

When the doctor can do no more

Pontiac hospital program that eases the way for dying patients and their families gets national honor

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July 11, 2006

Most people who end up at the bedside of a dying patient aren't there by choice. Nurse practitioner Peg Nelson is someone who is, dedicated to making sick and dying people more comfortable.

Just as some medical professionals specialize in cancer, some in feet, others in kids, Nelson specializes in pain. The Supportive Care program at St. Joseph Mercy Hospital in Pontiac deals with pain relief and end-of-life management. Nelson's efforts for the 26 years she's worked at the hospital have helped create a culture of improving comfort and the quality of care for patients with chronic pain and end-stage illnesses.

For her efforts in support of patients and their families during one of the hardest times of life, Nelson and the program will receive a Circle of Life award, which includes \$10,000, from the American Hospital Association on Thursday in San Francisco.

Nelson's work is based on just the value the award honors: pain management. She focuses on managing patients' pain and making them more comfortable, "helping people die better," she says. For most doctors, the point when nothing more can be done to cure a patient signals the end of their efforts. Nelson, director of pain and palliative care, says that's when her job begins.

"A lot of doctors walk away when they feel they can't do anything more. I'm the one who always has something else. ...

"There's a team of us, chaplains, other nurses, doctors," she says. "All of us feel the privilege" of being there to share those moments and serve patients and their families.

Nelson's team is skilled in assessing a patient's pain: "On a scale of 1 to 10, what is the pain?"

"Is it more like a burning or an ache?"

"Are there any other questions you'd like to ask about your sickness?"

Nelson, 48, wrote her master's thesis on resuscitation and is board certified in palliative care. She began focusing on end-of-life care when she thought about how often dying patients were being resuscitated, usually unsuccessfully, in an attempt to stave off death.

One of the special parts of Supportive Care is a program called No One Dies Alone. Nelson helps coordinate more than 40 volunteers who can be called to sit with patients in their last moments of life.

"People who are dying are afraid of two things: pain, and being alone," Nelson says.



Pontiac St. Joseph Mercy Hospital Nurse Practitioner Peg Nelson, right, visits with Miyoshi Scott of Auburn Hills, who is on dialysis and has other serious health problems. Her program has won an award for its care of severely ill patients. (Photos by REGINA H. BOONE/Detroit Free Press)

What you can do for someone who's dying

- Share with the dying person what he or she has meant to you: "You were a great dad," or, "I learned so much from you."

- If you are part of the inner circle of loved ones, continue to speak to the dying person, say what you need to say, and help him or her let go.

- Letting go is also important for those left behind. Say good-bye. It achieves closure and makes the final release possible.

"There were just so many times I'd walk into the room and there would be nobody there."

Having another presence in the room not only eases the fear of the dying person, but also relieves the regular staff, and the potential guilt of family members who are unable to be present.

"I think it's a privilege. It's a journey that's like watching a baby be born. It's miraculous. Even though it's death, there's something very magical and beautiful about it," Nelson says, but concedes, "It does get overwhelming at times."

Every Thursday morning at 8 a.m., Nelson gathers with the Supportive Care committee -- an interdisciplinary hospital group that works to spread improvements in pain management and the care of dying people throughout the hospital. Nelson leads committee members through a list of the patients who are in the most pain, some with multiple medical problems, some in their last days of life.

Last Thursday, the list had 15 names.

One dying patient sobbed for her dog when she realized she wasn't going home. Another worried about the grandchildren in her care. A few others are in and out of the hospital, and Nelson has come to know them well.

As Nelson makes her rounds from patient to patient, harp music, courtesy of volunteer Margaret Warczak, tinkles through the halls of the ICU and dances with words like Ativan, Dilaudid and Valium. The harp is only one of the comforting tools. Every floor has a comfort cart that holds music, a CD player, a Bible and homemade blankets that the families can take home.

Each patient needs a different approach, and after so many years Nelson can tune in to their needs with precision. Each topic is gently broached to gauge the patient's attitudes and willingness to talk about it. "Lots of stuff going on here," Nelson often begins. "Sometimes people with this type of illness want to know what will happen to them," she'll say before talking about death with a terminal patient.

Patient Kathy Light, 55, of Lapeer, had lung cancer. Nelson also cared for Light's sister, who died of pancreatic cancer; her husband, who died of liver cancer; and her father, who died of a stroke.

"She and I cried together because I didn't want to do for her what I'd done for her sister, dad and husband," Nelson says.

On Sunday, as Nelson and two of her children were traveling to San Francisco to receive the Circle of Life Award, Light died.

Barbara Hertzler, executive vice president and chief operating officer at St. Joseph, says, "Peg has an incredible passion. When you're around her for a very short period of time, she's real infectious."

"The most impressive thing Peg has done is to raise people's awareness," says Dr. Don Bignotti, vice president of medical affairs and chief medical officer.

"People in pain have probably been overlooked for too long, because people have always assumed that pain was part of the illness that people felt was, for lack of a better word, acceptable," he says.

Continuing her rounds on Thursday, Nelson is called to a meeting of family members in a dying patient's room. They're here to say good-bye as she's removed from a ventilator. Three generations listen to Nelson explain that the patient has had a massive stroke, her brain has serious injury and she would have already died if she weren't getting help breathing. "She's actively dying right now," she tells them.

• If you're not part of the inner circle, you may be feeling left out. You have given what you can and can say good-bye.

Source: The Final Days by Mercy Supportive Care Service, St. Joseph Mercy

How to volunteer

To volunteer with Mercy Supportive Care, the No One Dies Alone program, contact Peg Nelson at nelsonp@trinity-health.org. The next volunteer orientation for No One Dies Alone training is July 29 at 9 a.m. Pre-registration is required.

Nelson helps prepare the family for what will happen next. They learn about the sounds the throat makes after a tube is removed. They hear what will happen -- sometimes people don't breathe at all and die quickly; sometimes they breathe and live a while longer.

The tube is removed, and the woman in the bed peacefully breathes on her own. Family members take turns holding her hand. Nelson strokes her forehead and says, "Isn't that better?" She's talking to the patient, not her family. Assume she knows you're there, she tells them, talk in your normal voices. Finally, the tension in the room lifts, and the family members wait for the last moments.

Nelson sometimes brings her children to work. Her oldest son, Steve Yakel, 21, volunteers with the No One Dies Alone program. She wants her kids to experience the feeling of helping someone.

Many people cannot imagine Nelson's job, thinking it's too depressing.

"I get asked that all the time," Nelson says. "I don't get depressed. I get very sad." As for the \$10,000 award, Nelson and others in the program are considering using it for family rooms for sleeping or watching television.

She's proud of the program she helped build and thankful for the hospital's support. "They've given me everything I need," she says.

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