Hospice fosters dignity in dying

More people choosing home-based care for their end-of-life needs

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Agnes Wirth knows each day could be her last.

The 91-year-old grandmother and great-grandmother suffers from heart failure and diabetes. She swallows six pills in the morning, a couple in the afternoon and six at night. But she has led a long life and is ready to die.

"I want to sit here in this chair and say goodbye to everyone. This is where I want to die," Wirth said as she glanced around the cozy apartment in Seymour that has been home for more than two decades. Without hospice care, she might have ended up in a nursing home or a hospital. Instead, she lives at home and plays cards with friends several times a week.

More people like Wirth are opting to spend their last days in hospice or palliative care programs — a combination of medical and home-based care — and as the population ages, the numbers likely will continue to grow. Still, some say the medical field may not be as prepared as it should be to handle this shift in philosophy over end-of-life care that focuses on dying.

Its origins and advancements

Hospice programs serve thousands of people like Wirth, patients with terminal conditions who need a combination of medical and home-based care.

In 2005, 1.2 million people opted for hospice care, and a third of the nation's 2.4 million deaths occurred in hospice programs, according to a Wharton School of Business analysis.

This represents a 36 percent increase from 2002, and a 55 percent increase over 2001, according to data collected by the National Hospice and Palliative Care Organization.

In Wisconsin, the Department of Health and Family Services reported a nearly 20 percent increase — from 15,236 hospice patients in 2003 to 18,213 in 2004.

There are more than 3,000 Medicare-certified hospices around

Certified nursing assistant Mary Cady visits with 91-year-old Agnes Wirth on Friday at her apartment in Seymour. Photos by H. Marc Larson/Press-Gazette

Hospice in Wisconsin

- In 2004, 61 hospice programs served 18,213 patients.
- Hospices in Milwaukee, Dane and Brown counties served 55 percent of all hospice patients — or about 10,000 patients.
- Northeastern Wisconsin is home to five hospice programs, which serve more than 2,000 patients per year.
- Unity Hospice in Green Bay estimates it serves about 400 patients on an average day; Heartland Hospice of De Pere looks after about 150.

Source: Department of Health and Family Services

What is hospice?

- "The whole philosophy of hospice affirms that each person should have death with dignity," said Sarah Wilson, associate professor in the college of nursing at Marquette University.
- Hospice focuses on caring, not curing and, in most cases, care is provided in the patient's home. Hospice care also is provided in freestanding hospice centers, hospitals and nursing homes and other long-term care facilities. Hospice services are available to

the country with about 61 located in Wisconsin. That number isn't static, either — in the past few years, the state has added at least two new hospice programs annually, says Melanie Ramey, executive director of the Madison-based Hospice Organization & Palliative Experts of Wisconsin.

In Northeastern Wisconsin, there are five hospice programs that serve the area, including the oldest hospice program in the state — Unity, which has served the area since 1977.

Medicare and Medicaid both cover the majority of hospice-related costs. To qualify, a physician has to determine that a patient has fewer than six months to live, given the nature of the illness, and refer him or her to a hospice-care program.

Despite the six-month prognosis, people often live longer and can still continue to receive hospice care.

"It's a very nice benefit that some people are just not aware of," said Rochelle Salinas, administrator of Heartland Hospice in De Pere, which has been in the area for four years and serves about 150 patients a day.

A hospice is not a place, although many programs set up residential services. The services can be provided at home, at nursing homes or at hospitals, although about 80 percent of people choose to remain home, Ramey said.

"It provides anything the patient needs — hospital beds, commodes, soft music, pain management," Ramey said. "It varies a lot depending on what a person wants."

patients of any age, religion, race or illness. Hospice care is covered under Medicare, Medicaid, most private insurance plans, HMOs, and other managed care organizations.

- Typically, a family member serves as the primary caregiver and, when appropriate, helps make decisions for the terminally ill individual. Members of the hospice staff make regular visits to assess the patient and provide additional care or other services. The hospice team usually consists of: the patient's personal physician, hospice physician (or medical director), nurses, social workers, clergy, counselors, trained volunteers and other therapists.
- Hospice isn't a new concept. It's been around since mediaeval times, when the word referred to a place of shelter for ill or tired travelers on a long journey, according to the National Hospice and Palliative Care Organization. The idea was then applied to care for dying patients in the 1960s by an English doctor Dame Cicely Saunders, who is credited with founding the first modern hospice in London. But it wasn't until 1986 that hospice care became a benefit under Medicare.

Source: National Hospice and Palliative Care Organization; Sarah Wilson, associate professor in the college of nursing at Marquette University

A multidisciplinary team of nurses, doctors, social workers and clergymen is involved in each case — their visits vary by need. For Agnes Wirth, nurse Mary Cady of Unity checks in about three times a week to help her bathe and fills her medications for her. A social worker then alternates weekly visits with a clergyman.

"They are experts in caring for people at the end of life, whereas a hospital environment is more focused on finding a cure," said Sarah Wilson, an associate professor in the college of nursing at Marquette University in Milwaukee.

Initially, Wirth had concerns often expressed by others in her position: How much would it cost, and would it allow her to live in her home? Thanks to Medicare and the adaptive nature of hospice care, both her concerns were assuaged.

A doctor's role

Unlike controversial end-of-life topics such as doctor-assisted suicide, hospice care enjoys a positive reputation.

"People are just becoming more aware of hospice and what it does," Ramey said. "People use it, they tell others and word just gets around."

As the aging population grows, it's not difficult to imagine that more people will choose hospice care, said Rance Hafner, medical director for Unity Hospice in Green Bay. Since he joined the organization about five years ago, the patient load has doubled to about a 400 patient load on an average day.

Despite an increased awareness of hospice programs among doctors and nurses, medical training is lagging behind.

"We're really taught to think in terms of fighting for life, so it's hard to come to terms with death," Hafner said.

Nurses are better equipped to handle hospice duties because many nursing programs have a practical component within a hospice program, Wilson said, although in 1995 the American Board of Hospice and Palliative Medicine began certifying physicians.

This fall, the board expects the American Board of Medical Specialties to recognize hospice medicine as a specialty, according to its Web site.

"Both nursing and medicine recognize that we need to do a much better job caring for people at the end of life," Wilson said. "We need to increase the amount of end-of-life training in curricular and look at how we educate practitioners."

Although family members can also make referrals — many of them do for relatives living in assisted living facilities or nursing homes — physicians must be involved in some capacity, Salinas said.

"It's not necessarily making a change in philosophy as a broadening in their philosophy," Salinas said.