

*Minding Our Elders contains six stories of my own, plus  
twenty stories obtained through interviews with other boomers struggling  
to keep up with the needs of their aging loved ones, and not go crazy doing it.*

## Chapter 9

# Janice

The front door is open, indicating to this stranger that she has found the right place. I knock on the storm door, and a tall (by my standards) woman dressed in soft red, with blonde styled hair, comes to the door and invites me in. Janice and Cynthia work together at the clinic. Janice is welcoming and gracious. She asks if I'd like some refreshment, as she takes an overstuffed chair in her living room. I settle on one end of a mile long couch. Here is a woman who, after two years, is still passionate about the experience of losing her mother to dementia and death. She is articulate and occasionally teary. The prairie sun fades into dusk as Janice tells her story.

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My mother got along well up until that last year and a half of her life. It was when she started having mini strokes things started to get bad. I feel fortunate we only had to deal with this for about a year and a half, because when you're in it, it's with you every day and every night. It never leaves you.

My kids were grown, so I didn't have young children to worry about. And I have two sisters. I don't know how people do it alone. My sisters and I lost our dad when we were pretty young – I was only fourteen – so we're very close. When something was going on with Mom, we'd all show up at the emergency room.

The mini strokes induced dementia in her. With some people, it takes an area that controls movement or speech. With Mom, it took pieces here and there of her brain, and that caused the dementia. She was in her own apartment at The 400 on Broadway, and at first, it was just the little things that you'd notice.

She started doing really strange things. Mom had worked as a cook in the hospital when she was younger, and she'd have to get up at three o'clock in the morning to get to work by five. Well, what she started to do was she'd call us about three o'clock in the morning. She would be so confused because she thought she had to get to work.

One night she called my sister. She said my husband and I had been in a car accident on the corner by her apartment, and that Larry was in bad shape and had been taken to the hospital, and she didn't know how I was. She said she had to get to the hospital. My sister called me at home, and I called Mom to try to calm her and tell her we were fine. She really didn't seem to be connecting, so I went over there so she could see I was all right. When I got there she was really surprised to see me and wondered what I was doing there!

We got more and more worried. The 400 is just down the street from Hardee's, where Mom used to like to go. And it's right by the railroad tracks, where she heard train whistles all the time. She was used to them. We were deathly afraid that she would decide to walk down to Hardee's, and a train would come by and she'd pay no attention. Or that she'd just wander off.

One of my sisters lost her husband a couple of years back, so she began to make excuses to stay overnight with my mother, and we also started having home care. At first someone came to clean a couple of days a week. Then we went to having someone come in a couple of hours in the morning to help her with small things and with her medication.

Each of us had our own way of coming to the conclusion that something had to be done.

For me, it really sunk in that Christmas. I said, "Next weekend, you come over here and we'll wrap gifts and things." Well, when we started wrapping, she really didn't want to have anything to do with it. I realized it was because she couldn't figure it out. So I said, "Let's do some name tags." It just hit me – Mom couldn't write out a name tag either! She was frustrated. She wanted to do something, so I ended up writing the name on a piece of paper and then she would copy it.

The month of January was pretty good, but then it went downhill quickly. We noticed that she would go into the bathroom and come back and have water splashed on her arms and her face. It turned out that she was afraid of the shower. She couldn't figure out the faucets and she'd get burned when she turned on the hot, so she didn't get in. She knew something was happening, and she kept trying to compensate so we wouldn't know. But it kept getting worse.

Mom grew up in the Depression and I suppose that's why she got so afraid that something would happen to her money. She got so she carried all of her money with her. We'd take her to the grocery store and just kind of let her go about her business. I remember one time we were at the checkout. I had been writing out her checks for her. This time she just took this big wad of money out of her purse and told the carry-out boy to take out that he needed! He and the checker both just stood there – they didn't know what to do.

Mom had problems with phone sales and with soap operas – thinking they involved family

members – but the worst was the sweepstakes. When she'd get an entry, she'd think she had won, and wanted to fly out to California or down to Florida to collect her winnings. A lot of those old people get into that. It's really sad.

The more the dementia progressed, the worse the things were that she thought were happening. My dad died over and over for her. Family members were attacked. Everything she imagined was just horrible.

Mom had always been fiercely independent. Just fierce. The worst thing was... she said she never wanted to go to a nursing home. You knew that was just not an option for her. Yet we got to where we didn't have an option either. None of us was in a position to quit a job and stay with her. We started to take turns and spend the night, and she had help during some of the day, but we couldn't keep that up either. She got to the point where she couldn't be alone at all. We finally did have to put her in Eventide for her own safety.

I'd been trying for years to talk her into moving into their retirement home, so I thought a nursing home wouldn't be all that different. We all got together and said, "Why don't you just try it for awhile?"

We were fortunate that a room opened up, so we moved her stuff in. It kind of seemed okay until we were going to leave, but then the crying began. "Why are you doing this to me?" It was kind of back and forth, like she'd say it was okay, but when we were leaving, then she'd begin to cry. It was so hard to leave her there. It was just like leaving a little kid.

She kept having more strokes and she got worse rapidly. She didn't always know where she was. It got to the point where the room was her house and the hall was the street. One day when she saw me coming down the hall, there was this big flood of emotion. She figured now she had a ride home. And then I had to leave her!

Mom always liked to dress nicely. She was very conscious of her appearance. We tried taking her out to eat, but then when she'd drop food on herself – you wonder, should you reach over and wipe it off? How would that make her feel? And she would be so embarrassed to have food all over her. You just don't know what to do.

Then she fell and broke her arm. That traumatized her system, and she grew weaker. I was in a job transition then, and was to start a new job on Monday, so I was trying to get all this stuff done. Then my daughter called and wanted me to go to a rummage sale, so we did that. Her little boy was newly potty trained, and while we were in the car he said he had to go. I said, "Let's stop at Eventide. He can go there, and we'll take Grandma down for coffee."

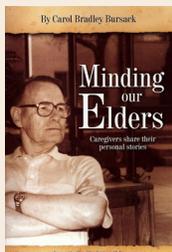
A couple of nurses saw me getting off the elevator and hurried over and told me that Mom had fallen and they didn't think she would make it. Well, they took me to her room and she was gone. She had already died and they were trying to get in touch with everyone, but, of course, I wasn't home. They didn't want to tell me she died while we were standing in the hall.

They had taken her for a walk and she had just dropped. She was smiling and talking and then she was gone. It was such a shock! The whole thing – it’s about the little things. You don’t know how you’re gonna do it one more minute. But then you do it anyway. And then suddenly, it’s over.

I think I have learned to deal with death now. And I also know there are a lot worse things than death. To watch someone you love go through these changes. When they have no quality of life. That’s worse than death.

I couldn’t give up on Mom no matter how bad it got. I had to make her life as good as I could. Yet, I sometimes wonder if I did any good. But ...well, I couldn’t just not try.

No matter what you do, you don’t think you can do enough. It’s always on your mind. I still – when I drive off in that direction – automatically start going to Eventide.



#### **About the Author**

Over the span of two decades, author, columnist and speaker Carol Bradley Bursack cared for a neighbor and six elderly family members. Because of this experience, Carol created a portable support group – the book “Minding Our Elders: Caregivers Share Their Personal Stories.” Carol’s newspaper column runs weekly in print and online, she speaks at workshops and conferences, and has been interviewed by national radio, newspapers and magazines. She is also a contributing author to “Dementia: Frank and Linda’s story: New approaches, new understanding, new hope” (Lion-Monarch, March 2010).