

# Tough Decisions About End-of-Life Care

Readers offer personal stories in response to a doctor's guest essay about advance directives.

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Credit...Jo Zixuan

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## When Faced With Death, People Often Change Their Minds

Jan. 3, 2022



By Daniela J. Lamas

Dr. Lamas, a contributing Opinion writer, is a pulmonary and critical-care physician at Brigham and Women's Hospital in Boston.

My patient had done everything possible to avoid being intubated. After a traumatic hospitalization when she was young, she had consistently told her loved ones that she would never again agree to a breathing tube. She had even filled out an advance directive years ago to formalize that decision.

But when she arrived in the emergency department one night this past spring with severe pneumonia, struggling to breathe, the doctors called her husband with a question. Should they intubate? If they didn't, she would likely die.

He hesitated. Was this really the scenario that his wife, now in her late 60s, was imagining when she told him that she didn't want a breathing tube? He could not ask her now, and faced with this impossible choice, he gave the team the OK. She was intubated and sedated and transferred to our intensive care unit later that night.

I believed this to be a failure of our health care system: A patient was in exactly the scenario she had long wished to avoid. When I stood at her bedside, I murmured an apology.

After several days, the medical team gathered her family to make a plan. We would continue to treat her pneumonia and try to take her off the breathing tube. Based on our understanding of her prior wishes, we would not put the tube back in once we had taken it out. We would also not consider a tracheotomy, a procedure in which doctors cut a hole in the windpipe to help with breathing for patients who need a longer-term connection to a ventilator. Instead, if she could not breathe on her own, we would focus on her comfort, knowing that she would die. This was what she would have chosen. Or so I thought.

When she was finally awake and off the breathing tube, the team told her what had happened. I assumed that she might feel betrayed by the decisions that had been made for her. But she surprised me. She said she would choose to be intubated again, and even undergo a tracheotomy, if it meant more time with her family.

She had changed her mind. And if the doctors and nurses treating her had made decisions based only on the preferences that she had articulated years ago, we never would have known.

I want advance care planning to work. I want to believe that advance directives — written statements of a person's wishes about medical treatment — can be completed when someone is relatively healthy and offer doctors and family members a clear road map in the event of serious illness.

But experiences like this one, along with a growing body of academic research, are leading me to rethink that belief. Some palliative care experts have begun to ask a controversial question: What if the present model of advance care planning does not actually deliver better end-of-life care?

This would be a major change in thinking for doctors and policymakers. Since the [Patient Self-Determination Act](#) of 1990 went into effect, advance care planning — which encourages all adults, even those in good health, to choose a surrogate to make medical decisions and to draw up an advance directive — has been promoted as the way to make sure that people receive the care they want at the end of their life.

But this well-intentioned effort has not worked as promised. In [a recent](#) commentary published in The Journal of the American Medical Association, Dr. R. Sean Morrison, a palliative care specialist, and colleagues wrote that despite decades of research on advance care planning, there are scant data to show that it accomplishes its goals. A [2020 review](#) of more than 60 high-quality recent studies on advance care planning found no impact on whether patients received the care they wanted, or how they rated the quality of their lives afterward.

When doctors talk to patients about advance directives, they implicitly promise that the directives will help patients get the care they want and unburden their loved ones, Dr. Morrison told me. “And the reality is that we’ve been pushing a myth,” he said.

I once thought that the only barriers to effective advance care planning were practical. Not all people are aware of how to write such a directive, and even if they are, the document [is not always uploaded](#) into patients’ medical records or is easily retrievable.

But the bigger obstacle, and what has increasingly troubled me working in the intensive care unit, is the difficulty of asking people to make decisions about future scenarios.

Humans have an amazing capacity to adapt to illness or disease. From the vantage point of youth or good health, it is easy for people to say that they would rather die than live with significant limitations, pain or dependence on others.

But people evolve in ways they cannot expect. This is why some survivors of catastrophic accidents, such as spinal cord injuries leading to complete paralysis, nevertheless come to rate their [quality of life](#) as good — even if they never would have imagined being able to do so before the accident. As a result, what people are willing to go through to extend their life might change depending on the context. Advance directives written at one point in time about hypothetical scenarios cannot capture what someone actually wants at every point in the future.

