

HealthCare

Hospice houses help provide comfort at life's end

"You matter because you are you. You matter to the last moment of your life, and we will do all we can not only to help you die peacefully, but also to live until you die." Cicely Saunders, founder in England of the modern hospice movement that spread to this country.

By Kathleen Schwar
Freelance writer

Ten years ago Mt. Carmel House opened. Then Isaiah House. Then Sunset House, Advent House, Elisha House, and September House. And soon, perhaps, Benincasa. Clifton Springs has House of John; Geneseo, Teresa House.

All are homes for the terminally ill and provide hospice care. However, legally they may not be called "hospices." Only Medicare-certified agencies such as Genesee Region Home Care, Visiting Nurse Service, and Ontario-Yates Hospice (of the Finger Lakes VNS and Health Care) can call their programs for the terminally ill hospices under official regulations.

The care at the certified agencies is

primarily home-centered (and sometimes at hospitals and often now in nursing homes). But often the patient has no family or friends who can be the required primary care givers.

"This is where the little 'hospice houses' have come into play," said Kathie Quinlan, RN, director of Isaiah House, 71 Prince St., Rochester. "We always say it is a collaboration between a certified health agency, the hospice house, and the attending physician."

These "little hospice houses" here are an unusual development. Maggie Duncan of the National Hospice Organization estimates that 25 to 50 hospice houses exist in the United States, with the majority being larger residences. "This is a new trend. I'm not even sure you can call it a trend yet," she said.

Indeed, Rochester-area hospice houses have had requests for start-up advice from Alaska to Florida.

Rose and Raoul Grossi opened Mount Carmel House, 4 Planet St., Rochester, July 16, 1984, at the urging of Dr. Fernando Ona. It was apparently the first hospice house in the state.

Because of the modern hospice movement's growing acceptance in the United States since the first program opened in 1974, about 250,000 people and their families are estimated to be served annually by more than 2,000 hospice programs in this country. Most insurance plans cover hospice care, as do Medicare and, in New York, Medicaid. Providers expect any health care reform legislation to include hospice care, as it has proven so cost-effective.

"We've all grown and understand what hospice is about. It's really a philosophy," said Pam Brady, hospice manager for Visiting Nurse Service. "We've increased our catchhold of who we can serve, and figure out a way to do it."

Three criteria for official hospice pro-

grams are: 1) the patient has a terminal illness and the attending physician believes the patient has six months or less to live, 2) the patient agrees to treatment that is comfort-giving rather than aggressive, and 3) the patient has someone to be designated primary care giver who at least will oversee the care plan.

"The biggest misconception is that you have to go to bed and just start dying," Brady said. "The whole purpose is to keep the person functioning as well as possible and maintaining a quality of life."

Hospice care (from *hospes*, Latin for host, guest) centers on serving physical, social, emotional, and spiritual needs. A hospice house requires as many as 90 volunteers a week to care for two residents. A staff nurse/director is present during the day and is on-call during the night. A physician may be on-call on a volunteer basis. And a home health-care agency supplies an aide usually overnight. Generally residents have a prognosis of three or less months left to live. Most have cancer. Some have AIDS.

Aggressive measures are out. "We don't do CPR, intravenous or artificial feedings, and typically don't use antibiotics because they are life prolonging," Quinlan said.

Having become inevitably entwined with the health-care system, the hospice movement has been criticized for often losing its original primary focus of spiritual care. Agency hospice programs and hospice houses in the Rochester area, however, talk of their spiritual focus. Many are ministries of churches or at least have their support. For example, the Livingston County Coalition of Churches organized Teresa House, which opened a year ago in Geneseo.

Lise Kunkel, RN, assistant director of House of John, explained that first of all, comfort is essential for residents. "If

you aren't physically comfortable it is hard to address your spiritual or social comfort. We work hard to make the person as comfortable as can be at a level they can handle. Some want to be more alert, others want to be out of pain entirely. When people are in pain, there is more anxiety, more depression."

Residents may ask a clergy member they've known to visit. If unfamiliar with a religious organization, they may ask for a visit to be arranged. Sometimes even a volunteer will sit and talk with them.

"It's not something we'd ever let go by the wayside," Kunkel said. "Just to explore with somebody, having a discussion, holding their hand, feeling and understanding what their beliefs are, and how they're changing as they approach death."

"What nurses your spirit?" Quinlan asks. "Is it music? Nature?" An Isaiah House volunteer found that for one woman it was "being psalmed" for hours, either with someone reading the Psalms or a tape recorder playing them. House of John found that for a farmer, it was watching the budding trees and flowers outside. He was moved to a recliner by a window for three hours. VNS volunteers took a man fishing.

A spiritual attitude is pervasive in a hospice, and it is not just relegated to a pastoral care counselor, said one such counselor, Jim Mulcahy with VNS. Nurses and aides are trained to deal with death and dying, family dynamics, and other aspects. "Hospice really deals with people in critical times of their life when bridges need to be built where they may not have existed before, and we've gotten good at it," he said.

Beverly Clark, supported by St. Catherine of Siena Parish in Mendon in her current quest to start Benincasa ("good home") and St. Catherine's fam
Continued on page 7A

When Health Care Decisions Are Necessary and Comprehensive Services Are Needed, Call...

We provide the Highest Caliber
• Registered Nurses • LPN's • Home Health Aides • Personal Care Aides •

We provide flexible, dependable service at reasonable rates. Our employees are carefully screened and supervised. All services are available 24 HOURS A DAY, 365 DAYS A YEAR.



JCAHO Accredited
New York State Licensed
242-0050
1655 Elmwood Ave.



(716) 436-9800
1-800-836-9729
FAX (716) 436-5340
7 DAY COVERAGE 8:30-5 DAILY
200 Buell Road • Suite 14
Rochester, NY 14624

IN HOME X-RAYS • EKG's
ULTRA SOUND • HOLTER MONITORING



When You Need Us

Residents are assisted by trained staff who are on duty around the clock. Services included in the daily charge are:

• Private or semi-private rooms, furnished or unfurnished, featuring air conditioning and the latest in smoke detector or sprinkler systems. Semi-private rooms are ideal for married couples.

- Three meals and two snacks each day
- Supervision of medication and special diets
- Supervised bathing
- Extensive activities program
- Religious services
- Transportation for shopping
- Housekeeping
- Personal laundry service
- 24-Hour supervision

Services available, but not included in the daily charge are:

- Beautician
- Private telephones
- Cable television
- Newspapers

Call
381-0282



2006 Five Mile Line Rd. • Penfield, New York

"I'm always there
on Sunday.
It's the other days I
worry about."



"After we leave and
Mom's all alone, I always
worry about her. But
now that she has Handi-
Call, I worry a whole lot
less."

With HandiCall, the touch of a button connects you to experienced professionals who have all of your emergency information - from neighbor's numbers to ambulance service - at their fingertips, and can summon whatever help you request.

You can rent Handicall for a small monthly fee, and keep it as long as you like.

For more information contact:
HandiCall
a program of St. John's Home
150 Highland Avenue
Rochester, NY 14620
(716) 461-5280



HandiCall
It's there when you need it.