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Not “Just the Daughter”

Amy Getter, RN, MS

A whiff of lavender can still transport me to the bedside of my dying mother. In the early morning hours, Mom began breathing in shallow gasps, with periods of apnea. Several hours had passed since she had responded to any of us, and her physical form seemed to slip into another realm. My sisters and I had lovingly cleansed our mother with a ceremonial washing, the scents of lavender soothing and preparing her for the journey ahead. Before the early light of dawn, we gathered together and carefully washed the wasted body of the woman who had birthed us and loved us throughout our lives. Amid the cleansing tears and the soft singing, there were prayers for a quickened flight and the final transformation.

I had been preparing my siblings for the past few days as I observed mom's detachment and the otherworldly look on her face. Her disease process had advanced to the point that very small sips of fluids were minimally tolerated, and most of the body-system failure signs were occurring. She was unafraid, peaceful, relishing the moments with her 6 children in attendance. An earlier evening that same week, she had looked across the living room from her hospital bed, laughing at all the frolicking grandchildren, her children, and their spouses, and said to my daughter, “This is heaven on earth.” The love in her little duplex permeated the sadness in her children's hearts. We were losing our mother a little piece each day, but we were also making a party from the opportunity to be together.

I often think back to the day the surgeon met us in Mom's hospital room to say there was no additional surgery or interventional treatment possible,

that Mom's prognosis was terminal, and she had stated simply, “Then it's curtains for me, Doctor.” Her lightheartedness and gentle humor sustained us, as Mom's family accepted her final desire to forgo palliative chemotherapy or radiation.

I am a hospice nurse. I was also the out-of-town daughter. Mom had lived alone since Dad died many years before, and she would require assistance with her wound and colostomy as well as daily care. As I sat with her in the hospital, a day before her planned discharge, I listened to Mom express her 1 wish: “I just want to go home” rather than a rehabilitation center. (One of my sisters had already made the selection and arrangements).

Advocacy became my directive.

That Sunday morning, I cornered Mom's doctor, who happened to be the local hospice medical director, and said, “I want to change the discharge plan and send Mom home with hospice.” She smiled and said, “It's always the out of town relative.” But she agreed with my suggestion. I was certain with 6 children in the family we should be able to do what I had seen many families with far less resources provide for their loved ones who were terminally ill. I announced to my siblings that we were granting Mom her wish. We wrote out a calendar, each of the children taking turns being the round-the-clock caregiver.

I was not present during the hospice admission, but I met each of them as they came and went, helping Mom and her children. I was certain that I irritated Mom's case manager by requesting a number of changes in medications. I was the interfering daughter who called on more than 1 occasion when I heard via phone report of symptoms that needed nursing intervention and my family members were unclear what should be done. So many families don't want to “bother the nurse after hours,” and my family (especially Mom) was one of those who would wait until the morning, having unnecessarily suffered throughout the night.

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I had been encouraged at one visit to "just be the daughter."

I checked in with my mom each day by phone when I wasn't there. Every other weekend I made the nearly 7-hour trip down for my 3-day care-giving schedule (working for a hospice, I had phenomenal support to do whatever I needed to be available for my mom's care). Every one of Mom's children stepped up to the plate, the squeamish and ill-prepared along with the more capable caregivers. This was one of the gifts Mom gave to each of her children, allowing enough time for us to give back some of the love and care we had received from her through the years. When a task needed doing that she felt was humiliating or difficult and she would say, "Oh honey, I hate that you have to do that!" we would often remind her that now it was *our* turn to do for her.

After 7 months and thousands of miles driving to and from Mom's humble home, I realized on this final trip that I would stay the duration. Having cared for so many at the end of their lives, the physical changes were apparent to me. I was struck as I walked through the door by that transparent face with the beautiful smile. Mom was so happy I was there. She would always remark how wonderful it was to have her "personal nurse." As the days blended together, and the final hours were spent alternating medications in her subcutaneous site with drops in her mouth to decrease secretions and pain, I was on auto pilot in a strange way. As I managed the symptoms of my mother's dying, I blended the nursing skills, which were second nature to me, with the loving hands of a daughter. The nurse and daughter merged into the one who was able to

recognize the physical and emotional needs and know how to provide the care.

I have, since that time, corrected other hospice staff I work with whom I have heard say of a family member "she should just be the daughter."

What an amazing privilege to use my acquired skills for my mother's dying process.

My family would not have called after hours when Mom's symptoms were out of control since Mom always minimized, and they didn't know many things could be readily treated. My sisters perhaps would not have known the relief of soothing scents of lavender as we sang and cried over our mother, except what I had learned from the bedsides of others: that we needed to comfort ourselves as well as our mother. My life would not have been as immeasurably complete had I not been able to come full circle, delivering Mom into the next world just as she had brought me into this one.

After the battle was won, and Mom's spirit soared to worlds unknown, Mom's hospice nurse arrived. I was at the bedside, where I had been for the past 5 days continuously, starting to remove a Fentanyl patch. One of my older sisters, repeating what had been said to her by a well-meaning hospice person, said, "Let the nurse do that, Amy, and just be the daughter."

In that instant I lashed out, surprised by my vehemence, "I *am* the daughter, and I *am* a nurse." I knew then, as I know now, how privileged I was to have both the loving desire *and* the knowledge to care for my mother.

Never have I been more sure of a wonderful truth: I was not "just the daughter."