

Maria's Story: Being there with Mom

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When my mother was in her early nineties and living on her own, we noticed changes in her behaviour. She would leave the stove on or forget to put a cup underneath the coffee maker. The first sign that it might be dementia, was when she asked us to put the names of the grandchildren and great grandchildren on their photographs so she would remember them. But she never went to the doctor to get a diagnosis, and my sister and I didn't suggest that she go to the doctor, because we all thought this could just be a normal part of getting older.

As a young child in Italy, dementia wasn't talked about. Changes like memory loss were considered to be one of the things that can happen when you get old, so I don't remember anyone going to the doctor for them. People just lived with it and family would take care of them. The culture was just different in Italy.

My mother never wanted to impose on anybody and didn't like talking about herself. Talking about dementia, getting a diagnosis, or even admitting that she had dementia was not something my mom could do. Knowing there was stigma attached to dementia, we probably resisted seeing the doctor for fear of being judged. Some people seem to think that anything to do with the brain indicates that a person is "crazy".

We came to Canada when my mom was in her early thirties. She took English classes and learned to drive so she could take care of us.

"Truly an incredible woman and a real Italian mom, always thinking of her family first; which made us want to take care of her even more."

I lived further away from my mother, so my sister was her primary caregiver. Sometimes my sister and I approached things differently, and it bothered my Mom when we weren't in agreement; she didn't want anything to come between us. Not being the only caregiver, we had to find our peace even in disagreement, so mom could have peace.

When my mom needed to move to a retirement home, she was resistant because she wanted to be cared for at home. I offered to come and live with her, but it wasn't something she would let me do. It was hard for me that I couldn't be what I wanted to be for her, but still we did the best we could. Eventually we visited a friend of hers who lived in a retirement home and knowing there was a friend there was enough to encourage her to move in.

After mom was in the retirement home for a while she became more forgetful. Even though she was forgetting our names, most of the time she knew who we were.

Mom also became much quieter, I think it was a way of not revealing that she was becoming more forgetful. When her Italian friends would come to visit her, she wouldn't tell stories the same way as she used to - they did all the talking in Italian. Sometimes there would be activities at the retirement home that I'd want her to go to, but she was just content to sit on the couch and hold hands.

“Eventually I learned that what makes her happy can be more important than what I think is best.”

Mom could still speak English, but we didn't always talk that much. We'd sit together and knit or crochet, or just hold hands. In those moments you almost didn't notice she had dementia. But there would also be times when she would want to be walking night and day. She would take my arm and urge me to go with her, because she had to get to someone that needed her. It was sometimes a grandchild when they were small - but most often her thoughts were back in Italy. There was nothing to do besides walk with her. When that happened, one of us would stay at the retirement home with her through the night, until her mind was calmer and she caught up on sleep.

At the time, I never thought to tell my friends or other family members that my mom had dementia. The word “dementia” wasn't in my vocabulary back then. We'd say “oh she forgot this” or “she did this” but I never labeled it as dementia. I became interested in learning about dementia after my mom had passed away and my husband and I started aging ourselves.

“One shock was that there were different kinds of dementia! All I heard was about Alzheimer's. I didn't realize that there were other types.”

I am grateful that today I am using the word dementia more often as I have been learning that it's a health condition, just like lupus or rheumatoid arthritis. That makes it easier for me to talk about it.

“The biggest lesson I learned from this experience was to enjoy Mom and the time that I had being there with her.”

To find resources about dementia for the Italian community, visit:
www.forwardwithdementia.ca.