

Confronting Physician-Assisted Suicide and Euthanasia:

My Father's Death

BY SUSAN M. WOLF

Duty: An act . . . required of one by position, social custom, law, or religion. . . . Moral obligation.

—American Heritage Dictionary of the English Language, 4th ed.

My father's death forced me to rethink all I had written over two decades opposing legalization of physician-assisted suicide and euthanasia.¹ That should not have surprised me. Years ago, when I started working on end-of-life care, he challenged my views on advance directives by insisting that he would want "everything," even in a persistent vegetative state. "I made the money, so I can spend it." More deeply, he argued that the Holocaust was incompatible with the existence of God. There is no afterlife, he claimed. This is it, and he wanted every last bit of "it" on any terms.

My father was a smart, savvy lawyer, the family patriarch. He was forceful, even intimidating at times. We had fought over the years, especially as I neared college. That was probably necessary—my separating and our disengaging. When I was a child, it was a family joke how often he and I said the same thing at the same time. We were alike in many ways.

My father was diagnosed with a metastatic head and neck cancer in 2002. His predictable view was "spare no effort." A top head and neck surgeon worked through conflicting pathology reports to locate the primary tumor in the thyroid

and excise the gland. Metastases would crop up from time to time, but radiation and then CyberKnife radiosurgery kept them in check. For five years he did well.

Things changed in June of 2007. The last CyberKnife treatment was billed as the worst, with significant pain likely to follow. Sure enough, ten days later, my father's pain on swallowing became severe. He began losing weight—a lot of it. He weakened. He fell twice in his apartment. His regular internist was out of town, so he went to the emergency room of a local hospital. Doctors did little for this seventy-nine-year-old man with a five-year history of metastatic thyroid cancer plus emphysema and chronic obstructive pulmonary disease.

He was briefly discharged to home but finally made it to the head and neck surgeon who had found the primary tumor in 2002. One look at my father and the surgeon admitted him, ordering a gastrostomy tube to deliver nutrition. Now my father was in an excellent hospital, with the head and neck, pulmonology, and gastroenterology services working him up. The mood brightened and the family gathered around him. I spent days in his sunny hospital room reminiscing, plowing through the *New York Times* with him, singing the college fight songs he offered as lullabies when I was little.

With multiple services focusing on my father's condition, I hoped the picture would soon come clear. I waited for a single physician to put the pieces together. And the medical picture was becoming worse. A surgical procedure revealed cancer in the liver. Pulmonology added pneumonia to the roster of lung ailments. Meanwhile, dipping oxygen saturation numbers drove a trip to the intensive care unit. Attempted endoscopy revealed a tumor between the esophagus and trachea, narrowing the esophagus. But no physician was putting the whole picture together. What treatment and palliative options remained, if any? What pathways should he—and we—be considering at this point?

He Said He Wanted to Stop

My father was becoming increasingly weak. He was finding it difficult to "focus," as he put it. He could not read, do the *New York Times* crossword puzzles he used to knock off in an hour, or even watch TV. Fortunately, he could talk, and we spent hours on trips he had taken around the world, family history, his adventures as a litigator. But he was confined to bed and did little when he was alone.

Then one morning he said he wanted to stop. No more tube feeding. No one was prepared for this switch from a lifetime of "spare no effort." He told me he feared he was now a terrible burden. I protested, knowing that I would willingly bear the "burden" of his illness. I suspect that what others said was more powerful, though. I was later told that the doctor urged him not to stop, warning that he would suffer a painful death, that morphine would be required to control the discomfort, and that my father would lose consciousness before the day was out. Instead of assuring my father that health

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professionals know how to maintain comfort after termination of artificial nutrition and hydration, my father was scared away from this option. Weeks later, my father would wish aloud that he had carried through with this decision.

Convinced now that he had no choice, my father soldiered on. But hospital personnel announced that it was time for him to leave the hospital. We were incredulous. He could not stand, walk, or eat. He had bedsores. Even transferring him from bed to a chair was difficult. And the rigors of transporting him in the early August heat were worrisome. But they urged transfer to a rehabilitation facility. My father was assured that with continued tube feeding and rehab, he could be walking into the surgeon's office in October.

