

How Hospice Works and What It Can Do

Published in *The Lakeville Journal*

December 11, 2008

Living Well

A column from SVNA by Cyd Emmons

“It’s about helping you do what you need or you want to do.” That seems a simple statement, but it’s how Eileen, Rydel, M.S., R.N., Salisbury Visiting Nurse Association’s hospice coordinator, describes, in its most basic sense, what hospice or end of life care is all about.

The “you” to whom Rydel refers is inclusive: the patient, who is in the later stages of a terminal illness, and the caregivers, family and friends who are trying to cope with caring for a loved one while dealing with their own emotions.

Specialized end of life care was first termed “hospice care” in the late 1960s, and, in the 40 years since, the concept of humane, compassionate care for those in the late stages of an incurable illness has spread around the world.

Hospice is about quality of life, meeting the patient’s physical, emotional and spiritual needs to help make that life not just comfortable, but meaningful, even if all that remains is months, weeks or days.

SVNA Hospice, which has cared for more than 60 patients since 2005, takes a team approach to care that includes the patient’s personal physician, nurses, therapists, home health aides, medical social workers, and clergy or other counselors. Rydel stressed that the makeup of the team is fluid, reconfigured as necessary to conform to the individual patient’s requirements and preferences. “There’s no script,” Rydel said. “You’re driving the bus. It’s whatever you need.” That includes making the decision to interrupt hospice care and resume curative treatment if the patient chooses.

Rydel said that many hospice patients are far more fearful of pain than they are of death. Hospice places great emphasis on palliative or comfort care. The assurance that the hospice team will take all necessary steps to relieve pain provides great peace of mind.

Two Issues

Rydel said there are two issues that are of particular concern to patients and families when considering turning to hospice: accepting that the patient has a very limited life expectancy and paying for hospice care.

“Some people find hospice difficult to talk about,” Rydel said, “but referrals can come from any well-intentioned source, as long as the patient agrees. Sometimes doctors will broach the subject, but some doctors are reluctant to certify that the patient has a life expectancy of six months or less, which is required for insurance coverage of hospice care, feeling that making that judgment is giving up.”

As to cost, Medicare, Medicaid and most private insurances cover virtually all the costs of hospice care, and both hospice care and insurance coverage can continue should the patient be moved to a hospital or nursing facility. Additionally, SVNA has established the Friends of Hospice Fund to cover the cost of care for those who lack

insurance coverage. “SVNA has never refused hospice care to anyone due to inability to pay,” Rydel said.

If Rydel could get just one message across, it’s don’t wait. “If you’re thinking about calling hospice now, now is the right time to call. If hospice is brought in soon enough,” she said, “we can do so much to help the patient and the family. Sometimes we’re not called in until the last few days, and there’s really not time to provide all we have to offer.”

Why Not Volunteer?

An adjunct to the nursing, personal care and therapy that SVNA Hospice provides is a corps of volunteers, all of whom have completed a course taught by Louisa LaFontan, R.N., B.S.N., coordinator of Hospice Volunteers of Northwest Connecticut. Many of the volunteers, LaFontan said, are the families and friends of former hospice patients who know first-hand the difference that hospice care can make in the lives of those they serve.

Others have no direct experience, but are simply interested in that type of volunteer work. “I look for volunteers who know how to listen carefully, hearing what’s behind the words,” LaFontan said. “If a patient says ‘I’m tired,’ what’s he really saying?”

Volunteers provide no nursing or physical care of any kind, but do offer the sort of neighborly help that can make things a little easier for caregivers to manage. That may be staying at home with the patient so that caregivers can attend to other concerns or simply have a break. “Volunteers run errands, water plants, walk the dog, really whatever needs doing,” LaFontan said. “One mows the lawn,” Rydel noted.

The 20-hour, six-week volunteer training course meets for three hours once a week. LaFontan said that volunteers are not required to commit to a set number of hours or span of time. “We ask them to plan on two to three hours a week, depending on both the time the volunteer has to give and what the patient needs.”

For further information about hospice care call Eileen Rydel at SVNA, 860-435-0816. For information about becoming a hospice volunteer call Louisa LaFontan at Hospice Volunteers of Northwest Connecticut, 860-364-1796.