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The Voice of the Patient

By

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My mother's end of life was 15 years long. It began the day my father died and she became involuntarily dependent upon her children to perform all the roles that he had played in her life during their 61-year marriage.

My father's death was unexpected. He had survived a quadruple bypass at 80 and five years later was still riding his bicycle and fishing with his grandson. Suddenly he became sick, was hospitalized, sent home bedridden and confused a few days later, with his inexperienced and anxious family to care for him.

His doctor encouraged us to hope for a recovery, saying he had other patients who had survived such conditions.

A few weeks later my sister Dolores, who is 15 years older than I, was standing with me outside the swinging doors to the ER. She leaned into the doctor and firmly said, "We don't want any extraordinary measures." He nodded and slipped away from us.

I spent what would be my father's last night alive in a small double room, alone, sitting on a hard chair leaning against the cold windowsill. Someone gave me a pillow; another offered directions to the vending machines.

I left at 7 AM, with all the things I could have said to him still inside me. He died an hour later and my grief was so painful that it infiltrated my life and manifest in unhealthy behaviors that took years to recover from.

Though terribly lonely, my mother adapted to the freedom of widowhood and managed well for seven years. There were regular doctor's office visits and a cataract surgery but she was in good health, taking only one prescription drug for high blood pressure.

Over time, maintaining the 3-bedroom house she had treated like a lover for 54 years became too much to manage and she suffered a psychological meltdown that put us on the institutional glide. Just as I retired from my business career.

She spent three months on a geriatric psych ward where discussions of her care revolved around medication adjustments and what test would be given next. I had to call a family meeting with key staff to force a plan, at which the MD recommended she move to an independent living facility he served nearby and it needed to happen soon because her Medicare allotment was coming to an end.

No one talked to us about the future as we stood at this frightening crossroads. We were running on low and no one held up a lantern to guide our way. Mother was 86.

My sister and I slowly and painfully emptied the house I grew up in and sold it while my brother, retired in Florida, played golf. We all tried to settle into life in an institution. I used to tell her it was like living on a cruise ship because she had all her needs met by cheery young people whose only goal was to make her happy—and to make sure that she took the increasing number of pills required every day.

She adapted to life on the SS Kenwood. I visited often, my sister less so. For two years Mom was entertained and happy in her little studio apartment, handling her walker with ease and making some friends. It was a shock to all of us, when, on her 88<sup>th</sup> birthday, she stopped walking. It was as though her warranty ran out.

My sister and I left her after having cake and ice cream, and she was fine. A few hours later I was in the ER—I lived closest—and Mom was being bounced around having tests while I waited. She was terrified. No one talked to her; no one talked to me.

She was sent back to the Kenwood, wearing a diaper for the first time in her life. I lay on the sofa all night tearfully watching my mother become an old woman before my eyes while she slept, or pretended to, a few feet away across the room.

She did not adjust to this change and there was another ER ride a few days later and another hospitalization. Tests revealed stenosis in her back. She would never walk again.

The sweet young girl in charge of the resident's comfort called me into her office the next day to say, "We suggest that Mom moves to a nursing home now."

Where were the guideposts?

We found a good home where a cousin worked as the part time social worker. My sister signed a DNR, which angered me because I felt we were withholding something good from mother, life-saving CPR. The bigger sister won out.

I've since learned that some places are using AND, Allow Natural Death, which I would have signed in a heartbeat. I also understand that when patients are shown videos of CPR, and other aggressive low-success, high-burden forms of treatment, they opt not to take them. No one talked to us about the future.

Consigned to a nursing home, Mom didn't speak to me for three months and she boycotted the Christmas party. But she adapted. She eventually made friends and came to truly love some of her caregivers, and some truly loved her. Years later she would say she was treated like a queen.

Five years into this artificial bliss, a fall sent her back to the hospital where she stayed a couple of days and returned bruised and mad but basically fine. What a wonderful opportunity to have a conversation with us about her future. No one talked to us.

The day she returned from the hospital, I asked, “What can I do for you?” She said, “Just be with me.” I took off my shoes and got in bed with her, which is where I spent part of every visit I made after that, five days a week most weeks. After all, I was retired.

Given her new level of frailty, I suggested to her MD, who was also the Medical Director of the home that she have a hospice consult. He bridled and snapped, “Why? She doesn’t have something like cancer.” I replaced him, and she got better.

My mother was not only fully competent she was often profound. One day I asked if she ever thought of the future. She replied, “I’m living my future.” She was wrong. There was more ahead and we were totally unprepared for it.



Life there went on and I began to notice how many residents went to the hospital and never came back. Sometimes there would be a notice of a funeral service, but mostly they were listed in an In Memoriam paragraph in the irregularly published newsletter and named during the memorial section of the monthly mass. They disappeared, vanished. If they had loved ones who visited, which only half of the nursing home residents do, they also disappeared leaving.

