowly; getting worse over time and eventually interfering with daily tasks.

Currently, the disease is incurable. There are no known proven approaches that prevent it, nor any treatments that will markedly slow the disease down. It is the 6th leading cause of death in the United States.

In 2013, research indicated that the estimated direct cost of caring for Americans with Alzheimer's was at \$200 billion and projected the cost to increase to as much as \$1.2 trillion by 2050. In 2012, 15.4 million unpaid caregivers provided 17.5 billion hours of care. The value of this care was estimated to be around \$216 billion. Of those caregivers, about 30% fall into the "sandwich" group – caregivers that are both taking care of their dependent minor children while also caring for their aging parents.

Being the caregiver of a person with Alzheimer's is a challenge on many levels. The work is both demanding and undervalued. These caregivers sacrifice their time, their physical and emotional energy, and often financial stability in order to provide for the well-being of their loved one. They may also compromise their own relationships with spouses or children.

Helping family members, communities, and society better understand the impact this disease has on American families is an important part of providing support to caregivers working with this growing population.

Another caregiver shares "My father talks about his Dad coming to take him fishing. When I try to tell him this can't be true, he just gets mad and accuses me of lying to him. I am at my wits end and don't know what to do!"

Stories such as the ones provided are the reality of the disease. Understanding Alzheimer's enables caregivers and their support group to avoid taking these conflicts personally. Although there is no approach to caregiving that is

universally successful, there are some basic understandings that will help caregivers cope more successfully.

Difficult Behavior is Not Willful

Alzheimer patients are not intentionally trying to be difficult. A caregiver who lacks this understanding is opening themselves up to a long and painful journey with their loved one. Their behavior has a reason and the caregiver will be better served to try to understand the “why” of their loved ones behavior.

The Person is Always Right – At Least from Their Own Point of View

Trying to convince a person with this disease to consider someone else’s point of view becomes more difficult as the disease progresses and is nearly impossible in the later stages of Alzheimer’s. A caregiver who chooses to press their own point of view on their loved one often ends up being viewed as untrustworthy. Perceptions, thoughts, and feelings of those with this disease are skewed. For example, a tree branch hitting against a bedroom window may be perceived as someone trying to break into the house.

The Brain’s Capacity to Learn and Record Information is Lost

People diagnosed with Alzheimer’s are no longer able to remember a major event that may have occurred in their life the day before, nor the information shared and instructions given just moments before present time. For example, a caregiver may tell their loved one that they are going outside to get the newspaper and the loved one walks past the open door only to shut and lock it.

The Past is More Real and Endearing than the Present

Memories are erased as the disease progresses. Their “today” may be what was occurring 10, 20, or 40 years ago. As a result, the person may talk about a friend or loved one who long-ago passed away as if they were still alive. At the same time, they might not recognize the people around them or the person caring for them. For example, a man who is talking to his daughter, who looks like her mother, may think she is his wife.

Many Emotions and Feelings Remain in Tact

Although people with dementia lose their memory, they do not lose their capacity to feel emotions and respond to the emotional climate around them. It isn’t uncommon for a feeling or emotional reaction to remain long after the triggering event has passed.

The Person Cannot Change – So the Caregiver Must Adapt

Instead of trying to change the person with dementia, caregivers have to adjust to the loved ones “new reality.” The disease steals the ability of the loved one to reason or rationalize. The caregiver needs to remain flexible to the changing environment around their loved one. If the branch hitting against the window is

causing emotional outbreaks, the caregiver should simply trim the branch back away from the house.

Alzheimer's is a very challenging disease to work with. Increasing family, community, and society awareness helps caregivers face this challenge more successfully. For more information on caregiving, contact me at the Geary County Extension office at 785-238-4161. Until next time, keep living resourcefully!