

FEATURE STORY

Confronting Death

BY JO CAVALLO

Understanding how and why people approach death differently.

“I am not interested in quality of life,” the author Susan Sontag told her doctor when he offered her a drug that would alleviate the symptoms of myelodysplastic syndrome—a blood cancer—but would do little to prolong her life. Her son, David Rieff, recalled the conversation in a story he wrote about her illness and subsequent death in *The New York Times Magazine* last December. “My mother was determined to try to live no matter how terrible her suffering,” wrote Rieff.

Why do some terminally ill patients furiously fight to live even in the face of poor survival odds, trading whatever quality of time they may have left for painful or even risky treatments that have a high probability of failure? And why do others view death as a very gentle and normal life process? The answers are as numerous as the individual patients themselves.

“My job is to help people get the kind of care they would want, that they may not know they want,” says Stephen Nimer, MD, head of the division of hematologic oncology at Memorial Sloan-Kettering Cancer Center in New York and Sontag’s doctor. “There’s not a cookbook approach where you tell the patient you need to do this. The first step is to get a sense of what the patient wants, and that, I think, is a very individual thing.”

Living in a society in which death isn’t openly discussed only fuels the sense of anxiety and fear dying people have, says Ira Byock, MD, director of palliative medicine at Dartmouth-Hitchcock Medical Center in Lebanon, New Hampshire. “Dying patients fear the unknown. We live in a culture where nobody talks about dying, so patients have a sense that the reason nurses and doctors won’t talk about it is that dying must be too horrible to even think about. But in fact, for most people, dying is a very gentle process.”

Researchers say that a person’s age, religious belief and life experiences all contribute to how well that patient copes with a terminal diagnosis and can even determine the will to survive. “The psychological, experiential and spiritual path a person follows toward death looks and feels different depending on who that individual is, and it’s based on everything that shapes who and what we are,” says Harvey Max Chochinov, MD, PhD, professor of psychiatry at the University of Manitoba, Canada, and principal investigator of a study called Dignity Therapy: a Novel Psychotherapeutic Intervention for Patients Near the End of Life. “I think in general, young people struggle more than older people because there’s a sense of the untimeliness of dying and the many expectations and fantasies that will go unfulfilled.”

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Dr. Chochinov says things like pain, depression, lack of support, a feeling that one's dignity is undermined and feeling that one's life lacks meaning and purpose are all things that can take away a person's will to live. What does seem to make a difference in how well dying patients fare is having a spiritual belief. "We find that even for people who may not have a formal religious connection or affiliation, people who have a sense of spiritual well-being or belief seem to do better in terms of their ability to cope with various challenges near the end of life," says Dr. Chochinov.

These are challenges Kelly Jo Dowd of Florida knows all too well, but she finds comfort in her belief in God and in an afterlife that will allow her to always have a spiritual connection to her daughter, Dakoda, 13, even as she prays that her life is spared long enough to see Dakoda go on her first date. Diagnosed with breast cancer in 2002, Dowd opted for the most aggressive treatment available to get the best shot at a cure, undergoing a double mastectomy followed by eight rounds of chemotherapy and 30 radiation sessions.

"I felt like it was a long battle that I fought very aggressively," says 41-year-old Dowd. "I couldn't have done anything more and I felt good about myself. My husband, Mike, was very supportive, as was my daughter. We got through it together." At first, the signs that Dowd had beaten the cancer looked good. Her blood tests for cancer markers came back negative, and she felt well enough to resume exercising and even went back to work full-time. So when she started having muscle and bone pain, she attributed it to her more active lifestyle and not a cancer recurrence. But in May 2005, the pain had become so severe that her oncologist ordered an immediate bone scan. The test showed that the cancer had metastasized to her bones and liver.



Kelly Jo Dowd with her daughter Dakoda, was told she had metastatic breast cancer one year ago. Photo by David Yellen/People Weekly.
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"I was completely devastated and very angry. It was the worst news I've ever gotten," says Dowd. Doctors told her that without treatment she had six months to a year to live but after months of chemotherapy, the cancer shows little signs of retreating. Still, Dowd says she's focusing on remaining strong for Dakoda. "When a mother is strong, you hand that to your daughter and she becomes strong as well. Dakoda has been involved every step of the way. She saw me after my double mastectomy, and she went to every doctor's appointment with me. There are times when she's crying and telling me how she feels and I'm crying and telling her how I feel," says Dowd.

Married for nearly 19 years, the candid family discussions about Dowd's illness are giving Mike the opportunity to express his feelings, too. "I'm glad I've had the

chance to say to my wife, ‘I’m sorry for the times I fell down on the job as your husband.’ That was good to get off my heart, because anyone who’s been married this long has had times when you weren’t all that you should have been,” says Mike, who admits to crying himself to sleep most nights. “Kelly Jo says, ‘Oh, honey, I’m sorry you’re so sad,’ but being able to show my emotions has a dual purpose. It lets me get my pain out and it shows Kelly Jo the depths of my love for her.”

Ways to Say Goodbye

Having the chance to be open and honest about feelings presents an invaluable opportunity to the dying patient, family members and friends to have closure on the relationship, says Dr. Byock, author of *The Four Things That Matter Most*. “People fear all of the losses with dying. If you have someone you love who is dying, the pain is incredible. You’re losing someone who is part of your life and part of who you are, but for the person who is dying, the loss is total, and it can be extreme. And yet the way to get through that pain is to feel that each and every relationship is as complete as it can possibly be.”

