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Reflections on My Role as David's Caregiver

By Marian Ninneman

September 11, 2001 – My husband David and I had just landed in Milan planning to spend a few days there before returning home from vacationing with friends in Sicily. I turned on the television to catch up on news and was shocked to see one of the World Trade Center towers in flames. My shock turned to horror as I watched a plane head straight into the second tower.

Had we not been travelling, David would have been in the second tower in meetings with other brokers from his team. We cried for lost friends and colleagues, and we cried with relief that David and I were together in Italy and not in New York.

What I didn't know then: That a few years later David and I would begin the long death-sentence journey of Alzheimer's disease (ALZ), and little bits of him would be lost with each passing day.

In 2006, David's first neuropsych exam results came back as "mild cognitive impairment." The doctor said to come back in a few years if David continued to decline. Oh boy – we went back for the second test less than a year later. This exam showed severe cognitive decline in all areas. Six months later, during a subsequent test, David was having such difficulty the doctor stopped the exam, saying there was no reason for further testing. While not formally diagnosing ALZ, the doctor provided a ton of reference materials on disease progression, care giving, and the resources available.

What I wish I had known: I would make mistakes – many mistakes – ALZ was all new territory. The ALZ information available is a great starting point. Our loved ones are unique individuals, and this disease affects everyone differently. Take advantage of basics provided in the reference materials and available resources, but use your perspective and experience to develop your own “operating manual.”

The hours David would be home alone while I worked became one of our early challenges. To fill those hours, we brought a Goldendoodle named Bella into our family. Trained by me as my version of a service dog, Bella became David’s constant companion. David loved to walk Bella through the streets of Shorewood and the UWM campus – especially the UWM campus, because, as David would say, “She is the perfect chick magnet!”

What I realized then: I live in a great dementia-aware community! I owe thanks to those who watched out for David, talked with him, gave Bella a pat, or even pointed David in the right direction home if he appeared confused.

I hated to give Bella up after David died, but she had a hard time being home alone while I worked. After watching her mope around, I realized I needed to let Bella go. She is such a special dog who loves to help people. David’s sister Joan and her husband Bob absolutely adore Bella and said they would drop everything and come get her whenever I was ready. Bella now works happily as a grief therapy dog at Bob and Joan’s funeral homes where she continues to bring comfort to those who suffer.

During the initial years, David and I entertained, socialized and traveled. As his abilities declined and he became less predictable and more easily agitated, some of our friends began to drift away. I was deeply hurt and at times a bit angry with them.

What I wish I had known then: People do and say stupid things when faced with uncomfortable situations or lack of knowledge of a disease or condition. Forgive them – let them know you need them in your life, and let them know how much you appreciate their support. Encourage them to ask questions about the disease, and share what you know.

In 2012, mutual friends introduced me to Peter, who was taking care of his wife, Mary, also diagnosed with early onset. We talked about how we might help each other – trading caregiving, making meals together, teaching each other how to care for a partner of the opposite gender. He showed me how to shave David’s face, and I guided him through bathing Mary. We agreed to be there for each other until both our loved ones completed their journey.

What I wish I had known then: This wretched disease has its own ugly timeline. Although there is great information available about the stages of this disease, don’t count on your loved one following them. Although Mary was more advanced than David when Peter and I first partnered as caregivers, David passed away more than three years earlier than Mary.

When I could no longer safely care for David in our home, I moved him into a memory care assisted living center. I felt guilty of not being a good enough caregiver, I felt guilty that I could no longer care for him at home, but mostly I felt guilty for just wanting some of my “normal” life back!

What I wish I had known then: That I had done the best I could. That, with help from others, I took excellent care of David for eight years. That I needed to make time for myself. That for me to provide David with the care he deserved, I needed to be healthy, well rested, and in good spirits.

What I wish I had done: Spent the money on long-term care insurance. Although premiums may be high, the money spent would not come close to the hundreds of thousands of dollars spent out-of-pocket to provide David's care.

When David's sister, Joan, visited Milwaukee in January 2015, we talked about our ALZ journey, about David's suffering, and about the emotional, physical, and financial cost on family and friends. I asked Joan the "what if" question – what if David had been in New York and perished with the rest of his team on 9/11? Maybe his death then would have been a blessing, painful – of course, but perhaps it would have been better not to have experienced what ALZ can do to a person, a family, and friends. Joan looked at me, somewhat aghast, and said, "Well I have to disagree. I am so very happy to have had the time with David." After diagnosis, Joan visited often and felt great joy as she and David developed a deeper relationship. She was grateful for the time to bond with her "big brother." I no longer wonder "what if."

And one final what I wish I had known: I wish I had known at the start of this journey how much I would change as a person. Now I feel I have more patience, compassion, empathy. Now I know the importance of maintaining a sense of humor during awkward moments: David walking up to a stranger and telling them they are pretty and asking to kiss; David screaming, "Leave your hands off me!" while guiding him through a busy airport concourse; David shrieking, "Help me" at the top of his lungs in a movie theater; and David answering the door butt naked. I also understand the impact of taking care of myself so that I could give until I thought I had nothing left to give and then give even more!