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When You Least Expect It

by Julie Rothstein Rosenbaum

My brother Jeff's voice on the cell phone said, "Julie, it's Mom." It was one of those calls you never want to receive. Some people think that being a physician insulates us from the impact of such a call, but when it involves your own family, the emotional shock still runs very deep.

My mother had end-stage Alzheimer disease. She had been in a nursing home for four years and virtually noncommunicative for the past three. She and my father had had several conversations over the years about how they wished to live the final days of their lives, usually sparked by the death of one of their parents or an event in the news. She was a vibrant, intelligent woman who never would have wanted to end up in a state of severe dementia, completely dependent upon others, being spoon-fed, unable to wear her Isaac Mizrahi fashions because they were impractical nursing home attire—clothes too fashionable to be stained by the drippings of mashed food that might not successfully stay in her mouth. She was unable to read any of the books that were constantly piled on her night table, nor any of the multiple Chicago newspapers she had once read every day. She would never have wanted to be in a situation where she could not interact meaningfully with her family. My son was born last year, and she did not know he existed. In her current state, and based upon her clearly expressed wishes, my father had the physician sign a do-not-resuscitate order.

When I received the call from Jeff about our mom, I was on vacation with

my family. We had just arrived at the swimming pool. My husband could tell from my face that I needed some time on the phone, so he splashed with the kids while I spoke with my brother.

Ironically, my father was also on vacation, taking the trip of a lifetime, hiking in New Zealand. He was the primary decision-maker for my mother, living near the nursing home and visiting her regularly. He paid attention to every detail to ensure that she received the best care. Jeff, who also lived near our mom, was watching over her in my father's absence. He told me that over the past few days she had developed a fever. The staff nurse at the facility had asked Jeff over the phone if she should send Mom to the hospital for evaluation, but this clinical pattern had occurred many times before without incident and without necessitating a hospital visit. He expected a routine, self-limited illness like anyone might experience.

When he walked into her room that morning to visit, he found her skin warm with a low-grade fever. She appeared to be asleep in the bed made with sheets from home, neatly tucked, beneath selected pictures of our family and her earlier travels. Jeff saw that the staff were now giving her oxygen through a tube in her nose. They had asked again when he arrived if she should be sent to the hospital, but they gave him no indication that this illness was any more serious than her previous ones.

By the time I received Jeff's phone call, he had been home from his visit for a few hours. He told me that he had just

received another call from the center, and that Mom had deteriorated. Her fever was higher, and her breathing increasingly labored. The staff were not able to wake her. Again, they asked for authorization to send her to the hospital.

Jeff wanted my help with this decision. Our father was twenty-one hours away over the International Date Line on his hiking tour, and my brother's copy of his itinerary showed that he was not scheduled to reach a hotel where we could contact him for another two days. "They said her oxygen level is 65 percent," Jeff told me. I gasped. Jeff is an attorney, a very smart man, with a general working knowledge of many medical issues, but from his tone I could tell that he did not understand the life-threatening implications of this number. Was her breathing really failing so rapidly? Was she in shock? I told my brother that if that number was true, then her death would come very soon.

My father had had numerous conversations about Mom over the years with me, my brother, my sister, and our spouses. We all had a clear sense that she was mentally and emotionally gone and had been for quite some time. None of us wanted her current state prolonged any longer than it needed to be. Although we had a clear consensus regarding her DNR status, in conversations with my father where we contemplated the possible medical issues that might arise in her care, I had learned that some family members might be less comfortable with other decisions. For example, what if she developed a serious urinary tract infection? My father said that in that situation, he might withhold antibiotics and let nature take its course one way or the other. But not all of us children believed this was appropriate. Should she *ever* be sent to the hospital? She had been sent in the past, with our father's authorization, for intermittent seizures. She had stabilized and returned to the nursing home. We deferred to our father's guidance here, which we knew reflected his love for Mom and his knowledge that she would not want this part of her life prolonged. We had contemplated several of the issues regarding

the end of her life, but not what it would really feel like when she was actively dying.

Despite her current demented state, she was still a presence for me in that nursing home—someone pulling me home. She had lost the majority of what made her herself, but I could still hold her hand and tell her that I loved her, even if I had no idea whether she heard. Her gaze could usually not meet mine—there was no connection. But suddenly, she was going to be really gone.

I knew this was going to come at some point, but I didn't anticipate that it would happen today, on this bright February afternoon. I looked at the beautiful, sun-soaked pool scene, feeling blessed to have my husband and my two children, who had already missed knowing my wonderful mother.

Jeff asked, "What about the hospital?" We both felt our father would likely not send her in this circumstance. But we could not reach him. What if we sent her? She would not be resuscitated, and we did not think we wanted to use antibiotics—although I am not sure we (the children and spouses) were unified on this point. We could send her and see if she were in shock from an infection that could be treated quickly, stabilizing her to give us one last chance to come to Chicago to say goodbye. We knew we did not want invasive treatments—no major tests and needles, just comfort—but perhaps we could extend her life a little longer, even if it was for selfish reasons.

As a physician and educator, I have seen the impatience that sometimes develops in medical trainees when families aren't making end-of-life decisions as quickly as the trainees think they should. A patient is near death and has poor quality of life. The resident thinks the family should let the patient go, but the loved ones are not ready to make that decision. A resident may repeat the inquiry regarding code status: if the patient loses his pulse or has a cardiac arrest, should we resuscitate? Tell us, family, what should we do? We sometimes forget that although we have these conversations all the time in and around our hospitals, for the family members, this is a momentous, life-altering event, filled with emotional and spiritual complexity.

Rationally, we had a clear answer—to let her go. We knew this was the choice our father would make, but there seemed too many variables, too much that was unsettled, too many of us away from Chicago and not at her bedside. We were not sure we truly had the authority to make the call to withhold all care at this point. Together, Jeff and I decided to let the facility call the ambulance and have her sent to the hospital for an initial stabilization and assessment. The medical staff were to be given clear directions not to resuscitate her and to call me as soon as possible after the initial assessment. We both realized that she might receive antibiotics during that process. We would try to get in touch with our father. I hung up the phone and started to explain the situation to my husband.

Several minutes later, my cell phone rang again. Jeff said, "She's gone." By the time the ambulance arrived, she had died. This was not what I had expected from my vacation. Feeling numb, we split up the calls and arrangements we had to make, and Jeff took on the challenge of reaching my father.

After the funeral, I had a few quiet moments with my father, and I asked him if we made the right decision to send her to the hospital. Although I knew that she likely would have died that day regardless of what we'd done, and thus that the decision my brother and I had made did not matter in the grand scheme of things, I was still concerned. Did we appropriately honor her wishes? What if our decision had unintentionally led to an uncomfortable and uncertain hospital course? My father hugged me, and with tears in his eyes that were answered by the tears in my own, he reassured me that Jeff and I had acted out of love and had done what we thought was best at the time.

Even when a patient's status is clear and the family's consensus unified, the moment of decision can be clouded with doubt and uncertainty. I try to find peace in the notion that my mother's suffering at the end was brief. I try to encourage my patients to discuss their wishes with their families, but I will always keep closely in my mind that there is only so much advance deliberation you can engage in, and that nothing can quite prepare you for the actual decisions when the time comes.