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The Unwitting Birthplace of the 'Death Panel' Myth

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LA CROSSE, Wis. -- This city often shows up on "best places to live" lists, but residents say it is also a good place to die -- which is how it landed in the center of a controversy that almost derailed health-care reform this summer.

The town's biggest hospital, Gundersen Lutheran, has long been a pioneer in ensuring that the care provided to patients in their final months complies with their wishes. More recently, it has taken the lead in seeking to have Medicare compensate physicians for advising patients on end-of-life planning.

The hospital got its wish this spring when House Democrats inserted that provision into their health-care reform bill -- only to see former Alaska governor Sarah Palin seize on it as she warned about "death panels" that would deny care to the elderly and the disabled. Despite widespread debunking, those warnings have led lawmakers to say they will drop the provision.

"It's really distressing," hospital official Bud Hammes said. "These things need to be addressed."

President Obama's health-care initiative was nearly consumed by the furor over that provision, and Republicans continue to argue that the legislation would ration care for the elderly. The debate has underscored how fraught the discussion is on end-of-life care in a country where an optimistic ethos places great faith in technology and often precludes frank contemplations of mortality. That tendency has a price tag: A quarter of Medicare costs -- totaling \$100 billion a year -- are incurred in the final year of patients' lives, and 40 percent of that in the last month.

But the controversy has had most resonance where it arguably took root, in this town of 52,000 where nearly everyone of a certain age has an advance-care directive.

La Crosse became a pioneer in addressing end-of-life questions in the mid-1980s, after Hammes, a native of the city who has a doctorate in philosophy from Notre Dame, arrived at Gundersen as the director of medical humanities, charged with educating resident physicians about ethics. He noticed a "troubling pattern," he said, in which family members struggled to make medical decisions, such as whether to continue dialysis after a stroke.

"We'd turn to the family and say, 'We need your input. If your mother or father could speak now, what would they tell you?' And the family would say, 'If we only knew,'" said Hammes, 59. "I could see the distress. They were going to have to live with themselves, with the worry about making a mistake. This was unacceptable."

The hospital began urging families to plan while people are healthy. For those who want help writing a directive, a physician will discuss the powers and limits of medicine and explain to family members what it means if they agree to serve as the "health-care agent." They will also help people define the conditions under which they would no longer want treatment. Hammes said people often define this as "when I've reached a point where I don't know who I am or who I'm with, and don't have any hope of recovery."

The directives are power-of-attorney forms that protect physicians and family members against liability, and the hospital makes clear to its doctors that they are expected to follow them. Today, more than 90 percent of people in town have directives when they die, double the national average.

The reliance on directives has an impact on the type of care people receive: Gundersen patients spend 13.5 days on average in the hospital in their final two years of life, at an average cost of \$18,000. That is in contrast with big-city hospitals such as the University of California at Los Angeles medical centers (31 days and \$59,000), the University of Miami Hospital (39 days, \$64,000) and New York University's Langone Medical Center (54 days, \$66,000).

Those disparities are not explained just by the hospital's end-of-life philosophy. Under Medicare formulas, Gundersen and other Upper Midwest hospitals receive lower reimbursements. The high-spending hospitals argue that they are also dealing with a more diverse and costly patient base.

Gundersen and other Upper Midwest providers are also less costly in general, partly because they follow a model of integrated care where doctors work closely together to minimize waste. At Gundersen, doctors receive a salary instead of being paid for each procedure they perform.

But locals say the city uses less health care in large part because of how people view the end of life. Some of this may be rooted in the down-to-earth sensibility of their German and Scandinavian forebears. (Hammes said his late mother, who had dementia, was a "pragmatic German" who thought that paying to keep herself alive was a "waste of her money.")

