



# SPIRITUAL CARE AT THE END OF LIFE

In hospice work, where the focus is on comfort rather than cure, pastoral care professionals should be an integral part of the staff. This is the case in the Stella Maris Hospice Care Program in Maryland.

Stella Maris, founded 15 years ago in a Baltimore suburb to provide care for terminally ill people, today comprises a home care component, which on average has 40 patients, and two inpatient units, one with 19 beds and another with 20. The home care unit provides on-call hospice care 24 hours a day for an area that ranges from Baltimore to the Pennsylvania border.

Most of Stella Maris's patients receive their care in their homes or in nursing homes with which the hospice has a contract. Home care patients are usually expected to live six months or less. But home care is not always a viable option. As a patient's illness progresses, it may produce problems—especially pain—that family caregivers cannot manage. By admitting such patients to one of its inpatient units, the hospice ensures that they get more intensive care and consistent monitoring and that family members get a respite.

## PASTORAL CARE IS TEAMWORK

Good hospice work is provided by a team, which at Stella Maris includes physicians (the hospice physician and, if the patient is in home care, his

## *Hospice Uses Teamwork to Address Spiritual and Physical Needs*

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or her primary physician), nurses, nurse practitioners, nursing assistants, social workers, dietitians, secretaries, pastoral care professionals, and trained volunteers.

Team members respect and support each other. For example, I do not have a medical background, but my teammates encourage me to let them know when a patient seems to be in pain or requires other physical attention. By the same token, my colleagues do not hesitate to notify me when a patient or a family member appears to be in spiritual distress.

Team members meet weekly to discuss each patient's condition, considering spiritual, emotional, psychological, social, and family concerns as well as physical ones. Because we provide holistic care, we try to be alert to physical problems that might affect patients' ability to think about transcendent matters. And distress of the soul can interfere with pain control and physical well-being.<sup>1</sup>

## THE NEEDS OF THE DYING: BOB AND NEIL

Both experience and recent research indicate that when a patient is dying, spiritual issues become more important and the search for meaning becomes more intense.<sup>2</sup>

I recall, for example, a young man I will call Bob, who was extremely angry and bitter when he was admitted to one of our inpatient units. Bob maintained, for the first month or so, that he wanted to have no contact with clergy.

Then one day Bob asked to see the chaplain. His main complaint, when I went to his room, was that he was "bored." But he rejected all the ways I suggested he might entertain himself. I waited in silence until Bob, apparently realizing he was being negative, returned to one of my suggestions: that he try painting. He was in fact a professional artist, but, as a result of his illness,



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had lost most of his fingers to amputation at or just above the top joint. "Maybe I can try watercolor," he said.

The next day Bob's sister brought him a set of watercolors and some good brushes, and within a few days he showed me a beautiful picture he had painted of some friends. He asked me to print "untitled" beneath the painting. Then he struggled to affix his signature to what turned out to be his last work of art.

Bob, who at first had refused to see any clergy, sobbed during one of our last visits. "All I have left are God and my religion," he said. Hospice had given him time to regain both his identity as an artist and his deep faith in God.

Accompanying people on their journey to eternal life makes pastoral care work in hospice a great privilege. Of course "care of the spirit" is not limited to serving religious needs alone. As St. Matthew reminds us, Jesus bestowed his father's blessing on those who perform simple deeds of mercy, such as feeding the hungry and giving drink to the thirsty (Mt 25:31-46). I try to encourage my fellow team members—especially those who spend many demanding hours feeding and bathing dying patients—by reminding them (and myself) of the high value God puts on such everyday acts of caring.

However, it is especially rewarding for a pastoral care professional to be able to offer a religious service that enriches the lives of devout believers. Such people, who have been deprived by illness of communal worship, long for the sacramental rites and religious practices that are an important part of their lives.

