



# Helping Hands

## Welcome

Pastoral care is an essential function in palliative care, the chaplain an essential member of the palliative care team. In some ways, addressing patients' and families' spiritual issues and needs is the heart of the palliative care process, its most indispensable and characteristic function. Long before there were effective measures to adequately address pain and other symptoms, hospice and palliative care workers focused their efforts on easing the patient's suffering. No less today than in the past, a substantial measure of that suffering is associated with feeling alone and abandoned, estranged from others, from a shared humanity and - for those of faith or religious affiliation - from God. More than any other palliative care professional, the chaplain is sensitive to these issues and confident that patients and families can find strength and comfort within themselves, the support of others and the avenues of faith, in whatever form. The pastoral care professional's striking commitment to be present for the seriously ill and dying is found in their vow, described in the articles in this issue, that "no one dies alone."

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### ACKNOWLEDGEMENT

We gratefully acknowledge the generous support of the Summit Area Public Foundation in making the ongoing publication of Helping Hands possible.

## Spirituality and Pastoral Care

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The connection between mind, body and spirit intrigues the imagination. Newsweek dedicated a recent cover story to the topic. A Google search on 'spirituality and health' returns 49 pages of references. Professional journals feature studies about the impact of spirituality and religious involvement on physical health. In my daily rounds as a hospital chaplain it is common for me to see physical illness accompanied by spiritual suffering. Patients often experience profound feelings of dread, uncertainty and fear, even of eternal punishment. Disconcerting doubts may replace the comfort of previously held beliefs. There may be anger at God. Illness is, for everyone, a difficult situation.

Eileen Cox

Scarlett O'Hara epitomizes the popular attitude toward facing difficult situations with her words in *Gone With the Wind*: "I'll think about that tomorrow." But for a very seriously ill or dying person 'tomorrow' is the present. Serious illness shifts us out of ordinary life and plans; it is a moment of truth. In that interruption profound questions surface: Who am I? Why am I here? What is - has been - the meaning of my life? What do I still want time to do? Regrets surface. Unfinished business becomes a priority. Our focus may shift from the outer to the inner world. Even if a recovery takes place, an innocence about life is lost. There is a new sense of our - and loved ones' - vulnerability. The change is profound.

In my work as a chaplain I see that serious illness and the attendant spiritual questions arise equally in the religiously affiliated and those who are not, in those who believe in God as well as those who do not. Spiritual needs may arise directly, in a patient's questions about suffering, life and death, in strug-

gling for forgiveness and hope. But spiritual issues and needs may also arise cloaked and embedded in other conditions: in depression, in feelings of sadness, anger and guilt, in perceptions of abandonment and loss.

Ideally, the patient experiences these intense states in contact with other people. The philosopher Martin Buber says, in *Ten Rungs*, "When a man is singing and cannot lift his voice and another comes and sings with him, another who can lift his voice, the first will be able to lift his voice too. That is the secret of the bond between spirits." But patients may face serious illness and dying without the support of others. In the stress of illness, unresolved conflicts with family and friends may be exacerbated, estrangement may persist, or arise. Patients may be - or feel - abandoned, isolated, alone. From the beginning of the palliative care movement, from its early origins in hospice, excellent care of the seriously ill or dying has included pastoral - spiritual - care. The chaplain's role is to assess and address the patient's—and family's—spiritual concerns, and to help ensure that no one suffers - or dies - alone.

### Reconciliation and Love

Ms. T, almost 90, nearly blind, lives alone, with no close relatives or friends. Given her poor health, the outcome of surgery to remove a life-threatening blockage is not promising. She has the surgery, with the goal of returning to her own home and her beloved garden and cats. Post-operatively, still very fragile, she describes to me the estrangement between herself and her only living relative. When asked if she wants to talk to her relative, she says, "Yes, I wouldn't mind." A call is placed from her room. I hear her say, "This is T, I'm in the hospital. Yes, it has been a long time since we talked ... " They talk through old grievances and decide to be together, resulting in a hastily arranged plane reservation to Newark and Ms. T making arrangements to have her hair and nails done. She wants to look her best when her relative arrives. They are together, in the hospital, before Ms. T - weeks later - dies.

