

In the last few years, one study after another has reported how ineffective advance directives are, and one speaker after another has pointed out how advance directives have failed to achieve their intended purposes. Recently, at a conference for members of Alzheimer's support groups, I heard a well-informed, educated, well-intended co-presenter, a physician/ethicist say, "Everyone knows living wills aren't worth the paper they are written on." Now our own publication, *Bioethics Forum*, adds to that body of literature.

Questions that challenge the usefulness of advance directives are by now familiar:

- How can clinicians know with confidence that true clinical circumstances will match the scenarios the patient was concerned about when he or she completed the document?
- Are patients well enough informed at the time they indicate their preferences?
- When patients indicate they *never* want to be on a ventilator, do they *really* mean they wouldn't be willing to do so, even for a short time, if it meant they could return to life as they had known it before they were unable to breathe independently?

Guest Editorial

Myra Christopher

- What if the patient changes her mind?
- What if a patient's durable power of attorney contradicts decisions the team believes are indicated in the directive?
- When a directive indicates that a patient does not want life-sustaining treatment but indicates she would want antibiotics, what can clinicians deduce about other interventions?

I recognize the problems. I understand the arguments, and I appreciate them.

In recent years, Midwest Bioethics Center has distributed more than 1.5 million advance directives. Members of our speakers' bureau have presented more than 1,000 educational programs about them, and our small staff has responded to thousands of phone calls and letters. I have made dozens of presentations all over the country about the importance of advance care planning. Our ethics committee consortium consulted with Senator John Danforth in

drafting the Patient Self-Determination Act, and I had the privilege of being with Senators Danforth and Moynihan the day they introduced PSDA and was honored to speak at the press conference immediately following.

Advance directives have not led to the progress in patients' rights for which we had hoped. The number of adults who have completed documents still is unacceptably low. The SUPPORT study and similar research inform us that even when we have completed valid documents, crossed every "t" and dotted every "i," our wishes may not be followed because clinicians may not take the time to read or to discuss the documents we give to them. They may honestly not understand how our directions apply to the situation at hand.

Even a clearly written document may leave ambiguity and doubt about what is right. But taken in their totality, I do not think these are reasons to abandon advance directives.

The reason for continuing to encourage people to make advance directives is to promote conversations among physicians and patients and patients and their families about end-of-life decisions. In doing so, we promote end-of-life care based upon and respectful of the goals and values of patients. It is the *communication* which leads to or results from the making of an advance directive that is important. It is not documents, forms, pieces of paper, witnesses, or notary publics themselves. Advance directives are, at best, tools to facilitate difficult conversations, conversations that seem almost impossible to have in clinical situations.

We *should* be critical of the current situation. There is still much

work to do, but to reject advance directives is, in my opinion, premature. Advance directives will continue to:

- empower people to discuss concerns with their clinicians
- stimulate families to talk about advance care planning
- promote useful ethics consultations

Abandoning advance directives now because not enough people complete them or because not enough show up in medical charts or because not enough physicians read them is throwing out the baby with the bath water.

I close with a story that happened some years ago, not long after the Cruzan decision was handed down by the United States Supreme Court and people were in a frenzy to control their treatment at the end of life.

early departure.

My new secretary announced that two gentlemen outside my office were asking for help. Someone at Saint Luke's Hospital had sent them over, she said.

I could see them now through the open door, sitting silently side by side, looking strangely out of place in the cramped office waiting room. At first I thought they were twins — middle-aged, slightly overweight, with pleasant, weathered faces. They were dressed alike — plaid polyester shirts with silver snaps down the front, well-worn baseball caps on their heads. CHEVY was emblazoned across the front of one in hot pink letters; the other read PIONEER SEED. They reminded me of wranglers from my hometown in Texas.

"Help with what?" I asked.

"Filling out an advance directive."

We at the Center had constructed, lectured,

distributed, and explained advance directives for months. And I had talked family and friends through the questions on the form innumerable times in recent months. But I had never helped a stranger.

I looked out at the pair again, and noticed now that one was slightly older, in charge, it seemed. He spoke occasional words to the man on his left, inclining his head solicitously to hear the reply. And there was concern etched on both men's faces.

Wranglers and Words

I was in my office at Midwest Bioethics Center, then located on the second floor of a small brick office building in midtown Kansas City. It was hot, I remember. One of those Kansas City days when even kids leave swimming pools early to retreat into the cool, dark shadows of television sets, and a steamy haze hangs over asphalt parking lots. In the office we had shed as much clothing as decent and fans assisted the over-burdened air conditioning unit as staff worked feverishly toward an

"Of course," I said. I pushed aside papers and smiled as the two men walked into the room and settled themselves in two chairs opposite my desk.

They were brothers, it turned out, born on a farm in southern Missouri. Then both had taken to the road, driving 18-wheelers across the country. The older brother took charge now, explaining that his brother had a tumor as big as an orange at the base of his brain. Surgery was the next day and they wanted things in order first. I watched his brother as the older man talked, saw the emotion sweep across his face; soon his eyes filled and he began to weep. He lowered his head in embarrassment.

"Can't control his emotions," his brother explained gently. "Part of the disease." He patted his brother's arm.

"Don't worry about that," I said. "We all cry around here."

And then I pulled out the advance directive form, placed it between us on the desk, and explained what it was all about. At first we went through the questions easily, and the younger brother answered with assurance. And then we came to the clincher — describing quality of life.

"The bottom line here is what are you willing to live with? What condition would be too much..."

He began to weep again and I pushed my box of tissue across the desk. We each took a fistful.

"His wife was sick, you know," the older brother said.

The other nodded, his thoughts turning to someone he clearly had loved deeply. "Tillie was in a wheelchair before she died," he explained. She had been sick for a long time. Been up to Mayo's and all over before they knew to call it post-polio syndrome.

"But it didn't stop her," he went on. "Tillie was something else."

Both, then, launched into stories of this well-loved woman who had raised two girls and refused to let a diagnosis or a wheelchair stop her.

"She got along just fine," her husband said, and they told stories of Tillie in the kitchen, chopping their home-grown vegetables at the specially built counter and keeping the household together.

When they told how she had written special rules for softball to accommodate her wheelchair, her husband began to laugh, and his laughter, too, came out in huge, uncontrollable heaves until he slumped, embarrassed, in the chair.

His brother hugged him. "Tillie was quite a lady," he said. "And that wheelchair just became part of her," he said.

His brother wiped his eyes. "I could do that, too. I could live in a wheelchair just fine. That would be okay." He nodded at the advance directive.

And back we went, to the intimate details of what he could live with. What he could not live with. And Tillie was there in the deciding. They talked about how her illness progressed, how she finally

couldn't breathe on her own anymore so they put her on a machine. Both brothers tensed as the memories grew strong.

"No," Tillie's husband said. "I would not want to live like that. Not on a machine. It was terrible for her."

I wrote as he talked, dictated his words exactly as spoke, as he clearly articulated his beliefs, his wishes.

He named his brother as durable power of attorney and when it was all over, we stood and all of us hugged each other.

I called the hospital the next day and learned that he had come through surgery all right and was in intensive care.

I never heard any more from the two brothers. I still think of them now and then. I hope the man with the brain tumor had a "text-book" recovery and is out today driving his truck over the open road. But if his surgery and recovery didn't go well, if there were complications, if "decisions had to be made," I know his brother was prepared. I know his directive gave insight and understanding into the wishes of this fine man. I know the time I spent with him was well spent, and I know I am wiser for having had the opportunity to learn from him.

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