Living and Letting Go in the ICU

Category: Stories
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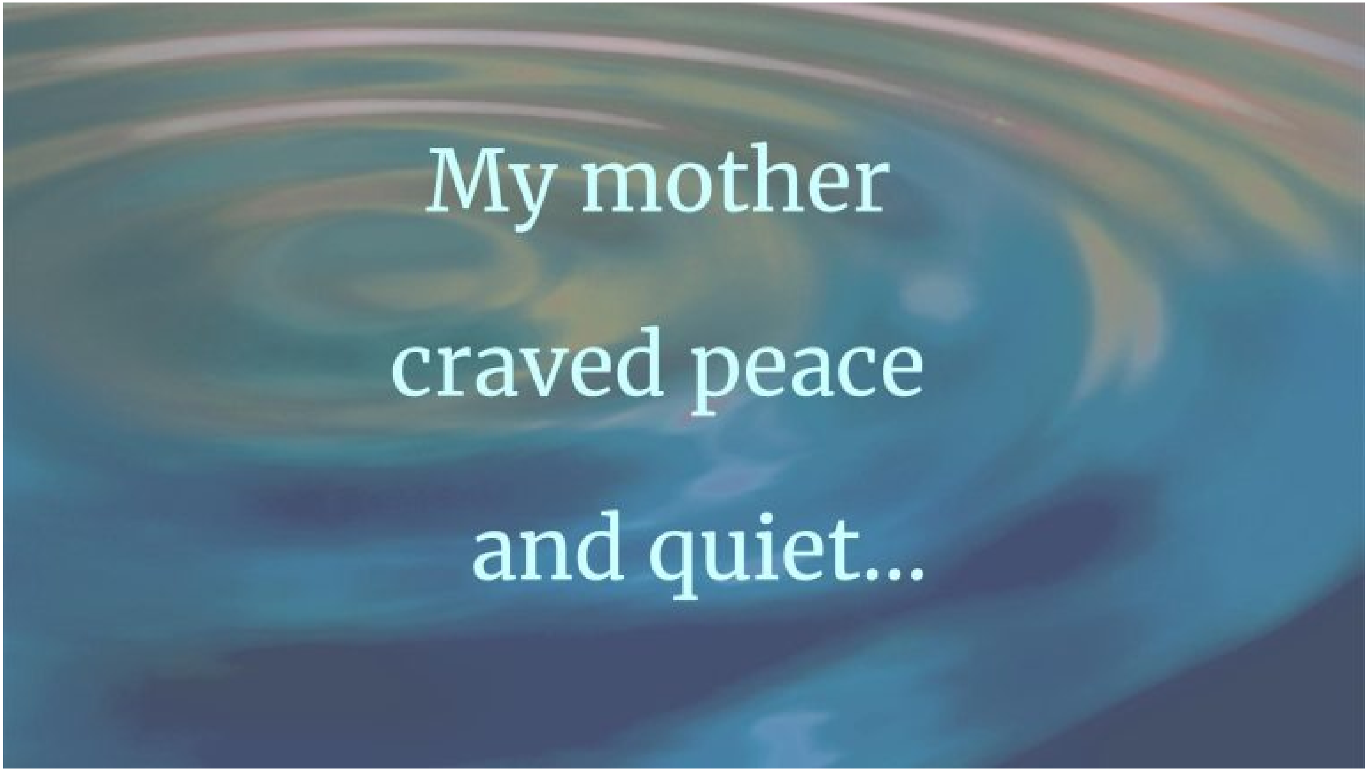

Driving from the Atlanta airport, I arrived at the hospital ICU where my mother had been admitted the day before for trouble breathing. This was the hospital where my siblings and I were born and where our father died. This was the hospital featured in *The New York Times* following the coronavirus outbreak in March 2020. The hospital still sees record numbers of COVID admissions, and I expected the staff to show signs of exhaustion and numbness to personal tragedy.

My brother was at our mother’s bedside, as he had been from the beginning. The critical-care attending physician was also present.

“Does the hospital have a palliative-care unit?” I asked.

“No,” the attending replied. “We’re prepared to navigate that process with you here in this room.”

As kind as the response was, I wished for more—or less. Less monitoring, less intrusion, less intensive medicine. More peace and quiet. My mother craved peace and quiet.

I had learned a lot since my father’s death. Back then, I’d been too naive to hear the meaning behind the doctor’s words “It doesn’t look good.” I couldn’t envision my father dying; I could only see him living.

