

Thy Will Be Done

Think your living will takes care of everything? Maybe not.

BY VICTORIA SWEET

PREFACE: Death is the proverbial 900-pound gorilla in all of our lives. We generally prefer not to think or talk about it, which isn't a problem—except when death visits us. To what used to be a natural or, at least, a minimally manipulable event, contemporary medical science has added a variety of life-extending options, many of which cause prolonged oblivion, pain, family disruption, and expense. In response to the advent of life-extending technologies, instruments known generically as an “advance directive” (or “living will”) have been developed, allowing us to express our wishes about our deaths, including the rigor of interventions and who should make decisions if we cannot. Despite the presence of such documents, three observers from the front lines of terminal illness report that all is not well. First, physician Victoria Sweet tackles the issue with a set of “terminal” vignettes—some of which prove less than terminal—and describes how she has framed her own advance directive. Then David Muller, who is part of a visiting doctors program, describes how even the best of patient-doctor relationships can go wrong in the face of death. Finally, sociologist Margaret Nelson reflects on her difficult role as the proxy for a dying friend and what the process requires of all of us.

YELLOW AND VISCOUS, the bag of liquid nutrition went by, held aloft by the ambulance driver. With his other hand, he pushed the gurney holding the next admission, a long, angular figure under sheets, closely followed by a sweating, middle-aged man who carried a book. I left my office to look at the new patient, a gaunt woman in her early eighties, her hands tied to the bed rails, and blue eyes roving the ceiling. The man introduced himself as her son, and could he talk to me privately?

The spectral figure in the bedclothes was, it seemed, Nan Nelson, a well-known writer. Indeed, her son informed me that it was she who had written one of the first books on living wills, and in it she had published her very own living will. Then he handed me the book he was carrying, and there it was in black and white:

To my Kind Friend, My Dear Relative, My Lawyer, My Physician: I ask you, individually or in concert, to ensure that measures will be taken to end my existence should I fall victim to the following: progressive degeneration of mental faculties, complete loss of memory, chronically unreasonable behavior, delirium, or any other appearance of advanced dementia...[or] any condition requiring the use, beyond fourteen days, of mechanical equipment for feeding, breathing, heart action.

Yet here she was with, it appeared, some sort of “progressive degeneration of mental faculties,” and not only were no measures being taken to end her existence, she was being force-fed by tube. How had this happened?

.....
 Victoria Sweet (Victoria.Sweet@ucsf.edu) is a physician and an associate clinical professor of medicine at the University of California, San Francisco. She is the author of *Rooted in the Earth, Rooted in the Sky: Hildegard of Bingen and Premodern Medicine* (Routledge, 2006). Names and certain identifying details about people in the essay have been changed.

Well, her son recounted, very gradually. Over the years his mother's mental processes had decayed, but slowly. First he had persuaded her to go to a boarding house, then later a board-and-care facility where her meals and medicines appeared on schedule and she was watched over. Eventually, she had needed even more help and went into a hospital and then a nursing home. As time went on, she became more and more difficult to feed, he told me. She spat out food or pushed it away, and, when forced to eat, she coughed and choked. Finally, "the hospital" suggested, and then insisted on, feeding her with a tube—by force, if necessary.

"I refused," the son told me. "I told them she wouldn't have wanted to be kept alive that way. I showed them her living will; I even brought them a copy of the book. They insisted. I refused. Finally, since I have her durable power of attorney for health care, I just checked her out of that hospital and brought her here."

Mrs. Nelson's living will seemed pretty clear to me, too. Certainly she was leading a life that she had specifically written she did not want.

"No problem here," I told him.

Together we went over to her bed. Mrs. Nelson hadn't moved at all since her arrival; her eyes still stared at the ceiling, while the tube drip, drip, dripped its yellow liquid into her body. Seemed simple. I untied her hands. She pulled out the tube.

Now, the story should end there, don't you think? Justice done, will and wishes carried out. Indeed, we were delighted to be able to send her to our hospice unit, dedicated to humane terminal care, and which her book had had so much to do with creating. In our hospital, it is the main unit for the dying and is run by the pale Dr. T. He is bold, a Gordian-knot cutter, and, as was his usual procedure—and following her living will—all of her medicines were stopped and a regular diet was ordered.

Which she ate. She didn't spit out the food or push it away or cough (much); no, she ate, quite well. In fact, during the next several months, she lived on the hospice unit and gained many pounds and did not die. Eventually Dr. T. transferred her to a regular ward, and, I believe, she lives there still.

Origin Of The Living Will

THE LIVING WILL, OR THE LESS EVOCATIVE "advance directive," could have only come out of that anti-authority, privileged, and confident decade of the 1970s and in the United States. The idea of a living will is in many ways remarkable, even bizarre, but given that particular moment in medicine, it was a necessary innovation.

