

Dr. Angelo Volandes's
low-tech, high-empathy plan
to revolutionize
end-of-life care

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N O T
T O D I E

BY JONATHAN RAUCH

Photographs by Eric Ogden

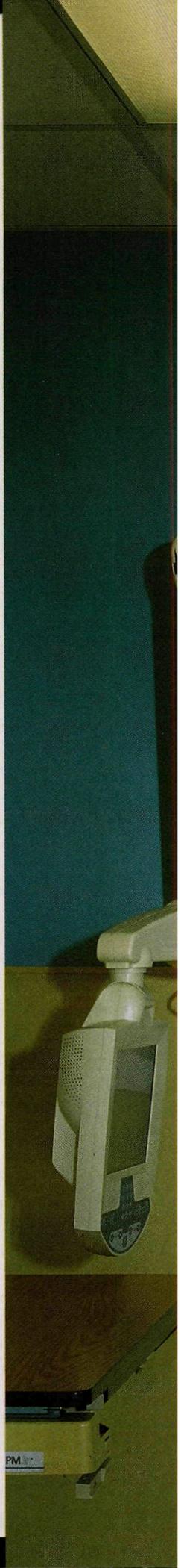
DR. ANGELO VOLANDES is making a film that he believes will change the way you die. The studio is his living room in Newton, Massachusetts, a suburb of Boston; the control panel is his laptop; the camera crew is a 24-year-old guy named Jake; the star is his wife, Aretha Delight Davis. Volandes, a thickening mesomorph with straight brown hair that is graying at his temples, is wearing a T-shirt and shorts and looks like he belongs at a football game. Davis, a beautiful woman of Guyanese extraction with richly braided hair, is dressed in a white lab coat over a black shirt and stands before a plain gray backdrop. “Remember: always slow,” Volandes says.

