

Why Do We Avoid Advance Directives?

By Paula Span

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When I visit my father, I make a point of checking: Is that battered leather folder full of legal documents sitting in its usual spot in the den?

At 86, Dad is managing quite nicely in his own apartment. But the day will likely come when he'll face choices about how much medical treatment to undergo, and he may be too incapacitated to make or express such decisions. It could happen in 10 years or next week; whenever it is, I want to be able to lay hands on one of those documents, called an advance directive for health care. In it, he authorizes me "to make decisions in my best interest, based upon what is known of my wishes."

We've had a number of conversations about those wishes, he and I. Nevertheless, the document goes on to specify what my father doesn't want (no C.P.R., ventilator or feeding tube) and what he does want (pain relief) in the event that he becomes "permanently unconscious" or is diagnosed with "an incurable and irreversible illness" that two doctors deem terminal. Nothing on paper can make such a moment less than wrenching, but the lack of something in writing can make it much, much worse.

It's startling how few Americans have advance directives, an umbrella term including living wills that state your wishes and health care proxies that designate someone to carry them out if you can't. A [Pew Research Center survey in 2006](#) found that only 29 percent of people had a living will; in 2007, a [Harris Interactive study \(PDF\)](#) put the proportion with advance directives at two in five. Even among "severely or terminally ill patients," the majority had no advance directives in their medical records, researchers for the federal [Agency for Healthcare Research and Quality reported](#) a few years ago.

That can put both physicians and families in an awful bind. If a terminally ill parent lands in a hospital and daughter A tells the staff no, no feeding tube, will daughter B accuse her of killing their mother? If daughter B tells the staff to go ahead and turn on a respirator, will son C argue that no, after the Terry Schiavo case in Florida, their mother declared she never wanted to be kept alive by machines? Sometimes, a hospital ethics committee has to get involved. Sometimes, courts and lawyers do.

"It gets so emotional," said Ronda Hughes, co-author of the A.H.R.Q. report. A onetime cardiac critical care nurse in Boston, she's seen "people crying, screaming, threatening."

"When you're faced with those decisions, you can't say, 'Let me get back to you in a week,'" she said.

If only the patient had left clear instructions!

So why don't we?

One reason is that advance directives may be misperceived, theorized Nathan Kottkamp, a health care attorney in Richmond, Va., and organizer of this month's National Healthcare Decisions Day. People may equate such documents with limiting care, with "pulling the plug." In fact, Mr. Kottkamp said, "Your living will can say you want every medical treatment known to science applied to you at the end of life. Or no treatment. Or anywhere on that spectrum."

Maybe people may think drafting an advance directive is complicated and expensive and requires a lawyer. But forms for every state (state laws regarding advance directives differ) are widely available on the Internet, at the [National Hospice and Palliative Care Organization's Web site](#) or through the [National Healthcare Decision Day site](#), among

others. An advance health care directive doesn't have to cost more than a couple of bucks for a notary.

People can have dreadful accidents or face incurable illness at any age, of course. Ms. Hughes, after she finished the A.H.R.Q. study, promptly drafted a highly specific advance directive for herself. She's 42. But most Americans die not suddenly, but of chronic diseases associated with aging. So I'm grateful that my father has an advance directive. As I steam towards 60, I have one myself.

The sad fact is that even with an advance directive, your designated decision-maker may still face a fight in trying to follow your instructions. It's not uncommon for doctors to disagree with a family about what should be done; it's not uncommon for family members to disagree — sharply and painfully — with one another. But, as Mr. Kottkamp said, "It's an uglier fight if you don't have the documents."

I hope my daughter is up for the battle, should one arise. At least, I tell myself, I've given her the ammo.

Paula Span is the author of "When the Time Comes: Families With Aging Parents Share Their Struggles and Solutions," to be published in June by Grand Central Publishing.

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