

and to the Psalms, read in the quiet of his hospital room. The songs of anguish and surrender and mercy seemed to comfort him.

At night, my parents or Dave slept in Jim's room on cots provided by the hospital. A big man and physically strong, Dave was the closest of the brothers in age to Jim. He kept a steady vigil.

On a cold Saturday evening, Dave and my mother and father were persuaded to return home for a much-needed rest. Shortly before dawn on Sunday morning, Jim woke from a fitful, sweaty sleep. For hours, he had struggled desperately to breathe. Now his chest rose and fell with gasping irregularity.

Dick lay on a nearby cot. From the moment he first received Dick's marrow, Jim had felt a profound bond with Dick. When Jim realized he was not alone, his labored breathing relaxed. Dick bent over him.

"It's OK to go, Jimmy. You don't have to stay," Dick said, echoing a realization the family had reached the day before. We had sensed that Jim was no longer struggling for himself, but for us — fighting not because he needed to stay, but because we needed him. We had to let go, too.

Dick forced back tears. He had given so much — his bone marrow, his blood, his courage. "We love you," he said.

Not long after, Jim died. Dick kissed him and began to cry. Then he rose, slammed his fist into the hospital wall, and slammed it again.

Seemingly within moments after being reached by phone, my parents arrived. They held Jim for a very long time.

"Don't let go of the Tree of Life until you've had a moment of beauty," Dr. Bernie Siegel has said. "Live your life. Take your moment, and when you get tired, let go. It's all right." Jim gave and shared many moments of beauty. And when he let go, it was, indeed, right.

At the wake, many family members and friends lingered in the flower-laden room or in the crowded hallway, recounting their memories of a popular student, a good friend.

Bishop John McCafferty, Father Robert Meng, and five priests — friends of the family from Holy Rosary and Aquinas — said the funeral.

Our parents had readily agreed to an autopsy. They knew that the pathologists wanted to look for clues about stopping cancer in others. What medical scientists learned from Jim's, and from those

following countless cancer deaths, has surely led to today's increased survival rate for leukemia patients. But this exposed tissue was not Jim. Nor was the anointed body placed gently in the grave, as our parents watched, torn with grief.

Jim was elsewhere, yet seemingly everywhere — in our daily thoughts, and perhaps hardest of all, in dreams. For weeks after the burial, he was there, waiting, trying to say that finally, unbelievably, he was OK.

Our memories and intimations of Jim drew the family together. We learned something new about carrying each other's pain. Endless days of grief dulled into months. Eventually, the healing set in and we could remember Jim without anguish at his young death.

Years intervened. Not long ago,

recovered cancer patient Joe Koegel spoke in a Greenwich Village hall. I had attended at the urging of a friend, who accompanied me. A playwright and poet, Joe spoke about how his cancer had taught him to live life fully in the face of any threat, any illness. He spoke about the redeeming power of hope, about the healing nature of joy, about finding God — however one might think of the Creator — in ordinary, everyday experiences, of living one day at a time.

More than 100 people sat in the small room, with Joe on a slightly elevated stage in front of us. Just behind him, outside an open window, rain pelted a brick wall. Inside, it was hot and muggy, but no one rose to leave during the two hours that he spoke.

After the talk, many members of the audience moved forward to hug him, to shake his hand, to kiss him. Among them

were cancer patients and cancer families, and quite a few doctors.

I was unsure how to begin. I told Joe how, as he spoke, I felt close to my brother. "I felt him, too," Joe replied, explaining that often when he talks in various places across the United States, he feels a bond with cancer patients who have gone on.

I spoke a little longer about Jim. Joe had tears in his eyes, and I did too. I thanked him and we shook hands.

Today, to remember my brother, whose bone-marrow transplant took place more than 12 years ago, is to honor the realization that those who have cancer, or any fatal illness, fight not just for themselves, but for all of us. Their legacy is not tragedy, but hope. Not death, but love.

The truth is that people like Jim never die. That, especially, is how I remember Jim.

Dealing with death as a daily routine

By Teresa A. Parsons
Associate editor

For most families, death is a trauma that disrupts their lives rarely, but permanently.

Among medical professionals — doctors and nurses, as well as hospital chaplains — death is part of the everyday routine, or at least an everpresent reality.

How they cope with it depends on the individual. Some pray and grieve; others hold their emotions at a safe, "professional" distance. But almost invariably, those who deal regularly with death can cite particular cases that stand out from the rest of the landscape.

For Dr. James K. Brennan, Jim DiNolfo was such a patient.

A hematologist and attending physician at Strong Memorial Hospital, Dr. Brennan treated DiNolfo for three years. Particularly during the latter stages of the young man's battle with leukemia, his doctor's customary detachment sometimes gave way. "I was pretty involved at that time, and watching somebody that young have so many problems was difficult," he said.

Although the emotions that surrounded caring for DiNolfo have dulled with the passage of time and hundreds of other cases, his impact on Dr. Brennan remains vivid, even after more than a dozen years. "It's hard to build off of failure, and obviously physicians that treat these wretched diseases fail frequently," he said. "The way that people like Jim DiNolfo contribute is by making you angry and frustrated ... by motivating you to work harder (at finding more successful treatments.)"

