

Sharing comfort



Hospice workers gain as much as they give

by Bruce B. VanDusen

“Hospice” is a word few people fully understand. They suppose it has something to do with hospitals, but since it seems to have something to do with death many of us lose interest in pushing for a more precise understanding. It’s not a joyful word.

But for those who have had personal contact with a hospice organization, a hospice worker, or one who is receiving hospice care, the word conveys a strong sense of loving, selfless attention, tenderness and reassurance, and a willingness to give of oneself in a nonjudgmental, unconditional way.

As it happens, a number of our college community—alumni, faculty, staff, and friends—have been or are now closely associated with hospice care in a professional or volunteer capacity. A large number of them responded to a call, issued in January over the “online community” Internet service provided by the Office of Alumni Affairs, to submit to an interview about their own hospice experience.

The result is not a full report on the status of hospice work in America. It is not a sociological study of the typical hospice worker or a guide to the best practices found in the field. It is simply a sampling of experiences.

We began with Malvina Williams, who administers the outreach programs of the Mercer County Visiting Nurse Association, one of which is its Hospice Program. She and Chelsea Dixon manage the VNA’s hospice work. Dixon, who earned a master’s in education at the College in 1993, coordinates 20 to 22 volunteer workers who have direct contact with seriously ill people whose doctors do not expect them to live more than six months.

In fact, most do not. Many of our alumni volunteers tell of very brief periods spent with their patients—a

week or 10 days at the low end, two or three months more commonly. A few had longer-term relationships: 18 months in one case, nearly two years in another.

Nearly all the volunteers interviewed had learned about hospice through experience with a loved one, often a relative, whose final days or weeks had been under hospice care. They had an opportunity to observe the professionalism of the hospice nurses and the positive effect their visits had on the family and the terminally ill patient.

Another experience most volunteers shared was a period of training. The practice at the Mercer County VNA is typical and usually takes a few weeks of evening meetings (approximately 20 hours) at which experts in the field review basic concerns and have the volunteers role-play common situations to prepare for what to expect and how to react.

Williams said the training gives volunteers the opportunity to hear

hospice nurses, sociologists, bereavement counselors, funeral directors, physicians, ministers, and experienced volunteers explain how a volunteer can help or, perhaps, create added difficulties. All the volunteers we spoke with said the training was extremely helpful, and those whose organizations called their volunteers together for later meetings to exchange ideas and experiences came in for high praise.

One of the most experienced volunteers who responded to our appeal was Gregory Smiles, an adjunct professor of psychology at the College whose professional counseling practice sometimes includes grief and bereavement workshops. He has been volunteering off and on for six years. A key point Smiles made was that the volunteer often can do little for the extremely ill patient, but a great deal for the family.

“Every family is unique,” Smiles said. Some have discussed death with the

patient well in advance of the end, and both patient and family have reached agreement on what they want done. Then it is a matter mainly of the volunteer asking the family how he or she can be of help: doing some laundry, running errands, sitting with the patient while a family member takes care of personal business away from home.

And then Smiles recalled a family in which the patient was dying of lung cancer. “The family had not processed the situation at all. Here he was, dying of cancer and with oxygen tanks in the house for him, they were smoking in the house, talking business, showing little sympathy, and full of anger. He was a real teddy bear of a man, living alone.” Smiles said he visited the man on and off for two years, just trying to be a comforting influence.

“Just listening was the most important service one could perform.” This observation could have been made by nearly every one of the volunteers we spoke with, but it actually came from Mary Ann Lothian ’72, now of Williamstown, MA. In 1996 she signed up as a volunteer for the VNA and Hospice of Northern Berkshire, and over the years has helped patients dying of AIDS, cancer, and many other diseases.

Many, she said, were in nursing homes; some were in their own homes with a family member helping. Others were living alone with a helper coming in regularly. “One was 99,” she said, “a pilot in World War II, sharp as a tack, and showed me his pilot’s license signed, he said, by Wilbur Wright.”

“For me it was a positive emotional experience. Most of all, the patients just wanted to talk, to reminisce about good times. I never really had ‘difficult’ patients. Some were ‘challenging’ but most wanted to talk about their families

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and children and what they were doing. My role when they were in pain was to inform the VNA nurse, not to do more than that, other than find them ways to help change positions. Occasionally I would have to change a dressing. Just listening was the most important service one could perform."

