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## Hospice: Easing the journey for the terminally ill 5 organizations in area offer help to dying, families



Sharon Schmidt immerses herself in nature's beauty at Hospice of Northwest Ohio.  
( THE BLADE/JEREMY WADSWORTH )

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Some mornings it's still fairly dark when Sharon Schmidt heads outdoors, hoping to again glimpse a deer in the trees, among the flowers, or at the pond's edge.

"I'll get up early in the morning and sit outside," the 48-year-old mother of two said. "It's just real peaceful."

That feeling is precious these days for Ms. Schmidt, who was diagnosed a couple of months ago with pancreatic cancer that has spread to her stomach.

About a month ago the Monroe woman moved into Hospice of Northwest Ohio's center in Perrysburg Township, where pain relief and emotional support are available whenever she needs them.

"The nurses are great," Ms. Schmidt said. "They need to be a nurse and psychologist all in one."

An increasing number of terminally ill people are choosing hospice care for their final months or weeks, forgoing aggressive treatment and learning to accept their impending deaths. The goal of hospice is to get patients' pain and other symptoms under control so they can mentally and spiritually prepare for death - and enjoy life as much as they can.

Yet hospice has become more than just a service for the dying and their loved ones, who get help with care-giving and counseling. Hospice, after all, is not a place but a philosophy of end-of-life care, and many patients remain at home with the support of loved ones.

Hospice also is a business - often a competitive one.

The Toledo area alone has five hospice organizations, although the oldest - Hospice of Northwest Ohio - remains by far the largest and best-known after 26 years in existence. The other local nonprofit, Visiting Nurse Hospice & Health Care, has been part of Toledo's ProMedica Health System for a half-dozen years and expects to double its patient load this year before opening an inpatient center in Sylvania next spring.

Three of the other hospices are for-profit entities, with the largest believed to be the one owned by Toledo's Manor Care Inc., which is being purchased by Carlyle Group, a private-equity firm. Officials for Manor Care's Heartland Home Health Care & Hospice declined to be interviewed.

## For-profit, not-for-profit

The number of for-profit hospices nationwide has been on the rise since Medicare started reimbursing for end-of-life care in the early 1980s, a trend that troubles some patient advocates worried that striving for profits and pleasing shareholders will supplant care or services. Cutting corners or outright fraud is a risk - and, at times, a reality, they say.

The parent company of one local for-profit hospice, Odyssey HealthCare Inc. of Dallas, agreed a year ago to pay the federal government \$12.9 million to settle allegations that it submitted false Medicare claims by billing for patients who were not terminally ill and ineligible for the entitlement. The Odyssey office in Maumee that serves areas patients, however, was not involved, said Janet Firestone, the office's general manager.

There is, of course, potential for problems with nonprofit agencies too, said patient advocate Ron Panzer, founder of the Hospice Patients Alliance Inc.

"Just because it's a nonprofit doesn't mean it's all about compassion and care," Mr. Panzer said.

He also warned: "People need to be aware of what services are required to be provided. If their loved ones aren't getting those services, they need to speak up."

### THE ROOTS OF HOSPICE

The first modern hospice to provide specialized care for dying patients was founded 40 years ago in a residential London suburb by physician Dame Cicely Saunders. At St. Christopher's House, a combination of pain relief and holistic care was used to meet the physical and emotional needs of dying patients and their loved ones. Volunteer-based hospices cropped up in the United States a few years later, but most hospices now are run by either nonprofit or for-profit agencies. Medicare began covering hospice care for terminally ill patients in the early 1980s, and many state Medicaid programs and most private insurance plans also cover the care.

Medicare covers doctor services, nursing care, medical equipment and supplies, medications, and other expenses related to terminal illness by giving hospice programs a daily rate depending on the level of care. For routine home care, the most common level, hospice programs get about \$130 a day.

Medicaid also covers hospice services in Ohio and some other states, as does most private insurance plans.

The biggest disadvantage of having competing hospices in an area is that they all vie for the same core group of the highest-skilled employees, which can also be positive by helping boost wages overall, said Michael Galazka, executive director of the Hospice Education Institute.

"Competency is the key to everything in successful hospice care," he said.

Meanwhile, for-profit hospices pay taxes and don't solicit donations like their nonprofit counterparts. And a national for-profit, such as privately held SouthernCare Inc., the latest hospice to come to the Toledo area about three years ago, can transfer a patient to another area served by the company to be near family without disrupting care and get other corporate assistance, said Patty Eyink, community relations director.

Hospice of Northwest Ohio, however, can offer whatever will help patients - including massage, music, and art therapies - because the nonprofit does get additional income from donations, said Judy Seibenick, executive director.

"There are differences between hospice providers, and we encourage people to shop around," she said.

Even among each type of hospice, nonprofit and for-profit, there are differences.

Hospice of Northwest Ohio does only hospice care, and it has the Perrysburg Township center and another in South Toledo to house up to 49 patients if needed. ProMedica's Visiting Nurse has both hospice and home-care services, and it is opening a 12-bed hospice center next year as part of Flower Hospital's \$42 million Cancer Institute.

None of the local for-profit hospice organizations has an inpatient center. Both Odyssey and SouthernCare offer just hospices services, while Heartland also does home care.

There is room in the Toledo market for multiple providers, said Ms. Firestone, the local Odyssey manager.

"Even with all of us here, there's so many people that don't utilize the benefit," said Ms. Firestone, adding, "A lot of families just try to take it all on their own."

### **Education is key**

About a third of Americans who died in 2005 were under the care of a hospice program, according to the latest statistics from the National Hospice and Palliative Care Organization.

