

Dancing With Dementia

It's hard being me, dementia, dancing from one person to another, day after day, moment to moment. Today, it is his turn. My arms are outstretched as I twirl, tapping him on the back, then her, only she's not aware of me quite yet. "Fear not," I think to myself, "she'll get the hint soon enough". As light as I am on my feet, the weight of me will descend on her as she watches him decline. The slow dance between us will begin, continuing until I am gone, leaving her depleted, sad, and alone.

I remember the night it began. For as long as we were married, we had been listening to, and going to the opera. Our favorite composer was Puccini whose La Bohème, and Madam Butterfly we adored. Every season we hoped they'd be on the roster, and when they were, we were there. We especially loved the aria Che Gelida Manina from Bohème which reduces me to tears whenever I hear it. On this particular evening, it was playing during our drive to meet friends for dinner. When it ended he turned to me and asked, "What opera is that from?" I sputtered the answer, feeling completely blind-sided, wondering what had just happened. Ever so slowly over the next few months, more changes became evident. I felt like I was on a roller coaster, reaching the peak on a clear minded day, descending to the bottom on a day filled with confusion. My role as wife and caregiver was gradually being transformed, and forever changed.

I don't know why I choose a certain day or time to add to one's misery, I just do it. I watched as she questioned what was happening to him. Did a little pirouette, and continued my dance with both of them. As he forgot more and more things, she'd try to hold it together. He stopped walking, shuffling instead which she tried so desperately to prevent. When the shuffling led to him needing a cane, she and her kids decided a neurological evaluation was needed. You can imagine how I danced around as I realized I had succeeded in creating yet another victim...he had early dementia. Yay for me!

Day after day I could see the small transformations as they occurred. His thought processing diminished, his sun downing increased, and his gait turned into a shuffle. Hard as I tried, begged and cajoled, nothing changed. I so wanted to keep it together, to hold my tongue, while at the same time, get him to do what I believed was needed, rather than leave it be. God,

it was so hard. At times, I felt like screaming, and letting it all out. But, in the beginning, I didn't. I held it in and on as long as I could.

Oh, what happiness I derived from watching them both as I continued my dance with them. I'd just sashay in and out of their lives when I felt like it, setting off many different reactions. His shuffling got worse by the day to the point where he needed a walker, and in the end, a wheel chair for long distances. To that mix, I added incontinence, forcing him to wear an adult diaper, demeaning to him. Sad to her, short circuiting their remaining social activities...unable to go to friend's homes, restaurants etc. Perhaps the worst was his gradual inability to read in depth the way he normally did. Before my interference, he was able to knock off three or four books in a couple of weeks. When I got through with him, he could barely read a page of the newspaper. He conversed less and less, which was dismaying to her, yet, she held it together. She was completely devoted to him, as are many other caregivers, but like them she did lose it bigtime, once. She regretted it, while I laughed my head off. Only proved she's human and I had the power to directly affect her.

This was certainly not the way I thought we'd spend our golden years. It was so difficult seeing the man I married slip away inch by inch. At times such as this, I often wonder on who it is the hardest. I really really wanted to be a helpmate not a hindrance, though there were times when I did lose it. I got so tired of his obsessing over his dying, his repeating the same questions over and over, and his not listening. It began to wear me down too. One morning when he refused to get up for his shower and breakfast, I threw up my arms, yelled at him and walked out of the room. Of course, when I was alone, realizing it was not his fault, I dissolved into tears. I regained my composure, went back in the room and apologized to him. He said if I felt the way I did, could I imagine how he felt. Made me feel about two inches tall. It was not an easy road to walk down. How I longed for the old days when we were so sympatico, so in sync with each other that we could finish each other's sentences.

I continued my pas de deux with them until the day he fell. I had decreased his ability to do most anything and watched from the sidelines as her sadness built after each difficult day. Then, he fell, and needed an operation, after which he didn't require me to cut his memory short. The anesthesia did that. They replaced part of his hip without much success. He couldn't

stand up, and the medications he needed for his kidneys fought the ones he needed for his heart. Eventually, he passed on without any additional help from me. This was one dance that came to an abrupt end. Never mind, I shall just dance on, and find another partner to destroy.

If someone had told me it'd all end the way it did, I would not have believed it. Watching him slip away from me was difficult enough. He knew what was happening, and told me he felt sorry for me...I felt sorry for him. Here was this intelligent, soft spoken, well-read, gentle man diminished to a shell of what he once was. It broke my heart to see him fade away, to be demeaned, reduced to sleeping in a chair most of the day. The knot in my stomach grew tighter and tighter after his operation, as I knew what was coming. Finally, when his state was so weakened, I kept telling him it was all right to leave, and one day he did. The desolation is indescribable. I like to think he is in a better place. Our dance has ended, though I can still feel his arms around me as he pulls me close, and kisses me on the nose one last time.