It seemed to me my father was being abandoned. His prognosis was clearly bad and he himself had now raised the prospect of stopping tube feeding and dying, but it shocked me to see the hospital try to get rid of him. Yes, the hospital said he could return (somehow) in late September to see the ENT oncologist. But as far as I knew, that physician had never even met my father. And I doubted my father would make it to September. Still, no one was integrating the big picture. There seemed to be little choice. My father was successfully transported by ambulance to another hospital with a well-regarded rehabilitation unit.

The transfer provided brief respite. My father was delighted that he was now only blocks from his apartment, and the enticing possibility of actually going home beckoned. But the rehab unit demanded hours per day of rigorous work from each patient. My father was too weak. And his pneumonia was an issue. He was moved off rehab to the medical floor. A compassionate and attentive hospitalist appeared, trying to put together the big picture. She set about collecting the reports from the prior two hospitals and integrating them. Again, many teams were on board, including rheumatology now for flaring gout.

I requested the palliative care team. Even though my father could be lucid and "himself," I listened painfully as he faltered through the questions on their minimal exam. It was hard to accept that this paragon of analytic and verbal precision was failing. I alerted a member of the palliative care team that my father had evidently been misinformed at the prior hospital about the consequences of stopping artificial nutrition and hydration. I urged her to find a time to reassure him that he indeed had choices, could refuse treatments if he wanted to, and could be confident that his comfort would be maintained. I made clear to her that I hoped he would choose to stay the course for now and remain with us, but that he deserved to know that he had the choice. My father had designated his two proxy decision-makers (one of them me), but could still participate in the medical decision-making. His values and his subjective experience—whether he wanted more interventions or had reached his limit—were key.

Still unresolved, though, was the question of where we were headed. Could tube feeding and rehab bring him home and even walking into the surgeon's office in October? Was there treatment that could slow the growth of the newly discovered

cancer in his lung? Should we instead pursue hospice care? At times, my father's illness seemed like *Rashomon*, a story with conflicting versions and possible trajectories. But soon my father was back in the ICU, with oxygen saturation percentages dipping into the seventies. Tube feeding was so uncomfortable that it was administered slowly through the night. Pain medication was a constant. Despite this, he held court in his room, enjoying the banter, and offering his own with that wry smile and cocked eyebrow.

He was briefly transferred to the pulmonary care unit, as the most pressing issues at this point were actually not cancer but lung mucus and secretions, as well as pneumonia. I arrived one morning to find him upset. His nurse was not answering his calls, and his immobility left him at her mercy. I summoned the highly experienced and empathetic supervisor, but even behind closed doors with her he was afraid to speak plainly. I saw this tough-as-nails litigator reduced to fearful dependence.

"Can We Accelerate?"

By morning there was a new problem. My father had developed a massive bleed. Nursing had found him in a pool of his own blood, lying among the clots. The gastroenterologists took him in for a procedure, spending hours trying to find the source of the bleed. They never found it. My father required transfusion of most of his blood volume. The bleeding abated, but we knew it could resume any time.

That was it—the final blow. My father was back in the ICU now, but the bleed and the hours spent searching for its source were too much. He waited until we gathered at his bedside. His speech was halting now, but his determination obvious. "Tell me my choices." We went through each option—you can keep going like this, or you can go back to the floor if the ICU is bothering you, or you can halt the tube feeding and IV hydration. You also can wait, rather than deciding right now.

For close to an hour we stayed in a tight circle around his bed, straining to hear his every word, crying, responding to each question. At one point, I thought he wanted to wait, but he called us back. "It could happen again. At 2 a.m.," he said. He wanted a decision now. "That's what I want. To terminate." He made it clear he wanted to stop tube feeding and IV hydration. But that wasn't enough. He wanted consensus.

With the decision made, we set about communicating it to the caregivers and getting new orders written. It was then that he uttered three words that shook me. "Can we accelerate?" It seemed he was asking for more—a fast death, by assisted suicide or euthanasia. Reflexively, I said no, but with a promise—we can make absolutely certain they keep you comfortable. Even if you can't talk, even if you appear comatose, if you merely furrow your brow, we'll know you need more pain medication.

I knew right away that I needed to think through my "no." In reality, we were in the ICU of a major hospital in a jurisdiction that allowed neither assisted suicide nor euthanasia.

Indeed, no jurisdiction in the United States allows euthanasia, and my father was beyond assisted suicide by swallowing prescribed lethal medication, as he couldn't swallow anything. But I still needed to think this through.

