

# THE NURSES WHISPERED

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*Patricia A. Nugent*

*Our parents' deaths can confront us with some of the most difficult decisions we'll ever make. Here, a daughter pays tribute to the nurses who steadfastly offered their compassion, guidance, and support during the final eighteen months of her parents' lives.*

It was the doctor who told us, in a neutral and matter-of-fact tone, that it was time to refer my father to hospice. It was he who sat down with us in the cold, sterile hospital environment to lay it on the line, to tell us there was no hope. "We'll do what we have to do," my mother replied stoically, looking simultaneously sad and radiant. Just a few weeks before, they had gone for a walk, and he had fallen and broken his hip. Anesthesia and hip replacement surgery had left him weakened and unable to swallow correctly.

The doctors tried to convince my mother to allow a feeding tube. She called me from the Florida hospital. "They want to put a feeding tube in your father. I said no, but they say they must." She was more unglued than I'd ever heard her and desperately looking for direction from me—a rare occurrence. "Your father won't tolerate a feeding tube," she continued. "He'll tear it out. He'd rather die than live like that. I can't let them do this to him. They keep sending different doctors in to try to convince me. But one nurse whispered to me that I was right, that she wouldn't do it either. And I won't."

The nurse who'd had the courage to whisper in my mother's ear that day, when both my sister and I were living out of state, made all the difference.

Thanks to her informal counsel, my mother stuck to her guns and insisted that my father not receive a feeding tube. Instead, he received speech therapy to improve his swallowing; he eventually graduated out of hospice, living another eighteen months. He would live long enough to witness the passing of his best healthcare advocate, his wife.

A few months after that phone conversation with my mother, it was a doctor who told us, in bold declarative statements, that my mother had brain cancer. "I have the biopsy results. I'll meet you in the conference room to discuss them," the neurosurgeon said. I hung up the phone in the nurses' station, numb but fully aware of the implication. A face-to-face meeting with a busy neurosurgeon signaled a negative outcome. I could see the conference room from where I stood but didn't know if my legs could carry me there. The nurses hugged me, whispering in my ear that it would be OK. The doctor arrived and took a seat; I remained standing. "Not only is it malignant," he said, "but it is also aggressive. Radiation will help." I barely heard him. I realized that I was alone in the room only when a nurse came to get me sometime later. She stayed while I sobbed over the news I'd been given, offering words of encouragement and hope.

My mother endured the radiation, though she said it was squeezing all her brains out, and she endured what she called the "seismic pounding" of repeated MRIs. She withstood these procedures because the doctor said they would help. Her paralysis grew worse by the day, and the nurses struggled to turn and move her, exerting much physical energy to keep her comfortable. The nurses also worked to keep her spirits high during this time.

"It's a lousy diagnosis with a lousy prognosis," another doctor said after the thirty-two radiation treatments were completed. "No more interventions are called for." It was the nurses who whispered, "We will do everything we can to make her comfortable." And they did. Yet, due to staffing shortages, I frequently ended up waiting and watching in the hallway as the overworked nurses passed me by. I would try to get their attention, but I also realized that I couldn't be too bold or demanding; there were many family members

standing in the hallway, and we were all dependent on those nurses who cared for our loved ones. Doctors making their rounds walked by, but few of us had the courage to stop them. But the nurses kept a steady pace, often working extended shifts with large and severe caseloads. They looked exhausted but did everything they could to accommodate requests. So many requests.

They toileted, washed, dressed, fed, kissed, and loved my mother. Most important, they accepted the person she had become as a result of her illness—it was the kindest of gestures. They didn't reflect back to her any pain, disappointment, or frustration with her decline like her family did, those who knew how capable she had once been. Instead, they emanated total acceptance and support. They modeled a mindset, teaching me both to accept my mother as she was and to cease wishing for the return of my "real" mom.