When she was about 30 years old, **Carol Curbishley '89** went through what she called the "very comprehensive" Mercer VNA training course and looked forward to having a long-term relationship with a dying person. It didn't work out that way.

She recalls her first experience with an elderly lady dying of cancer in a home she said "was dark and hot, and smelled badly. She was very sick, too much so to walk, and felt badly

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whenever she had to be moved. She had diarrhea, too, and it was so sad, really so sad. When I was there it seemed so hopeless. I was there only for a couple of hours when her husband had to go out for his own medical appointment."

But there was another woman. Just the opposite situation. Her family was all around her and Curbishley relieved a daughter so she could attend to personal needs. The lady, she said, was "just magic, very spirited and understanding, unafraid and ready for the end. A complete woman."

The volunteer experience, she said, "certainly puts life into perspective. I would come home to my husband and we'd both say, 'We are so-o-o lucky because we have this day.'"

But when she had children, her attitude changed about death. The children became the center of her world and life was entirely different. These days, she said, "the dying thing is harder for me now" and she's no longer a hospice volunteer.

While most volunteers express interest in the work after reaching middle age, **Ali Navqui '99**, was just out of college and beginning graduate school in the Miami area. He and a fellow student, both interested in health careers, decided to sign on as volunteers with Vitas Hospice Care, a private firm that has 39 locations in 15 states. Following training, the two were assigned to a 60-year-old man who was dying of brain cancer and whose family was very distraught. His friend found it easier to talk with the patient, mainly of sports and other light topics, while Navqui spoke more with the family and found that "reflective listening" to the patient was a preferable approach.

"There's a reason we have two ears and only one mouth," Navqui said.

"Listening is best" under those circumstances. The two men spent about 90 minutes a day, visiting every two weeks for six months. He said he would definitely recommend the experience, but it's important, he cautioned, "to be aware of your own humanity."

Perhaps the most experienced volunteer alumnus in our sampling was **Bill Burke '53**, now retired and living in Oregon. This former CIA operative over the years came in contact with hospice wards in many regions of the country and overseas. An inveterate story-teller who loves to share adventures and humorous tales with strangers, he has visited hundreds of terminally ill military people in veterans' hospitals, and scores of dying AIDS patients in America and in Thailand, where facilities are operated by Maryknoll priests and Buddhist monks.

One of many anecdotes he passed along involved an incident many years ago in an American hospital for AIDS patients. It demonstrates how intense and life-altering the hospice volunteer's work may be.

Burke had been asked to work on a floor devoted to the most seriously ill AIDS patients. A Catholic who had strong negative feelings about homosexuals, he told the woman in charge that he could not bring himself to care for such patients. He was not proud of his attitude, but thought it would prevent him from providing compassionate care.

"She looked at me in silence for the longest moment," Burke wrote later. "Then, with understanding and great sadness, she humbled me. She explained, as Mother Teresa might have done, 'You are here to help the dying with compassion and love, the last they will know on this earth. Does it really matter

why they are here? They are in need of what you can give. Open your heart, my friend. Help them in their final hours.'

"For hours afterwards I did little ... besides focus with great intensity on the wisdom of her words and the tenderness and compassion of her personal commitment. On my next turn in the wards, I told her that I had changed my mind and I would work wherever she needed me. Perhaps to test my new resolve, she took me immediately to the bedside of a man dying of AIDS. She told me he would pass on in a matter of days and I was to do what I could for him (or have done unto me, I later thought).

"Every touch from me brought him pain as I cleaned him ... bathed him, and changed his linens. He helped me as best he could, in silence, except for the cries of pain whenever I moved him. Mercifully for both of us, finally it was over. With the little strength he could muster, he grasped my hand and gently squeezed it. His eyes spoke the words that could not brush his lips.

"It was perhaps the best day of my life. And I had tried so hard to avoid it... When I returned to the wards the next day, I learned that the friend I had acquired had crossed over to the other side within hours of our union. So much had passed between us in the short time

we had spent together. I knew the moment I had turned to leave him in his loneliness that I had received more from him than I had given to him."

While few of the volunteer hospice workers told of such dramatic experiences as Burke's, virtually all of them agreed their own personal contacts with the dying and their families provided extraordinary opportunities to serve others and to draw strength from helping them in their final hours.

Bruce VanDusen is the former editor of TCNJ Magazine, now retired in Pennsylvania.



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