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I asked for help to care for dying brother

By: VAILIA DENNIS - For the North County Times

"Many may know of a family member, close friend or neighbor whose final days were made more peaceful and less painful through the compassionate services offered by a hospice provider. Yet according to a recent federal report, this government benefit for the terminally ill may be underused by thousands of dying patients every year." U.S. Sen. Chuck Grassley, Special Committee on Aging.

Vailia Dennis, pictured with her dog, reached out to a hospice to get assistance for her brother, an Alzheimer's patient.
Courtesy Photo

In 1982, Congress expanded the Medicare insurance program to include hospice care. In conjunction with Medicare, hospice was then able to offer much-needed physical and emotional assistance to both terminally ill patients and their families. The question facing the Special Committee on Aging was why hospice benefits were not used until the end of life, why families neglected to access all the available hospice help throughout long periods of terminal illness.

I understand why. I have had the experience of living through the dilemma of placing a loved one in hospice care. My difficulty was that I simply was unable to cope with the requirement that the patient must have an estimated six months left of life.

When I thought of asking the doctor for a referral to hospice, I felt that I was placing my Alzheimer's-afflicted brother in the position of standing before a judge and being given a death sentence. I also blocked out the word "estimated."

In the meantime, I watched my brother, Marshall, refuse to eat or accept fluids. He was fading while I struggled to accept the fact that further medical treatment was not possible for someone so frail.

During my conversation with San Diego Hospice professionals, I learned that the dying patient responds differently to food and fluid. A small bite or sip may be enough to relieve hunger and thirst. They will lose weight regardless of the food intake due to malabsorption, which is when the body is no longer able to get nutrients from food. Intravenous fluid may help for a short time, but it is not food nor does it help prolong life. In fact, intravenous fluids may build up in the body and cause severe discomfort.

During the time that I refused to focus on the inevitable, I existed with the most acute form of denial. In doing so, I neglected to receive assistance that would have eased the stresses and pressures of our daily life. I kept fighting a losing battle and it was only at the end of my brother's life that I reached for the help I needed. A few days after his admission, Marshall died peacefully and gently under hospice care. The fact that I was emotionally blind might be best explained in a letter that I received from Jan Cetti, president of the San Diego Hospice.

I wrote to Mrs. Cetti after I completed the book I had written about my life as an Alzheimer's caregiver. I decided to send her a copy of the manuscript to ensure her approval of my description of hospice. Her response contained the following paragraph:

"As I read your story, I was so sorry that you did not have the hospice care much earlier. Though your experience with hospice at the very end is a familiar situation, we could have provided so much more assistance.

"A study in Congress was made to determine why people do not access the hospice benefit until the last few days of life. They found many barriers. One very large barrier is both physicians and families worry that turning to hospice means "giving up" on a loved one, though the facts indicate that hospice care ---- good pain and symptom control ---- actually prolongs life in some situations.

"And the assistance for caregivers is enormous. The comprehensive care you were entitled to, free of charge to Medicare beneficiaries, included respite care, home care nurses, social workers, homemakers (to help with all types of household chores), certified nurse's aides to help with bathing, skin care, etc., counselors, volunteers and some visits by hospice physicians (if approved by a personal M.D.)"

I spent many years being my brother's only caregiver. I did all the things that comprehensive care could have done for me. I slept less and worked at tasks beyond my strength. I watched my face and body age more rapidly under the stress and effort. I did expect that my body would grow old with aging years; I did not expect that I would lose my energy, my strength, and the enthusiasm I have always had for life. I have no guilt about the way I cared for my brother. I do have guilt about the way I cared for myself.

We may not realize that in allowing outside help, we are not giving up on our responsibilities. Feeling that is understandable. The long period of caring for your loved one may have become a way of life and difficult to change. Sometimes I liken it to watching your first child leave home. The "self" gets involved. The sense of responsibility is weakened. In that loss the benefits to the child (or patient) may not always be recognized. Letting go is very hard. I think I was involved with that struggle. I felt that I needed to be all things to a beloved brother.

Now I know that those who keep their afflicted family members at home, while receiving hospice care, are doing a remarkable job. Love and compassion are part of the caregiver's efforts. Care and compassion are part of the hospice's efforts.

Those wise people who reach for help are not giving up nor are they limiting the life of their loved one. Placing a family member as a hospice patient does not end their lives and it may not prolong their lives, but it does greatly help make life more bearable for the patient and the one who cares for them.

According to Sen. Grassley, "Hospice care is Medicare's hidden treasure." It is time for families of dying patients to discover it.

Vailia Dennis lives in Rancho Bernardo. She is the author of "Marshall's Journey: The Power of Understanding Alzheimer's." She can be reached at vailia@pacbell.net or www.vailia.com.