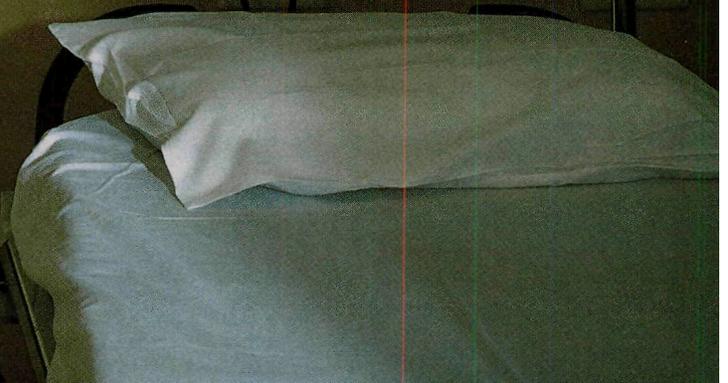
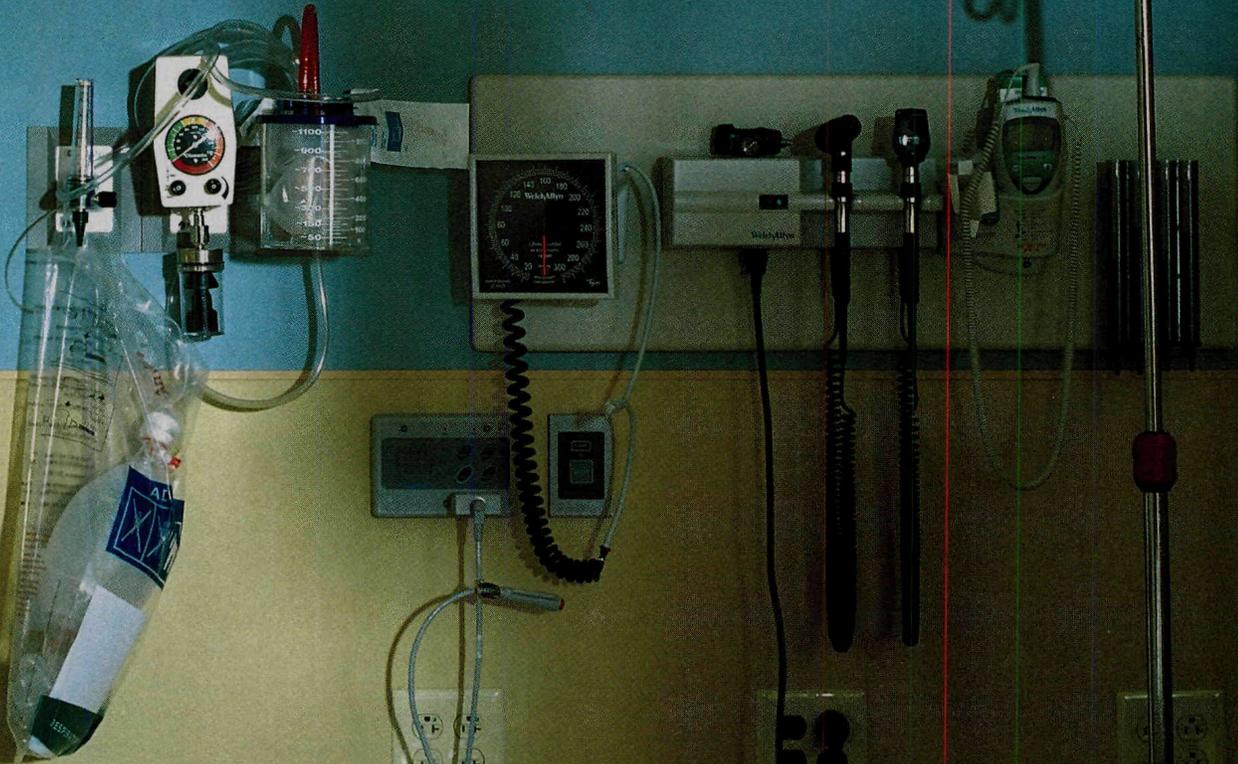
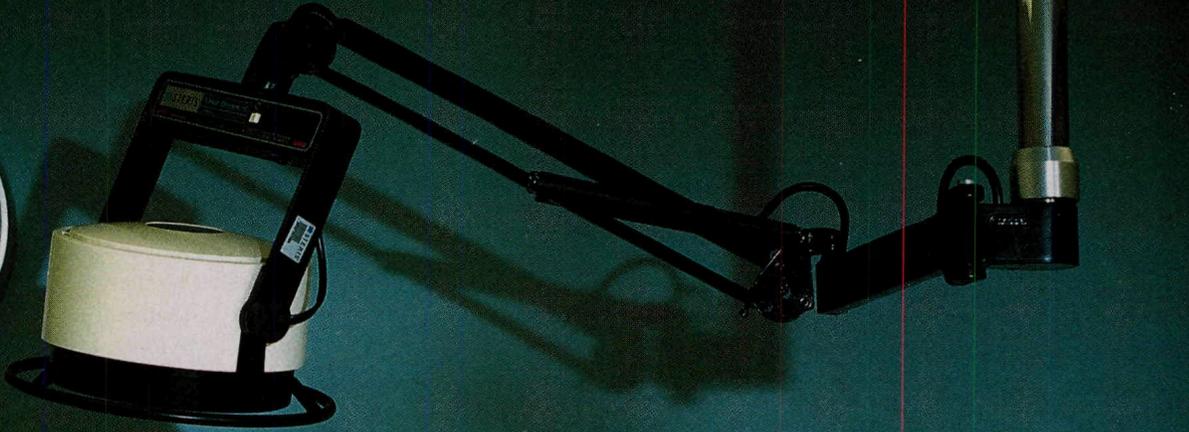
“Sure, hon,” Davis says, annoyed. She has done this many times.

Volandes claps to sync the sound. “Take one: Goals of Care, Dementia.”

You are seeing this video because you are making medical decisions for a person with advanced dementia. Davis intones the words in a calm, uninflected voice. I’ll show you a video of a person with advanced dementia. Then you will see images to help you understand the three options for their medical care.

Her narration will be woven into a 10-minute film. The words I’m hearing will accompany footage of an elderly woman in a wheelchair. The woman is coiffed and dressed in her Sunday finest, wearing pearls and makeup for her film appearance, but her face is vacant and her mouth is frozen in the rictus of a permanent O.





This woman lives in a nursing home and has advanced dementia. She's seen here with her daughters. She has the typical features of advanced dementia ...

Young in affect and appearance, Volandes, 41, is an assistant professor at Harvard Medical School; Davis, also an M.D., is doing her residency in internal medicine, also at Harvard. When I heard about Volandes's work, I suspected he would be different from other doctors. I was not disappointed. He refuses to let me call him "Dr. Volandes," for example. Formality impedes communication, he tells me, and "there's nothing more essential to being a good doctor than your ability to communicate." More important, he believes that his videos can disrupt the way the medical system handles late-life care, and that the system urgently needs disrupting.

