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New tool lets patients call the shots at end of their lives



David Joles, Star Tribune

"I want to die just like he did. Wouldn't that be what we all want?" Carol State, on husband Doug, who died at home.

The document allows people to discuss and spell out medical wishes before a crisis hits.

By **JOSEPHINE MARCOTTY**, Star Tribune

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Doug State entered hospice care two years ago knowing exactly how he wanted to die: at home in Cambridge, Minn., with his wife,

Carol, and his dog, Teddy.

He got his wish a year ago at age 83, when his failing heart finally stopped just as he was sitting down to breakfast at his kitchen table. What Carol State remembers most clearly about that moment is that she was able to hold her husband and tell him she loved him as he left her life forever.

It almost didn't happen that way. But State was one of the first people in Minnesota to obtain a new kind of medical document that told his family and doctors exactly what kind of care he wanted at the end of his life.

Now, that same directive is slowly being adopted at hospitals, nursing homes and hospices across the state as part of a quiet groundswell within the medical community to give terminally ill patients more control over how and where they die.

The document has an awkward name -- Provider Orders for Life Sustaining Treatment, or POLST -- but it seems to work. Where it is standard practice, most notably Oregon and La Crosse, Wis., far fewer people die in intensive care units hooked up to machines they didn't want.

More importantly, experts say, the document

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and the careful decisionmaking that precedes it lift a terrible emotional burden from patients' families.

"If he had been in a hospital, we would have had to make the decision to pull everything," said Carol State, 71. "He saved us from having to make it."

Breaking the silence

Such end-of-life medical planning is assuming more importance in the debate over a health care overhaul, and has even turned into a red-hot political ignition point. Proponents argue that billions of dollars are wasted in aggressive, expensive medical treatments for people in their last weeks of life. Opponents have derided such end-of-life planning services as "death panels."

Supporters in Minnesota say it's actually about breaking the silence around death and giving patients what they want at the end of their life -- whether it's comfort care or as much intervention as possible.

"The reality is that patients are not allowed to make informed decisions about their medical care," said Dr. Donald Grossbach, director of hospice care for Allina. "They [should] have the right do that."

In recent years, Americans have tried an array of tools to direct care at the end of life -- living wills, advanced care directives and do-not-resuscitate (DNR) orders. Most of the time, experts say, they don't work. For example, polls show 90 percent of people say they want to die at home, but only 20 percent do.

"We were hopeful twenty years ago," said Mary Faith Marshall, a professor of bioethics at the University of Minnesota. "But fewer than 10 percent of people actually use an advanced directive."

Advanced directives and living wills are long, complex legal documents, experts say. Often they grow outdated or lie buried in a drawer at home, little use to frantic relatives or doctors, nurses and paramedics who have to make instantaneous decisions in an emergency.

To replace them, Minnesota's largest health care organizations have a statewide plan to do more advanced care planning and to make POLSTs the standard of care for patients in hospice or long-term care.

The documents will be placed with other medical records -- a uniform bright yellow, s

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o relatives or paramedics can find them.

This year Allina Health System plans to use specially trained staff to talk to at least 4,000 patients about end-of-life planning, including POLSTs for 1,500 patients in hospice and long-term care.

An emergency

Doug State, for one, was clear about his wishes and had a DNR order. But a few months later, when Carol was away from home and her daughter was caring for him, he suddenly got dizzy. Her daughter got scared. "She couldn't reach me," said Carol State. "She did not know what to do."

Paramedics rushed Doug to the hospital in Cambridge. When Carol arrived, doctors and nurses were working frantically to keep him alive. She told them he was in hospice care, and her other daughter said, "This is not what he wanted."

But in a hospital or clinic, the drive to save a life often overrides everything, and State was airlifted to a Minneapolis hospital. He ended up exactly where he didn't want to be: far from home, in intensive care.

To Carol's joy, Doug survived, and a week

later he became one of the first patients in Allina's pilot project. Carol and Doug State sat down with a nurse from Allina's hospice program and talked through his goals and wishes. He checked a box saying he chose not to be resuscitated. He checked one saying he wanted to go to a hospital only to help alleviate uncomfortable symptoms. He wanted no tube-feeding or fluids if he was unable to feed himself.

He and his doctor signed the document, and it became a part of his electronic medical record. A copy was posted on the couple's refrigerator door.

To experts like Grossbach, the document itself is less important than the conversations that precede it. Sure enough, when Doug died three months later, he didn't need the POLST because Carol knew not to call the ambulance. "It was what he wanted," she said.

Converting the skeptics

Some health care experts remain skeptical that POLSTs solve the underlying problem.

"We basically have an ongoing non-discussion on the topic of end-of-life planning" in this country, said Dr. Steven

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Miles, a bioethicist at the University of Minnesota. "Until families talk about it, it doesn't make any difference how you rearrange the bureaucracy."

Doctors don't generally talk about it either. Beth Virnig, a professor of health policy at the U, surveyed 4,074 doctors about advanced care planning with terminally ill patients. Her study, published in the journal Cancer, found that half would wait until all curative treatments had failed before discussing end-of-life care. "There is this idea in medicine that if you can't cure them your job is over," she said.

Nonetheless, over the last two decades POLSTs have made a difference in La Crosse. Dr. Bud Hammes, who has led the program there for two decades, said the key was giving the responsibility to trained nurses and facilitators, not doctors, and making it a regular part of part of health care.

Today, he said, at death 96 percent of the patients at La Crosse's Gundersen Lutheran hospital have an advanced care directive, a POLST or both. Only 30 percent die in the hospital, compared with 50 percent nationally.

Experts say it could take a long time before

POLSTs become routine in Minnesota. But they already have at least one convert.

Doug State lived his last days at home with his wife and the pets he loved, and died at his kitchen table without tubes and machines, just as he planned. "I want to die just like he did," said Carol State. "Wouldn't that be what we all want?"

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