
ESSAY/PERSONAL REFLECTIONS

Being-with, being-there: An end-of-life care narrative

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The following narrative is an amalgamation of many experiences shared by eleven bereaved family caregivers who spoke with me about providing end-of-life care to a relative with advanced dementia. Inevitably, I too am included in the narrative with my experiences as a nurse and family caregiver. I introduce a small family who are dealing with the imminent death of a wife and mother in a long-term care home. It is a simple, yet detailed, narrative that attempts to capture what it is like to lose a family member with dementia.

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George and his daughter Sheila reluctantly drive away from the long-term care home. Today, George's wife Martha moved there in order to be cared for 24 hours a day. George cannot stop looking at the closed door that separates him from his wife. He is unsure how his legs are able to carry him away from her. Sheila is relieved that her mother will be safe and under constant supervision, but she too finds it excruciating to ignore Martha's pleas to go with them. Gnawing at both of them is this question: Are we doing the right thing? Sheila looks over at her dad and sees how much he has aged in the last two years and wonders how he has managed for so long to take such good care of her mother. Neither George nor Sheila tells the other what a horrible day this is. This is the day they stopped caring for Martha in the house in which she and George had lived, loved, and raised Sheila for more than half a century.

Except that you cannot stop caring, even with a loved one in a home. They decorate Martha's room with the things she treasures—her bedspread, the picture of Sheila as a baby, their anniversary photo, and a seashell from their beloved vacation home. George visits every day and continues to feed and

walk with Martha. It is almost as if they are husband and wife again instead of caregiver and care receiver. At night, though, in the house, all alone, he can hear Martha's footsteps, and he gets up to see if she has gotten away on him again. After a moment, he realizes where she is and returns to bed. A new day arrives, and he is able to go and see her at her new home.

Sheila also visits her mother often. She looks for details that tell her that her mom is well cared for and content: is her hair done, is she wearing lipstick? She also looks for her mother's recognition of her, because she knows that will go soon. Already her mother does not recognize objects or remember how to dress herself. But she can still walk, and that is something they can do together, as if her mother is *normal*, is free from this disease that is slowly stealing her away.

Unfortunately, it does not take long for Martha to wear Depends pads instead of being toileted and, even worse, to begin to have falls. Martha does not know how to use the call light and cannot wait for someone to come and help her up; she needs to get up when she is ready to get up. George and Sheila do all they can to keep Martha walking, because that is all they have left of the *old* Martha. So the walks continue but with Martha in a wheelchair. As Martha sits in her wheelchair, she still gets a twinkle in her eye when George arrives. She smiles at his teasing, but her verbal replies have been long forgotten. That does not stop George and Sheila from talking with and sometimes answering for Martha. Sheila recognizes the downhill decline in her mother more so than George. Is it because she does not see her mother each and every day, or is it because George does not want to face what is inevitably approaching? Perhaps it is a bit of both. This downhill decline is what happens when you put a loved one in a home. . .

Martha begins to sleep more and eat less. George feeds her. He pleads with Martha to take the Ensure

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and pureed foods. Sheila has taken to coming at night and bathing her mother in bed, applying lotion and massaging her, talking to her about what a wonderful childhood she remembers. Sheila is silently thankful she can do this for her mother; she knows it is only a matter of time now. Sheila does not dare tell her dad that she is giving her mother permission to die. Sheila wonders if her mother is confused by their different approaches to caring—as Sheila provides care as a way to say goodbye and George cares in order to hang onto Martha no matter what her state of being.

It seems almost out of the blue when the nurse on night duty calls Sheila and tells her that her mother's had a "bad night"—maybe she should come and see her? Maybe Sheila should bring in George? Together, in the early morning hours, George and Sheila sit by Martha, listening for life (breaths) and death (absence of breathing). The staff brings George and Sheila coffee and toast. Sheila tells her dad to go home and rest, that she will call if there is any change. George does not hear her—he is in a fog; his beloved is dying, and he is simply not ready. His mind races with thoughts that if Martha were still at home this would not be happening. A few hours later, Martha opens her eyes and turns her head, George moves close to her bed, smiles at her, Martha reaches up and touches his face—she too smiles weakly. Sheila notices what has just happened, and she goes to the bed, but Martha has already closed her eyes and slips into unconsciousness again. Now neither of them wants to leave in case they miss another moment like that. But there isn't one.

Eventually, Sheila and George begin to take turns sitting with Martha. Sheila makes sure someone else is with her father, so he is not alone if her mother dies before she can get back to the home. Sheila tries to count how many days it has been since the last time her mother was awake. It is hard to tell. Time melts away. An hour seems to last only a moment. They wonder: *How much longer will it be now?* After five days of constant being-with and being-there,

Sheila knows something is different. She calls her aunt to go and get George to bring him back, even though he only left the home two hours earlier. Martha makes gurgling noises. She appears to struggle with her breaths, but in a way she looks peaceful. Her breaths come slow and infrequently. Sheila wonders a few times: Was that the last one? Sheila holds her mother's hand and rests her head on the bed. She is thinking that it is okay for her mother to go, to be free of a body she doesn't recognize and would never want. "Just let go, Mom. Dad and I will be fine. You had a good life."

George arrives and sits on the other side of the bed holding Martha's other hand. He is weeping quietly. He knows she's not coming back. He wants her suffering to be over. He is consumed with sadness deep in his heart that she is finally leaving him. George ponders all the things he is losing: Martha will not walk with him on the beach again. In the spring they will not plant their garden, and there will be no talks over tea and the newspaper at breakfast. Sheila reaches over and holds her father's hand—they are a complete circle, and love passes among the three of them. George and Sheila realize that Martha has not taken a breath for some time, but they do not call the nurse to confirm what they already know. The serene look on Martha's still face tells them she has died.

"Come on Dad, go with Aunt May. I'll get Mom ready." George is led away. He is unsure where he is supposed to go or what is supposed to be happening now. Staff members come and hug him. They cry with him and say, "I am so sorry. Martha was one of my favorites." With the help of the nurse, Sheila bathes her mom for the last time. They dress her in her favorite ruffled blouse and grey slacks because Sheila thinks her mom would have liked that. With the air still filled with the smell of lotion, Sheila watches as the funeral home takes her mother away. Sheila is ready for the next part of the journey, and she will make sure that George is ready, too.