"I think we're probably the most subversive two doctors to the health system that you will meet today," he says, a few hours before his shoot begins. "That has been told to me by other people."

"You sound proud of that," I say.

"I'm proud of that because it's being an agent of change, and the more I see poor health care, or health care being delivered that puts patients and families through—"

"We torture people before they die," Davis interjects, quietly.

Volandes chuckles at my surprise. "Remember, Jon is a reporter," he tells her, not at all unhappy with her comment.

"My father, if he were sitting here, would be saying 'Right on,'" I tell him.

Volandes nods. "Here's the sad reality," he says. "Physicians are good people. They want to do the right things. And yet all of us, behind closed doors, in the cafeteria, say, 'Do you believe what we did to that patient? Do you believe what we put that patient through?' Every single physician has stories. Not one. Lots of stories.

"In the health-care debate, we've heard a lot about useless care, wasteful care, futile care. What we"—Volandes indicates himself and Davis—"have been struggling with is unwanted care. That's far more concerning. That's not avoidable care. That's *wrongful* care. I think that's the most urgent issue facing America today, is people getting medical interventions that, if they were more informed, they would not want. It happens all the time."

UNWANTED TREATMENT is American medicine's dark continent. No one knows its extent, and few people want to talk about it. The U.S. medical system was built to treat anything that might be treatable, at any stage of life—even near the end, when there is no hope of a cure, and when the patient, if fully informed, might prefer quality time and relative normalcy to all-out intervention.

In 2009, my father was suffering from an advanced and untreatable neurological condition that would soon kill him. (I wrote about his decline in an article for this magazine in April 2010.) Eating, drinking, and walking were all difficult and dangerous for him. He ate, drank, and walked anyway,

because doing his best to lead a normal life sustained his morale and slowed his decline. "Use it or lose it," he often said. His strategy broke down calamitously when he agreed to be hospitalized for an MRI test. I can only liken his experience to an alien abduction. He was bundled into a bed, tied to tubes, and banned from walking without help or taking anything by mouth. No one asked him about what he wanted. After a few days, and a test that turned up nothing, he left the hospital no longer able to walk. Some weeks later, he managed to get back on his feet; unfortunately, by then he was only a few weeks from death. The episode had only one positive result. Disgusted and angry after his discharge from the hospital, my father turned to me and said, "I am *never* going back there." (He never did.)

What should have taken place was what is known in the medical profession as The Conversation. The momentum of medical maximalism should have slowed long enough for a doctor or a social worker to sit down with him and me to explain, patiently and in plain English, his condition and his treatment options, to learn what his goals were for the time he had left, and to establish how much and what kind of treatment he really desired. Alas, evidence shows that The Conversation happens much less regularly than it should, and that,

when it does happen, information is typically presented in a brisk, jargon-y way that patients and families don't really understand. Many doctors don't make time for The Conversation, or aren't good at conducting it (they're not trained or rewarded for doing so), or worry their patients can't handle it.

This is a problem, because the assumption that doctors know what their patients want turns out to be wrong: when doctors try to predict the goals and preferences of their patients, they are "highly inaccurate," according to one summary of the research, published by Benjamin Moulton and Jaime S. King in *The Journal of Law, Medicine & Ethics*. Patients are "routinely asked to make decisions about treatment

choices in the face of what can only be described as avoidable ignorance," Moulton and King write. "In the absence of complete information, individuals frequently opt for procedures they would not otherwise choose."

Though no one knows for sure, unwanted treatment seems especially common near the end of life. A few years ago, at age 94, a friend of mine's father was hospitalized with internal bleeding and kidney failure. Instead of facing reality (he died within days), the hospital tried to get authorization to remove his colon and put him on dialysis. Even physicians tell me they have difficulty holding back the kind of mindlessly aggressive treatment that one doctor I spoke with calls "the war on death." Matt Handley, a doctor and an executive with Group Health Cooperative, a big health system in Washington state, described his father-in-law's experience as a "classic example of overmedicalization." There was no Conversation. "He went to the ICU for no medical reason," Handley says. "No one talked to him about the fact that he was going to die, even

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though outside the room, clinicians, when asked, would say ‘Oh, yes, he’s dying.’”

“Sometimes you block the near exits, and all you’ve got left is a far exit, which is not a dignified and comfortable death,” Albert Mulley, a physician and the director of the Dartmouth Center for Health Care Delivery Science, told me recently. As we talked, it emerged that he, too, had had to fend off the medical system when his father died at age 93. “Even though I spent my whole career doing this,” he said, “when I was trying to assure as good a death as I could for my dad, I found it wasn’t easy.”