More than 1.2 million Americans received hospice care in 2005, up from 700,000 five years before, the organization said. Of those 1.2 million patients, 800,000 died, it said.

Education is the key for hospice, which some people mistake for a death sentence instead of care at the final stage of life. Doctors are becoming more willing to refer patients to hospice, a condition Medicare requires for admission, and now providers need to better educate patients, said John Kimberly, a management professor at the University of Pennsylvania.

"The growth of hospice really has less to do with business than it has to do with being the right thing to do," Mr. Kimberly said.

He added: "I'm really hopeful now the roots of the movement are deep enough. I believe they are."

The need for hospice will continue to grow because people are living longer overall and surviving longer with terminal illness, and the large baby-boomer generation is advancing in age, said Nancy Host, vice president of ProMedica's home care and hospice.

As with any major event, patients should plan how they want their lives to end, and hospice care helps them achieve physical and emotional comfort, Ms. Host said. Grief counseling for loved ones after patients' deaths is another critical component of hospice, she said.

"We don't help them to increase the duration of their lives at all costs because sometimes that just isn't living," Ms. Host said. "But that's a very personal choice."

SouthernCare's Ms. Eyink kept track of the late Otto Herman for nearly a year after she saw the Northwood man struggling in a Pharm store and talked with him about his battle with lung cancer. They talked every week, and when Mr. Herman's doctor recommended hospice after a second unsuccessful chemotherapy attempt, he knew whom to call, said his widow, Joyce Herman.

Mrs. Herman continues to miss her husband of nearly 49 years, who died April 14, but the compassion Ms. Eyink and other hospice workers showed the family in the last few months of his life was wonderful, she said. Hospice provided a hospital bed with a special mattress that helps prevent sores, along with other items, and a social worker would take walks with Mrs. Herman while the home-health aide was with her husband, she said.

"I always told him I'd take good care of him, but I couldn't have made it without hospice," said Mrs. Herman, who treasures a teddy bear with a final recorded message from her husband.

### **Misconceptions**

Despite the growing use of hospice care, a number of misconceptions remain.

Hospices, for example, no longer care just for cancer patients such as Ms. Schmidt and Mr. Herman. At Hospice of Northwest Ohio, which has more than 400 employees and typically cares for more than 430 patients a day, less than half of patients have cancer.

With other diseases or conditions, though, it is harder to predict how long patients have to live, Hospice of Northwest Ohio's Ms. Seibenick said.

Under Medicare, hospice patients are expected to live less than six months, although a doctor can recertify patients who live longer. Patients can leave a hospice program if they improve, decide to resume aggressive treatment, or transfer to another organization, managers said.

Patrick and Mary McManamon of Toledo continue to hope for a cure for Parkinson's disease despite his entry into hospice.

For two decades, Mr. McManamon repeatedly adjusted to the disease's symptoms progressively transforming his body, but his struggles intensified four years ago. The McManamons researched and considered both surgery and brain stimulation to ease the effects of Parkinson's, but they had concerns about the risk for life-altering problems afterward.

After much discussion about death and dying, Mr. McManamon started being cared for by Hospice of Northwest Ohio eight months ago.

"It's something that doesn't dawn on you right away," said Mr. McManamon, 72, a retired math teacher. "You think, 'I'll deal with it - I've dealt with it so far.'"

Said Mrs. McManamon: "It wasn't a matter of giving up on life, but to live well and to embrace this mystery of life that is approaching us."

With the help of a home-hospice aide, Mr. McManamon has resumed composing e-mails and letters, tasks he was no longer physically able to do. Hospice care has helped improve his sleep and lessen his pain and provides other benefits, the couple said.

Mr. McManamon gets daily visits from hospice staff or volunteers, which help when Mrs. McManamon is teaching special education at Springfield High School.

"Really, now Pat's just loved five times more," she said. "It's really made Pat's life so much better."

### **Seeking care**

So many times, though, patients and families don't seek out hospice care until shortly before death, which is troubling because staff members can only address physical and not emotional needs, local hospice managers said.

Hospice of Northwest Ohio board members were alarmed to see their organization's average length of service was about two weeks less than the national average. So it started an advertising campaign to raise awareness and has increased that measure to be on par with the national average at 59 days, said Judy Lang, director of communications.

"We recognize, really, that advertising will help all hospices, and that's fine," she said.

Toledoan Tom Colvin, whose first wife, Audry, died of cancer at 53 after a year's illness, advises patients to seek hospice care as soon as they need it. The retiree had struggled to teach school and take care of his wife, who died in 1994, until Hospice of Northwest Ohio helped them in her final weeks.

"I am constantly telling people, 'You need to do it as soon as you possibly can,'" he said.

Mr. Colvin has volunteered for the organization for more than a decade, and he even headed up volunteer landscaping crews at the Perrysburg Township center for several years. He continues to do outdoor work at the center and has become a home-care volunteer, which at times calls for gardening, he said.

"People who are gardeners and are dying are often worried about their gardens," Mr. Colvin said. "I have people who absolutely can't die until their garden is OK."

### **Settling in**

For Ms. Schmidt, whose sister discovered Hospice of Northwest Ohio on the Internet, going to one of the organization's centers and getting 24-hour care were the best option as her life draws to a close.

"If I was home, and I woke up at 2 o'clock in the morning in pain, I would have to figure out which pill I was supposed to take," she said. "I take anywhere from 20 to 30 pills a day."

Ms. Schmidt said she enjoys jewelry-making sessions and other activities at the center, but among her chief concerns are her daughters' reactions and the waiting, Ms. Schmidt said.

"I think the worst part is not knowing when," she said.

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