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Defining Moments

by Dina Emberlin
Family Care Partner

My mother, Susan, was diagnosed with Lewy Body Dementia in 2016, and I have the honor of being her care partner. This has, by far, been the hardest thing I've ever had to do in my life. My mother has always been a force to be reckoned with. After surviving 19 years at the cruel, abusive hands of my father, she climbed her way to a six-figure salary with the IRS before she was forced to retire. So, watching my mother, the person I knew could get through anything, lose pieces of herself, is a heartbreak I've never known.

One of the most difficult things for me to come to terms with has been my mother's changing personality. I didn't want to accept that my mother is no longer who she once was. To be honest, I didn't like this new person. There are times she isn't very nice to me and that hurts me deeply. I didn't know how I was going to care for this person I didn't like. I was angry and when I wasn't with her I cried a lot. I missed my mom. I wanted my mom back. I wanted the woman I could confide in, tell anything to, and get advice from. I had to work through a lot of grief and a lot of anger to get to a better place. But I knew I couldn't go on fighting against something that wasn't her fault. No, my mom would never have chosen this. She would be devastated knowing she was hurting me in this way.

After much research, I knew I had to put myself into her world and find things I liked about this new mom. As it turned out, I found many new things about her that I really liked. She is no longer a stickler about being on time. If we are a few minutes late she doesn't care. She is less inhibited in many ways now and I appreciate that. We even have a girl's hair day now which is something my mother wouldn't have been interested in before. Just last week we had such a day. Right before I was about to wash her hair she looked at me, smiled, and said "See, isn't this girl day fun?" For a split second, I could see my mom staring back at me and I took a deep breath and lingered in the feeling of love between us. Just as quickly she was gone again, yet her smile still remained. I smiled back warmly and said "Oh, yes, it is a lot of fun." During the times I am feeling the most despair and questioning how I am ever going to live with this broken heart, I remember moments like this. It is this kind of moment that I have learned to cling to. They serve as a reminder why this journey is so meaningful and worthwhile.

Dina Emberlin lives in Carlisle, Iowa, on an acreage with her husband, Joe, two cats, four mini horses, and one mini mule. She has the honor of being the full-time care partner to her mother, Susan, who has been living with LBD for two years. Dina and Susan are extremely grateful to have the convenience of living next door to one another.