Hospice Uses Teamwork to Address Spiritual and Physical Needs

BY SR. SHARON BURNS, RSM, PhD

Sr. Burns is chaplain, Stella Maris Hospice Care Program, Stella Maris, Inc., Timonium, MD.
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 last work of art. "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.

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.7

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 treated 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.
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.

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**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.”

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 calming 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.”

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, 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.” Or, as the authors of Palliative Care Ethics put it, “Palliative care is the right of all who suffer and die from whatever pathology.”

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

**NOTES**

5. Randall and Downie, p. ix.
6. Organizers of the project, launched in 1998, are studying patterns of dying and griefing 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.