Mostly, though, locals say it is because Gundersen and the town's other hospital, Franciscan Skemp, have urged planning. "People here have their feet planted in the ground," said Barbara Frank, a retired teacher. "They're no-nonsense sorts of people, without a lot of illusion. That was the fertile soil upon which it was planted. But there's no question it was helped by the two medical centers taking the lead and saying, 'This is a good thing for you to do.' "

She and her husband, Donald, a retired train engineer, signed a directive 10 years ago, when they were in their 60s. "You increasingly realize that they're not going to make an exception in your case. We all die, and we want to do so with the most dignity and most control," she said. "It seemed a no-brainer. And it spares our children from making those decisions."

Over time, the practice caught on. "People talk to people who talk to people. They say, 'Do you have one?' 'Yeah,' or 'I have to get that done,' " said Ann Kotnour, a nurse whose 89-year-old mother is receiving care at home for her advanced Parkinson's after signing a directive in 2001 saying she did not want aggressive measures taken.

Financial planner Jeff Lokken's parents had met with their children and doctors in the mid-1990s to draw up directives, a step that was helpful a few years later, when he and his siblings needed to decide whether to keep their 77-year-old father on a ventilator after heart surgery. The living will also helped when his mother's health failed when she was 82. "There needs to be a conversation. In our case we had good conversations," he said.

But Gundersen staff members say those conversations take a lot of time -- a good hour, plus follow-up talks to alter directives as medical situations evolve. And Medicare does not reimburse doctors for the time spent on such discussions.

Backed up by a few other hospitals, Gundersen set out to change the federal rules to reward end-of-life planning. A Gundersen administrator testified on Capitol Hill last fall, and, with the help of a lobbyist, reached out to lawmakers such as [Sen. Herb Kohl](#) (D-Wis.), [Sen. John D. Rockefeller IV](#) (D-W.Va.) and Rep. [Ron Kind](#) (D-Wis.).

After sporadic bipartisan attempts in recent years to add consultation payments to Medicare, [Rep. Earl Blumenauer](#) (D-Ore.) submitted legislation this spring, with several Republican co-sponsors, that included a provision to reimburse doctors for consultations. A few months later, House Democrats tucked similar language into their health-care reform bill -- a legislative triumph for the small hospital in La Crosse.

Then the uproar began, capped by Palin's "death panel" remark. Gundersen officials and town residents were aghast. "It's totally absurd," Frank said. "It's just the opposite -- it's giving you a choice of how you want to be treated."

Gundersen officials were particularly upset when [Sen. Charles E. Grassley](#) (R-Iowa), whom they had considered an ally, said that the government should not "pull the plug on Grandma" and that the provision would be dropped. They were also dismayed when the provision was criticized by former House speaker Newt Gingrich (R-Ga.), who had been open about how much he appreciated the end-of-life care his father-in-law received at Gundersen.

Rep. Paul D. Ryan (R-Wis.) admires Gundersen generally but said it erred in pushing for Medicare to cover consultations. "It's right and proper for Gundersen to innovate in these directions, but it's a wholly different thing for the federal government" to endorse end-of-life planning, he said.

Gundersen officials are still fighting to keep consultation payments in the bill, with support from Sen. Mark Warner (D-Va.), who has become a leading advocate for such planning. But this week, word came that the White House is willing to drop the provision. The hospital officials are even less hopeful about more ambitious terms they sought to add -- changing Medicare payments for end-of-life care so that they are based not on the procedures a patient receives in the final months but on whether care complied with the person's wishes.

No matter what, they will keep trying to get payment for consultations into future legislation. "The [directive] itself doesn't really matter very much -- it's the clearly expressed belief and shared understanding that it represents," Hammes said. "The family members have to believe that what they do is not only legally right, but personally right. If Mom said, 'Don't do this or do do this,' it's much easier for them to say, 'I'm doing a loving thing,' and it's a decision you can live with."

The discussions do not promote less aggressive care, he said: "We're not trying to talk them into anything. We're trying to understand their values and goals, and tell them what medical science can and can't do." But many people do settle on less care. "In our community," he said, "people don't want to die hooked up to machines."