If it is this hard for doctors to navigate their parents’ final days, imagine what many ordinary patients and their families face. “It’s almost impossible for patients really to be in charge,” says Joanne Lynn, a physician and the director of the nonprofit Altarum Center for Elder Care and Advanced Illness in Washington, D.C. “We enforce a kind of learned helplessness, especially in hospitals.” I asked her how much unwanted treatment gets administered. She couldn’t come up with a figure—no one can—but she said, “It’s huge, however you measure it. Especially when people get very, very sick.”

Unwanted treatment is a particularly confounding problem because it is not a product of malevolence but a by-product of two strengths of American medical culture: the system’s determination to save lives, and its technological virtuosity. Change will need to be consonant with that culture. “You have to be comfortable working at the margins of the power structure within medicine, and particularly within academic medicine,”

Mulley told me. You need a disrupter, but one who can speak the language of medicine and meet the system on its own terms.

ANGELO VOLANDES was born in 1971, in Brooklyn, to Greek immigrants. His father owned a diner. He and his older sister were the first in their family to go to college—Harvard, in his case. In Cambridge, he got a part-time job cooking for an elderly, childless couple, who became second parents to him. He watched as the wife got mortally sick, he listened to her labored breathing, he talked with her and her husband about pain, death, the end of life. Those conversations led him to courses in medical ethics, which he told me he found abstract and out of touch with “the clinical reality of being short of breath; of fear; of anxiety and suffering; of medications and interventions.” He decided to go to medical school, not just to cure people but “to learn how people suffer and what the implications of dying and suffering and understanding that experience are like.” Halfway through med school at Yale, on the recommendation of a doctor he met one day at the gym, he took a year off to study documentary filmmaking, another of his interests. At the time, it seemed a digression.

On the very first night of his postgraduate medical internship, when he was working the graveyard shift at a hospital in Philadelphia, he found himself examining a woman dying of cancer. She was a bright woman, a retired English professor, but she seemed bewildered when he asked whether she wanted cardiopulmonary resuscitation if her heart stopped beating. So, on an impulse, he invited her to visit the intensive-care unit. By coincidence, she witnessed a “code blue,” an emergency administration of CPR. “When we got back to the room,” Volandes remembered, “she said, ‘I understood what you told me. I am a professor of English—I understood the words. I just didn’t know what you meant. It’s not what I had imagined. It’s not what I saw on TV.’” She decided to go home on hospice. Volandes realized that he could make a stronger, clearer impression on patients by showing them treatments than by trying to describe them.

He spent the next few years punching all the tickets he could: mastering the technical arts of doctoring, credentialing himself in medical ethics, learning statistical techniques to perform peer-reviewed clinical trials, joining the Harvard faculty and the clinical and research staff of Massachusetts General Hospital. He held on to his passion, though. During a fellowship at Harvard in 2004, he visited Dr. Muriel Gillick, a Harvard Medical School professor and an authority on late-life care. Volandes “was very distressed by what he saw clinically being done to people with advanced dementia,” Gillick recalls. “He was interested in writing an article about how treatment of patients with advanced dementia was a form of abuse.” Gillick talked him down. Some of what’s done is wrong, she agreed, but raging against it would not help. The following year, with her support, Volandes began his video project.

The first film he made featured a patient with advanced dementia. It showed her inability to converse, move about, or feed herself. When Volandes finished the film, he ran a randomized clinical trial with a group of nine other doctors. All of their patients listened to a verbal description of advanced dementia, and some of them also watched the video. All were then asked whether they preferred life-prolonging care (which does everything possible to keep patients alive), limited care (an

intermediate option), or comfort care (which aims to maximize comfort and relieve pain). The results were striking: patients who had seen the video were significantly more likely to choose comfort care than those who hadn't seen it (86 percent versus 64 percent). Volandes published that study in 2009, following it a year later with an even more striking trial, this one showing a video to patients dying of cancer. Of those who saw it, more than 90 percent chose comfort care—versus 22 percent of those who received only verbal descriptions. The implications, to Volandes, were clear: "Videos communicate better than just a stand-alone conversation. And when people get good communication and understand what's involved, many, if not most, tend not to want a lot of the aggressive stuff that they're getting."

