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Easing the pain of the terminally ill

Hospice aids people in their final days

By SUKHJIT PUREWAL
Herald Staff Writer

Even as she struggles to breathe through long, thunderous coughs, Mari'Antonia Dudley demurs at any talk of her pain.

With her pixie-cut hair and painted red lips, Dudley prefers to talk about living every day to its fullest.

Dudley isn't seeking treatment for her condition. She instead keeps an oxygen tank by her bed and medications in the kitchen to soothe her pain. Dudley resolved several years ago to die with dignity.

Dudley is nearly 80 years old and suffers from chronic obstruction pulmonary disease, a combination of emphysema and chronic bronchitis, and congestive heart failure.

"I don't believe in victims," she said.

With hospice care, Dudley receives medical supplies, visits from a nurse and a home-health aide several times a week in her small Carmel home.

Hospice care is for people such as Dudley who have chosen to stop treating illnesses that haven't responded to therapy.

Dudley's caregiver is her friend Dan Terallo, who spends much of the day by her side. Dudley receives visits from a nurse and an aide twice a week.

"Our goal is to get them as independent as possible," said Mary Brusuelas, assistant manager of Hospice of the Central Coast of Community Hospital of Monterey Peninsula.

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Dudley says her activity is diminished. Most days she reads or watches TV. But she has maintained her independence and is content.

End-of-life care is liberating, Dudley said, and anyone who is terminally ill should consider its benefits.

"They deserve freedom of fear, freedom of pain," Dudley said, an oxygen tube dangling from her nose.

How it works|

Patients agree to give up aggressive treatment of their disease. Selecting hospice care means ceasing chemotherapy, blood transfusions, feeding tubes and emergency resuscitation.

In return, patients and their families have access to a social worker who coordinates a care plan for the patient, to make dying as comfortable as possible.

Patients and their families are eligible to receive medications, medical supplies, and medical equipment such as wheelchairs and special beds. Included in the plan are nurse visits, personal care services, respite care, and spiritual and bereavement counseling. Short-term hospitalization, if necessary, is included.

"We want to improve one's quality of life in those last months," said Dr. James Helmer, a general practitioner with a focus on geriatrics at Natividad Medical Center.

Helmer regards a hospice referral as his way of protecting his patient, ensuring the person will be free of suffering.

There are facilities such as Westland House that provide in-patient hospice services. Hospice is available for the terminally ill living in nursing facilities.

Medicare, private insurance and HMOs cover nearly 100 percent of hospice care in most states.

"Dying in this country can be very expensive. Hospice helps families so that it's not so devastating," said Jon Rudolvic, a spokesman for the National Hospice and Palliative Care Organization.

Increase in hospices|

The use of hospice care has risen steadily during the past 20 years, according to the National Hospice and Palliative Care Organization.

In 1985, 158,000 people used hospice care. By 2000, that figure had risen to 700,000. A

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little more than 28 percent of 2.4 million Americans who died in 2004 received hospice care.

While more Americans are embracing hospice care, it's a topic that induces squeamishness among many, including doctors.

Introduced by an English doctor 40 years ago, the adoption of in-home end-of-life care increased as more health-care advocates called for providing comfort rather than continuing painful treatment when it becomes evident such measures are fruitless. In the United States, hospice care was offered by volunteers until the 1980s, when it became covered by medical insurance, including Medicare and Medi-Cal.

A bounce|

What isn't so well known is that a person can leave hospice care if their health improves -- not a rarity, according to hospice care providers.

Figures from the Centers for Disease Control and Prevention indicate that 100,000 people will leave hospice this year.

"We call it the hospice bounce," said Jennifer Pettley, communications director with the Hospice Foundation of Monterey County. "It's not curing their illness, their pain is better."

Dudley has been on and off hospice care several times.

People with her condition can be fixed, Dudley said, but they don't stay fixed. Last year, family and friends gathered around her bed to bid her goodbye. Dudley robbed them of the opportunity when she didn't do as planned.

"She has been told she should have been dead by now," Terallo said.

Dudley sits up in bed and smiles modestly.

The hardest part for Dudley has been convincing her six children she is doing what is best for her. They would like her to put up a fight against her illness, she said.

Dudley enjoys her own version of spirituality, regarding death as another stage in a complicated, spiritual journey.

"I have no desire to prolong death," she said.

Doctors' reluctance|

Despite its promises to comfort -- physically, emotionally and spiritually -- hospice care has a tough public relations row to hoe.

"Nobody likes to talk about about death," said Mitch Matthews, director of provider relations and contracting with Central Coast Visiting Nurse Association and Hospice.

That includes doctors, said Matthews and other hospice care providers.

Too many doctors "don't get it," they say. Even when multiple rounds of treatment yield only continued misery and crushed hopes, many doctors can't bring themselves to acknowledge a terminal outcome and order hospice care at a time when it can improve quality of life.

"They (doctors) just don't want to give up," Helmer said. "To them it admits defeat."

Dr. Mark Tunzi, Helmer's colleague, concedes he isn't the best at making timely hospice referrals.

"It's bad," Tunzi said. "When you make a referral in the last few weeks, a person is not really able to take full advantage of the menu of options that hospice offers."

A report released in June 2006 by the American Society of Clinical Oncology in Atlanta found that in the late 1990s, even as the use of hospices increased, doctors were continuing chemotherapy in the last two weeks of patients' lives. Patients were often admitted to hospice in the last three days of life. At that point, all that can be done is to alleviate pain.

"So much can be done for a person who has terminal illness," Helmer said. "The last four to six months can be the most enriching time."

To learn more • For information about hospice care, call the helpline at (800) 658-8898 or see the National Hospice and Palliative Care Organization site at www.nhpc.org. Information in Spanish is available on the Web site and by phone.

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