

CONTENTS

Deconstructing Grief

BY ERIK NESS

Caregiving's many facets shape emotions before and after a loved one's death.

Bob Kaalberg is not apologizing for dragging me clear across town in the first heat wave of summer. If he's going to talk about his grief, he's doing it on his terms: in person. He teases me for getting lost on the way, then ushers me into his air-conditioned apartment. Family photos abound of one face in particular: his wife, Verla.

Kaalberg and I very nearly met 17 months ago. Verla died in the Don and Marilyn Anderson HospiceCare Center in Madison, Wisconsin, in early January of 2008. My wife was admitted a few days later, passing in early February. He's 72, and Verla was 67. I'm 44, as was my Cindy. Both women were tougher than the docs imagined, long outliving the doctors' predictions.

Before we can talk about the aftermath, Kaalberg sets the scene. Verla was a life-long smoker who had quit just six months before discovering stage 3 squamous cell lung cancer—he's written the diagnosis on the oncologist's business card, which he still keeps in his wallet. He details the treatments, the pain, and the difficult decision to stop therapy and focus on quality of life. As he talks, occasional tears roll slowly down his weathered face.



Bob Kaalberg, at his home in Wisconsin, lost his wife, Verla, to lung cancer in early 2008. Photo by Eric Tadsen.

He goes into painful detail, but the storytelling is a form of therapy, explains Holly Prigerson, PhD, director of the Center for Psycho-oncology and Palliative Care Research at the Dana-Farber Cancer Institute in Boston. "The emotional valance usually does fade," she says. "You acclimate and get used to it. Talking about it is helpful, and useful."

As cancer caregivers, it's not the story we hope to tell. We work hard in our hope for remission and survival. But we're not in control, and so caregiving weaves another complicated layer of connection between patient and caregiver.

"I think that cancer does offer an opportunity to adjust to the loss, in terms of planning and thinking about it ahead of time," explains Prigerson.

Talking about end of life issues can help both the patient and the caregiver better accept what's happening, which can, in turn, mean less regret, less grief, and even

lower rates of major depression for the caregiver. “Having the conversation, processing, and planning ahead, and thinking about life after the person might be gone is helpful to the bereavement adjustment process,” Prigerson says.

Labor of Love

In 2006, Darlene Landsittel of Wilmette, Illinois, was staying with her sister Patti in a Chicago-area hospital while doctors treated complications from multiple myeloma.

Darlene, now 66, was the youngest of three sisters. That night, she woke to hear Patti—the middle child—say: “Darlene, I have a plan to leave this earth.”

“Let me know when you’re checking out, because I have to be ready for this,” answered Darlene. Patti answered that it would be two years, and indeed it was. But in the meantime, Darlene lost her other sister, Alice, to pancreatic cancer. Their treatment schedules coincided a few times, and Darlene found herself between the two while they received chemotherapy.

“If you can be there as you can, as painful as it is, I think it lessens your grieving,” she says now. “It lightens your load.”

“Caregiving may facilitate the grieving,” agrees Kenneth J. Doka, PhD, a professor of gerontology at The College of New Rochelle Graduate School in New York. “The very fact of care-giving gives you a chance to finish business.”

But while the caregiver has seen the deterioration and the pain, caregiving can also set up myriad uncomfortable experiences and memories. Doka recalls one day caring for his own father, who wanted the window shade situated just right. “We spent a half an hour negotiating the difference of about an inch,” he recalls, and admits he lost his temper. Later, he realized: “This wasn’t about a shade; this was about his lack of control.”

Caregiving is hard work, and as a rule the recipient would rather not be there. Combine this with the loss of independence, bodily breakdown, and a cocktail of mind-altering medications and there is ample opportunity for disquieting memories. “It’s easy to have these experiences and be troubled by a sense of guilt,” says Doka. Complicating this, a sense of relief is often among the first emotions felt at the end.

He suggests that caregivers examine and validate their own grief. “Recognize how the caregiving experience itself may have influenced your reaction and your grief,” Doka explains. “You may need time to unpack that whole experience.”

Now What?

A few weeks after my wife’s discouraging initial breast cancer diagnosis, I found myself on a business trip, walking on an unfamiliar street. I entered a coffee shop and took out a piece of paper. I had decided to make a list of what to do if she lost the coming fight. At first the decision felt like a betrayal. Then I realized that

as a father of two young children I had a duty to them not to get blind-sided by the worst-case scenario. The list was short, and I threw it away even before I left the café.

☒ Grief hits you in so many ways: intellectually, emotionally, physically, spiritually. ☒

—Laura Andersen, grief counselor

But just a few days after Cindy died, I activated my simple plan. First on the list was to join a gym, and I headed to the local YMCA, where I soon discovered the pool. Before the end of the month I was swimming four to five times a week. The exercise was key, but the water itself was healing, enfolding, meditative. On days when I didn't swim I could feel the constellation of negative emotions rising. And during that first six months, the worst I ever felt was during a several-week period when circumstances kept me from the pool.

“Grief hits you in so many ways: intellectually, emotionally, physically, spiritually,” explains Laura Andersen, LCSW, a grief counselor at Midwest Palliative and Hospice CareCenter in Glenview, Illinois. She believes the foundation of a healthy grief process is self-care. That's because the varied manifestations of grief include disturbance of appetite, anxiety, forgetfulness, and inability to focus and concentrate.

“What are the ways that you can focus on yourself to get through it the best you can?” Andersen asks. “Because when you're not sleeping, when you're not eating properly, it's much harder to manage your emotions and manage your life.”

A Human Experience

Grief researchers organize grief around different models. There are the classic stages of grief proposed by Elisabeth Kübler-Ross in her 1969 classic *On Death and Dying*. In this original model, denial, anger, bargaining, depression, and acceptance were experienced in sequence; now practitioners realize mourners may experience these out of sequence, or even at the same time. Another model, by J. William Worden, PhD, talks about mourning tasks: accepting the reality of the loss, working through the pain, adjusting to a new world without the deceased, emotionally relocating the deceased, and focusing on the present.

It's become axiomatic among grief counselors that grief is an individual journey, each path unique. It's a distinction that frustrates Dana-Farber's Prigerson. The journeys may be individual, she says, but it is a universal human experience, and studying it should make it easier to catch people before they fall. For example, she says that between 80 and 90 percent of people adjust well. “They've come to accept that their loved one is gone,” she says. “They don't feel that their identity is totally shattered because they don't know who they are.”

For that small percentage at risk, Prigerson says, it's not that difficult to predict who is at risk for self-soothing in unhealthy ways, such as drinking and smoking, and at risk for many physical and mental health impairments. In a Swedish study of the parents of children lost to cancer, those who said their grief was unresolved were more likely to miss work and seek more medical care.

"If it really is impairing your ability to function in other roles, then I think it's important to seek help," concludes Doka.

Bob Kaalberg had no particular worry, no warning signs that he wasn't doing well. But one day, arranging his photographs yet again in his living room, he suddenly wondered if he was going to be one of those bereft spouses who become unhinged. A day or two later, hospice called, a standard follow-up asking if he wanted to talk to anyone.

Kaalberg had attended one disastrous support group and wasn't interested in that route. But this time he said he had just one question for the hospice counselor. That led to another, and week after week Kaalberg found himself talking things through. "I would tell her most anything," he says.

He even decided to try a support group again. "I didn't want it to end," he discovered. "These other people have got the same problem. Just like you. I can talk to you and you can to me, and we know what we're talking about. It just makes all the difference in the world."