That moment was the appearance of powerful, life-preserving technologies in a world not prepared for them, a world whose conception of life and death, doctor and patient, suffering and freedom had changed little from the medieval era. In that world, death was Death; it came when God or fate willed it, and when one's

time had come, well, one died. Doctors observed patients and their passings, and they ministered to them. But often in the final hours they withdrew, permitting the family to take its leave and letting “nature takes its course.” In the 1960s, however, something unprecedented occurred: Suddenly there were—*interventions*—that doctors could make in this ancient process. For instance, they could try to resuscitate the patient after he or she died, or they could feed a patient who was no longer able to eat.

Although such attempts do go back centuries, a new technology—an innocuous rubber tube about twenty-six inches long—had been perfected in the 1950s. It was initially employed for emptying the stomach of the overdosed, then for postsurgical care, intractable vomiting, and feeding the temporarily anorexic. But it could also be used for feeding the permanently anorexic, those whose brains could no longer tell their bodies how to eat: the terminally demented and the brain-dead. At first it was simply inserted through the nose into the stomach (the nasogastric or NG tube); later it could be placed surgically, through the abdominal wall, into the stomach or intestine (the G-tube, J-tube, or GJ-tube). This was more comfortable and decreased the risk of aspiration pneumonia, but it had the unintended consequence of making the tube invisible to family. By the late 1960s other technologies were becoming routine: chemotherapy, transfusions, and antibiotics, whose use with the terminally ill was undefined.

The living will was developed to clarify these new possibilities. It gave potential patients—that is, all of us—the option of stating in advance the circumstances under which we would not want expensive, often painful, and usually futile treatments to be used. It was to be a will, but instead of being about giving property, it would be about receiving—or not receiving—certain new medical technologies. And it would be not merely written while one was alive (what will isn’t?) but would go into effect, at least in theory, while one was living.

But as the story of Mrs. Nelson exemplifies, there were problems with the living will. Not, of course, the irony that she lived for quite a while after her wishes were honored. That is simply nature taking its course, and, despite a living will, there’s nothing to be done about it. Nor should there be. Mouth opening, gums chewing, and esophagus propelling are clear signs that a will to live is still present—and, therefore, that something remains to be felt, understood, or experienced.

A Disinclination For Death

ONE OBVIOUS PROBLEM, CERTAINLY, is simply not making a living will—because you never thought about it or, perhaps, you want to be kept alive indefinitely. A second problem, as Mrs. Nelson demonstrates, is having a living will that no one pays attention to or that someone actually countervails because they don’t agree with your wishes, perhaps. But there is still a third problem, I was to learn, probably the most important one of all: a disinclination to accept,

not death exactly, but the idea of death, on the part of doctors, nurses, and families.

Thus, when the sisters Previn rolled in, one ninety-two-year-old twin on the gurney and the other striding after, white-haired, vigorous, and less than five feet tall, it was evident that the transferring physician and the family just hadn't let themselves think the whole thing through. Although Previn A on the gurney weighed only eighty pounds, rarely recognized her sister, and had a living will, she rolled in with a G-tube, being fed almost surreptitiously. Her sister, Previn B, asked to speak with me, and this time I was shown a notarized living will. It, too, was very clear. Previn A did not want to be kept alive with a feeding tube inserted into her stomach if she had end-stage dementia.

"Explain something to me," I asked Previn B. "Putting the tube in was a surgical procedure and not an emergency. Didn't you have to sign a consent for it?"

"Yes," she told me. "I did sign the consent for the tube, but that was because the doctor told me my sister would die if they didn't put a tube in."

"But did you want the tube in?"

"No, certainly not."

"Do you want it in now?"

"No."

I was puzzled. So I tracked down Previn A's physician, the one who had put in the feeding tube. He turned out to be a young, second-year medicine resident. Hadn't he read Previn A's living will? Oh, yes, he had. But, he explained, she would have *died* if they hadn't put the feeding tube in.

When Previn B heard that we had a hospice unit and that the feeding tube could be removed, she was delighted. It was removed, all medicines were stopped, and Previn A...woke up and started to eat. She ate enough to live three more years on the hospice unit, long enough for us to learn about both sisters' very remarkable lives. Trained as classical pianists, they enlisted during World War II, and Previn A ended up as a court transcriptionist at Nuremberg.

Eventually Previn A did die. There was nothing dramatic or even unsightly about her death; she just faded away, pound by pound and month by month. Until the end, her sister visited daily, bringing homemade food not only for her sister but also for the other patients and all of the staff. I remember particularly one of her offerings: a metal bowl of yellow, orange, and green-striped tomatoes, fragrant with vinegar and olive oil, lime, and cilantro.

Advice To The Willing

SO IN THE END, THESE ARE STORIES about eating and not eating, about not wanting to eat, not being able to eat, being forced to eat, and the difference between eating and being fed. That is the essence of the matter; that is the problem for which Mrs. Nelson's living will tried to be the solution. Because, truth to tell, it doesn't really matter whether or not you check the Do Not Resuscitate

box on a form—we won't be able to resuscitate you, not if you are really, really dead. So don't check the Do Not Resuscitate box if it makes you feel better. Enjoy the feeling that life is, potentially, eternal.

