

A Better Way to Face Death

By Daniela J. Lamas

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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.