

The Right Paperwork for Your End-of-Life Wishes

By [Jessica Nutik Zitter](#)

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The patient's heart was barely contracting under my ultrasound probe, like a limp handshake. He was in shock, his ineffective heartbeat unable to maintain the pressure necessary to keep his organs alive.

And now he was on full life support on my service in the intensive care unit.

Our ultrasound completed, the resident resumed her presentation of the case. The troops had already been called in, she assured me. The cardiologists were considering taking him for a heart catheterization to determine if there was a blockage that could be reversed. The respiratory therapists were fiddling with the knobs on the breathing machine. It hissed as it rhythmically inflated and deflated his lungs. The I.C.U. nurse was connecting a dobutamine drip to the large plastic catheter that had been inserted deep into a neck vein by the emergency room physician. This medication is like a shot of adrenaline to a dying heart, conjuring any remaining fumes of life to keep it beating until an intervention might solve or improve the problem. Unfortunately, and far too commonly, dobutamine simply serves to prolong the inevitable, and the patient's heart, which would have tired and stopped long before, sputters along on this high-octane fuel. Our patient was tucked in as we awaited next steps.

“But,” my resident went on, looking at the floor, “the daughters are on their way in. Apparently the patient had told them no machines. They're very upset.”

Suddenly, this case was turned on its head. What had just felt like a satisfying process may in fact have been assault and battery with a dose of hostage taking. None of it intentional. But the effect was the same.

The daughters arrived 20 minutes later. They'd received frantic phone calls from their mother as the paramedics were zapping her husband's chest and performing chest compressions. Before they'd even hung up, he'd been whisked away into the night. They had spent an hour calling several local hospitals before tracking him to our I.C.U.

His wife had been too distraught and overwhelmed to tell the paramedics that her husband, an 86-year-old man with a chronic heart condition, multiple recent hospital admissions and I.C.U. stays at another hospital, had adamantly, repeatedly and clearly told his family he wanted no more of it. No more shocks, no more hospitalizations, no surgeries or catheterizations, no pacemakers.

His daughters rushed right into his room. “You’ve got to take him off,” one of them said. “He absolutely did not want to be on a machine. He made us promise.”

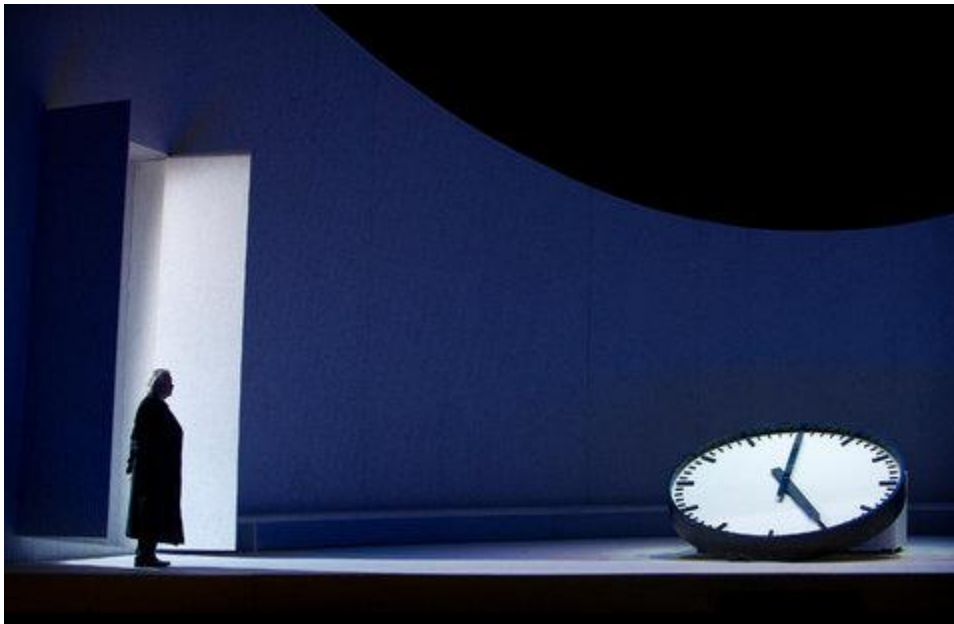
“I’m so sorry this is happening,” I said. “The good news is that he’s calm and sedated, so I think we have a little bit of time to decide how to proceed. The best thing we can do is to make sure we know what he would have wanted in this exact situation, where he was already on a machine and might die if it was removed. Did he ever write any of his thoughts down?”

“His doctor helped us fill out a form.”

