

Dying wishes: Advance care planning in La Crosse, Wisconsin

by [Jennifer L. Hollis](#) in the [November 12, 2014](#) issue



PLANNING AHEAD: The health system in La Crosse offers many opportunities to talk about end-of-life care. PHOTO COURTESY GUNDERSEN HEALTH SYSTEM

When Jean and Paul Pearson married in 1991 they made a commitment to treat each of the six children in their blended family as their own. “There are no stepchildren,” says Jean. In their will the Pearsons listed all the children as equals. Since they were already thinking about end-of-life choices, they also completed a living will.

Twenty-one years later, Paul went to the emergency room for breathing problems. When he and Jean looked at the x-rays they could see that he had lung cancer. Paul received chemotherapy but knew early on that he was not going to recover. “The doctor said he could give us one or the other, quantity or quality,” says Jean. “We opted for quality of life.”

Paul was treated at Gundersen Health System in La Crosse, Wisconsin, where a remarkable 96 percent of patients have made a plan for their deaths. The advance care planning program at GHS, which is called Respecting Choices, provides training and certification to advance care planning facilitators who have conversations with patients and their families about their values and beliefs and help them document their choices for future medical care.

Not long after Paul’s diagnosis, the Pearsons reviewed Paul’s advance directive with a representative from Respecting Choices. Paul “did not want to go to a nursing home if that could be avoided. He did not want to be resuscitated,” said Jean. At the end of his life, Paul used oxygen to ease his breathing but took no other heroic

measures.

Once Paul and Jean had a plan for Paul's medical care, they made a bucket list. Paul wanted to continue to play pool, attend historical reenactments with Jean, and celebrate his birthday. At his party he gave diamond pendants to his daughters and to Jean, all made from a ring he had inherited from his father. He gave each of his sons a pocketknife from his collection.

Paul died in January 2013. Jean says the conversation about care was a gift and just as important as having a will.

"It's not an easy conversation," she says. "But once you sit down and talk about the pros and cons, and about how your choices will affect you and the rest of the family, a huge boulder is taken off your shoulders."

Advance directives were developed in the 1970s to give patients more control in light of proliferating medical technologies. According to a recent Pew Research Center survey, only 35 percent of U.S. adults have put their wishes for end-of-life medical treatment in writing.

Respecting Choices was born out of a desire to improve patient care by understanding patients' values and goals. It emerged in the 1980s, when Bernard Hammes, now Respecting Choices director, was a clinical ethicist for GHS. Hammes had held ethics consultations with the families of several patients with end-stage renal disease who had been disabled by strokes. The patients could not communicate and had no advance directives; as a result, their families did not know what the patients wanted. Hammes talked with members of the Gundersen ethics committee about a new advance care planning program.

A March 1991 profile of the La Crosse community revealed that only 15 percent of residents had some form of advance care planning. Health-care leaders created a task force and set a goal: the number of critically ill patients admitted to the hospital with an advance care plan in their medical records would increase to 50 percent.

The two health systems in La Crosse decided to collaborate on a standardized approach to advance care planning. They created educational materials with a common name and logo. They engaged religious and civic leaders, attorneys, educators, and librarians in developing the program. And they provided training and ongoing education to more than 120 local advance directive educators.

In 1998 the first La Crosse Advance Directive Study was published. While it was not designed to be an evaluation of the education program, it seemed to have had a profound impact on the use of advance directives. In a review of 540 medical charts, the number of patients who had died with advance directives in place had increased from 15 to 85 percent. When the LCAD study was replicated ten years later, advance directive use had risen to 90 percent.

Today, GHS offers individualized advance care planning in three stages: First Steps ACP is for healthy adults 55 and over; Next Steps ACP is for patients with chronic, progressive illness; and Last Steps ACP is for frail elderly patients or those close to the last year of life.

Verona Lachman is an RN care coordinator in the GHS Palliative Care Department and an advance care planning facilitator. When she talks to patients about their choices, she is surprised by how open they are about their deepest concerns and about dying. Although the conversation can be emotional, patients are relieved to communicate their fears about being in pain or having difficulty breathing. Lachman explains treatment options and reassures patients that they are not going to suffer. She also helps them plan for modes of treatment, including being able to stay at home.

