

Caring for the terminally ill

Hospice volunteers don't try to cure patients

By Richard Ballo
Contributor

Hospice is not a place. It is a working concept of patient care to make the last days of life high in quality, as pain free as possible, in an environment of care and support. That caring environment is mostly the home. However, sometimes this care is given in a hospital, or a nursing home.

"A larger and larger percentage of the Massachusetts population have had direct or indirect experiences with hospice care," says David LeSchohier, executive director of the Hospice Federation of Massachusetts.

Hospice is different from traditional hospitals. Hospitals try to cure a disease or illness with the technology and medicine available. Many times the patient is alone during their hospital stay, with the realization that nothing more can be done. Hospices do not try to cure a patient.

They take a terminal patient and maximize the quality of the remaining days through non-curative drugs, pain control, therapy, and attention to the patients' emotional, social and spiritual needs. The family is the primary caregiver instead of the hospital. Hospice provides a team of doctors, nurses, social workers, spiritual or religious practitioners, and volunteers, who are available 24 hours a day to help the primary caregiver. The patient and family are together. And family members are directly involved in making decisions and helping someone they love.

Remembering the good things

The decision to enter hospice is made by the patients' physician. It is required that the patient know that their prognosis is terminal. A flexible guideline is in place where a patient may be admitted at 12 months, or less than six months, but adequate time is needed to best serve the patient. "If a person is referred in the last stages of terminal illness it's very hard to do the counseling and preparation," LeSchohier adds. Patients can go back to the hospital if it is needed, or the patient wants to go back.

It is tragic losing a loved one, but helping them cope with dying has its rewards. "It wasn't a devastating experience (caring for dying husband). It was a rewarding experience and we want to share that with others," says Linda Belliveau, R.N. Hospice Coordinator for Diversified Home Services of Fitchburg. "That's what I remember," says volunteer Nancy Cieri, "the good things. You don't remember the pain and suffering. You remember those special little times that you've spent together."

Hospice across the state

This year marks the 10th anniversary of the National Hospice Organization. The Hospice Federation of Massachusetts (HFM), which is just as old, oversees 40 state-wide licensed hospices that cover 90 percent of the communities. The goal of the federation is to make hospice available to all communities in Massachusetts.

Diversified Home Services (DHS) is the new hospice provider serving all

communities in a 25-mile radius of Fitchburg. The DHS is associated with and will be moving to Burbank Hospital in the fall, from their present location on Myrtle Avenue. DHS is the combination of Community Home Health Care and the Visiting Nurse Association of Fitchburg. Both had been providing hospice service for six years and finally joined forces to better serve the community.

The HFM cares for over 3,000 terminally ill people each year. DHS' staff of 50 serves eight to ten patients a month, sometimes as few as two. For the most part the patients are seen in the home.

Payment for hospice comes from a variety of sources. Forty-nine percent of the state's patients are covered by Medicare hospice benefits. Thirteen percent are covered by Blue Cross/Blue Shield, 16 percent by Medicaid, and the other 22 percent are covered by private insurance, HMOs, self pay, or free care.

The HFM's 1987 survey reveals that 89 percent of the hospice patients had cancer, 10 percent had AIDS, the other 1 percent divided among other terminal illnesses. Fifty-four percent of the patients were 65 or older, 41 percent 19-64, and 5 percent under 18 years of age.

"Many studies have said that hospice care is cost effective," LeSchohier says. A close estimate would be \$89.42 per day. This is less than the average 1986 hospital cost of \$325 per day (1986 Consumer Reports). But it is more than the \$60.27 average for a nursing home (Consumer Reports May 1988). Con-

tributions help keep the cost down and there is a heavy reliance on volunteers.

Medicare regulations stipulate that hospices have volunteers. "Volunteers provide a unique and practical service that money can't buy," David LeSchohier adds. Volunteers are an important part of the hospice team. DHS volunteers receive 20 hours of training and ongoing courses in communication skills, bereavement, and dealing with families in crisis.

"We try to match the patient with the special skills of the volunteer," says Cynthia Childs, spokesperson for DHS. Volunteers usually work one day a week, three or more hours a day.

Sometimes volunteers just listen. "They [family] can talk about their fears. One of the main skills is to listen," says Cieri.

Contributions, which equal one-quarter to one-half the hospice budget, are needed to bridge the gap between government and insurance payments and the actual cost of paying health care professionals and the cost of medication.

For hospice and volunteer information in the Fitchburg area call Diversified Home Services at 342-6013.

For more information on career opportunities, or to make a donation, contact the Hospice Federation of Massachusetts at P.O. Box 8980, Waltham, MA 02154-8980, or call 647-0018.

As volunteer Ashley Cook observes "It is not depressing because you've done something good for someone, you've helped them die with dignity." □