A Farewell Gift from My Mother

Katherine A. Wayman, M.D., September 24, 2020, N Engl J Med 2020;

After performing my beachside neurologic exam, complete with lobster hammer to check reflexes, I made a mistake I would never have made with a patient. “Mom,” I said, “There are some subtle findings. You need an MRI, but don’t worry — it’s not like you have a brain tumor.” I advised my mother to see her primary care doctor when she returned home from our vacation, and when her symptoms worsened, I told her to go to the emergency department (ED) instead. So when my mother handed the phone to the rural emergency physician who struggled to pronounce “corpus callosum” while reading me the MRI report, my subconscious fear was confirmed. I arrived the next evening at the small community hospital, and my mother greeted me with the same wide-eyed, enthusiastic smile she had given me since I was a baby, only now with mild right facial weakness.

My mother was awaiting a transfer to neurosurgery at the large urban center 3 hours away, but we were told it might take several days, and I couldn’t wait. Prompted by my no-nonsense Midwestern neurologist friend (“Just take her out!”), I wheeled my mother to her partner Kate’s waiting car. With my mother in the back seat and Kate riding shotgun, we drove off. My mother faced the open window, her short silver hair swirling around her head, her neck craning upward to take in the last gulps of the sea air as we sped toward the city. Kate yelled out over the sound of the wind, “We are escaping like Thelma and Louise!” and my mother said wryly, “We all know how that ended.”

Once we arrived in the ED and she was taken back to the triage doctor, I felt like I could just be the daughter. But throughout her time in the hospital, my mother would never miss the chance to introduce me as her daughter the neurologist.

During the 8 days of workup and awaiting brain biopsy, my mother held court from her hospital bed. Friends visited from around the country. We all discussed plans for her wedding to Kate, still hopeful it could occur at home. We also discussed funeral plans, and my mother, who’d grown up in Asia, had always loved the thought of Chinese professional mourners wailing at her wake. She gave up that idea quickly, though, at the thought of scaring her young grandsons.

We had never been a family to shy away from discussions of death or illness. My mother had been widowed at 28, and our family’s awareness of mortality was only amplified when she was first diagnosed with breast cancer in her 30s. I recall several detailed “what if” discussions at that time. So it came naturally to ask my mother very specific questions about what she could live with and what she valued most. We went through several scenarios, and it came down to this: “If I can’t sit on the floor and play with my grandsons, I don’t want to live.” She made it clear that she valued her mobility, her golf game, and her language. If there were no treatments that could ensure all those abilities, she wanted to be allowed to die, quickly and painlessly.

My mother had her brain biopsy on Halloween and had no shortage of jokes about the Frankenstein’s-monster–like surgical markers that were placed that morning. When the neurosurgeon emerged from the operating room, he confirmed the worst: “It is glial-based.”

I stayed with my mother that night in the ICU through the torture of hourly neuro checks. When she emerged from the sedation, she was hemiplegic with a moderate expressive aphasia. I was assured that the worsening deficits were from an intraoperative bleed and she would probably improve, but I knew she had crossed the line and that it was my job to ensure the ending she desired.

I met with a remarkable amount of resistance when, less than 12 hours after my mother's biopsy, I requested a palliative care consult and a switch to comfort measures only. Nurses, residents, and attendings cautioned that she was still under the effects of sedation and she might improve and feel differently. We were offered oncology and radiation oncology consults. I realized how many times in my training and career I, too, had practiced without the greater perspective in mind — how many times I had continued to check labs, do imaging, and focus on small details because that's how it's done. If I hadn't had such a detailed discussion with my mother about potential outcomes, I might have delayed this decision. Perhaps I would have agreed to follow the neuro exams a little longer in the ICU, repeated a few more scans, considered subacute rehab since her death wasn't imminent. But we had discussed this exact scenario, and every minute in the ICU was robbing my mother of peace. If faced with a terminal brain cancer and significant deficits, she wanted only to marry Kate, her partner of 20 years, then fly to Vermont to see her grandsons before having a painless "death with dignity."

This was the fall of 2013, and Vermont's Death with Dignity Law, in effect only since the previous May, was largely untested. I didn't have the heart to tell my mother that she was required to be a Vermont resident and that there were other barriers such as her worsening aphasia. After arriving at the hospice in Vermont, my mother made her wishes known to the palliative care doctor. This doctor sat with my mother, listened to her stories, learned what she valued most, and reassured her that though she was not a candidate for physician-assisted suicide, there were other options to ensure a death with dignity — "For example, you could stop eating and drinking." After a pause, my mother dead-panned, "What else you got?'"

Over the next several days of visitors and hospice singers filling the room, there was a shift in my mother. She was no longer smiling. She was not entertaining the nurses. Her doctor recognized her psychic suffering and offered palliative sedation that would hasten death. The next day, my mother was sedated, and 5 days later she took her last breath. I do not remember her last words before she was sedated, but truthfully, it didn't matter — in the 4 weeks since her diagnosis there had been nothing left unsaid.

My mother certainly could have lived several months more with ongoing medical interventions, at a great financial and emotional cost. It was a gift to us that she was so resolute in her desires and that there was no ambiguity about her prognosis. Those conditions don't always apply, and as physicians we have been witness and party to too many regrettable and prolonged endings. I'm grateful that as my mother's life drew to a close, I was able to use my knowledge of the medical system, neurology, and my mother's values to help her have a good death. But I am most grateful that my mother, who feared loss her whole life, showed me how to let go at the end.