But those little Yes/No boxes about being given a feeding tube: Think twice before you check one. Give a good physician someone who is tube-fed, and that patient can be kept alive, oh, I think, indefinitely. In that state of suspended animation that is the tube-fed, comatose patient, cancers stop growing, seizures no longer occur, high blood pressure disappears, the cholesterol normalizes, and diabetes improves. Don't ask me why. But I have yet to see a patient on the feeding-tube ward die.

There's more. Your living will has to be "living," and it has to be a "will." For that, just checking boxes won't do the trick. At least it hasn't done the trick yet, although, perhaps, once the health insurance industry realizes how much money it spends on futile end-of-life interventions, living wills will be required and respected. Until then, however, make sure that your living will is living, that it expresses, somehow, what you wish. Also that it is a will, forcefully conveying what you do—and do not—want done.

Because somehow a lot of family members have second thoughts when they feel the cold breath of actual death breathing down their necks—not their own death, though, but someone else's—their spouse, mother, brother, daughter. Partly this does have to do with their own death, with the notion that being in the suspended time capsule that is the body of the tube-fed patient is not death. And this is because for most people, dying and death happen someplace else, hidden away in a hospital or a nursing home. Where death is not hidden—at our hospital, for instance—not a single staff member, not even pro-life advocates, wants a feeding tube to keep them alive "in case of an untreatable terminal illness." But mainly, their second thoughts have to do with their own loss when you die, with what they become afterward—a bereaved widow, a grief-stricken mother, an adult orphan.

I finally understood this deep reluctance to follow the directions in a living will the day I watched an elegant woman in a dove-gray business suit enter the private room where her mother lay. Her mother was eighty-six years old and terminally demented, tiny and curled up into a stiff, contracted ball. Her eyes stared at the bedrails, and her hands were restrained so that she could not pull out her G-tube. A few minutes later, I looked in. There was the daughter sitting next to the bed, leather briefcase by her chair. She was holding her mother's hand, leaning forward, and in a soft voice telling her mother all about her day. The curled up body did not, in any apparent way, acknowledge the daughter's presence, but the daughter told me later that she was certain her mother knew she was there. Maybe she was right. She came every day after work, for years.

So don't just check those little boxes on a form and think you're done. Write your living will while you're alive and healthy and have the energy to explain what you want, and what you don't want, to those who love you.

Final Thoughts

CAN ANYTHING ELSE BE DONE? Well, at my hospital, starting about fifteen years ago, we made a concerted effort to establish advance directives as soon as patients were admitted. There were conferences and journal clubs for doctors and nurses, certified nursing assistants, and activity therapists. In the admitting history, we inserted a paragraph that requires a patient to state some desires or feelings about resuscitation, tube feeding, and curative versus palliative care. And we made it a policy to revisit those wishes regularly with patients. It took us years, but eventually we had a “culture of attention” to patients’ wishes, to their quality of life, and, especially, to their personal style. Today we have many fewer futile code blues and many fewer curled-up and contracted tube-fed bodies.

But we still have quite a number, for two interlinked reasons. First, too many people, by the time they come to us, can’t understand the concepts—the difference between treatment and resuscitation or between palliative and curative care, or what it means to end up as a tube-fed body. And second, because those for whom we have no evidence of what they would want do get a feeding tube, the cultural presumption being—don’t ask me why—that absent some directive to the contrary, you would want to be tied down, restrained, and force-fed, virtually indefinitely.

Since it might be a long time until that default policy is changed, let me end by telling you, in the spirit of Mrs. Nelson, what I have done. I got one of those forms under one of the names they go by (durable power of attorney for health care, living will, advance directive), and I filled it out; you can believe I checked the box about no feeding tube, as well as the Do Not Resuscitate box. But that’s not all I did. I also talked with my family about those checkmarked boxes and discovered that not everyone understood why I wouldn’t want to be kept alive as long as possible. I took the names of those family members off the form. Last, I wrote a letter about what I want and, especially, about what I don’t want. Personal is best. You can type yours or dictate it, videotape it, or even scribble it, but document what you want in your own words, with your own images, and in your own spirit.

Why is this so important? Because times change, medical technologies change, and ways of prolonging your existence will also, doubtless, change. Today’s checkboxes about resuscitation and feeding tubes might not be relevant by the time your living will comes to be read. What will be relevant will be some indication of who you were, how you lived your life, and how you weighed freedom against security, mental anguish against physical suffering, change against stability. Leave us a sense of you, a flavor, a melody, so that in those decades to come when those who knew you are gone and you yourself are unreachable, we still can intuit what you would have wanted. That’s how to make a living will.