

The Trouble With Advance Directives

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The man had written an advance directive four years ago, before his advancing [dementia](#) had made communication difficult. He had been very specific.

In case of a life-threatening condition, “he wanted comfort care only, no heroics,” said Dr. [Rebecca Aslakson](#), a critical care anesthesiologist at Johns Hopkins Hospital in Baltimore.

But last month an uncontrollable [nosebleed](#) caused the 79-year-old to begin [vomiting blood](#). The nursing home that cared for him sent him to a hospital, where doctors put him on a ventilator. They slowed the bleeding, but couldn’t stop it.

After a week and two surgical procedures, the patient was transferred to Johns Hopkins. There, physicians stopped the nosebleed, performed a [tracheostomy](#) (a procedure to create an opening in the throat that would permit long-term ventilator use) and placed a feeding tube in his stomach.

Two weeks after that, a surgeon happened to find the patient’s advance directive in his medical chart. None of the other health care providers had noticed it, which meant they had all inadvertently violated it.

Such missteps occur more commonly than most of us, with our carefully composed documents stored in drawers somewhere, would like to think. They help explain why researchers and medical staff working with patients near the end of life have grown increasingly disenchanted with advance directives, including living wills and powers of attorney for health care.

The patient’s son, who had agreed to life-prolonging treatment, had never been given a copy of the document. “He very much wanted to follow his father’s wishes,” Dr. Aslakson said. But he hadn’t known what they were.

The patient, able to breathe after the ventilator was withdrawn, has returned to his nursing home with Maryland’s version of [a Physician Orders for Life Sustaining Treatment, or Polst, form](#), specifying comfort care only.

That should prevent another round of unwanted treatment. At the moment, though, “maybe severe dementia is not a quality of life he values,” Dr. Aslakson said.

Ever since [Congress passed the Patient Self-Determination Act](#) in 1990, health professionals and consumer advocates have urged Americans, especially older adults, to draw up advance directives and distribute them to families and doctors. The documents allow people with terminal illnesses to accept or reject medical interventions and to appoint surrogate decision makers if they become incapacitated.

The campaign does seem to have paid off in one sense: Among Americans over age 60, the proportion who had advance directives when they died [rose to 72 percent in 2010 from 47 percent in 2000](#), according to data from the national [Health and Retirement Study](#).

Too often, though, an advance directive hardly seems to matter. Stories [abound of documents misplaced](#), stashed in safe deposit boxes, filed in lawyers’ offices. Dr. Aslakson remembers a frantic search to unearth a directive that was eventually found tucked into a Bible.

Frequently, “the directive never gets to the right place, or isn’t referred to when a decision needs to be made,” said David M. English, chairman of the American Bar Association’s [Commission on Law and Aging](#).

And when hope trumps documentation, the patient’s instructions can be overridden. A [hospice](#) staffer told me of an older woman whose directive prohibited life-sustaining measures. Nevertheless, her sister assented to feeding tubes, which a physician had encouraged “just to see if it would help.” The woman lived for months with interventions she had expressly rejected.

But advance directives also fail because they are not medical orders. Their vague or outmoded language — When is a condition “terminal”? How long must a “persistent vegetative state” last? — doesn’t tell physicians exactly how to proceed.

“The ambiguities can result in receiving treatment for a longer time while they’re ironed out,” said [Dr. Susan Tolle](#), director of the [Center for Ethics in Health Care](#) at Oregon Health & Science University.

Moreover, emergency medical personnel operate under standing orders to attempt resuscitation, whatever an advance directive says. (Only a state do-not-resuscitate or Polst form can prevent that.) “You may already be on a breathing machine before you pull into the E.R.,” Dr. Tolle said.

The Polst form [does a better job than advance directives](#) of keeping dying people out of hospitals, research has shown. Completed by health care professionals in consultation with patients, this document can stipulate that only comfort measures be applied, or full life-prolonging interventions — or various options in between.

But a Polst can't always substitute for an advance directive. It is meant for people with severe illnesses: Asked if the patient's death within a year would be a surprise, their doctors would say no. "Most people over 65 are still too healthy to have a Polst," Dr. Tolle said.

Besides, putting Polst into effect requires a coordinated statewide system involving hospitals, [nursing homes](#) and hospices. Oregon and West Virginia, the pioneers, have well-developed systems with electronic registries, said Dr. [Alvin H. Moss](#), who directs the West Virginia University [Center for Health Ethics and Law](#).

Another 15 states have programs endorsed by a national task force, and 24 more are developing them, "so about 40 out of 50 states are well along," he said. (Confusingly, states use varying nomenclature to describe these documents: [Molst](#) in New York, [MOST](#) in Colorado, [Lapost](#) in Louisiana.)

In the meantime, people who aren't sick or frail, but have strong feelings about what should happen when they are, can't rely on a Polst or an advance directive alone.

What they really need, experts say, is an ongoing series of conversations with the relatives or friends who will direct their care when they no longer can. In a crisis, doctors will turn to those people — more than to any document — to learn what the patient wants.

Triggering those discussions may be the most useful thing an advance directive accomplishes. (Websites like [The Conversation Project](#) and [Prepare](#) can help.)

"Talk about what things make life worth living for you," Dr. Aslakson advised. People feel reassured, even downright virtuous, when they have completed their paperwork, "but if the family doesn't know about it, if the medical team doesn't know about it, it might as well not exist."

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