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Grief Before Death

BY MARC SILVER

Struggling with the sorrow of anticipatory grief.

Even before her husband died of lung cancer two years ago, Joyce Neifert was mourning. “I grieved for the life we used to have,” she says. She and Steve were close companions and nature lovers. The California couple went on hikes. They kayaked. After his diagnosis in 2003, those outdoor interludes became harder to manage.

When Neifert thought of their two teenage sons facing a world without a dad for company and advice, she felt even more bereft. As Steve’s health worsened, she had what she’d call “meltdown moments.” Hugs helped. So did long walks. After one trek, a neighbor told her, “I passed you today. It was obvious you just needed to be left alone.”

Mental health experts have a name for the jumble of emotions a caregiver experiences when a doctor delivers the news that the patient has little or no hope for cure or remission. They call it “anticipatory grief” or “anticipatory mourning.” They are only beginning to study the caregiver’s pre-death response and to figure out how best to offer assistance during the days, weeks, even months that precede a loved one’s death.

And for terminal cancer patients, there may be a number of months ahead. “There are almost no sudden deaths in cancer unless there is a very late diagnosis, which is rare these days,” says Matthew Loscalzo, who directs the Sheri and Les Biller Patient and Family Resource Center at California’s City of Hope, which specializes in cancer treatment.

Tears And Ties

There are plenty of misconceptions about anticipatory grief. “Originally there was this notion when somebody had a terminal or even questionable prognosis, the family might start grieving their loss in anticipation of death,” says Kenneth Doka, PhD, a professor of gerontology at the College of New Rochelle and senior consultant to the Hospice Foundation of America. “It led to this notion that you could almost finish your grieving prior to death.” The theory goes that a mourner has only so many tears to spend; the more that are shed beforehand, the fewer there will be after.

“Unhelpful,” says Doka.

The caregiver may indeed be thinking about the future loss but isn't necessarily grieving "this future, far-off death," he explains. Rather, he or she is mourning all the changes in life, large and small, as a result of the illness: the patient's loss of energy, the loss of sexual intimacy, even something seemingly as mundane as the loss of someone to go to the movies with.

At the same time, the caregiver and patient may be forging deeper bonds than ever. "People think anticipatory grief or anticipatory mourning means you're letting go," says psychologist Therese Rando, clinical director of the Institute for the Study and Treatment of Loss in Warwick, Rhode Island, and author of *How to Go On Living When Someone You Love Dies*. "That's not true. Some people tell you the most emotionally and physically intimate times are during the illness. There's an awareness of what's important and meaningful."

These final moments of intimacy can take surprising forms. Shera Dubitsky, a psychotherapist who works for Sharsheret, an organization that supports Jewish breast cancer patients and their families, remembers when her own mother was dying of the disease.

Dubitsky was 19; her mom was 47. Sitting by her mother's bedside in the hospital at 1 a.m., her mother seemingly "out of it," Dubitsky let loose the tears she'd been keeping inside. "Out of this unconscious state," she recalls, "my mother took her hand and placed it on my cheek. I will never in my life forget that touch. It was like her last maternal gesture to me. Twenty-two years later, I can still feel the heat on my cheek."

The Power of Hope

There is nothing steady about the period leading up to a loved one's death. One day the patient may accept the fact that he or she is dying; the next day the topic of conversation might be a fantastic cruise upon recovery. Caregivers ride a roller coaster as well. They melt down and repair, deny and accept, regret and embrace the moment in all sorts of variations.

In this dance of death and denial, hovering by the bedside is not recommended. "Patients tell us uniformly that it scares them when people sit and wait for them to die," says Loscalzo. He suggests coming up with an activity plan: read a book out loud, watch TV, play a game of cards.

At a time when all seems hopeless, hope can still surface. And that's normal. Paula Rauch, MD, a psychiatrist at Massachusetts General Hospital who works with children with serious illnesses, sees parents who hope their child will live to see snow melt or go to a Disney park. "They continue to imagine a future for their child," she says, not because they're in denial but because "the comfort of imagining the future can help them live in the present." These moments can provide laughter and enjoyment for parent and child, for husband and wife. "Nobody can live with the moment by moment terror of impending doom."

