

VIEWPOINT

Palliative Care Isn't Just for the Dying

A nurse wishes her son and family had received it after his cancer diagnosis.

Palliative care is often portrayed in terms of end-of-life hospice care and advance directives, but a focus solely on these aspects may be misleading. In palliative care, death is a possibility but not a certainty. The goal is to make the patient's life as meaningful as possible, regardless of the prognosis, and to provide some relief from the pain, symptoms, and stress associated with a life-threatening illness or injury.

In a letter to the editor published in the *New York Times* on August 29, 2009, Gail Austin Cooney, MD, the president of the American Academy of Hospice and Palliative Medicine, noted that palliative care "can help patients who will live years after they receive a diagnosis of a life-threatening or chronic illness. . . . [It] can help patients better tolerate treatments as they recover."

At some point, these patients—even those who are very young—will contemplate their own mortality, and it's important that palliative care specialists—including nurses, physicians, chaplains, social workers, and psychologists—meet with them regularly to evaluate their needs and offer guidance throughout their illness. But although the Center to Advance Palliative Care reports that almost 1,500 U.S. hospitals now offer some type of palliative care program, when and to whom this type of care is offered varies greatly.

My 10-year-old son, David, was diagnosed with leukemia in 1995. He endured two years of

chemotherapy, and we were all very optimistic about his prognosis. Even after he relapsed three years later and needed a stem cell transplant, his health



Sometimes patients just need someone to talk to.

care providers remained confident about his recovery. The procedure appeared to have been successful. (In fact, it was six months before David's body displayed graft-versus-host disease, and even then there was no indication that he would die.)

After the transplant, David was placed in strict isolation, where he began displaying uncharacteristically belligerent behavior. The members of his health care team told us they'd seen this before in pediatric patients placed in isolation, but we sensed David was struggling with a growing awareness of his own mortality. Unsure of how to broach this difficult topic with him, and without a palliative care team to assist him or us, my husband and I arranged for David to meet with the hospital's child psychiatrist. But his approach failed to draw out what was bothering David, and my son refused to see him again.

David's physicians and nurses were providing excellent, cutting-edge medical care, but his emotional needs and fears weren't being addressed. A palliative

care team could have been concentrating on these throughout his hospitalization, but instead we had to plead with David's favorite transplant team physician to sit down and talk to him. He was reluctant at first to do so but eventually agreed. Three hours later, he emerged from David's room exhausted. He told us that David had asked many questions about dying and needed "to vent." When we entered the room soon after their discussion, David smiled at us. He even appeared serene.

Six months later, David died due to complications of *Aspergillus* fungus.

If the doctor hadn't taken the time to listen to my son's deepest fears, David would have endured months of unanswered questions.

An important part of palliative care is offering patients someone with whom they can have difficult conversations, who can help them deal with the everyday challenges of living with a life-threatening illness or injury. Even the most knowledgeable parents can't be expected to objectively examine the situation and decipher what needs to be done. Whether the patient ultimately lives or dies from the illness or injury, palliative care plays a crucial role in helping patients and their families endure. ▼

Robin Bennett-Kanarek is a member of the nursing advisory board at Fairfield University, Fairfield, CT, and president of the Kanarek Family Foundation in Greenwich, CT, which was established in honor of her son, David. Contact author: rbemk1@aol.com.