For instance, I often gave Communion to "Neil" when I served in home care. Neil suffered from AIDS and had Kaposi's sarcoma lesions on his face; one of his ankles looked as if it were covered with alligator skin. But he had an inner sweetness and earnestness, and it was his gratitude for each remaining day of life, rather than his physical appearance, that caught one's attention.

On the afternoon that was to be Neil's last, he requested that I bring him Communion one more time. When I entered his room, his parents were standing at the foot of his bed and a nursing assistant sat beside him holding his hand. Neil was still conscious. He and I exchanged a few words, and then he received the Eucharist. He closed his eyes and smiled. "How wonderful, how wonderful!" he whispered. In the ensuing five minutes of silence, he died.

Many dying people cannot get hospice care. One obstacle is physicians' failure to understand the value of palliative care.

### OBSTACLES TO PALLIATIVE CARE: RACHEL

Unfortunately, many dying people cannot get the kind of care Bob and Neil received from hospice. Insufficient third-party coverage is one obstacle. Another is the reluctance of patients and their family members to acknowledge the illness as terminal. Yet another is the unwillingness of physicians to refer patients to hospice care, perhaps because they fail to understand the value of *palliative* care, the kind of care hospice provides.

This last obstacle is perhaps the greatest. Physicians are trained to cure illness; to do otherwise, it seems to them, is to fail. Recent studies indicate that physicians especially lack training in the control of pain, even though pain control is one answer to the increasing demand by some patients for physician-assisted suicide.<sup>3</sup>

In this connection, the case of "Rachel" is particularly vivid in my memory. Rachel was in her early forties when she was admitted to our inpatient unit with a terminal illness. Twenty years before, she had converted from Judaism to Catholicism, an act that—especially in view of her loving relationship with her father and mother, who were observant Jews—must have required much courage and conviction.

Before coming to Stella Maris, Rachel had been in unbearable pain. In fact, despite her deep faith and her understanding of the teachings of the Church, she had tried to commit suicide by slashing both wrists and her throat. It was the only way she knew to end the pain.

Rachel spent her last four months in our unit,

*Continued on page 49*

## HELP FOR THE BEREAVED

Since its inception, the Stella Maris Hospice Care Program has offered bereavement services to grieving families and friends of deceased patients. The hospice has sponsored support groups for adults, teenagers, and younger children, as well as counseling for individuals.

In 1995 the hospice opened its Center for Grief and Loss to provide counseling, assistance, and education to the greater Baltimore community. The center was staffed by a full-time manager, a full-time clinician, and three part-time clinicians.

Unfortunately, many bereavement services are not reimbursable under Medicare. Recently, the center's staff had to be downsized to four half-time clinicians and a pool of contracted counselors who become available as needed. Trained volunteers help facilitate adults' and children's groups. This center's outreach services are partly financed by the Ryan White Fund and the Sisters of Mercy Mission Fund.

## SPIRITUAL CARE

Continued from page 46

faith community and the pastor. To be successful, they must share a sense of ownership of the community vision. On the other hand, parishioners must understand the parish nurse program and the opportunity it gives all community members to participate in the healing ministry of the Church. Whether they are cooking a meal or providing child care to a family experiencing the crisis of illness, parishioners have many gifts to give. It is through a shared approach that the work of health ministry is accomplished.

### FUNDING A PARISH NURSE PROGRAM


The cost of providing a health care professional to the faith community is, of course, a concern. Yet many creative options can help make this valuable ministry possible. Many churches form partnerships with local hospitals to develop health ministry. In this arrangement, the hospital helps the church hire a parish nurse and pays a percentage of the nurse's salary for the first year or so.

Other churches recruit volunteer nurses to oversee their parish nurse programs. This can be an effective way to broaden the scope of ministry without adding a significant financial burden to the church budget.

Still other churches seek grants, funding from denominational resources, and private funding to finance their programs. Financial aid is often available for new ministries via these avenues. With creative planning, financial obstacles can be overcome. Collaboration and partnership are key aspects of launching and sustaining new ministries.

