

Dementia Doesn't Mean Demented

It was shortly after my husband was diagnosed with vascular dementia that he had a stroke. He had just turned 71 but you wouldn't guess it by his smooth complexion that hardly had a wrinkle. One thing I loved about him was his sense of humor. But since his stroke, his humor had diminished so I should have known he wasn't kidding when asking me if I thought he was crazy.

You Think I'm Crazy

This happened one day after pushing him in his wheelchair to the living room. He had asked, "What happened to the closet out here?" When I giggled and flashed him a look like he was a bit off, he sounded like I had hurt his feelings. Then he said to me, "So, you think I'm crazy now!" I first assumed that he was kidding except the tone of his voice was more like pouting than kidding.

There had never been a closet in the living room of our little apartment on South Street in Long Beach, California, so it was a natural reflex for me to laugh thinking he was playing a joke as he so often did. I was taken back by his hurtful expression, so I assured him he was not crazy and that his mind was just playing tricks on him, as can happen to anyone growing older. He was okay with my explanation but still grumbled on about what had happened to the closet.

In the 28 years I had known him, I often kidded him about being crazy and he agreed I was right in a joking way. One of his favorite things to tell me when I asked where he was going was to say, "Crazy!" I would come back with, "What do you mean? You're already there."

I realized later that he was most likely thinking of the home we had in Gardena about 15 years earlier that did have a closet in the living room. I felt bad and made a promise to myself that this would never happen again. I would have to find a way to let him know the reality of things without making him feel like he was stupid or going crazy.

After all, he may have been a bit on the crazy side but not what-so-ever stupid. Anyone that knew as much about flying as he did was the opposite of stupid and very intelligent, which was the biggest thing that attracted me to him so many years ago. What was sad to see was that out of all his so-called friends that hung around in his drinking days, none came to visit anymore except for maybe two that were true friends.

The Stigma of Dementia

There is a stigma to the word dementia, maybe because it sounds a lot like "demented," and most people associate a demented person with someone who acts like a maniac due to mental illness. Unfortunately, the actual meaning of demented is "Suffering from dementia or a loss of cognitive function" or "Mentally ill; insane." However, if you've ever been around someone with Alzheimer's or other types of dementia, you would not think of them as crazy or insane. Rather they are like being sadly trapped in a slow body and mind that doesn't work as it once did, lost in a world they're unable to describe because they've forgotten the words to use.

Learning a New Language

The next few years would have as much impact on me as it did on him as we learned to live together under these new circumstances that dementia forces upon you. I began to feel a bit demented just trying to make it through learning the new language that caregivers need to know

to communicate with a loved one who has Alzheimer's or other dementia diseases. I call it the 'love language' because it takes a lot of love and patience to understand a loved one when he is losing his memory and he is unable to find the desired words that enable him to express himself as he has done in the past.

Moving Too Fast

My dear husband brought an interesting and rather humorous point to light one day while I was trying to help him with his food. I was getting impatient with his slowness instead of letting him do it at his own pace, when he cantankerously said, "I know what your problem is now." I was taken back because he had not spoken that many words so clearly in some time. So, I said, "Oh really, what's that?"

He softly said, "You move too fast." I tried not to laugh to keep my promise to myself, but I couldn't help making a short snort of a laugh. I told him he was right even though I know I move a lot slower than I used to but it's much faster than he's able to move so it seems like I'm moving fast to him.

I can only imagine how frustrating it must be for him to see everyone whizzing around while feeling as if he was stuck in slow-mo. I think of myself as slow compared to younger and healthier people, but to him, I was moving way too fast and he needed me to slow down.

That night is when I accepted that this was to be a journey for both of us, not just him. My intuition was telling me I needed to change the way I was looking at the situation to survive the huge challenge of taking care of my precious loved one. I never dreamed that some good times would come out of this seemingly devastating situation.

Crazy Fun Guy

What's ironic about his being afflicted with this condition is that his friends used to kid him, calling him "Crazy" because of the way he was, but it was meant in a fun, wacky way because he just was not normal! It was in a way you can't really understand unless you had the privilege to know him. Many people who didn't know him that well thought of him as "crazy" because he had no qualms about speaking his mind. Most of those times were without regard to other people's feelings. He always said exactly what was on his mind without beating around the bush and didn't care what anyone thought of him for it.