Although his death did not directly influence my career path, it does inform my work as an associate professor of clinical bioethics at an Upstate New

York academic medical center and medical school, where some of my closest colleagues are palliative-care providers. In the department of health humanities and bioethics, we teach medical students and residents how to listen to patients and families, think critically, self-reflect and imagine other perspectives using the humanities and arts. We teach them how to sit with suffering and respect differing values. How to attend to the nuances of verbal and nonverbal communication. How to meet patients and family members wherever they are.

As my brother and I stood at our mom’s bedside, the travel nurses kept asking if we’d considered transferring her to the local hospice facility. They were reading my mind: How could they know how much I wished Mom to have a peaceful environment in her last days, and a good death?

My brother, on the other hand, hoped that our mother would continue to have a good life.

She had recently moved in with his family. He and his loving wife spent months cooking and caring for Mom while she played gin rummy with their kids and dispensed wisdom and advice, welcome or not. I have a phone full of photos of them smiling and raising wineglasses over meals that make my mouth water. They had plans to build a small backyard cottage for Mom as a way of meeting her increasing needs while also respecting her strong opinions and fierce desire for independence.

My brother couldn’t envision our mom dying; he could only see her living. Part of me was painfully jealous of his perspective.

My mother had full decisional capacity. She’d already told the medical team that she refused intubation and chest compressions. Several months earlier, she’d told me that she didn’t see the point of intubation; her statement hit me like a ton of bricks. It was hard to hear her refusing a potentially life-prolonging treatment—one that I imagined as temporary. I did not challenge her, which was unusual for me.

Lung disease is often invisible to others. For many years, Mom managed her illness with sophistication and grace. She took extraordinarily good care of herself, rarely looked sick and frequently had to remind others of her physical limitations. She instructed her doctors and advance-practice providers how to treat her.

Towards the end, she made choices about how much home therapy she would tolerate. Quality of life mattered to her, and although air hunger was her biggest fear, she was unwilling to use her home BiPAP machine, a device that helps with breathing, as often as was recommended.

Four days into her ICU stay, with her breathing ability deteriorating, my mother still retained full mental capacity. My brother and I took turns staying at her bedside. I read out loud to her from *The Sound of a Wild Snail Eating,* a book she’d recently discovered and loved. I suspect that the story about a bedridden patient who found solace made Mom feel less alone, and even lucky. I’ll never forget the joy in her face as I fed her ice cream from the hospital cafeteria.

I awoke one night to movement—her arms waving in the air, as though she were dancing. The light from her monitors cast an eerie glow, pulsing, it seemed, in time with the sounds of the ICU. It was surreal.

My first thought was that she must be hallucinating.

“Mom, what are you doing?” I asked anxiously.

“Remembering,” she replied. I watched in awe as she looked inward and said, “That was fun,” over and over, then concluded: “Buddy was a hoot.” My dad.

Later that night she seemed restless. Worried about her comfort, I asked if she wanted medications. She was slow to respond, and I eventually asked, “Do you want me to decide for you?”

She turned her head, looked me straight in the eye and said clearly, “No, I do not.”

The next morning, she awoke confused. After orienting her to her surroundings, the nurses and I asked if she needed anything.

“A new brain,” she scoffed.

This is where I most wish for a talented songwriter: This story deserves a love song. In a just world, my mother could have been or done anything she wanted. Her exquisite observational skills, keen financial acumen, shrewd critical thinking and entrepreneurial spirit could have propelled her to the top of any organization. Instead, she gave her family everything. I imagine that it was hard to parent me—a daughter she perceived of as being in a constant fight with the world. A Dolly Parton song might gracefully capture the relationships that developed over time and distance, climaxed in an ICU and continue today. A song celebrating complex love, grief and gratitude.

At the end, there was nothing to fight. All I could do was give her what she had really always given me: unconditional love and support.

Her last words to me were, “Thank you, thank you, thank you, thank you, thank you.”

Critical-care providers and nurses, and the intensive-care setting, enabled this—everyday critical care delivered in the midst of a pandemic. Where I had expected to find exhaustion and numbness, I witnessed remarkable care delivered with kindness.

We ultimately transferred Mom to the hospice facility, where she died less than eighteen hours later.

As grateful as I feel for the peace and quiet and care she received there, the gifts from her ICU stay are the ones I hold most dear.

To the critical-care providers and nurses who compassionately treat all patients, whether they are likely to live or likely to die:

Thank you, thank you, thank you, thank you, thank you.