

Changing the Way We Talked About Alzheimer's Changed My Dad's Experience for the Better

By Trish Laub, guest article for Being Patient, Words Matter series, May 12, 2020

I should have known that there was a stigma that surrounds Alzheimer's disease, because when I learned of my dad's diagnosis, I felt like a shadow had been cast over my family. Everything that I had heard about the disease had been said in near secrecy, as though the words should not be uttered. My own mother did not want anyone — including her three daughters — to know until absolutely necessary that Dad was diagnosed with Alzheimer's. She feared that we might think that my dad was somehow less than the brilliant and loving man that he had always been.

Throughout my dad's journey with Alzheimer's, I would come to understand the negative stigma of Alzheimer's through the negative words so often used to speak about it. The mere mention of the word "Alzheimer's" evoked a strong negative feeling, ranging from loss and pity to dread and even grief. I now know that perhaps the greatest detriment to a person living with Alzheimer's, and those who love them, is the harm that comes from the language we use to talk about it.

Once familiar with this stigma, I quickly learned that it was contrary to both my philosophy and experience with my dad. Choosing a different word made all the difference. My dad was a meticulously clean person, and was specific about his clothing and appearance. On a few occasions, a caregiver took shortcuts on my dad's hygiene or appearance. It was as though they thought that what was important to him didn't really matter because he was somehow less due to his illness. But I knew that my dad and his life were different, not less.

The symptoms of forgetfulness and resultant difficulty managing activities were once accepted as a normal part of life by families that then saw to the welfare and safety of their loved one. Today, Alzheimer's and other dementias are identified based on symptoms. While labeling a person with a diagnosis may help them get treatment for their specific symptoms, the label can also be a target for inaccurate information and insensitive language.

Here are three guiding principles I used to help shift the dialogue around my dad's disease from one that was potentially hurtful to him and to us, to one that was thoughtful, accurate and helpful — guiding principles we can all use to help improve the experiences of those living with Alzheimer's.

1. Positivity

We know there are negative things about living with this disease. But through my dad's journey, I saw there is much to be positive about. Someone living with Alzheimer's continues to have tens of billions of active brain cells that are functioning properly. Those cells allow for continuing a life with possibilities.

2. Accuracy

I had heard people say, “I have lost my loved one.” I learned that while this may feel emotionally true, the truth is that they are not lost. Compare that with the declaration, “My loved one no longer recognizes me, but I still recognize them.” That statement allows for what remains.

I had heard people say that Alzheimer’s “makes a person mean.” I learned that while [aggression and agitation](#) are known symptoms of the disease, they are not shared by every person who has it. On the rare occasions we saw these behaviors in my dad, he had been mistreated in some way. These blanket statements and the presumption that negative behaviors are a given color our outlook on Alzheimer’s.

Even health care professionals, with the demands on their time, may use insensitive word choices in front of patients and their loved ones. “I try to ensure that my clients are treated with respect and dignity during medical appointments. I was stunned when I heard a neurologist tell a patient, ‘You are not demented,’” said Roseanne Geisel, a board-certified patient advocate in Northern Virginia.

To someone living with the disease, which is part of a group of symptoms known as dementia, as demented – meaning mad, insane, deranged and crazy – is inaccurate and potentially damaging. It describes undesirable behaviors as opposed to a person who is ill and also valued. *A person living with dementia* is a person. People have value and warrant aggressive medical management. A reference to a *demented patient* implies that the disease defines the identity of a person, and results in an assignment of the disease to the person.

3. Sensitivity and protecting Alzheimer’s language from jokes and misuse

Beyond the stigma, careless language used for humor can be insensitive and hurtful to both families of those living with Alzheimer’s and those who have been diagnosed. The statements, said jokingly or carelessly, “I’ve lost my mind,” or “I’m having an Alzheimer’s moment,” can be hurtful to those who have been touched by the disease. Alzheimer’s is a serious diagnosable illness, not a characteristic. The statements diminish the severity of the illness. Additionally, careless statements can result in a further misunderstanding of the disease, fueling the stigma.

By working to shift my own language from inaccurate and fearful to accurate, sensitive and loving I did my part in showing by example that people with Alzheimer’s are not living in the shadows of darkness and shame, but with limitless possibilities for continuing a meaningful life.

My dad lived with Alzheimer’s for likely 20 years. He spoke something of personal relevance to his wife and each daughter prior to passing away in his Denver home at the age of 92. I believe that his success in continuing to live a meaningful life with Alzheimer’s was largely due to my family’s willingness to shift our language from limitation and deficit to limitless possibilities. It

was possible for my dad to live a most meaningful life to the end with Alzheimer's in part because we used language that supported that possibility.

[Trish Laub](#) is the author of [The Comfort in their Journey](#) book series. This article is part of the [Words Matter series](#), in which she discusses language, communication and the way it affects those living with Alzheimer's or cognitive impairment.