My mother clung tightly to the hospice nurse's hand during their first visit to her nursing home room. She was a very private person, and I had never dreamed she'd be willing to confide in a stranger. Yet she told the nurse of the traumatic radiation treatments, describing them in detail. And I heard her whisper, when she thought I was out of earshot, "I need more support. I need more *outside* support. Do you know what I mean?" I heard the nurse whisper that she would be there for my mother, that she would be the support my mother needed. Despite my daily presence at her bedside, she needed more comfort than I could provide. She needed to speak openly about her fears and feelings without the worry of upsetting her family. Try as I might, I was not enough. That hospice nurse would serve as my mother's true confidante for the rest of her life.

When you spend so much time in elder care facilities, you get to know the other residents and patients; they become part of your extended family, and I had the privilege to observe the nurses' relationships with them. One day, two nurses went to see my mother's ninety-year-old roommate together, knowing that reinforcement would be needed. True to form, she was ready for them. They gently tried to talk her into a tuberculosis test, a hearing

aid, a flu shot—she declined them all, with attitude. Then they asked more significant questions. “You haven’t been eating very much, Peggy. Are you depressed? Have you given up?”

“My dear nurses, it is simply that I am already too old,” Peggy responded. “May I take a nap now?” They whispered soothing words of understanding and respectfully left. I could tell that while they’d done what they’d had to do, they had also supported Peggy’s decision to decline intervention.

Despite my mother’s terminal condition, she was scheduled for another MRI, a procedure she had grown to strongly dislike. I wasn’t sure whether to proceed or not. What if additional information could be gleaned that might suggest a different course of treatment? What if a miracle had occurred? I was stymied, unable to say “yes” or “no.” A nurse came and sat with me. So neither my mother nor the doctors would hear, she whispered that she didn’t support the scan, which would require my mother to be transported by ambulance to the radiation center; it would put her through unnecessary trauma while changing nothing. I felt at peace and told my mother that she wouldn’t be subjected to any more tests or treatment. She, too, felt at peace. The nurse had made an agonizing decision easier.

When her time came, there were no monitors or beeping gadgets to tell us that her life was leaving—just real people who took her pulse, listened to her heart, looked at her. Real people who assessed the best interests of a real person who was dying. The nurses whispered to me the indicators that death was near; when they examined her, they told me what they were looking for. I didn’t know whether to hope for the presence or absence of these indicators. I passively watched the nurses, scared to hear their reports. The oxygen machine hummed loudly in the room, reminding us that her condition was worsening. But I didn’t need a machine to tell me she was leaving. The nurses closely monitored us both. They were the first ones on the scene when I awoke on the cot next to my mother’s bed that morning and realized she was gone. They were the first to offer condolences.

My parents had been placed in different facilities based on room availability and their specific medical needs. While my mother was alive, I spent my days with her and then rushed off to visit my father by night. His little room was a stop on the way home. Too often, he was already sleeping when I snuck in through the employee entrance; the nurses had whispered to me this secret way of getting in after visiting hours. They knew it was better for my father to get a good-night kiss from a loved one than to toss and turn in a fist-clenched sleep. The night was a little less dark thanks to the nurses who looked the other way, permitting me to crawl into bed and comfort the lonely man. They never asked me to leave—they even slipped me cookies.

Yet the stress of caregiving for two parents was sometimes too much. One day, my father and I were in his room, screaming at each other. *Screaming.* He wanted to get out of there, to go home. He asked why his wife never came to see him; he asked if there was “someone else.” I was at my wit’s end, torn between two desperate parents whose lives had come unraveled so suddenly. “Mom has a brain tumor, Dad!” I screamed back at him. “A brain tumor! She’s dying, OK? Can’t you think about someone else for a change?” I instantly regretted having told him in that way; it had just slipped out. For months I had tried to shield him from the grim reality of his wife’s impending death. My deception weighed heavily on me, but my disclosure didn’t seem to have any impact on him now.

