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The "Foresty Way": My Mother's Brave Choice of Medical Aid in Dying

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ABSTRACT

I miss my mom, who died last year, and I want to tell the happy story of her death, or perhaps the story of her happy death through her choosing and accomplishing medical aid in dying. My mom was 85 when she died, had atypical presentation of lymphoma which took time to diagnose, and went through 3 painful months of surgery, radiation, and a single horrific round of chemotherapy. She suffered a lot. When she was in the hospital recovering from chemo, I witnessed 3 amazing doctors being true to core values of their profession. But the most profound aspect and gift of the events surrounding her death was the way in which making an informed choice gave my mom back her presence—allowing her both peace and power in the end of her life.

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My feet crunch on the rocky soil as I take the shortcut through a mini forest of about 30 pine trees that makes up the incongruous view outside my office window in high-tech San Francisco. The juxtaposition of pine trees with urban space always reminds me of my mom, who would often drive me to the supermarket in our urban community on a side street, known always between us as "the foresty way." It was a dark, mysterious avenue of mature pines that one could imagine led to some otherworldly realm. When I got to my desk, which looks out over endless construction and these pines, I wanted to call her to tell her about today's foresty way reminder. I miss my mom, who died last year, and I want to tell the happy story of her death, or perhaps the story of her happy death through her choosing and accomplishing physician-assisted dying.

My mom was 85 when she died. She had been extremely healthy, and happily living independently in the mountains a couple of hours away from me. She had atypical presentation of lymphoma which took a while to diagnose. To treat the cancer, she went through 3 painful months of surgery, radiation, and a single horrific round of chemotherapy, and she suffered a lot through it. When she was in the hospital recovering from the chemo, I witnessed 3 amazing doctors being true to core values of their profession. Although I am surrounded by talented physician colleagues at work and I see my husband who is a family practice-trained hospitalist take good care of people, I was nonetheless impressed at their excellent care.

First, a wonderful palliative care doctor with a strong spiritual energy came in and discussed my mom's pain, the wishes she had in her life, and the ways that hospice might help her. She took her time in the visit, a noticeable shift from the hectic pace we had become accustomed to in the previous few months of diagnosis and treatment. What was most remarkable was how deeply connected my mom felt toward her and how this connection also made my mom believe this doctor understood her life—the trajectory of her life. At my mother's prompting, their conversations led to a discussion of the End of Life Act, which became law in 2015 in California and has been in effect since 2016. The End of Life Option

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Act allows an adult diagnosed with a terminal disease, who meets qualifications, to request aid in dying drugs from their attending physician. My mom practically hopped out of her bed when she heard the details and that she qualified; she was so excited. She told me right away after the doctor left, "That's what I'm going to do—physician-assisted dying. I don't want to compete with this disease—that's not what I want to do with the rest of my life." I sat with her and my sadness and then, over the next few days, we set upon the logistics to put her right to choose into motion—the who, how, when, where of finding a local group to provide the medical evaluation, signing of documents, payment, etc. By law she had to wait 15 days from the time she had her first medical assessment, establishing that she had a less than 6-month prognosis and was of sound mind in the decision to choose and then actualize the dying.

One afternoon during this waiting period, we were packing up her things, preparing to leave the hospital and return to her home in the Sierras. Suddenly, her oncologist knocked on the door, whooshed in, and looked her straight in the eye. "This cancer could go into remission, maybe for the rest of your life." He took her hand and said, "It's rare that I get to say this to my patients, but you have a very good chance of being cured." He was clear and direct, but not at all pushy. I could see, however, that she did not return his enthusiasm. They spoke more about treatment options, what she was feeling about the next few months of being in remission, and her next steps. "I'll give it some thought," she demurred but her eyes had no brightness. I was not surprised. I had already felt her shift, from coping to preparing, to focusing within—it was that simple. His good intentions, openness, and clear summarizing of his viewpoint regarding her options were meaningful and deeply appreciated.

Moments later, the doctor from the physician assisted-dying group we had contacted arrived. The 2 doctors literally passed each other in the hall. I marveled at how this third doctor, an emergency physician by training, gave an amazing "non-pitch." He described the details of how the medical aid in dying process works in California—the mandatory waiting period, the 2 required medical authorizers of her status as terminal, how she would have to self-administer the "cocktail," and that many people were reassured to have the medicines prescribed "just in case" but that only a much smaller proportion went through with it, and that was perfectly okay. All of this was easy mannered, clearly phrased—while also being kind and comforting to her. She beamed. "Yes, thank you, and how soon?" Switching to countdown mode was incredibly hard for me, but not awful. I could see she was invigorated in spirit, alternating between peaceful energy and her familiar

attentive, detailed "conquering" of lists, of things to do before she was gone. I wanted her to have her own forestry way at the end of her life, so we were on the same page. Her resolve was reassuring too, as was recalling our past conversations about advanced care planning, which fully aligned with her decision. She needed my support to get through it; her dying was not going to be easy for either of us. So, we watched some cat videos and nature shows, visited with my 3 kids and husband, and we talked about the plants I would bring home from her garden. Three weeks later, she died at her house with her beloved cat, my brother, and myself. It happened very fast—I had not finished reading her the poem we had chosen, *Evening* by Rainer Maria Rilke, before she lost consciousness and slipped away.

There is not much medical literature about how informed decision making might look at the end of life in the context of physician-assisted dying. What I have read seems to draw attention to the things that are to be avoided, like the medicalization of dying or a culture of "prolongivism,"—a perspective that the prolonging of life can create end-of-life meaning. I feel that such an avoidance-oriented view misses an important part of what was so wonderful for my mom—what was gained. In looking at the situation, one might be tempted to focus solely on the palliative care and assisted-dying doctors' behaviors and actions, as they are the "managers" of the experience in the medical-legal context. To me, though, what was vital for my mom's decision to feel right for her, to actually comfort her, was the oncologist's engagement with her, even as much as she valued the other 2 clinicians' wonderful ways of being with her suffering. The clarity the oncologist gave her through his honesty and explanation was essential to her peace of mind in her decision making, and as a result she gained her life back. She was able to "die well," feeling content in her resolve, because she could see that she had the option to live, but it was one she could reject, because she believed her suffering would be too great. Being able to reject her treatment options because they were options, not defaults or platitudes, made it clear to my mom and to me that she was choosing her path based on her desired quality of life, not on her expected health outcomes. Because of that clarity in knowing her choices, she felt free. She could "just" prepare, enjoy her world a bit longer, and feel proud to be so brave. This is what she gained and what I gained too.

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Key words: end of life; informed decision making; physician-assisted dying; medical aid in dying

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