A seven-year old boy is comatose on a ventilator with severe brain injury following a terrible car accident. "Blessing's name tells

his story," his mother said. Our conversation reveals deeply held cultural and religious beliefs about life. "God is intimately involved in daily life," his mother said. Blessing's birth followed an intense period of prayer and waiting. God heard the mother's longing for a child and responded with the gift of a baby son, the family deeply believes. With such evidence of God's intervention already in hand, the child's mother and family turn to God now to ask for a miracle for Blessing: "God, repair the damage to Blessing's brain and restore his health." Days turn to weeks and months as the family steadfastly holds to the belief that God will do what medicine cannot. In the last days, the child's weakened body begins to slip away. Death is near. Only a question is offered: Is it possible to hold, without resolving, the tension between her understanding of God answering prayer and God calling her son home? Is it possible for her to return her precious gift to God? Through sorrow almost too painful to watch, the mother nods assent, shoulders collapsing as she whispers it. In tears, she holds her son's hands and resumes praying. The gift of love soon returns to love's one source.

The privilege of the pastoral care role in palliative care is to be present during the struggle for reconciliation and love, in all the forms it takes.

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## Cultural Spirituality and the End of Life

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It was late afternoon in the Intensive Care Unit. I had visited the dying patient, an African-American woman in her 80s', earlier in the day and prayed with her and her two sisters. A number of hours had now passed and I wanted to check on them, but as I approached the room I noticed that the curtain was drawn around the bed. Drawing nearer, I could hear the woman's sisters gently singing spirituals to her as she was

dying. I stood and listened in awe for a few moments, aware of the beauty of their spirituality in the face of death. I left the room quietly for I felt as though I had entered a sacred space where the Divine was very much present and not to be intruded upon.

As the end of life approaches people often return to their roots, seeking answers—and hope. The hospital room frequently becomes an arena both of holiness and of a specific family and cultural understanding, as the dying patient is surrounded by friends and family. Pastors, priests, rabbis, imams and other spiritual leaders come and go, representing age-old traditions and belief. Each culture and religion has, over time, developed its own philosophy of death and the dying process, and related prayers, rituals and beliefs. These customs are so ingrained that to ignore or attempt to change them is to commit a sacrilegious act.

Two or three decades ago hospitals and chaplains rarely had to concern themselves with cultural differences in end of life protocol. Protestants, Catholics and Jews each had their own customs that were assumed and practiced, and these were relatively well known and accepted. However, as the demographics of the United States continue to evolve, hospitals have had to make many adjustments in their end of life procedures, and it is the responsibility of professional caregivers to be aware of the differences among various groups.

To further complicate matters, there are many variants within each cultural and religious tradition. What may be considered appropriate by one family may be taboo to someone else, even within the same religious or cultural group. Discovering how best to meet spiritual needs and cultural expectations near the end of life, especially when language is a barrier, can be daunting for everyone. As a result, many hospitals have launched cultural awareness initiatives and provided training in cross-cultural caregiving for their employees.

Adequate communication is the critical factor. Upon admission, patients and their families should be asked if they have any dietary or other special cultural or religious needs or preferences of which the hospital should be aware. But even with a good start, failure to communicate throughout the duration of the hospitalization can easily lead

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to misunderstanding and indignation. For example, most non-Muslims do not realize that as the Muslim patient is dying, a pillow should be placed under the head to elevate it above the rest of the body and, if at all possible, the bed should be positioned so that the patient is facing toward Makkah (Mecca). This can provide great comfort to both patient and family. After the patient dies it is considered a desecration for a non-Muslim to handle the body. Preparation of the body for burial should be done by the family or by the Muslim community. By communicating with the family in advance and gaining a clear understanding of their needs and expectations, hospital personnel can prepare to do the right thing.

Not making assumptions based upon the majority culture or practice is also important. For example, in modern American medical practice, it is assumed that medical personnel will inform the patient of his or her condition. However, this is not the practice universally. In Hindu society, for example, it is the responsibility of the eldest son to tell the patient what the community decides the patient should be told. While not everyone who is Hindu will have the same preferences or customs, it's important to discover what the patient and family prefer. Knowing and honoring preferences and differences strengthens our ability to care. Not long ago, upon the death of a Hindu patient at Mountainside, arrangements were made to transport the deceased to his home so that the body could be washed and dressed prior to cremation. Chanting by the men of the community could be heard as the patient was dying and taken from the hospital.

In most hospitals today, staff chaplains are still predominantly Protestant, Catholic or Jewish. Increasingly they receive specialized training enabling them to minister to people of all faiths. However, it is an important development that chaplains of other faiths are becoming members of Pastoral Care Departments, especially in areas where significant numbers of Muslims, Hindus and other cultures and religions are now living. Even if a particular religious group is not represented on the staff, most departments have developed working relationships with area leaders of other spiritual communities, calling upon them when needed. In this way, dying patients and their loved ones may receive appropriate spiritual care during their last days.

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