The head nurse suddenly appeared and began to calm us down, gently whispering words of comfort to my father. She suggested that I leave, saying she’d take care of him. I quickly gathered my stuff and ran down the hall, crying. I heard him yelling after me with his booming voice, “Get me out of here! Patty? Get me out of here!” Between his outbursts, I could hear the nurse as she continued to whisper gentle, calming words. “Why can’t I relate to him like that?” I thought. “She’s better with my own father than I am!” The nurses clearly provided more than just medical procedures.

A few days later, a woman with jet-black hair walked into the little room where I was sitting with my dad. She told us to watch out for athlete’s foot in the

shower and not to leave valuables lying around. She was animated and spoke with great authority, so I assumed she was a new employee. We told her we'd be careful; she reminded us once more before leaving. And then again. I followed her out and was told by an aide that her name was Mary, that she was once a nurse on that floor, and that she was now a patient. Many times afterward, I sat and chatted with Mary about the work she'd done several decades ago—something she could remember much better than more recent events. "It was hard work," she said. "My back hurt. But I enjoyed helping people who needed me." She struggled to accept that she was now the one in need.

Erin was a young, red-haired nurse with a personality that wonderfully counterbalanced my father's grumpiness. She brightened the dark nights by always greeting me with a smile, no matter how exhausted she was from her demanding work. She told me I was a good daughter, something I desperately needed to hear. "In fact," she said, "you're one of the best." Erin cheered up my dad when he was hurting and validated my concerns about his medication when the doctor was dismissive or unreachable. She took the time to look in my dad's chart to answer my questions. She made us feel as if we were in good hands, regardless of how busy she was. She helped to keep my dad alive through tough times and consoled me when it was time for him to take his leave.

One morning, ten months after being told that his wife of sixty-three years was dead, my father refused food and drink, ripped off his oxygen mask, and spit out the antibiotic they tried to give him. He belligerently told the nurses, "No more" and "Get away" and "That's enough." I told him he would get better if he took the pills. "I don't care," he responded.

"Do you want to go to the hospital?" I asked repeatedly. He declined emphatically every time. My father's nurse told me that the doctor was refusing to prescribe any more morphine and might have to send my father to the hospital for antibiotics to treat pneumonia and, possibly, for tube feeding, as he was again having difficulty swallowing. I panicked, remembering my mother's phone call from the Florida hospital eighteen months earlier. I could not allow him to have a feeding tube now. The nurses whispered to me that

rather than attempting heroic interventions, it would be more peaceful for him to die in his own room with those who had cared for him for more than a year. They gave me the strength and courage to advocate that this ninety-year-old man with dementia not be whisked off to a strange environment. Although I lost that battle, the nurses were by my side all the while, whispering words of encouragement as I challenged the doctors and the medical establishment. I'll never forget their sad faces as they watched my father being put into an ambulance; he weakly waved to them. He died three days later.

Nurses were there every step of the way during my parents' eighteen-month journey from life to death. They were there for both my parents and for me. They had different styles, different faces, different specialties, but one trait was the same: they provided quiet, behind-the-scenes support and guidance to a family in trouble. They were assertive when the situation demanded it. When we didn't know what to do or where to turn, they were brave enough to give us counsel based on humanistic concern and personal experience. Counsel drawn not exclusively from volumes of medical journals and training but from their intimate experiences with families. They were not afraid of personal or professional liability when offering an opinion, but they whispered to avoid offending those with whom they disagreed. (It is well-known that many doctors do not like to be challenged.) During these desperate times in our lives, their whisperings seemed like the messages of angels. Such whisperings gave us the grace to keep going and the knowledge we needed to make informed decisions under duress. I will forever hold their service in gratitude, and I write this in their honor.

**Patricia A. Nugent** is the author of *They Live On: Saying Goodbye to Mom and Dad*, a compilation of vignettes portraying the stages of caring for and saying good-bye to a loved one. She has been published in national professional journals and has received awards for her creative nonfiction essays, including one bestowed by Susan Sontag. She has served as a teacher, administrator, adjunct professor, and consultant.