

Quality Time for the Dying

BY CAROL WENZL

I first met Janet and Robert when one of our Mercy Hospice nurses said she was concerned that Robert was thinking of killing himself. Robert, who was terminally ill, had just started using the hospice program.

When I arrived at their home for a special meeting, I realized that Robert was very serious about suicide. He was suffering a great deal of pain and did not want to be a burden to his wife. On the living room table was the book *Final Exit*, which explains different suicide techniques (Derek Humphry, Hemlock Society, Eugene, OR, 1991).

This retired college professor, a man who had always been in control of his life, had some pills hidden at his bedside that he planned to take when he could no longer stand the pain. Although she disagreed with him, his wife felt she had no right to interfere with his decision.

I spent most of that first meeting just listening to him. Then I tried to explain that anything approaching suicide is completely foreign to Mercy Hospice. Our goal is to control the pain and provide the family with all the help they need to get through this difficult time. Robert was still hesitant, so I asked him to at least let us try our approach. He agreed to try (primarily to get his wife some relief from care giving), but he said he would not rule out suicide if the pain became too great. Although he was not a religious man, he also agreed to talk with our chaplain.

We worked with Robert for about two months, using various medications to control his pain. One night Janet sat at his bedside, holding his hands while he

*Ms. Wenzl is
comanager, Mercy
Hospice, Oklahoma
City, OK, and
secretary, treasurer
of Oklahoma State
Hospice
Association.*

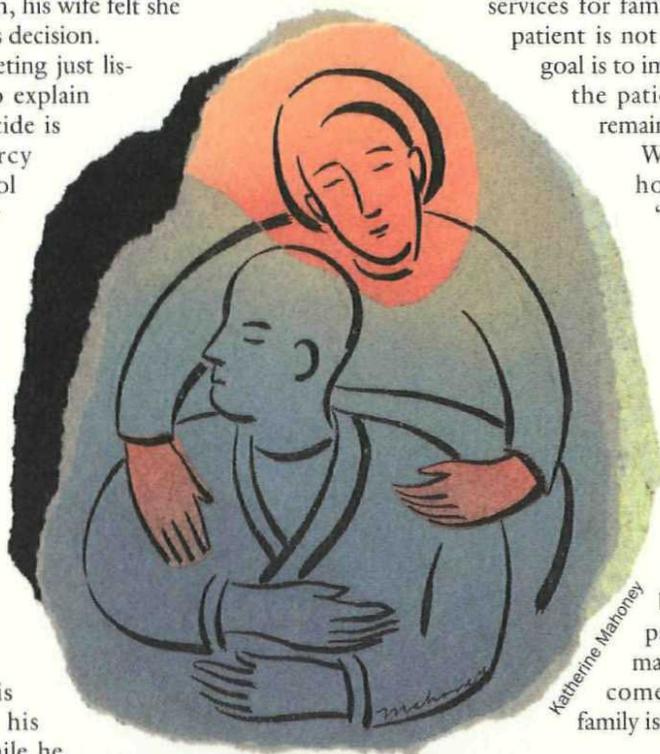
told her how much he appreciated all she had done for him, how much he valued the extra time he had had with their children, and how he had come to realize for the first time how much people cared about him. Then he said, "Tonight, let's both dream about peace and contentment and love." The couple softly repeated these words, and Robert fell asleep. He never woke up.

THE HOSPICE PHILOSOPHY

Robert was a perfect example of many patients we see through Mercy Hospice: a person who does not want to be in pain and does not want to be a burden to the family. Through hospice, we try to bring the pain under control, using a variety of medications that allow the patient to remain alert and give him or her precious time to spend with family and friends. And we provide services for family members, so that the dying patient is not an overwhelming burden. Our goal is to improve the quality of life for both the patient and the family in the time remaining to them.

When Cicely Saunders founded hospice in the 1960s, she said: "Hospice manages pain, so the patient is free to manage the rest of his life." This is the core of our philosophy: allowing the patient to set his or her own agenda.

Once the pain is under control, the patient can begin to think about how he or she wants to spend the time left. Our nurses say, "So what do you want to do? Do it today!" Since Mercy Hospice was begun in 1990, we have seen patients marry, go on trips (one made two trips to Las Vegas), and come to terms with long-standing family issues.



Katherine Mahoney

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People want to be with loved ones as long as possible.

A LIBERATING EXPERIENCE

The hospice philosophy can be liberating for the family as well as the patient. On our first visit to a home, we generally find a patient whose pain is out of control and whose care giver is exhausted. When the hospice team (a physician, nurse, chaplain, social worker, nursing assistant, and volunteers) arrives, family members can relax a bit, get some of the help they need, and learn about what to expect. We teach them about the symptoms they will see as the disease progresses and show them how they can help the dying person. By the time the patient is near death, the family usually understands and can spend the time quietly, saying the things that need to be said.

A well-trained hospice staff can provide intensive work with anticipatory grief to ameliorate the actual grieving process. We keep in touch with the families for 13 months after the patient's death to further help them through the grieving process.

In 18 years of working with cancer patients, I have seen again and again that people want to be with loved ones as long as possible. I have seen people with incredible nerve pain battle for just one more day. I had a hospice patient say she would agree to any treatment necessary, no matter what the side effects, if it would give her a few more days with her family. These are the people who taught me the value of every single day. □

 For information on starting a hospice, call the National Hospice Organization at 703-243-5900, your state hospice association, or Carol Wenzl at 405-752-3890.

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