Meanwhile, caregivers don't just worry about the dying patient. Richard Ogden, a Maryland psychologist who lost his wife, Laura Bonneville, to breast cancer in 1999, believes it is perfectly normal to ask self-focused questions. Will I be OK? What is life going to be like without him or her?

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—Therese Rando

Wrapped up in those questions may be practical concerns that the caregiver feels guilty even thinking about. Can I pay the bills? Will I be able to keep the house?

Ogden sees parallels between anticipatory grieving and what psychologists call “anticipatory anxiety.” A student, for example, needs just the right amount of anxiety before a test. If there's too little, why study? If there's too much, who can concentrate? The caregiver needs to balance anticipatory anxiety as well. Deny that a loved one is dying and you might avoid any kind of meaningful interactions. Similarly, being totally overwhelmed might prevent the caregiver from spending time with the person. Expressing fears to a therapist or a close friend can enable the caregiver in this anxiety balancing act.

Respite and Release

More than anything, the caregiver may need a break. But guilt may keep the caregiver from seeking respite care—whether from hospice or a family member or a good friend.

Hospice care can ease the pain of both the dying person and the caregiver. “The hospice people were absolutely amazing,” says Peggy Harrington, whose husband, Richard Burgess, died of pancreatic cancer in 2003. They emphasize how important it is to say all your goodbyes, she recalls, and their grief counseling helped her after her husband's death.

But knowing when to turn to hospice is difficult. The patient and caregiver might say early on to the doctor, “Let us know when it's time to think about hospice.”

In this stressful time for caregivers, exercise can be a balm. After the breast cancer came back as metastatic disease for Ogden's wife in 1998, four years after her initial diagnosis, Ogden went to the gym nearly every day and rode the stationary bike. But he wasn't just pedaling and getting nowhere. “It's such an emotional and cerebral time that to have a physical focus was just a good break to me.”

Mental release can be beneficial, too. When Bob Pond's wife, Pam, was diagnosed with lung cancer in 2000 at age 55, the news seemed “so big and so awful and so brutal, with the fear of the unknown, and like on guard duty—you can't rest.” Their oncologist taught them a form of Chinese meditation. Pond and his wife and three children meditated 45 minutes a day, even when her condition worsened and she was confined to a hospital bed in their family home. Chanting

gave them a sense of direction and calm—far better, he says, than sitting and brooding.

Comfort

Even small gestures from the medical team can buoy the caregiver. “Although nurses are so very busy, some came over and sat down and put their arms around me and said, ‘I know this is very hard,’ ” Neifert recalls of the months when her husband was dying. “I found this very helpful that they were a shoulder to cry on. It’s very helpful for the medical community to just say, ‘You’re not just another patient lying in the bed. We really do care.’ ”

Making plans with the patient to find some meaning in the disease can give comfort. Harrington’s husband, Richard, learned about a program that takes samples of pancreatic tumors for study after the patient’s death. Knowing that he would contribute to this program helped both him and his family. “It was a wonderful thing to feel proud of him for helping others,” Harrington says.

Ileana Geestman’s daughter, Desiree, had dreams of recovering from the neuroblastoma that struck in 1997, when she was 10. And she wanted to help other kids with cancer. When she died of the disease, her parents founded the Desi Geestman Foundation, which provides financial and emotional support to families with a child or children dealing with cancer. “After Desi was gone,” says Geestman, “I turned a negative into a positive.”

Some caregivers believe the ultimate meaning is to be found in the moments before death. “I often say you had 40 years with this person. Your husband knows how you feel,” says Jimmie C. Holland, MD, a psychiatrist at Memorial Sloan-Kettering Cancer Center. “I don’t think those last breaths and last moments are as important as people sometimes think they are.” Some patients may want to die alone. Sometimes the caregiver may be by the bedside virtually all day and all night, then go to take a shower. And that’s when the patient passes away.

Grief is a tricky emotion to manage. When it comes to anticipatory grieving, doctors and therapists aren’t always sure what will work. Caregivers often don’t have the time or energy to talk to researchers while caring for a dying family member. But recent findings that anticipatory grief and post-death grief are unique phenomena will hopefully lead to new research.

Peggy Harrington found relief in speaking openly and honestly with her husband. “There was nothing left unsaid on my part. I was with him in the hospital every day.” That feeling—that their presence has made a difference—can be a source of great solace for the caregiver before and after the patient is gone.