EVEN NOW, after years of refinement, Volandes's finished videos look deceptively unimpressive. They're short, and they're bland. But that, it turns out, is what is most impressive about them. Other videos describing treatment options—for, say, breast cancer or heart disease—can last upwards of 30 minutes. Volandes's films, by contrast, average six or seven minutes. They are meant to be screened on iPads or laptops, amid the bustle of a clinic or hospital room.

They are also meant to be banal, a goal that requires a meticulous, if perverse, application of the filmmaker's art. "Videos are an aesthetic medium; you can manipulate people's perspective," Volandes says. "I want to provide information *without* evoking visceral emotions." Any hint that he was appealing to sentiments like revulsion or fear to nudge patients toward a certain course of treatment would discredit his whole project, so Volandes does all he can to eliminate emotional cues. That is why he films advanced-dementia patients dressed and groomed to the nines. "I give them the nicest image," Volandes told me. "If with the nicest image we show a huge effect, you can imagine what it would be like if they really saw the reality."

The typical video begins with Davis explaining what the viewer is about to see, stating plainly facts that doctors are sometimes reluctant to mention. She says, for example: *People with advanced dementia usually have had the disease for many years and have reached the last stage of dementia. They are nearing the end of life.* The video cuts to a shot of a patient. Then Davis outlines the three levels of care, starting with the most aggressive. Over footage of CPR and mechanical ventilation, she explains that in most cases of advanced dementia, CPR does not work, and that patients on breathing machines are usually not aware of their surroundings and cannot eat or talk. Then she describes limited care and comfort care, again speaking bluntly about death. *People who choose comfort care choose to avoid these procedures even though, without them, they might die.* She concludes by recommending *The Conversation*.

It seems a minor thing, showing a short video. As, indeed, it will be, if it happens only occasionally. I didn't get my head around the scale of Volandes's ambition until I understood

that he wants to make his videos ubiquitous. His intention is not only to provide clearer information but, more important, to trigger *The Conversation* as a matter of medical routine. "We're saying, 'You're not doing your job if you are not having these conversations in a meaningful way with patients and their families,'" he tells me. "If every patient watched a video, there's standardization in the process. That's why I call it subversive. Very few things in medicine can change the culture like that."

Routine use, however, is far, far away. According to Volandes, only a few dozen U.S. hospitals, out of more than 5,700, are using his videos. I spoke with physicians and a social worker at three health systems that are piloting them, and all were very enthusiastic about the results. Volandes is particularly hopeful about a collaboration with the Hawaii Medical Service Association, the state's dominant health-insurance provider, which is

piloting the videos in hospitals, nursing homes, and doctors' offices. Officials say they hope to expand use statewide within three years. Right now, though, Volandes's videos have a limited reach.

The problem is not his product but the peculiar nature of the market he wants to push it into. His innovation is inexpensive and low-tech, and might avert misunderstanding, prevent suffering, improve doctor-patient relationships, and, incidentally, save the health-care system a lot of money. He goes out of his way not to emphasize cost savings, partly because he sees himself as a patients'-rights advocate rather than a bean counter, and partly because it is so easy to demagogue the issue, as Sarah Palin did so

mendaciously (and effectively) in 2009, when she denounced end-of-life-care planning as "death panels." Anyone who questions medical maximalism risks being attacked for trying to kill grandma—all the more so if he mentions saving money. For all its talk of making the health-care system more rational and less expensive, the political system is still not ready for an honest discussion. And the medical system has its own ways of fighting back.

VOLANDES WORKS ON his videos ceaselessly. He has curtailed his medical practice and his teaching responsibilities, both of which he misses, and last year gave more than 70 speeches evangelizing for the video project. In an effort to batter the medical establishment into submission with the sheer weight of scientific evidence, he has conducted 13 clinical trials using videos to depict different diseases and situations, and he has seven more studies in the pipeline. He says he gets by on three or four hours of sleep a night. The project has taken over his house. Davis would like her living room back; there are floodlights and a big gray backdrop where her paintings should be.

Volandes thinks he can sustain this pace for perhaps five years—by which time he hopes to have revolutionized American medicine. Davis tries to dial back his expectations, but he resists. "Not when I have nurses and doctors use words like *torture* as often as they do," he says. "In order to make a change, you've

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got to be ambitious. If not, then just publish and get your tenure and move on.”

During my visit, I realized that I had encountered Volandes's type before, but in Silicon Valley. Volandes has entrepreneurial obsessive-compulsive disorder: the gift, and curse, of unswerving faith in a potentially world-changing idea.

