

# Untitled

By Judy Donoghue

Life is forever changing. And when we live intimately close to change, it's not always as noticeable. So it was with my husband Tom's journey into dementia. It was our primary care physician who first noticed something during a routine visit. He spent more time than usual with Tom and ran a series of memory tasks – What day is it? Who is the President? What month is it? Tom was scheduled for a psychological assessment. Those results led to the formal diagnosis of “unspecified Early Onset Dementia” in 2006. I sought to determine what I had missed. Was it over-reaction to situations, grudges held over simple matters that should easily have been let go, or unreasonable and often inappropriate responses? Tom's reaction was that the doctor didn't know what she was talking about. At age 60, he was still able to drive and run his window washing business.

By 2008, Tom could no longer figure out how to get to customers' homes and admitted that he had frequently gotten lost and confused while driving. He made the decision to retire and created a new lifestyle of watching TV while enjoying a beer. This concerned me, and I felt I was not doing a very good job of helping Tom cope with the changes the dementia was creating. I was so distracted by the situation, I was no longer effective at work. I retired from a teaching career that I still loved.

At this point, I needed more knowledge and help if I was going to be any good in this role as caregiver. I contacted Senior Services and scheduled a meeting with a mental health counselor. I underwent my own psychological assessment and through the course of three visits, I vented my anger and built up resentment about how this disease was ruining my life. Tom hated his life and I hated mine just as much. In her kind and helpful way, the counselor helped me look beyond this abyss of despair and begin to define, accept, and control a new way to live.

The local Senior Center advertised a Caregiver Support Group. Tom was able to be left alone for a few hours at a time, still finding comfort in his two best friends, TV and beer. I contacted the facilitator for details and this is where my life took another huge turn! Meeting and sharing with other caregivers offered me a preview of what was to come. Many of these caregivers were already dealing with behaviors and changes far beyond anything like ours. I took notes on how each change was dealt with and began to build my own “tool kit” for survival. The next saving grace came in the form of a class entitled “Powerful Tools for Caregivers”. By then, I was no longer comfortable leaving Tom home alone. I spent months searching for the perfect caregiver. It needed to be someone Tom would relate to, someone fun, to go for walks, and offer companionship. I tried a private agency but Tom disliked each caregiver. It was a former acquaintance who helped me realize that there never would be a perfect caregiver, in Tom's mind, other than me. Being that she had caregiver experience, I hired her to come in under the guise of a housekeeper while keeping an eye on Tom. The first week, Tom never came out of our bedroom. The second week, he said she could be here, but he wasn't going to talk to her. By the third week, I found them sitting on the sofa talking and laughing. And the next week when I got

home, Tom was teaching her to dance. They reached a time when she was Tom's special friend, and the dust cloth wasn't needed anymore.

Dementia continued to change Tom's life, but it had even greater impacts on mine. I learned to slow down and enjoy the small things like moments when we laughed and danced. Tom loved to dance. When he didn't manage well in the bathroom anymore, we laughed about where those "puddles" came from that appeared on the bathroom floor. I created a sleeping space for myself just outside our bedroom door for those nights when Tom stole all the covers or pushed me out of bed when I accidentally bumped into him. That way I was safe yet nearby if needed. We continued to enjoy our love for dining out. Only now, Tom's meals didn't include a knife, fork, or spoon. I ordered foods appropriate to be eaten with the hands. I made small cards that said: "Thanks for understanding. My husband has dementia and gets confused sometimes." I had seen a similar card put out by the ALZ Association. I handed them out in restaurants when people stared and in the women's restrooms as Tom and I came out of the handicap stall together.

When the verbal and physical abuse started, I developed what I called my Turtle Wax, that hard shell finish, to avoid internalizing the remarks. I would change the name he called me to a compliment and say it back with a smile. And I learned to practice safe approach, asking for permission to help Tom button a shirt or fasten his belt rather than moving in to help only to be hit or pushed away.

I had to continually remind myself that these behaviors were the disease, not Tom. Eventually, I mentally redefined our relationship. No longer was Tom the man I married 43 years ago. He was this man-child I cared for, in sickness and in health, for better or for worse. It was a decision I grieved over two years, yet it was what enabled me to love and care for him through all the "stuff" dementia tossed our way.

During the last four years of Tom's life, we found activities we could still share. We enjoyed cruises with few complications. Tom attended a yoga class weekly with me, doing his version of the routines. We went to Mass regularly even after receiving Communion became unfamiliar to him, a cradle Catholic. The one thing Tom never forgot was his love for dance. We danced in the aisle on the cruise ships, we'd dance in the corner of restaurants with no dance floor, and we danced daily in our living room.

In January, 2014, we cruised seventeen days to Hawaii and back. Tom struggled with getting on/off elevators, sitting in a chair, finding the bathroom at night, and the time change. He never did adapt to any aspect of being on the ship. I realized that our shared activities now had one less option.

Along with the help of two caregivers, Tom remained in our home with me for eight years and two months. The night of May 27, 2014, something went terribly wrong. A 911 call placed Tom in the hospital. Eight days later, after not eating or drinking, he was transferred, under Hospice care, to a memory care facility where he died three weeks later.

I am a quilter, gardener, golfer, bicycle rider, and lover of books. I still grieve the loss of my husband, but I am learning not to let grief define me.