

A PIECE OF MY MIND

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Don't Fear the Reaper

I knew my grandma Eleanor couldn't have many years left. She was 96, and though her mind was unrelenting, she was increasingly physically frail. The last several years, I tried hard to savor every time I saw her or spoke with her on the phone. Do you know that feeling, when you know every conversation might be your last? Do you hold on to voicemails, just so you have a recording in case they die?

As the only doctor on her side of the family, I was my grandma's default resource and advocate. But I also learned more about medicine from my grandma than from any rotation in medical school.

Eleanor was always my fiercest, strongest role model, a force of nature and endlessly opinionated. A former biology teacher and principal in New York City public schools for decades, she was on the committee to write the sex education curriculum for the school system in the 1960s. She appeared on public television, performing science experiments to teach creativity in the classroom. Later, she taught an adult education class at the 92nd Street Y in New York, entitled "Controversial Conversations," on topics ranging from abortion to transgender issues until macular degeneration forced her to stop. If you knocked on her door, she would answer, "Friend or foe?" Yet she would open no

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matter what your answer, because, she explained, a foe might make for interesting conversation.

She spoke frankly about the world and had no illusions—about justice and fairness, about sex, about religion, about life and death. She told me that it was ridiculous to say the elderly were living their "golden years."

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Grandma started my medical lessons around the time I was in college and first considering medical school. She had just received a kidney transplant at 78 years old, the oldest recipient ever at the time for Jackson Memorial Hospital in Miami. To earn that kidney, she had spoken in defiance of the odds at her age, taunting the transplant surgeon by asking, "What would you say to your mother?" It surprised me how she felt the need to say that to get the right care. She fought for that kidney, and I remember that every time I see my patients struggling to get doctors to take them seriously.

To honor her as the oldest kidney recipient, the hospital gave her a plaque. She hid it in a drawer, saying she didn't want to be known for being the oldest anything. Every year on her transplant anniversary, she wore leather pants to honor the young motorcycle crash victim whose death gave her that chance.

Starting medical school, I was startled when Grandma first bluntly shared her end-of-life plans. "Jules, I don't want any life support. I've lived a good life. When it's my time, let me go." As a young doctor, no matter how hard you try, how can you really understand a person being so comfortable with her life ending? Furthermore, Grandma's forthright wishes made me realize how some patients might worry less about death itself and more about their death's impact on others. Several years ago, when my wife and I traveled out of the country for 3 months, Grandma gave instructions to my mom that if she died, I was not to be told until after the trip, because she didn't want her death to ruin any vacation. Other times, she said to "keep me on ice" and finish out any trip first.

Over the years, as a dermatologist, I ended up being an especially helpful advocate for Grandma, as she had several skin cancers related to her immunosuppression. In her last year of life, we considered options for treating a large and growing squamous cell carcinoma on her leg with lymphedema. The cancer had failed nonsurgical treatments such as intraliesional methotrexate and fluorouracil. The logical reasoning was that if we expected her to die in the next year, a surgery would not be worth the trouble.

The cancer was lower risk, and a surgery was sure to cause a large and painful wound that would take many months to heal in the most optimistic circumstances. But we didn't know how long she had, and her mind was as strong as ever, so it was not an easy decision. I tried to make sure she understood what a surgery's risks would entail. "Whatever you think is best," she would say. She taught me that even the most intelligent and informed patients still depend on trusting their doctors. As much as I valued patient autonomy and wished to avoid paternalism, in the end, I had to make some decisions for her.

I see many older patients with cancers and premalignant lesions. Grandma taught me the importance of not thinking about diseases in terms of cured vs not cured but rather to individualize and ask if a treatment adds value to a patient's life. If a lesion has a tiny chance of turning into a cancer and an even less likely chance of being life-threatening, opting out of treatment is more than a rational choice.

You might forgive me for thinking that I was prepared for her death, given how much we had talked

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Section Editor: Preeti Malani, MD, MSJ, Associate Editor.

about it. We had done all the right things, signed the DNR form, and knew that she didn't want interventions and wanted to be at home. Yet we hadn't expected that she would go from the woman who listened to all 8 hours of the Kavanaugh Supreme Court confirmation hearings taking pages of detailed notes, to overnight barely knowing her name. It happened after what seemed a minor fall and subsequent urinary tract infection and pneumonia, but even with antibiotics, this woman who never had cognitive impairment was never fully coherent again. With an unremarkable head CT scan result, the only explanation given was an unsatisfying but truthful analogy provided by the on-call physician: "Sometimes you're driving fast on the highway, and out of nowhere, suddenly you're stuck in traffic."

As baffling as that was, at the end, my grandma was still teaching me, showing me the limits of medical knowledge. As physicians, we often think we understand everything, but the truth is we have more questions than answers. Still, I think my practice is stronger, the greater my humility and acknowledgment of my limitations. I hope my patients can trust and respect me when I tell them, "I don't know."

As soon as her clinical situation was clear, I flew down and initiated home hospice care that night. It was the Fourth of July. While the hospice nurse assessed Grandma inside the apartment, I stood on the balcony, staring into the distance at a line of fireworks exploding above the canals. The celebratory mood in the air was a sharp contrast to the events unfolding behind me. I invited the nurse to take a break, and she joined me. We stood silently side by side for

several minutes, taking in this beauty of life as a respite from our negotiating the terms of my grandma's death.

Later that night, as I drove back to my hotel in darkness, a classic rock station played "(Don't Fear) The Reaper." In that moment, it resonated with me how, despite all my medical knowledge, all that my grandma taught me, and all that I've seen through medical school, residency, and years of practice, I'm still learning to accept the inevitability of death. On the contrary, Eleanor hadn't seen death as a foe.

In the following days before she finally died, with every new shift, I tried to explain to every new aide, every nurse and doctor who had never met her before, that this was not some frail demented woman. I regaled them with tales to show how this was a bold and opinionated, sassy, and controversial person, whose current state didn't do her justice. Though she did have moments of clarity, I didn't want them to treat her like a lifeless vegetable. When I saw oversights, even as a physician, I was afraid to complain for fear it might negatively impact her care, debating if I was getting hung up on nitpicky details. In truth, I think I was trying to get a foothold, a sense that I was doing something, anything to make it easier and follow her wishes. How many patients and physicians must feel the same way?

I tried my best to be my grandma's advocate, to represent what she would have wanted. Given that she died comfortably, in her home, with her family all visiting in her last days, I can only hope that I did right by her, or at least learned something that can help my own patients.

I think I was afraid I would forget my grandma Eleanor, but through her example and many lessons, I know she remains with me.

Conflict of Interest Disclosures: None reported.

Additional Contributions: I thank my mother and sister for their support of this essay, my mother for granting permission to publish this essay, Jeffrey Millstein, MD, for his feedback (for which he was not compensated), and Eleanor Capson for being my grandma.