

Looking for a home

Corpus Christi waits for vision of hospice to become reality

By Teresa A. Parsons

Light streams in through the large windows of the home, throwing the shadows of hanging plants onto the walls. Bright blue curtains decorate the roomy kitchen, where volunteers are preparing a meal. Soft music echoes through the hall and into the two bedrooms on the first floor.

In one bedroom, a dying man shares a treasured photo album with another volunteer. In the other, an ailing woman cuddles a child on the bed as they watch a kitten chase its tail.

This is Corpus Christi Parish's home for the dying, a place where terminally ill persons can spend the remainder of their lives in comfort, surrounded by friends, family and familiar things.

It's a very real place to coordinator Kathie Quinlan and to the other people who have envisioned it for the past year and a half.

They're just waiting for an address.

Wanted: a safe, well-structured home within a three-mile radius of the church at 864 East Main Street; at least two bedrooms, basement needed; on or near bus line; large kitchen; can renovate; eternal gratitude offered in return; call (716)325-2424.

Planned: a 24-hour-a-day home for two economically or psychologically deprived persons in the last stages of terminal illness, regardless of circumstances or ability to pay; staffed by an interfaith volunteer team of professionals; bereavement care offered to families.

There they go again, making the impossible look easy. For those who have wondered over the years how a small parish like Corpus Christi manages to nurture such a variety of vital ministries, the home for the dying provides a case in point.

First there was someone who understood the need — in this case, Kathie Quinlan. A Corpus Christi parishioner and nurse at St. Mary's Hospital, Quinlan has heard dying patients plead to go home or somewhere like home, and she has seen many die waiting. "It's extremely frustrating," she said.

Her frustration is shared by other health-care workers, but particularly other nurses. "A hospital is a very cold environ-

ment in which to die," said nurse Terri Connor. "It's not because of the people there, but the situation. Your priority has to be keeping people alive."

Hospital and nursing home staff are committed, both emotionally and ethically, to saving life. Often that includes the lives of people that are acknowledged to be dying.

That commitment is reflected in treatment, from pain control to "Do-Not-Resuscitate" orders. "Pain control is based on the idea that the person's going to get well," Connor said. "That means you can have some pain dying in the hospital. And it can be very difficult getting a 'Do-Not-Resuscitate order' in the hospital, so you can end up pounding on someone's chest even though they have terminal cancer."

Hospice care, on the other hand, affirms life without hastening or postponing death.

"Dying with dignity," is the way medical social worker Debra Fromm defines the difference. "It's not being alone, letting you just be you to die," she said.

"Non-threatening, non-judgmental, unconditionally loving and giving," is the way Quinlan, whose specialty is hospice care, describes the home. "Hospice is not necessarily a place, but a philosophy devoted to holistic care," she said. "It embodies all the needs of a dying patient and their family as a unit, and it's translatable to almost any setting. Unlike a hospital, the patient will have control. It's letting the patient die the way he or she wants to die."

In a hospice environment, patients or "guests" are freed from the prescribed hospital routine to live at their own pace. "Terminal patients need someone to be ready to talk to them, turn them, bathe or powder them, position their pillows or just hold their hand. That just can't always be done in a hospital," explained Barbara Umbach, a continuing-care nurse at St. Mary's Hospital.

Because there are fewer patients in a hospice, pastoral ministers and volunteers can be available 24 hours a day to listen and spend time with people when they're ready to talk. "So often you find in the hospital that people want to talk when you have no time.

Dying people have an uncanny ability to know when you're in a hurry," Quinlan said. "They need you to listen as if the whole world has stopped."

That kind of individual care can be given to terminally ill persons who return home from a hospital. Support for families caring for a dying relative is available from the Genesee Region Home Care Association. But

"Ours is an effort that's rooted in faith," Quinlan said. "Father Callan (Corpus Christi pastor, Father James Callan) listened to the idea and just said 'OK, let's do it.' He has faith that all things are possible and somehow they seem to be."

Each time Quinlan encountered a new obstacle or worry, she met the same response from her pastor. "There will be people who

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— Terri Connor, nurse

many families are either physically or emotionally unable to handle the demands of caring for a terminal patient. Others have no families.

"A person who does not have family dies in the hospital pretty much — especially the very poor," said Connor.

Few choices are available in Rochester for those people. In fact, aside from hospitals and nursing homes, the only place in the city is Mount Carmel House, which has two beds available in a home-like setting.

Although Mount Carmel operates under the hospice philosophy, it is not, strictly speaking, a hospice. With only two beds, it is considered a private home. Corpus Christi plans to follow the same route with their home for the dying.

The guidelines imposed by state law on hospices are cited as one reason for their scarcity. "Hospice is a specific legal term — you have to be licensed to be one," Connor explained. To be approved, a hospice must comply with specific regulations on everything from room size to ceiling height to the number of stairs in the house. "It's a huge undertaking," she said.

Huge undertaking or not, once the need became clear, Corpus Christi's commitment and enthusiasm have been unwavering.

will know how to do that," Father Callan kept telling her.

Thanks in part to parish backing, he was right. Forty people attended the first hospice meeting last March. Among them were Connor and other nurses who volunteered to staff the hospice and to set up policies and procedures. Business people came and formed a finance committee. Others organized a steering committee and a group to plan volunteer training.

Meanwhile, as word spread, offers of help began to roll in. A man whose late wife loved to cook donated money to renovate the yet-to-be-found kitchen in her memory. A young doctor volunteered to visit the hospice weekly and to be on call. A computer programmer offered to write a program that will keep track of volunteers and scheduling. Wheelchairs and beds and supplies began to accumulate.

Is it any wonder that Quinlan believes a house is just around the corner?

"It's been an incredible journey," Quinlan said. "We keep holding on really hard to the vision and when we're ready, God will give us the house."

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