### A NEW HEALING OPPORTUNITY

Both the Church and healthcare are facing new and complex dilemmas as the new millennium approaches. What better way to address human needs than to forge a new commitment to caring for the whole person? The faith community has been a source of comfort, hope, and healing for centuries. Let us strengthen this tradition by making parish nursing one more stage in the continuum of care. □

 For more information call Karen Mustoe, 573-334-8723.

where the medical staff was able to manage her pain without robbing her of consciousness. Freed from pain, this very intelligent, devout woman quickly became a great favorite of the unit's staff and visitors. "I am astounded," said the hospice physician. "The closer Rachel gets to death, the more peaceful and radiant she becomes."

### WANTED: WARMTH AND COMPASSION

Perhaps another obstacle to good hospice care is a lack of understanding of the competencies required in those who provide the care.

In general, hospice care workers need to be "well-developed, wise, and compassionate people, whose common sense is combined with professional knowledge," according to the authors of a book on palliative care ethics. "What can and ought to be offered, if the patient seeks it, is the comfort and reassurance that can come from the company of a warm and balanced personality."<sup>4</sup>

It is true that pastoral care professionals who work in hospices should be grounded in solid theology, well versed in Scripture, adept at communicating with others, and ecumenical (i.e., neither proselytizing nor dogmatic). But one of the greatest gifts a pastoral care worker can bestow on a dying person is a genuine listening and a calm, supportive presence.


These traits may be overlooked or undervalued in today's healthcare milieu, where competencies tend to be measured in quantitative, even numerical, terms. I, for one, am glad to be reminded that "it is not morally acceptable to omit [such qualitative competencies as warmth, calmness, and compassion] because they cannot be evaluated numerically."<sup>5</sup>

### PALLIATIVE CARE IS EVERYONE'S RIGHT

Partly because of the assisted-suicide controversy, many healthcare organizations are today seeking to improve palliative care for dying patients.

Indeed, some are trying to broaden the definition of hospice care so that it includes chronically ill patients who may live much longer than six months, the generally accepted time frame for hospice care.

Ira Byock, MD, a hospice physician who leads the Missoula Demonstration Project,<sup>6</sup> has said, "America's hospices have a tremendous opening to share their experiences, define quality for end-of-life care generally and thus influence the reformation of such care throughout the health care system—and not just for the minority of dying patients who receive hospice care currently."<sup>7</sup> Or, as the authors of *Palliative Care Ethics* put it, "Palliative care is the right of all who suffer and die from whatever pathology."<sup>8</sup> □

 For more information call Sr. Sharon Burns, RSM, 410-252-4500.

### NOTES

1. For a discussion of the holistic approach to pastoral care in hospice, see Sharon Burns, "The Spirituality of Dying," *Health Progress*, September 1991, pp. 48-54. For a discussion of the relationship between medicine and spirituality, see Larry M. Dossey, *Healing Words: The Power of Prayer and the Practice of Medicine*, HarperCollins, New York City, 1994.
2. Pam McGrath, "Putting Spirituality on the Agenda: Hospice Research Findings on the Ignored Dimension," *Hospice Journal*, vol. 12, no. 4, 1997, p. 3.
3. *Hospice Journal*, vol. 12, no. 4, 1997, p. 30.
4. Fiona Randall and R. S. Downie, *Palliative Care Ethics: A Good Companion*, Oxford University Press, New York City, 1996, pp. ix and xii.
5. Randall and Downie, p. ix.
6. Organizers of the project, launched in 1996, are studying patterns of dying and grieving in Missoula, MT, and planning to use the results of their study to help improve end-of-life care in the community.
7. Larry Beresford, "Sorting It All Out: Hospice, End-of-Life Care, Palliative Medicine—What's the Difference?" *Hospice*, Summer 1997, p. 34.
8. Randall and Downie, p. vii.