



Perspective

Learning about End-of-Life Care from Grandpa

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Grandpa married my biologic grandmother when I was 4 years old, after the deaths of their first spouses. A quarter-century later, at the age of 85, he officiated at my wedding after

undergoing a nonsectarian ordainment in California. He became the grandfather my wife had never had, and he taught me how to love her. Fittingly, our second daughter was born on his birthday, a mere 93 years behind him.

Two years after my grandmother died, Grandpa, then 95, moved in with a lovely 86-year-old woman he'd met at local political gatherings. They enjoyed 4 splendid years together before she died from cancer while receiving hospice care in their apartment. Having effectively become a widower for the third time in his life, Grandpa wrote in a memoir for his family, "My life was over too, only existence remained."

It was downhill from there. An attack of vertigo landed him in an acute rehabilitation facility. Then sudden-onset, unilateral

blindness compounded the communication challenges he'd long faced due to deafness resulting from active duty in World War II. I asked him to move in with us, but he'd have none of it. "You need to focus on your family, not on this old man," he told us more than once, despite our insistence that he played a central role in our family.

Instead, he moved into an assisted living facility in northern New Jersey. The location enabled a steady stream of visits from his children, a daughter of his recently lost partner, and my family. When none of us were with him, he kept in touch by email, and he passed the time satisfyingly enough by reading voraciously, as he had his whole life.

As his arthritis worsened, composing email messages of more

than a few words became onerous for him. "It's frustrating when the fingers can't keep up with the brain," he'd lament. And then visitation restrictions necessitated by Covid-19 cut him off from the outside world entirely, since his deafness had long since made phones useless to him. When the Northeast surge abated, Grandpa's son and I received permission to visit him outside his facility on separate days. Lucid as ever, despite nearing his 103rd birthday, he rendered the same plea to each of us. Whereas he had long wished to forgo measures to prolong life, he now sought any plausible option to hasten death.

I knew that New Jersey had legalized physician-assisted dying the previous year, but also that legality, availability, and propriety are three very different things. My long-standing ambivalence about physician-assisted dying had been reinforced by colleagues who joined me in organizing and presenting at the National Academy of Medicine's 2018 workshop on

the topic.^{1,2} I reached out to several of these experts to gauge whether Grandpa might pursue it. Would he even meet the criteria, given that he was dying of old age, frailty, and more than anything else, isolation and meaninglessness?

I learned that the Centers for Medicare and Medicaid Services (CMS) had previously allowed codes for “adult failure to thrive” to qualify people for hospice and that in states that had legalized physician-assisted dying less recently than New Jersey had, those codes had been used to confer eligibility. But CMS recently removed those codes from hospice eligibility, and in any event, I could not find a New Jersey physician willing or sufficiently experienced to provide this service.

I described another option to Grandpa: he could voluntarily stop eating and drinking. He’d never considered this possibility (which reminded me again how one’s family members and clinicians contribute to inequities in end-of-life care). The option intrigued Grandpa, and during subsequent visits he reinforced his plan to pursue it. I insisted that he first move into my home. I wanted to ensure the quality of his care, knowing that I could enroll him in my health system’s hospice program. But I also wished to test his resolve, reasoning that his mind might change once his isolation ended.

For a month after he entered our home, his spirits were brighter, his gait steadier, and his appetite heartier. He joined my wife, two daughters, and me for dinner each night, typically preceded by a vodka martini that I had stirred for him — a daily pleasure he’d allowed himself for 80 years and

had missed as a facility resident. He’d tell stories of the Navy, his career, and his family history and would regularly quip, “If you keep treating me this well, I might just stick around a while longer!”

But eventually he returned to his goal of hastening death. One night, he said he was ready to stop eating and drinking the next morning, but when morning came, he asked for his usual coffee and bagel. He confided that he was scared. When I asked of what, he replied, “It’s like trying to roller skate. I’m scared of starting. Though I know that once I do, I’ll probably roll.”

A week later, he’d built up his fortitude and again asked to stop eating and drinking. I convinced him to join us for dinner and sleep on it. He agreed, devoured everything on his plate and the ice cream sundae my daughters made him afterward, and shared a bottle of red wine we’d opened for the occasion. “My last hurrah,” he said, with a smile and fist-pump more vigorous than you’d think an old, frail man could muster. When I entered his room early the next morning, he was already dressed. “I’m ready to start,” he announced, almost before I could say good morning. “But do you think I could sneak a half-cup of black coffee?”

I went through the doctorly ritual of informing him that this was his choice; it would bring him pleasure while prolonging his life. He nodded. I served. He imbibed. On the third day of nothing but six ounces of black coffee each morning, he said, “I have a confession. While washing my face this evening I took a gulp of water.” The guilt and disappointment he conveyed immediately altered my views on physician-assisted dy-

ing. For people with a consistent desire to end their life, unencumbered by mental illness or immediate threats to their survival, the only alternative — to stop eating and drinking — is just too challenging. Hospice experts around the country had warned me that less than 20% of people who try to do so “succeed,” with most reversing course because of vicious thirst.

Even for this stoic Navy man, several requests for water followed. When I asked whether he was having second thoughts about hastening his death or just wanted relief from thirst, he resoundingly replied, “I just want it over with. Scott, do whatever you need to do.” In other words, I was now responsible for the success of his voluntary act — a responsibility that has been described by caregivers of other patients who have attempted to stop eating and drinking.³ When swabbing Grandpa’s mouth no longer provided relief, and after consultation with his hospice team, I began treating his thirst as I treat other forms of discomfort — with morphine and lorazepam. He became more tired, eventually bedbound and unable to interact, and after another 12 days that felt like a lifetime, he died peacefully.

I’ve learned many things in living this story that no amount of studying, teaching, or providing palliative care could ever reveal: the power of isolation and the countervailing force of family, the devastation of existential suffering and the paucity of options for relieving it, and the inequities at play, such that stopping eating and drinking is largely impossible without knowledgeable family members and dedicated hospice care. And I’ve learned that despite

many problems with physician-assisted dying, it may provide the most holistic relief possible for people who are not immediately dying, but rather are done living.

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1. National Academies of Sciences, Engineering, and Medicine. Physician-assisted

death: scanning the landscape: proceedings of a workshop. Washington, DC: National Academies Press, 2018.

2. Lo B. Beyond legalization — dilemmas physicians confront regarding aid in dying. *N Engl J Med* 2018;378:2060-2.

3. Lowers J, Hughes S, Preston N. Experience of caregivers supporting a patient through voluntarily stopping eating and drinking. *J Palliat Med* 2020 July 9 (Epub ahead of print).

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