According to Dr. Byock, people who say four things: please forgive me, I forgive you, thank you and I love you are better able to say goodbye. “We can’t change the fact that we’re mortal, but we can express our gratitude and forgiveness to the people we love and let them know there’s nothing left unsaid.”

Dr. Chochinov says that giving dying patients the chance to make peace with loved ones not only enhances their sense of dignity but also reduces their level of suffering and feelings of depression. In his two-year Dignity Therapy study, 100 terminally ill patients in Canada and Australia were given the opportunity to tape record their concerns or what they most wanted remembered about their lives. The conversations were then transcribed so that the patients could make revisions; the final document was then given to the patient to share with family and friends.

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—Ira Byock, MD

“We found that almost uniformly, people said this was helpful to them near the end of life. Even those who initially didn’t express a great deal in the way of psychological or existential distress said that it helped,” says Dr. Chochinov. In fact, 76 percent of patients said the experience heightened their sense of dignity and 68 percent said it increased their sense of purpose. But perhaps the most striking finding, says Dr. Chochinov, was that 81 percent said this type of novel therapeutic intervention had already helped or would help their family.

“When we looked at the results, they said something to us perhaps less about the process of dying than about the nature of loving relationships. The data say that the need to safeguard the well-being of people they care about is preserved. They were doing something to look after the people they were about to leave behind.”

While telling loved ones how he feels about them is essential, Stan Adler, 53, says battling his illness with grace and dignity so that they have positive memories of him is also paramount. Diagnosed with melanoma in 2000, Adler learned five years later that the disease had metastasized to his lungs and liver. Given six months to live, he enlisted family and friends into “Adler’s Army” to help him fight the disease. “I’ve learned things that I couldn’t possibly have learned about myself, my friends or my family without having gone through this,” he says. “I wasn’t afraid of dying. I had a sense of fulfilling my mission in life and I was dealt a good hand, so I didn’t really feel like I was being robbed.”

Still, he wasn’t ready to quit without a fight. A successful businessman in New York City, Adler used that same drive to find ways to prolong his life. “I did extensive research online to see what the treatment categories were and got quite an education,” he says. After getting several medical opinions, he chose a combination of chemotherapy and several rounds of interleukin-2, a genetically engineered immune system protein, which put him in a rare remission. “I saw getting through this treatment as a job and if you’re going to do this job, you’d better do it well because a lot of people are going to be watching you and these are going to be some of the most memorable experiences people will have of you, whether you live or die.”

Leaving family and friends with positive memories of how she’s conducting her battle against metastatic pancreatic cancer also concerns Rose Miller. More than a fear of dying, Miller, 59, says it’s the path she has to take to get there that has her worried. “I have an extremely painful cancer, and all my life I’ve tried to protect my children from harm. Now when I look in my children’s eyes and in my husband’s eyes when I’m in pain, it’s more painful for me to watch them watch me than the actual pain I feel from the cancer. If I do die, I want them to remember me smiling, and not as a sad little wimp.”

Told that she had six to eight weeks to live almost two years ago, Miller isn’t sure why she’s still alive, but she says it’s given her the opportunity to make peace with everyone she knows. “Having cancer pulls you closer as a family and you don’t mince words. If you feel something, you say it because you might not have a second chance to say what you need to say. Everything is resolved. If I die tomorrow, I don’t think I’m leaving anything unsaid or undone.”

To ensure that her wishes for her end-of-life care are carried out, Miller, who currently takes pain medication, has put her directives in writing and has made plans for hospice care at her Maryland home in her final days. “I don’t want my family to have to make any decisions for me. And if I get to a certain point, I want all medication to stop except for pain medication.”

Death Without Pain

Miller is right to be concerned about pain in her last days. Of 9,000 patients with

serious or terminal diseases who participated in the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT), more than half of the 46 percent of patients who died during the study spent their last moments in a hospital and nearly 40 percent of those patients were either in severe or moderate pain during the last three days of life, pain that could have been prevented with medication.

“That study defined for us what some of the challenges were and that healthcare professionals and patients were not adequately communicating with each other about adequate end-of-life care,” says Kathleen Foley, MD, attending neurologist for Pain and Palliative Care Service at Memorial Sloan-Kettering Cancer Center. “Talking about dying is not giving up hope, but rather it’s opening up the opportunity for choice and access to care they could receive.”

Dr. Foley served as the past director of Transforming the Culture of Dying: The Project on Death in America, a nine-year, \$45-million study to find ways to institutionally improve the care of the dying. By the end of the project in 2003, Dr. Foley says faculty scholars resided in about half of the medical centers around the country and were “the Trojan horses of change within their institutions” for advancing the cause and the need for palliative care.

But just as important as palliative care is “maintaining a sense of dignity, a sense of essence” at the end of life, says Dr. Chochinov. “We need to show people that what they say and think is important, and that they amount to more than a constellation of symptoms that have arisen from a disease process.”

Despite her cancer, Rose Miller considers herself lucky. She celebrated 36 years of marriage in May to a man she calls gentle and loving. “Maybe I don’t have much time, but the time I have is quality. I’ve lived a good life—the best I know how. Death is just another journey. It’s not the end. I don’t believe there is an end.”

Editor’s note: Kelly Jo Dowd passed away at her home in Palm Harbor, Florida, on May 24, 2007. CURE is proud to honor her memory.