Medical training has traditionally focused on how to keep people alive, largely ignoring the reactions and needs of patients and those who care for them once death is imminent. Thus it's not surprising that some doctors in particular view death as a failure of medicine, and of their own skills. Consequently, while they continue to supervise a dying patient's medical treatment, doctors often withdraw from the case in other ways, allowing a chaplain, pastor or nurse to confront the emotional and spiritual issues that surround dying.

Dr. David Austin doesn't believe that withdrawing is wrong, but he does regard it as a missed opportunity. "(Death is) similar to birth in its very intense, emotional side," he explained. "To participate in such significant moments of a family's life is an experience doctors are privileged to have."

Although he doesn't encounter a large percentage of dying patients in his family practice at the South Avenue Family Medicine Center, Dr. Austin also serves as medical director at Isaiah House, a hospice for the dying operated by Corpus

Christi Church. Experiences in both his work and his own family life have convinced him that "death can be a pretty healthy experience."

Having grown up in a small New England town, Dr. Austin recalls the dying remained close to the living. His great-grandmother died in her home, cared for by family members. His grandfather spent his last days in a small, 30-bed hospital, surrounded by family and friends. As a young adult, Dr. Austin cared for his stepfather during the last several months before he died of cancer — an experience which helped influence him to study medicine.

"When you see people who've gone through the stages of dying, who are comfortable with it, that's rewarding," he said.

What many refer to as the "medical model" — death in a hospital — has only taken hold within the last generation. Not long ago, most people spent their last days at home, cared for by family members and friends with occasional visits from the family doctor.

To receive the care they need, terminally ill patients now most often move to a hospital or nursing home. There, however, the latest technologies for prolonging life are sometimes employed to simply put off death.

Experimental treatments likewise can buy more time for a dying patient and for doctors hoping to learn how to treat a particular illness. On the other hand, Dr. Austin pointed out, that added time may be spent in misery, as the patient fights the side effects of treatment. "You may gain a few weeks, but you may also lose the chance at an alert, conscious experience of your last days," Dr. Austin said.

Technology's influence and increasingly frequent hospital staff shortages can further distance doctors and nurses from the human considerations of treating someone who is dying. "Technology physically separates us from the patients — there's less physical touching," explained Dr. Marguerite Dynsky. "So much of what we do in medicine makes a person feel not in control."

Thanks to a rare combination of disciplines, Dr. Dynsky may be better able than most to balance medicine's technological and human dimensions. A general surgeon at Rochester General Hospital, she has also been professed to the Sisters of St. Joseph for 23 years. "In a way, medicine has not given us a way to deal with dying," she said. "That's one area where my life as a religious influenced me by showing me how to reach a person on a human level and forget I'm a physician."

Which is not to say that Dr. Dynsky doesn't pay a price for such intimacy. "If you honestly try to get to know a patient, it's a loss for you if they die. It takes a lot out of you," she said.

Dr. Dynsky has several means of coping: attending the wakes of patients whenever

possible; and relying on spiritual support from her religious community. "There's a sense of strength I get from that," she explained.

At times, patients themselves become a source of strength. The struggle to overcome, and then to accept death may evoke extraordinary or heroic qualities in an individual. "Whenever someone has truly accepted their death, I see that as a real gift," said Dr. Dynsky. "Sometimes you find them helping others — even their doctors — accept it."

Nurses, who deal most often and most intimately with dying people and their families, are usually the witnesses to such quiet heroism. Perhaps for that reason, they tend also to find the experience least taxing and most rewarding.

Hospice nurse Patricia Burgmaier loves her job, even though every patient she has tended during the last six years has died. "I don't know how we survive multiple losses," she said. "From experience, you know how important what you do is and how (people) depend on it. You talk about professional highs — well, really being needed is the biggest one you can get."

A refugee from institutional nursing, Burgmaier worked for several years as a private-duty nurse, often caring for the terminally ill. Too often, she encountered patients and family members who needed more than existing nursing services provided.

Since founding Caritas, a program that provides hospice care for dying people in their homes, she and her staff of nurses have aided dozens of patients and families in preparing for death.

"Death is more than the death of a body," she explained. "Technology is wonderful, but you also need someone to be with, to sit and cry with ... and sometimes, someone to say, 'Yes, you are dying. We don't know when, but yes, that is what's ahead.'"

As difficult as those words might be to hear, Burgmaier's experience attests that death can be a beautiful and natural part of life. Among her most striking examples is the story of a 40-year-old woman who, after months of fruitless treatment in a hospital, chose to die at home, lying in the middle of her living room floor, flanked by her husband and son, dozens of relatives and friends, and even her dogs.

Earlier in the day, the woman had been able to soak in a hot bath, watch a favorite movie, and savor three glasses of orange juice, which she had long been unable to enjoy. At the moment the woman died, Burgmaier recalled, "the room was quiet and peaceful. There were tears, but no hysteria."

"The experience of death is a mini-transfiguration. The struggle goes, and you can see the peace come over the whole family," Burgmaier said. "It is something sacred, and it's an extraordinary gift to be able to share that."