

# A new approach to end-of-life directives

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Even for the 29 percent of Americans who have filled out basic legal paperwork to make their final wishes known, a drawn-out, undignified and uncomfortable hospital death remains all too possible, medical policy specialists admit.

And for the remaining 71 percent, such an end is even more likely.

"In many respects we've been doing a really bad job with end-of-life care, and we've done that for a long time," says Kenneth Goodman, director of the University of Miami's bioethics program.

"We have family members who insist that we do terrible things to their dying loved ones. We stick tubes in people and cardiovert them" — shock their hearts — he said.

So after decades of struggle to improve end-of-life care, and to give patients' wishes some power over the long reach of medical technology, an increasing number of U.S. health care professionals are supporting a new way to slice through the confusion, pain and sadness that can surround a hospital or nursing home death.

The emerging solution is a medical order form that instructs health providers to honor a patient's wishes — ranging from simple comfort care to the most intense and heroic measures.

The document, originating in Oregon in 1991, is known as a POLST.

"POLST" is not the prettiest acronym.

But with a growing emphasis on trying to make life smoother for terminally ill patients and their families, it looks likely to become a prominent part of the national conversation. Seen as an improvement over the controversial DNR — do not resuscitate order — the "physician orders for life-sustaining treatment" document is now an accepted aspect of medical care in five states.

These states — Oregon, West Virginia, Idaho, Utah and New York — have set up registries for POLST forms, giving paramedics and hospital staffers immediate guidance in emergency situations. While some states are moving to adopt the POLST approach through legislation or regulation, the strategy in Florida is to test this new tool in pilot projects around the state and build enthusiasm for the concept far from the political arena.

"We decided that what we need to do is get grassroots support, get providers and institutions to experiment through various pilot programs, to gather experience and data," said Marshall Kapp, director

of the Florida State University medical school's Center for Innovative Collaboration in Medicine and Law. "The data will allow us eventually to go to the Legislature and say, 'We don't have some crazy new abstract idea we're asking you to codify. We have experience that works.'"

Pilot projects are in early stages at JFK Medical Center in West Palm Beach, Suncoast Hospice in the Tampa Bay area, Citrus Memorial Hospital in Inverness, and the University of Miami and Jackson Memorial hospital systems in South Florida.

### **'The final common pathway'**

Because the POLST is signed by a person's doctor and more precisely reflects that person's wishes, advocates argue, health care providers and emergency responders are more likely to follow its instructions.

With so many health care providers involved in an end-of-life case, someone has to be "the final common pathway of all the patient orders and all the patient care," explained Robin Fiore, who teaches at the University of Miami medical school and leads the hospital's ethics committee. "That person is the doctor in the hospital culture."

The most widely used patient documents — known as advance directives — can help a person avoid the kind of ventilator-assisted existence that has befallen the ailing South African leader Nelson Mandela.

But they usually apply to life-support issues, such as whether to "pull the plug." They do not rule out aggressive life-saving measures that can leave a fragile patient alive but damaged.

Preventing resuscitation calls for a DNR — which is often not offered to a patient before a hospital stay, Fiore said, "especially in places like Florida. You may not in fact have one written until the day before the patient dies. We're not good at having that conversation with family members."

And designation of a health care surrogate — someone to make decisions if a patient is incapacitated — does not guarantee that the chosen person will understand or respect an individual's wishes. Quite often, the opposite can happen, Goodman, the bioethics professor, said.

"What they say is, 'I want you to beat the crap out of mom, so I don't feel guilty,'" he said.

The two-page model Florida form is simple.

Filled out by a physician in consultation with the patient, it first declares a preference about cardiopulmonary resuscitation in a crisis. Then it goes beyond the DNR, to spell out whether the patient desires comfort measures, limited intervention or full treatment.

"Our goal was to enhance the conversations that occur between doctors and patients," Fiore said. "Every physician has a view about what's the best way to treat patients at the end of life. We want patients' views."