I knew that in some ways, my father presented what proponents of assisted suicide and euthanasia would regard as a strong case. He was clearly dying of physical causes, unlike the controversial 1991 *Chabot* case in the Netherlands involving a patient who was merely depressed. He certainly had less than six months to live. He was probably depressed by his illness, but in a way that was appropriate to his situation. His decisional capacity had surely declined, but he was able to express definite treatment preferences.

Moreover, he wasn't asking for a change in policy or law. Statewide or national changes in policy require considering a huge range of patients, anticipating the predictable errors and abuses. The Dutch have bravely documented all of this through empirical study of their practice of legalized euthanasia—violations of the requirement for a contemporaneous request by a competent patient, doctors failing to report the practice as required, and practice falling down the slippery slope to euthanasia of newborns.² Oregon has documented its experience with legalized assisted suicide, too, but only the cases reported as required, leaving great uncertainty about cases not reported.³

My father wasn't asking for societal change, though, only whether he himself could "accelerate." I faced the highly individual question of how to do right by my own father.

We Kept Vigil, Around the Clock

In truth, it was life that answered the question, not logic. In some ways, it would have been psychologically easier, or at least faster, to bring the ordeal we all were experiencing to a quick end. I was in a city far from my husband and children, doing shifts at my father's bedside at all hours, fearful of more looming medical disasters increasing his discomfort. But instead of ending all of this and fleeing, we stayed, redoubling our attention to him. I stroked his thick white hair. He and I reminisced. He was always a great raconteur. We talked and talked over the next days. The decision to stop tube feeding actually seemed to lighten his load. A decision. In a way, it was a relief.

And executing the decision took work, itself a devotion. It was around 6 p.m. when the decision was made. The ICU doctor came to the bedside to confirm the new plan and as-

sure my father that he would be kept comfortable. But the palliative care professional, about to go off-duty, insisted that my father would need to leave the hospital. I was astonished. Was she saying he could not terminate treatment here? That the hospital had no in-patient hospice care? That you could accept invasive treatment at this hospital, but not refuse it? After years of working on end-of-life issues, I knew better. I confronted her: "You know that my father has a constitutional and common law right to refuse invasive treatment, including in this hospital." She acceded, but insisted that he would no longer meet the criteria for hospitalization; he would need to leave, to a hospice facility or home. The hospital evidently had no hospice to offer. Fine, we would set about arranging admission to hospice.

There was more—concerns over whether the fluid flowing through a remaining line would wrongly prolong his life and whether giving morphine by pump rather than through his line would do the same. I reached out by cell phone and e-mail to colleagues who were expert in maintaining comfort when artificial nutrition and hydration are stopped. We signed the papers requesting transfer to hospice. At one point, my father asked, "Will I see the end coming or fade away?" No one in the hospital was counseling my father. I worked my cell phone for answers and carried them to my father's bedside. To a man

who could hold no faith after the Holocaust, I even brought the words and experience of my rabbi.

We kept vigil, around the clock. He was out of the ICU now, in a hospital room awaiting transfer to hospice. As he began to doze more and talk less, we watched carefully for the slightest sign of discomfort. We had promised we would assure his comfort. That meant constant vigilance.

The last time I saw my father, he was motionless. His eyes were closed. He had stopped speaking. He appeared unresponsive. His breathing was quieter, rasps gone with dehydration. I took his hand. I told him I loved him. I stroked his hair, still full and silvered. I spoke to him from the heart, words that remain between him and me. Then I heard myself say, "If I am a good mother, it's because you were a great father." And to my surprise, he moved his jaw. Not his lips or his mouth. But he opened his jaw three times. It was our signal, the one we'd worked out in the ICU. Three means "I-love-you." Tears streamed down my face. I struggled, remembering the rabbi's caution that the ones we love most may need permission to leave us, to die. "I know you may have to

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leave before I get back. That's okay." It felt nearly impossible to let him go. My chest was bursting. The pain was crushing.

When I finally left, I was working to breathe. Taking one step then another. Breaking down, collecting myself, breaking down again. He died not long after.

In the End

I will not pretend—there was a price to be paid for going the longer way, not the shorter. My father died slowly. He had to trust that we would keep a ferocious vigil, demanding whatever palliative care he needed. It was he who traveled that road, not me. I paid my own price, though. I felt the heavy weight of his trust and the obligation to fight for him. I was scared I might fail. I felt very close to the jaws of death.