“Was it a [Polst form](#)? A bright pink form that you attach to your fridge?” I asked.

“Bright pink? No. It was called an advance directive,” she said, digging around in her purse.

Ah. Mystery solved. This family had planned and communicated about end-of-life issues more than most ever do, but they still hadn’t been shown how to kick the ball through the goal post.



Credit Joshua Bright for The New York Times

There is much confusion around this issue among patients and their families, and unfortunately among physicians as well. Which form is the right one? Who should have a copy?

An advance directive — each state has its own — is indeed an important legal document. Like any insurance policy, it is intended to prepare its owners in advance for difficult times. All responsible homeowners buy home insurance even though they will rarely, if ever, use it. But although everyone will eventually confront the end of life, their own and probably that of one or more loved ones, only about [20 percent of people](#) complete an advance directive.

And even when they do, there is no set of clear and sequential instructions for I.C.U. doctors like me to follow. An advance directive is too reductionist to possibly do that. The human body and its workings are too unpredictable to plan for all possible eventualities. And then there are the myriad other factors: psychological, familial and spiritual considerations.

The advance directive should be seen as a conversation starter, an idea generator, a philosophical tool. It is a guide for your loved ones to work with your doctors and make decisions that are based on your goals and values as the situation unfolds. Its purpose is to chart the broad strokes, to delineate the guiding principles.

But it simply cannot be a detailed list of dos and don'ts.

The form asks that you choose between two general approaches to treatment — to prolong life or not to prolong life. There will be no confusion if you choose the first option — physicians' default setting is to pursue every reasonable treatment, often until death. The problem is for those who would choose the latter.

Although the choice not to prolong life includes clarifying sentences — if the likely risks and burdens of treatment would outweigh the expected benefits, or if I become unconscious and, to a realistic degree of medical certainty, will not regain consciousness, or if I have an incurable and irreversible condition that will result in my death in a relatively short time — those conditions remain very subjective and can leave decision makers and doctors stumped. What does a relatively short time mean? Four days on a ventilator for someone with terminal cancer in excruciating pain might be a fate worse than death. But for someone else it might be a bridge to another six months of good life.

Emergency workers like E.M.T.s and paramedics are legally required to prolong the lives of dying patients unless they have a specific order from a doctor, which an advance directive is not. When called to the side of a dying patient, they do not have the time, the training, or the medical knowledge to try to parse the details of a patient's case. It is understandable that health care personnel on the front lines — E.M.T.s, paramedics and even physicians like myself — err on the side of prolonging life in patients whom we don't know.

And once the patient has been lifted onto the conveyor belt of life support, it can be very hard to take him off. And so a word of caution for those, like my patient, who are absolutely clear that they want to be allowed to die a natural death when the time comes — if you live in a state where it's available, you must complete a Physician Orders for Life-Sustaining Treatment, or Polst form (also known as a pre-hospital D.N.R.), and have it signed by your doctor. It is gaining acceptance rapidly across the nation and at this point Polst forms are recognized in 45 states (information is available at www.polst.org). Some states, like California, are calling for Polst

registries, electronic databases that provide rapid access to this critical information for health care providers.

A Polst form is not meant for use by healthy people, who could recover from resuscitation following trauma or acute illness. It should be used only by those who are unlikely to be restored by life support to a quality of life that would be acceptable to them. This may include the frail elderly or the terminally ill. The form summarizes a doctor's specifications for the use of specific treatments like breathing machines, chest compressions and electric shocks to the heart. It is not open to negotiation or pondering. (Even better, by the way, is a [MedicAlert](#) "Do Not Resuscitate" bracelet.) It is a blunt, clear instruction to the E.M.T.s and all of those who come after them. If the boxes "Do Not Attempt Resuscitation/D.N.R." and "Comfort-Focused Treatment" are checked, emergency personnel have a clear directive to allow a natural death, using whatever means necessary to keep the patient comfortable.

Twenty minutes after the patient's daughters arrived, we sat down together to figure out how to pick up the pieces. They felt that they had let their father down. You might as well kill me, he'd told them; I don't want to be on a machine, ever. I explained that while we couldn't promise anything, there was a very good chance he would continue to breathe on his own if we took him off the ventilator. And more important, if his physiological functions began to fail, we would not abandon him; we would be there with medications and treatments to keep him comfortable until he died.

We took him off the ventilator, and he held steady. And then we sent him home on hospice, Polst in hand, to be with his family for the precious time he had left — to live, this time protected from the type of death he feared the most.

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An earlier version of this article did not make clear that a Polst form is not appropriate for all patients.