It is not a huge exaggeration to say that obsessive entrepreneurs, from Cornelius Vanderbilt to Steve Jobs, made America great. It is also not a huge exaggeration to say that health care, more than any other nongovernmental sector, has made itself impervious to disruptive innovation. Medical training discourages entrepreneurship, embedded practice patterns marginalize it, bureaucrats in medical organizations and insurance companies recoil from it. And would-be disrupters are generally disconnected from patients, their ultimate customers: they have to take their innovations to physicians, who are notoriously change-averse, and then they must get the government—Medicare, first and foremost—to approve and pay for them. Imagine that Jeff Bezos, when he was starting Amazon, had needed to ask permission from bookstores and libraries.

Volandes, therefore, will fail. That is to say, he will fail if success means revolutionizing the doctor-patient relationship and making *The Conversation* ubiquitous within five years. Meanwhile, if the American health-care system does not learn how to harness the energy and ideas of people like Volandes, it will fail. Somewhere between those failures lies a path forward. We know medical culture can change for the better; it takes the treatment of pain much more seriously than it used to, for example, and it has embraced hospice care.

The best news about U.S. health care today is that a lot of reform-minded entrepreneurship is bubbling up from within. Volandes is not alone. So many patients and doctors and family members feel marginalized and bureaucratized and overwhelmed that some health systems and insurers, in spontaneous mini-rebellions, are starting to innovate, often on their own dime. I think of Dr. Brad Stuart of Sutter Health at Home, who is building a new late-life-care system that bridges the gap between hospital and hospice, allowing the very sick to receive more care at home; I think of Dr. Derek Raghavan of Carolinas HealthCare System's Levine Cancer Institute, who is building a “cancer center without walls” that uses telemedicine and other tools to make state-of-the-art treatment available to patients, regardless of where they live. I think of Dr. Woody English of Providence Health and Services, who is 67 and wants to make a difference before he retires. At his instigation, Providence has begun using Volandes's videos. “The changes will come locally,” English told me, “not nationally.” When I look at him and Volandes and the others, I see not only a test of whether the health-care system's medical culture can change but also a test of whether its *business* culture can change—and that change may, in the end, be even more important.

THE MORNING AFTER THE SHOOT, Volandes shows me some of the footage he plans to use. We watch a patient with advanced Alzheimer's being fed through a tube that has been surgically inserted into her stomach. An attendant uses a big syringe to clear the tube, then attaches a bag of thick fluid. Over the footage, Davis's voice will say, *Often, people hope tube feeding will help the patient live longer. But tube feeding has not been shown to prolong or improve the quality of life*

TWO

On a parking-lot staircase
I met two fine-looking men
descending, both in slacks
and dress shirts, neckties
much alike, one of the men
in his sixties, the other
a good twenty years older,
unsteady in his polished shoes,
a son and his father, I knew
from their looks, the son with his
right hand on the handrail,
the father, left hand on the left,
and in the middle they were
holding hands, and when I neared,
they opened the simple gate
of their interwoven fingers
to let me pass, then reached out
for each other and continued on.

—Ted Kooser

Ted Kooser is the author of several books of poetry, including Valentines (2007) and Delights and Shadows (2004), which received the 2005 Pulitzer Prize. He was the U.S. poet laureate from 2004 to 2006.

in advanced dementia. Tube feeding also does not stop saliva or food from going down the wrong way.

Volandes is explaining to me that tube feeding is overused in elderly dementia patients, but my mind has floated back to 2009. My father's disease, by then, had destroyed his ability to protect his airway when he swallowed; food, drink, and saliva ended up in his lungs. He coughed violently when he ate or drank. Doctors mentioned tube feeding as an option, and well-intentioned friends nudged us in that direction. But his friends had no real idea what tube feeding entailed, and neither did I, and neither did he.

“Let me ask you this,” Volandes says. “Suppose I'm having a conversation with you about whether your father would want this. And I said ‘feeding tube,’ and you're thinking to yourself, *Food, yeah, I could give food to my mom or dad.* We just want to make sure that regardless of the way the gastroenterologist is presenting the procedure, the patient's loved ones know *this* is what we're talking about.”

Not long before my father died, I asked a hospice nurse about tube feeding. He told me, with grim clarity: “I think that would be cruel.” I remember that nurse with gratitude, because he was right. But “that would be cruel” was not a substitute for *The Conversation*. ▣

Jonathan Rauch is an Atlantic contributing editor.

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