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## **Disappearing before My Eyes: My Mother and Dementia**

By

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My mother would've been 94 years old the week after she died. She passed quietly late the night of Labor Day, just hours after I'd called her to tell her that it was Labor Day and people were having cook outs and picnics everywhere. We'd just been together a week before and, after the nurse put her on, I was alarmed that it was 10:30 in the morning and she was still in bed, this woman who was up at dawn every day. With typical bluntness, she said she felt "crappy" and she sounded down, her tone off. Immediately after our conversation, I called my daughter to ask her to visit her grandmother. She did, taking her son who was my mother's favorite great grandson. By blessing or divine intervention, the last thing I said to my mother and the last thing my daughter said to her was, "I love you." She said the same to us.

For the last 20-30 years she was notorious for telling the same stories: how her brother Frankie had a rabbit and a goat who chewed up the kitchen pots, during the Depression in urban Boston; the time she got my brother and me and a car load of Cub Scouts lost in a snowstorm coming back from a visit to a miniature railroad park; how furious my father was when she came home to tell him that she'd spent \$100 on credit to buy an old Studebaker Land Cruiser.

She lived in her own house, two stories with a walk down cellar, for 50 years plus one month, 48 years by herself. She'd always been forgetful and could get lost so easily when driving that it was legendary. For decades she'd frequently go up or down the stairs and arrive having forgotten why she made the trip. We joked that, no matter what happened to her memory, she'd be in great cardiovascular shape because of all the climbing. And so it was.

She began to fall, first while raking in her back yard at 92, then while walking back from the grocery store, then inside the house at the upstairs landing. We bought her a medical alert watch but she would not wear it. Reluctantly, our family urged that she move into assisted living. Even more reluctantly, she finally agreed, moving in last August. She had a small efficiency apartment but was moved to the memory care floor in a matter of months. By February she had fallen in the facility three times.

The last time, on arriving at the hospital emergency room, she was diagnosed with having, in addition to a fractured pelvis, pneumonia, a urinary tract infection, and dehydration. After treatment, she was discharged to the same rehabilitation facility where she'd recovered after her previous falls; they knew her and she them, and so she stayed, this time in the skilled nursing section. From living in her own home to the end was just 13 months.

She worked until her mid-80s and was extremely proud of it, being a medical secretary for some 40 years, and assisting in minor office surgeries in a solo dermatology practice. The dermatologist loved her dedication and work ethic, and didn't want her to retire. He didn't know

or care how old she was, and she wouldn't tell him. She lied about her age, anyway. She actually changed her passport by altering her birth date of 1921 to 1927, but I guess she's beyond prosecution now. When I was in the third grade, I got into a fist fight in the school yard because another boy said my mother wasn't 18 as she'd told me.

Like her weight, which she said, with no sense of irony, ranged "anywhere from 99 to 100 pounds," she was a constant in my life, even to the end

As her memory worsened, contexts offered some cues for conversation but these were increasingly limited. If we were driving, she'd ask me repeatedly when I was going home (to Virginia), how I was getting to the airport, if the car I was driving was my own. In a brief, local drive, she might ask me this a dozen times in 20 minutes, sometimes prefacing the question with, "I know I've probably asked you this before, but I forget what you said." She tried in what were early stages of fading memory to use prompts, such as asking what my daughter did for a living; when I replied, "Which daughter?" she'd know that I had two, and so on. Later she abandoned all pretexts of remembering and I ceased asking, "Do you remember...?" Instead, I told her of my days and events. Near the end, she related many times that she liked that I talked with her, that we had conversation.

About 10 days before she died, she dozed off several times while visiting at her brother and sister-in-law's house, something she'd never done before. And her stamina evaporated as a day progressed: she could manage to stand or seat herself when exiting or entering my rental car at the start of our day but needed a fireman's hug to accomplish the same at its end.

During my last visit, we drove one day to Pembroke where we'd had a cottage near a pond. Her Uncle Billy and Aunt Millie had built it before World War II, and she and her sisters and female cousins visited there often during the war while the males, barely men, were away in the Navy. Being home-made, the cottage had quirks like a half-sized doorway entrance on the side to a cellar with a bar and neon signs. My parents bought it from Billy and Millie in the late 1950s and owned it for a few years. During that time my mother's sister and brother-in-law bought a nearby cottage and we cousins had great fun there during summers. I helped my mother out of the car and pushed her in a transport wheelchair up nearer the cottage. My friend Paul Raia of the Alzheimer's Association of Massachusetts and New Hampshire had advised me to stop asking, "Do you remember when...?" but rather to recall events for her with statements like "I remember when you and I..."

I described my memories of times in Pembroke as a kid, like her taking us to the Town Landing for swimming, which she did even though by her own admission she "swam like a rock"; visiting our cousins' cottage and provoking a stern uncle with our failures to be quiet while staying overnight. We then drove to a much loved place on the pond where we used to have burgers and hot dogs as kids; it's a honky tonk now but it still had the side window where they sold ice cream cones. We ordered two and she loved it. Later we drove to an Italian restaurant just up the street from her house of 50 years to have pizza inside. When I returned her to her skilled nursing facility that afternoon, she thanked me for "all the wonderful memories." She said that it meant

so much and that she'd treasure them. When I picked her up the next day, she remembered nothing.

That next day, my last in person with her on this earth, we went to Castle Island, a pre-Revolutionary War fort built by the British to help defend Boston Harbor. Again, she had taken my brother and me there as kids. It's recently been enhanced with a long pedestrian causeway that encloses as a lagoon the South Boston beach where she would take us to swim. We spent a couple of hours there enjoying a strong ocean breeze that refreshed an otherwise warm day. We sat on a bench and I recounted memories for her of climbing trees there as a young boy, having PB&J sandwich picnics there, and pointing out the nearby bath house where the "L Street Brownies" take their daring plunges into the water every February. Again, she said she loved the memories and would cherish them.

Maybe she did. Maybe in some way, at some level unrecognizable to those outside, these memories brought her comfort or pleasure. My friend Paul Raia advised me to think of the moment, not the durability, of these experiences. Perhaps it's like enjoying a soap bubble, blown up and shining with multicolored luminescence. It's there for just a moment before bursting. The fact that we know it'll break and vanish doesn't prevent us from blowing up another. With dementia, maybe it's all bubbles near the end.