

# AT MOTHER'S BEDSIDE, LESSONS HIT HOME

Most of us are familiar with the 1991 movie “The Doctor” starring William Hurt, Christine Lahti and Elizabeth Perkins. The story line follows the conversion of a hard-charging, swashbuckling, successful surgeon into a more sensitive human being as a result of his own experience as a patient. While I hope few of us identify with the intensity and insensitivity of the main character prior to his illness, we may likely admit that the volume and intensity of demands on us at times cause us to be less responsive or attentive to others.



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Our response may also be shaped by the wide variety of types of people we encounter, some of whom are very pleasant, others very difficult. We sometimes struggle to deliver on our personal commitments to compassionate care when pressed by time demands, institutional barriers and other elements that serve to drain our energy.

On January 3, 2011, I found myself on the “client” side of the health care system as I became involved in the care of my mother, who suffered a stroke just after midnight on January 1. Six weeks later, she fell and fractured her hip, after which she declined very quickly, dying on March 2. The nine-week period of her care was a great lesson in what can go very right or very wrong in both acute care and long-term care settings. I want to share some reflections on that experience.

First I will share my family’s experience of the palliative care service at the hospital where my mother was treated. I have been a great promoter of palliative care, and as a mission leader worked very hard at the hospital and regional level to promote the establishment of effective palliative programs. I witnessed the value of such programs as an expression of Catholic health care’s commitment to holistic care. I saw this expressed in quality clinical care and special attention to the emotional and spiritual needs of patients and families. I learned that key principles of palliative care include a fo-

cus on alleviation of pain, respect for patient and family, collaborative relationships among clinicians and between clinicians, patient and family.

Knowing what should be true about a palliative care program, my siblings and I were very disappointed by our experience of the palliative care consultation service at the secular not-for-profit hospital where our mother was treated. We expected a holistic, collaborative approach to my family’s care. Instead, our interaction was solely with physicians and a nurse practitioner, all of whom functioned more like case managers eager to maneuver us into quick decisions that would, one way or another, move my mother off their radar screen.

Although we fully understood and had accepted that our mother was actively dying, we were treated as foolish deniers of reality. This likely was

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because we raised questions when their clinical input did not match that of our mother’s attending physician, who had also been very honest with us about the prognosis. Rather than offering to communicate with the attending physician to resolve the discrepancies, the palliative care team dis-

missed his input, claiming, “he will look to us” for guidance. The arrogance was astonishing.

The team also failed to explore our spiritual background, instead presuming to tell us what was happening spiritually to our mother, who was by then non-communicative. They had never had a conversation with her. Their arrogance and ignorance was astonishing. No hospital chaplain was ever a part of the treatment process.

My siblings and I swung into full advocacy mode, directing the palliative care team to speak with our mother’s attending physician to coordinate information and recommendations. They were to change nothing about her treatment until that happened. In the meantime, we contacted her attending physician ourselves, preferring to trust but verify.

We also directed the palliative care team to suspend any presumptions about our mother’s or our spirituality.

On the positive side, we experienced nursing at its best. My mother had been treated in an intermediate care unit following her hip surgery and was transferred to a private room on the orthopedic unit so as to avoid her disturbing other patients, as she was agitated when awake. A nurse from the intermediate unit continued to visit our mother on her breaks and offered helpful advice to us regarding her care. In addition, the nurses on the orthopedic unit, not accustomed to caring for a dying patient, were still very sensitive and responsive. One remained after her shift with my mother to say “good bye,” knowing she would likely not see her again before her next scheduled shift.

The final phase of our experience was the transfer of our mother to a hospice on March 1, the day before she died. The hospital recommended a family-owned, skilled nursing center that had a hospice component, and from the moment we entered until after our mother died, our experience there was marvelous. Nurses were attentive, with no need to ask for very much from them. The admissions director carefully coordinated information about our mother with the hospital and with the nursing unit where she was placed.

Our mother died a few minutes before we arrived on the morning of March 2. The nurse man-

ager assured us that she was not alone when she died, but had a nurse with her holding her hand and praying with her as she took her last breath. Two aides came by to pay their respects to us as we stood with her body and they gently arranged the bed clothes around her as if she were sleeping. They said a short prayer for her before they left. My siblings and I commented on the “spirit” of that place, a palpable sense that staff cared and residents knew it. We knew it too.

I share this experience because it taught me more about the core of palliative care and the good that is possible within an organization that offers care to others.

### **My siblings and I swung into full advocacy mode, directing the palliative care team to speak with our mother’s attending physician to coordinate information and recommendations.**

■ I learned that palliative care is not a clinical research project, but should be staffed with clinicians who are as sensitive to family as we would expect any chaplain to be. The focus of palliative care is the patient *and* family.

■ I learned that palliative care clinicians need to check themselves at times to be sure they are focused on care at the end of life and not on hastening the end of life.

■ I learned that palliative care is not case management, recognizing that it may also appropriately contribute to an organization’s case management goals. This means that a hospital or long-term care facility must be clear about the core values that guide its approach to care, even if this means the sacrifice of some “efficiencies.”

■ I learned that, as in most other parts of life, the rule to “presume nothing” is important in palliative care. This means that a palliative care team must find the time to learn about a patient’s and family’s values, including spiritual values. Clinical information is not enough.

■ I learned that it is easy for clinicians, who are

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familiar with disease processes, to become impatient with families for whom this is a new experience and who are trying to sort through clinical realities and emotional challenges. Palliative care clinicians may well benefit from two important gifts of the Holy Spirit — wisdom and good counsel.

■ I observed that the best nurses are personally invested in the care of their patients, engage family as part of their “team” and find the time to pay attention to the details. I also observed that hospitals and nursing homes must organize themselves in a way that promotes those practices.

■ I learned that within an organization it is entirely possible for managers to set a tone that every staff person “gets,” so that all are oriented to the same goal of excellent care. The nursing home where my mother died exemplified that. Each person we met clearly knew what was expected of them and felt free to use their unique gifts to contribute to the care of their residents. Where this does not exist, it is because managers have made choices to allow less than excellent care.

Like William Hurt’s character in “The Doctor,” whose approach to care was forever changed by his experience as a patient, perhaps we might rediscover our own passion for excellent, compassionate care if we always saw our own face or that of our loved ones on those with whom we interact every day.

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