November Senior Sense: November is Alzheimer’s Awareness Month: Find Caregiver Education and Support

By Liz O’Donnell
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People often say they will never forget something – a person, a feeling, a moment, a day. One of those days, ironically, is the day that their parent no longer remembers who they are. The fact is, many people will suffer memory loss, often as they age, and often as a result of Alzheimer’s Disease. That moment, when your parent no longer knows you, is a painful rite of passage for a family caregiver, but it doesn’t have to be the end of your relationship. In a way, it can be a new beginning.

More than 6 million Americans are living with Alzheimer’s, a type of dementia, and that number is expected to rise to nearly 13 million by 2050. Caring for someone with the disease can be incredibly challenging. Caregivers report increased emotional, financial and physical difficulties compared to caregivers of people without dementia. That’s why it’s critical that those of us who are caring for someone with Alzheimer’s get educated about the disease.

I vividly remember the day Alzheimer’s changed things between my father and I. For weeks, he had been growing weaker and more confused. I visited him at his nursing home and wheeled him out to the front porch. It was early summer and we liked to sit outside. Sometimes we talked. Sometimes he slept. Always we held hands. That afternoon, he greeted me with a smile. He was happy to see me. But while we were talking, he asked me if he had a family. “Yes,” I told him. “Do I have children?”

“You do,” I replied. “I’m one of them.”

“You’re kidding,” he said, and he drifted off to sleep, still gripping my hand.

While he was napping, I decided to accept a new relationship with my father, one that had no labels – Alzheimer’s had made labels irrelevant. After that day, my father continued to know me – sometimes as the lady from the nursing home, sometimes as his sister, and every once and a while, as his daughter. It didn’t matter who he thought I was – he was my father and I was a positive presence in his life.

Getting to that point wasn’t so simple, however. Watching my father struggle with his disease was nothing short of brutal at times. Once so strong and independent, he needed help with everything - even getting dressed and turning on the television. Sometimes he was uncharacteristically confused and violent and it landed him in the geriatric psych ward at the local hospital. These changes also meant he was longer able to live in his assisted living apartment.
It was the staff at the skilled nursing facility where I decided to move him who helped me understand his disease and how best to support him. They encouraged me to “meet him where he was.” If, during our visits, he thought it was 1946 and he still drove a Packard sedan, I didn’t correct him. I asked him to tell me about his car. I learned to connect with his feelings more than his words. If he asked me where his mother was, for example, I assumed he needed to feel loved and secure, and I would redirect his question. “Your mother’s a pretty special person. Tell me more about her.”

The staff helped me separate the man from the illness. It wasn’t my father who sometimes said inappropriate things or who attacked an aide; it was the disease. It was also the staff that explained to me Alzheimer’s is a degenerative brain disease. Symptoms worsen over time and cognitive issues are only part of it. Eventually, speaking, swallowing and walking become difficult for people living with Alzheimer’s. Eventually, I would visit at dinner time so I could help feed my father.

If you are an Alzheimer’s caregiver, seek support. Ask medical providers for information, resources and tips. Share educational materials with family members and close friends and ask that they work to separate the disease and its symptoms from the person living with it. The Alzheimer’s Association ([https://www.alz.org/](https://www.alz.org/)) has lots of great educational information and links to resources. Teepa Snow ([www.teepasnow.com](http://www.teepasnow.com)) is another great resource. Her video series helps caregivers address common challenges like persuading someone with dementia to bathe – a common challenge. And most importantly, lead with compassion – for the person you care for and for yourself! You won’t always get it right, but that’s okay. Sometimes you will be frustrated or exhausted, sad or scared. All you can do is your best, and your best will be good enough.

*Liz O’Donnell is the founder of Working Daughter and the author of Working Daughter: A Guide To Caring For your Aging Parents While Making A Living. For caregiving support, information and resources contact a Senior Care Advisor at Care.com. We are master’s-level social workers specializing in adult and senior care. Call us today at (855) 781-1303 x3 or email questions to careplanning@care.com*