A few months ago Lachman went to a patient's home for a Next Steps conversation. The patient's spouse and five children were present. The patient had lung cancer and did not want to be put on a long-term ventilator. Lachman, who's been trained to help patients discuss disease-specific scenarios, explained that patients with lung cancer sometimes contract pneumonia, which might require a short-term ventilator during treatment. The patient decided that she would want a ventilator if she developed pneumonia.

When the patient did develop pneumonia, doctors thought she would not recover, but her family asked that she be put on a ventilator and she improved. When the patient saw Lachman in a restaurant she hugged her. "Thank you for being my advocate," she said. Lachman describes this as an "aha!" moment for her. "People who hear about Next Steps conversations or advance directives think it's about dying. It's not about dying. It's about how you want to live."

Respecting Choices has succeeded because it multiplies the number of opportunities patients have to express their wishes and make them understood to relevant

caregivers. According to a Respecting Choices training manual, “Building a Systems Approach to Advance Care Planning,” the model has four key elements. First, the program includes a standardized advance directive document, a reliable referral system, and a record system that allows caregivers to view and update a patient’s wishes from any site of care.

Second, Respecting Choices provides training and certification to advance care planning facilitators. Third, it engages members of the community so that patients receive information about advance care planning from trusted community members as well as from medical providers. Finally, Respecting Choices regularly measures how well the system honors patient wishes.

The advance care planning facilitators are at the heart of this system. Carol Berra is a nurse in the outpatient clinic at GHS and the coordinator for Next Steps facilitators. “I’ve always had a sense of the patient’s right to choose,” she says. “[They have] a right to information, and with that information the right to choose the kind of care they have.” Berra discusses advance care planning in the huddle of clinic staff and providers who check in with each other each day before patients arrive.

When a patient’s situation makes it appropriate to initiate a Next Steps conversation Berra talks to the patient about the benefits. First, the conversation gives patients a chance to look at specific medical situations related to his or her disease. Second, it helps a health-care agent to become comfortable about making choices on the patient’s behalf. Third, it helps the patient receive the kind of care the patient wants. “I always say, ‘If we’re not asking you, then how do we know what you want or don’t want?’” said Berra.

Berra was part of a Next Steps conversation with Louise Butterfield and her eldest daughter. Butterfield had worked as a health unit coordinator for 37 years at GHS and had helped many patients complete advance directives. “We need to prepare our family, and we need to prepare ourselves, both mentally and spiritually,” she said.

Butterfield had an advance directive that named her daughter as her health-care agent, but she had not had a Next Steps conversation until Berra suggested it. The conversation gave her an opportunity to think more carefully about her choices. “Advance care planning is not just for family members. It’s for us too,” she said. “We want to make sure our wishes are carried out.”

Though it has brought advanced care planning to a remarkable number of people, Respecting Choices has encountered some resistance. Britt Welnetz, the organization's business development consultant, said that she is often asked whether a nonphysician facilitator can effectively discuss medical decisions. She explains that the standardized, patient-centered conversation leads to an overall level of patient satisfaction.

Others ask if the Respecting Choices model can work in a community that's more diverse than La Crosse. Research indicates that it can. The Respecting Choices program was implemented in a hospital in Milwaukee, and the use of advance directives among racial and ethnic minorities increased substantially from 25.8 percent to 38.4 percent. Research suggests that it's knowledge of advance directives, regardless of race and ethnicity, that leads to their use.

The advance care planning facilitator model has gained acceptance both nationally and internationally. Respecting Choices has trained more than 10,000 facilitators, as well as nearly 600 instructors and nearly 30 faculty members who can implement system-wide changes. There are facilitators in 47 states in the United States, and Respecting Choices is the national standard of care in Singapore and Australia; the program is also the model for an \$8.5 million European Union study of advance-stage cancer patients and end-of-life care.

Advance care planning can transform families in unexpected ways. "I've had patients come back and say, 'After that conversation my kids come around more often,'" says Verona Lachman. Talking about end-of-life choices can help family members understand the disease process and realize the patient needs more help.

Advance care planning is most important when a loved one is called on to honor a patient's wishes. Lachman facilitated a conversation between a very active 90-year-old patient and his son. The patient mentioned a friend who'd had a stroke and was unable to speak and said that in the event of a stroke he did not want anything done.

Three years later the patient had a stroke. His son honored his wish to have only comfort care. He told Lachman, "Making that decision to let my dad go to comfort care was the hardest thing I've ever done." He added that the decision was easier because he knew what his dad's wishes were.

“He could no longer speak and live life as he had been living it,” said his son. “He wouldn’t want to live like that.”