A key goal of advance care planning is to free family members from the burdens of making decisions, yet these conversations can paradoxically leave relatives with even more conflict. A loved one may have said years ago that she would want “everything” done. Was she imagining weeks on a ventilator and continuous dialysis without a reasonable hope for recovery?

This does not mean that planning is useless. But there is a better way.

We all should choose a health care proxy, someone who knows us well and whom we would trust to make hard decisions on our behalf, and document that choice in writing. And there is likely some unmeasurable benefit for adults in good health to talk with the people they love about sickness and death. This should not be done in order to make statements about medical treatments that are in any way binding, but to practice what it is like to say those words and experience the complicated feelings that arise when these topics are at hand.

Most important, we need to shift the focus from talking to healthy people about what would happen should they stop breathing during a routine procedure, and toward improving conversations with people who are already seriously ill. All patients for whom these decisions are no longer hypothetical should have a documented conversation with their doctor that focuses less on their thoughts about specific medical interventions and more on their understanding of their prognosis, what is important to them and what gives their lives meaning.

When I am standing at a bedside in the intensive care unit, I want to be able to lean on that conversation. Is my patient someone who would be willing to go through aggressive medical treatments for the possibility of prolonging his life? Or is this someone who would prioritize comfort given the current medical realities?

It's this kind of information that helps medical teams make recommendations about interventions in real time, as we ultimately did for my patient.

After she was taken off the breathing tube, she did well for a few days. But when her breathing grew ragged, she was intubated once again and then had a tracheotomy. She spent a month in the hospital, and when I last saw her there, she was breathing on her own. The tracheostomy tube had just been removed, and a small piece of gauze was put in its place. She would make it home after all.

**More insights from the I.C.U.**

Opinion | Daniela J. Lamas

'You're Dying,' I Told My Patient. I Wish I Hadn't.

Oct. 6, 2021

Opinion | Daniela J. Lamas

What Should Doctors Do When We Experience a Miracle?

July 2, 2021

Daniela J. Lamas ([@danielalamasmd](#)), a contributing Opinion writer, is a pulmonary and critical-care physician at Brigham and Women's Hospital in Boston.

**To the Editor:**

Re "[A Better Way to Face Death](#)," by Dr. Daniela J. Lamas (Opinion guest essay, Jan. 6):

Too often, advance directives are construed as immutable guides to how one dies. We have found advance directives to be more helpful if we focus on how one wants to live.

If we ask about ventilators or dialysis or artificial nutrition, we are typically asking people to express opinions about topics that they do not know well, usually based on preconceived and often inaccurate notions about these medical technologies. It is little wonder, then, when actually faced with the technology, patients will change their mind.

What was once unacceptable may now be tolerable because life still holds a desired quality. The opposite may occur; treatment that was once strongly desired in the abstract may not deliver the quality of life that was hoped for.

Advance directives should accomplish two goals: identification of a surrogate — one who can “stand in the shoes” of the patient, and the identification of preferences — what is important in how you live.

A focus on evolving ideas rather than document completion will be more likely to bring the patient’s voice to decision-making at crucial times.

Margaret M. Mahon

Ann Berger

Bethesda, Md.

*Dr. Berger is chief of the Pain and Palliative Care team at the National Institutes of Health Clinical Center, and Ms. Mahon is a nurse practitioner with the team.*

**To the Editor:**

Dr. Daniela Lamas makes a strong case for careful consideration of advanced directives, but I would also embrace the advanced age of the patient as a critical factor for end-of-life decisions.

I was born during the Hoover administration, so for me death is not an abstract concept. While there is an overabundance of suggestions on how to achieve old age (many involve kale and Pilates), there is less information on what happens when you get there. In one’s 80s bodies begin to lose once reliable mechanisms, and there is no better proof than the aisles of adult diapers in our markets. Foods you once enjoyed penalize you. Mobility issues impose woeful limits. Your address book looks like a cemetery. Each day presents small challenges.

The documented horrors of nursing homes, the toll elder care takes on families and the obscene cost of protracted end-of-life nursing all come into play.

Heartfelt conversations with my aged friends assure me that we would all prefer dying in our sleep to lingering a bit longer in discomfort and humiliation.