Mom grew more frail and dependent, and also more peaceful, and happier. Then the ride began again, this time with an intensification of rescue.

One morning she was found unresponsive and taken to the ER and after six hours of waiting and testing, she was admitted to the hospital. We were in a relay race where the nursing home handed my precious mother off to the hospital and they handed her back to the nursing home. I was on the sidelines watching, and no one was talking to us about the future.

When I returned to her hospital room the next day, I got in bed with her, just as I had been doing for months. She was in a quiet state, not unconscious, and I held her gently. Within moments a staff person was standing at the door, her hands on her hips, saying with authority, "You can't be in that bed. We rent the bed to our patients. You have to get out of it."

I was certainly too tired and too sad to argue, but I really think I felt guilty about being where I shouldn't be, so I did get out.

After she left and then I found myself wondering what on earth happened to this employee that made her believe kicking me out of the embrace I was in with my 92-year-old mother, who looked like death, was doing the right thing? I felt compassion for her. And I felt very lonely.

Three days later, still unresponsive and not eating, I was asked to step into the hall by the pleasant PA who had been seeing mom. He said gently, "Your mother is not eating. She needs a feeding tube or she'll starve to death." I couldn't breathe for a minute. It was as if someone was holding a gun in front of me. "*Starve to death,*" echoed in my head.

Through all the emotions banging like drums in my head, I recalled the time not long before when I sat in bed next to my mother and asked her nervously, "Mom, what if something happens to you and you can't tell us what to do. What do you want us to do for you?"

Without taking a second to think she replied, "You girls will know what to do." And I knew she did not want that tube. He never offered an option, so I put it on the table: call hospice.

Within an hour a hospice nurse was in the room with us explaining their services and giving me a binder full of information, including this little *Gone From My Sight* booklet that for many hospice families is read until it falls apart. Finally, someone was talking to me.

Mother thrived in hospice and was discharged three months later, more frail yet more peaceful.

A few months after her 93<sup>rd</sup> birthday she was once again handed off to the hospital, diagnosed as not eating and I was once again, given one option: "She needs a feeding tube or she'll starve to death." Once again, I said, "No, we're taking her home."

I had gone to my house to sleep and had not called the hospice, hoping she would revive like the last time, waking up and asking, “Where’s my lunch?” Instead I got a call from the Director of Nursing. “Your mother isn’t eating. She either needs a feeding tube or she has to be on hospice. What do you want to do?” she demanded.

My hand shook. I knew the nursing home regulations put pressure on them for weight loss, the most natural preparation for death, but why did this choice feel like an ultimatum?

“Call hospice,” I whispered wearily. “Call the hospice.” Mother revived once again and graduated again--without ever having a feeding tube.

In March, with everything being reborn outside, she told me she was taking a trip on a cloud. She described, with child-like delight, that she would go to NY then travel back to Chicago, but Chicago’s too cold and California, where she’d never been, was her to be final destination. She was happy. I knew this was a sign.

I began to prepare myself so when she actually had a stroke ten days later, it was easy for me to tell the emergency room physician that we would take her home and call hospice.

For eight days we kept vigil. The only goal of care was comfort, hers as well as the loved ones who came to sit at her bedside. She was moved to a spacious, comfortable private room in the nursing home that I named for the stage of transformation where the caterpillar becomes the butterfly: the Chrysalis Room.



Her resident friends moved in and out of the quiet, softly lit sacred space, to keep me company, while mother, a woman we all loved, lay dying in the center of the room. It felt safe there, like home. I could spend the night in comfort, draw a chair up close to her bed and stroke her skin, or crawl in and hold her one more time.

Miracles happened in those eight days. Family, friends and staff got to say, “I love you,” “Thank you,” and Goodbye.” I got to touch my mother and memorize the feel of her skin

and the smell of her hair. I got to know myself better in those days living with death in the room. Everyone who came through gained something that will serve him or her the rest of their lives.

Joe turns 90 next months and has already asked to be in the Chrysalis Room at the end. Two of the others died not long after mother, also in this sacred space.

Mother died with the sun coming up and me at her side. Her hospice aid came and bathed her like the queen she was to me, and I helped dress her body. We held a little wake where visitors were offered rose petals to put on mother's bed as a final gift of friendship, and we grieved our loss together.



I hold this vision as a model for my own death. Just as I hold hope that by the time I die, which I will, the institutions and the professionals who care for me will share the same vision.

Post script:

I've given a great deal of thought to the obstacles that prevented the people who were helping us from talking about mother's death with us and I have decided it is because they are not comfortable talking about their own deaths with their loved ones. Lead by example and have "the conversation" this holiday season. It might just change the rest of your life.