Acceptance

I started writing this article four weeks after he came home from his last stay at the nursing home following his third surgery in four months. The surgery was to save his life due to the threat of dying from gangrene that started in his right toe spreading to his foot and then his leg. In the effort to save his leg, the third surgery was the last resort to save his life by amputating the leg above the knee.

Even though it was upsetting to see him like that, I accepted him just as I had always accepted him just the way he was. He did the same for me as I always felt like I could be myself around him. I'm sure this was one of the reasons our marriage survived for almost 30 years.

Dumas Demeanor

I realized that my husband's unwillingness to sign over his medical decisions to me was one way he could still have some control of what was happening to him. Not that he was any kind of a control freak but that he could be very stubborn even after the strokes. His well-known stubborn

streak was still very much intact—it was part of what I called the ‘Dumas Demeanor’ that he has passed on to all his children. Part of his orneriness was due to the dementia and while he was in the hospital, he would insistently try to get up out of bed to walk to the bathroom and then fall. Thankfully the doctor put him on a medication that helped him calm down, so the nurses didn’t need to restrain him to his bed.

The doctors told him that he could get a prosthetic leg, but most elderly people end up not using it because of how much work it takes to get used to wearing it. I tried to talk him out of it mostly because of the high deductible but he wanted it anyway. I took him to weeks of physical therapy and watched him struggle and struggle to learn to walk with his new leg. Eventually, the therapist said he wasn’t going to get strong enough to put it on, so I would have to help him. I had a hard time struggling with pushing that leg on him and he then decided he didn’t like it anyway so never wore it again.

Over the years, I had learned to live with the ‘Dumas Demeanor’ because it made me feel protected. I also learned from it how being assertively stubborn at times can work to your advantage when necessary. He had his own unique way of standing up for himself and I admired him for that. It was one of the things that made me fall in love with him and over the years I think a little of his strong personality rubbed off on me.

So now that I’m his caregiver, I’m sure it will come in handy at the times when I need to stand up for him because he’s unable to do it for himself. Ultimately, he helped me build up my self-esteem so that I would stand up for myself when needed and now my children call me the stubborn one.

Blessing in Disguise

Things had a way of working out better after that and his dementia became somewhat of a blessing in disguise since he was now a quieter, more gentle man. Another blessing was that I was able to talk to him more than I had ever been able to before. He now truly listened to me, which was something he used to have a hard time doing before because of his attention deficit disorder. Instead of interrupting me as he used to do regularly, he would just sit back and smile at me as I talked about whatever was on my mind. I became aware that there were some advantages to his dementia, but I still missed the lively man that I had married who made it seem like there was never a dull moment when he was around.

We spent the next couple of years enjoying each other’s company. It was a difficult time for me caring for him by myself while my health wasn’t that good, but I knew he didn’t have long. I told him we could go to Chicago to see his children from his first marriage and other family that lived there. I managed to hook up our travel trailer and we set out for the long trip but only got as far as Phoenix from California where we stopped to see our oldest son and family. It was while we were there that he suffered complications from pneumonia and passed away.

As much as I thought I was prepared for his death, it was still a gigantic shock, and I grieved for a couple of years before things seemed to get easier. What I miss the most about him are his humor and the way he put me on a pedestal with his love and respect. I was blessed to have known him and will forever hold his memory close to my heart.

I wrote this story to share with caregivers and loved ones of those with dementia to let them know that as hard as it is to deal with, they will be glad they cherished the time with their loved ones. You can read more about our life in my book called *One Last Flight Lesson* available on

Amazon.com. It's my story about how I met a flight instructor everyone called 'the Captain,' how he saved me from an abusive husband, how he taught me to fly, how we fell in love, married and built a family, how we spent 30+ years together, and how we proved that dementia does not mean demented.

Dedicated to my dearly beloved husband,
The Captain, Robert Henry Dumas Sr.
June 6, 1933—May 10, 2007
By Jessica J. Dumas