The anxiety, indignities and angst of advanced age demand acceptance — and a sense of humor. Like most of my peers, I am not afraid of dying but of being kept alive.

Terry Martin Hekker

Nyack, N.Y.

**To the Editor:**

My dad was one of those people who changed their mind about end-of-life care. Before getting cancer, he thought that his top priority when suffering would be to get lots of morphine.

When he was actually dying of cancer, he discovered that he hated morphine. It made him extremely constipated, gave him disturbing hallucinations and impaired his ability to be present for the many visitors who came to see him in his final illness.

His health care proxy came by every day and turned up the morphine, and my dad always turned it down. He said he didn't have that much pain if he lay still, and he found that he got more relief from holding hands than from morphine.

Anne Barschall  
Tarrytown, N.Y.

**To the Editor:**

Most of us can't exactly predict what will happen when facing death. Dr. Daniela J. Lamas discusses cases common to physicians: Patients change their minds about treatment options, sometimes only to please others.

While some patients are grateful that their wishes were overridden and their lives maintained, others resent unwanted treatments that prolonged their lives and suffering.

Patients should discuss advance directives with their physicians. Physicians should regularly review advance directives with patients to see if patients have changed their minds. New medical conditions and major life events provide reasons to review advance directives, but basically patients have a right to refuse treatments, and physicians should respect patients' advance directives and not override them.

Joel Potash  
Syracuse, N.Y.

*The writer is former medical director of Hospice of Central New York and emeritus professor at the Center for Bioethics and Humanities, Upstate Medical University.*

**To the Editor:**

"A Better Way to Face Death" raises the problematic issue of either the patient's family or the physicians in charge ignoring the wishes expressed in a health care directive because somehow they believe that the patient did not mean the instructions she legally formalized.

Were I the patient described in this guest essay, I would be furious that my wishes were not followed. I am 80, have a health condition that could land me in exactly the same situation described in this piece, and have been unwavering in my insistence that my

wishes never to enter an I.C.U. be followed. To leave it to others to decipher at any given moment if I have somehow changed my mind is exactly why a health care directive exists.

My family knows that what I have written is what I expect. I would want neither my proxy nor the physicians at the bedside to second-guess my wishes.

Susan Meister  
Pebble Beach, Calif.

**To the Editor:**

Dr. Daniela Lamas brought me back to a moment 11 years ago when I was required to decide if it was time to end active medical care for a dear friend. He was in his early 80s, and had fallen and suffered a traumatic brain injury. His lungs were filling with liquid. His medical directive was: If I am going to die, do not take extraordinary measures.

My experience affirmed Dr. Lamas's vision of meaningful conversations at the time of treatment if at all possible and in the presence of the medical team. My friend wasn't conscious, and I was getting conflicting opinions on whether he would die.

My decision, which I live comfortably with today, was to bring six close friends of his into his room. We had the conversation in his presence, and agreed that it was time to revert to palliative care. He died a few days later. A week later, there was a moment when I felt his presence around me, and I understood him to tell me that "everything was OK."

These decisions will be the hardest people will ever have to make. There is no easy way to do it and no real training for these moments.

Sam Simon  
McLean, Va.

**To the Editor:**

I am the son and health care proxy of a 92-year-father suffering from dementia and early-stage aspiration. Dr. Daniela Lamas hints at a truth I learn daily on the other side of the equation: While it is heartbreaking for me to see the father I so deeply love diminished, often lost and confused, he experiences love and joy every day.

Is his "quality of life" what I would wish for him or what he imagined when hale? No. Nevertheless the moments when he meets someone new and asks them questions, when he feels secure when walking because I support him, or remembers some odd, obscure detail of some object in his home, evince that his life has quality.

My “job” is to maximize the positive and manage the negative and pray that I will know when the equation has shifted so much that it is his time, should I have to make that decision. It hurts beyond hell, but it’s his life and it, not mine, is my responsibility here.

Joshua Mack  
New York

**To the Editor:**

Years ago when my mother was in hospice care with terminal cancer, she asked my father, “Am I dying?” He replied, “Maybe.” It was a compassionate answer that was honest, yet left a door open for unexpected changes. I am forever grateful to him for that loving, elegant and inspired moment of communication in her last days.

Paul Langland  
New York