But with every memory we shared while he could speak, every lilt of his eyebrow and wry smile, we basked together in life, reveled in a bit more of fifty-four years together and his nearly eighty on this earth. Family and caregivers did manage to keep him comfortable. He died loved and loving.

I grieve still. I reread the letters he wrote home from Oxford in his twenties, I pore over the genealogy charts he painstakingly constructed over decades, I finger the abacus he kept in his law office. I go to e-mail him, then remember. I would not want to bear the burden of having "accelerated," of causing his death by euthanasia or assisted suicide; this is hard enough. My father's death made me rethink my objections to legalizing assisted suicide and euthanasia, but in the end it left me at ease with what I've written. Staying, keeping vigil, fighting to secure a comfortable death, stroking his hair, standing guard as death approached was my duty. It was the final ripening of my love. We both changed, even closer at the end.

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1. In the mid-1980s, I had led the Hastings Center project that developed *Guidelines on the Termination of Life-Sustaining Treatment and the Care of the Dying* (Indianapolis: Indiana University Press, 1987). For a sample of my subsequent work on physician-assisted suicide, see "Gender, Feminism, and Death: Physician-Assisted Suicide and Euthanasia," in *Feminism and Bioethics: Beyond Reproduction*, ed. S.M. Wolf (New York: Oxford University Press, 1996), 282-317; "Physician-Assisted Suicide in the Context of Managed Care," *Duquesne Law Review* 35 (1996): 455-79; "Physician-Assisted Suicide, Abortion, and Treatment Refusal: Using Gender to Analyze the Difference," in *Physician-Assisted Suicide*, ed. R. Weir (Indianapolis: Indiana University Press, 1997), 167-201; "Facing Assisted Suicide and Euthanasia in Children and Adolescents," in *Regulating How We Die: The Ethical, Medical, and Legal Issues Surrounding Physician-Assisted Suicide*, ed. L.L. Emanuel (Cambridge, Mass.: Harvard University Press, 1998), 92-119, 274-94; "Pragmatism in the Face of Death: The Role of Facts in the Assisted Suicide Debate," *Minnesota Law Review* 82 (1998): 1063-1101; and "Assessing Physician Compliance with the Rules for Euthanasia and Assisted Suicide," *Archives of Internal Medicine* 165 (2005): 1677-79.

2. I discuss all of this in my work cited above. See also P.J. van der Maas et al., "Euthanasia and Other Medical Decisions Concerning the

End of Life," *Lancet* 338 (1991): 669-74; L. Pijnenborg et al., "Life-Terminating Acts without Explicit Request of Patient," *Lancet* 341 (1993): 1196-99; P.J. van der Maas et al., "Euthanasia, Physician-Assisted Suicide, and Other Medical Practices Involving the End of Life in the Netherlands, 1990-1995," *New England Journal of Medicine* 335 (1996): 1699-1705; G. van der Wal et al., "Evaluation of the Notification Procedure for Physician-Assisted Death in the Netherlands," *New England Journal of Medicine* 335 (1996): 1706-11; A. van der Heide and P.J. van der Maas, "Medical End-of-life Decisions Made for Neonates and Infants in the Netherlands," *Lancet* 350 (1997): 251-55; B.D. Onwuteaka-Philipsen et al., "Euthanasia and Other End-of-life Decisions in the Netherlands in 1990, 1995, and 2001," *Lancet* 362 (2003): 395-99; T. Sheldon, "Only Half of Dutch Doctors Report Euthanasia, Report Says," *British Medical Journal* 326 (2003): 1164; T. Sheldon, "Dutch Reporting of Euthanasia Cases Falls—Despite Legal Reporting Requirements," 328 (2004): 1336; B.D. Onwuteaka-Philipsen et al., "Dutch Experience of Monitoring Euthanasia," *British Medical Journal* 331 (2005): 691-93; E. Verhagen and P.J.J. Sauer, "The Groningen Protocol: Euthanasia in Severely Ill Newborns," *New England Journal of Medicine* 352 (2005): 959-62; A. van der Heide et al., "End-of-Life Practices in the Netherlands Under the Euthanasia Act," *New England Journal of Medicine* 356 (2007): 1957-65.

3. See K. Foley and H. Hendin, "The Oregon Report: Don't Ask, Don't Tell," *Hastings Center Report* 29, no. 3 (1999): 37-42; E.J. Emanuel, "Oregon's Physician-Assisted Suicide Law: Provisions and Problems," *Archives of Internal Medicine* 156 (1996): 825-29.

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