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# Getting Through Survivor Guilt

BY KATHY LATOUR

*Survivors work through feelings of anger, anxiety, and depression that are often rooted in guilt.*

In 2009, Hodgkin lymphoma survivor Rich Davila met Eric Cohen, RN, OCN, the program manager of Life with Cancer in Fairfax, Virginia. Davila wanted to volunteer with the cancer support program to honor the memory of his “chemo buddy,” Kelly Linderman, who died in 2007.

When Cohen casually queried Davila to see how much Davila knew about the program, Davila immediately began explaining why he hadn’t kept up with Linderman after her cancer recurred. Cohen listened, recognizing that Davila was struggling with overwhelming guilt.

“The poor guy asked me a simple question and I dumped all over him,” Davila recalls.

Little studied, survivor guilt brings with it a host of issues that can cause depression, anger, and self-blame that may even compromise health.

Davila and Linderman were both treated for Hodgkin lymphoma in 1999, when he was 33 and she was 31. The two bonded, creating a closeness that continued after treatment as they did volunteer work and fundraised for the Leukemia & Lymphoma Society. Then their lives diverged in 2000 when Davila met his wife at the same time Linderman’s cancer recurred.

Davila found himself pulling back further from Linderman with each milestone he reached—first marriage and then parenthood, an especially joyful event after having been told treatment would make him sterile. “I got all the things we both wanted out of life, and for me to watch her not get them was hard,” Davila says. “Just as badly as I wanted them for myself, I wanted them for her.”

Daily calls became monthly as Davila struggled with sharing his good news when Linderman was facing repeated recurrences. Then, in 2007, it became clear Linderman was dying. “Then we got back together and talked about how guilty I felt,” he says. She said, ‘That’s ridiculous.’”

Rich Davila, right, still misses his "chemo buddy" Kelly Linderman. Her death and his survival led to feelings of loss and guilt for him.

Even with her reassurance, Davila suffered when she died in May 2007. He still

keeps a picture of the two of them on his refrigerator, and he has some of her ashes in an urn on his desk. Three years after her death, he says he thought about her every day until meeting Cohen, who, he says, helped him see that “this was her journey and not mine.”

## Why Did I Live?

Cohen says he sees survivor guilt such as Davila’s in all age groups and around many issues.

For those who find they carry one of the identifiable cancer oncogenes comes the guilt that their children may also have inherited the predisposition to cancer. For example, women or men who carry either the BRCA1 or BRCA2 oncogene pass on a 50 percent chance that their children will inherit the gene and the increased possibility of cancer that accompanies it.

Cohen tells of the young woman who discovered she carried the BRCA1 gene when she was the first in her family to be diagnosed with breast cancer. Her mother and sister were later diagnosed; both died.

“She has been struggling with why she is here when she didn’t have kids like her sister, and she lost her mom,” he says.

Publicity of survivors such as Lance Armstrong has also created guilt for those who don’t feel they are doing cancer “right” or with the stamina Armstrong showed. “For someone who is really driven, he is a good model,” Cohen says. “But if they aren’t, there is a danger there.”

## Anger, Depression, and Guilt

Identifying guilt can be a challenge for the professionals who care for survivors. Jonathan Fish, MD, director of the long-term follow-up program for the survivors of childhood cancer at Steven and Alexandra Cohen Children’s Medical Center of New York, says he provides personalized screening for patients who are three years out of therapy with a low risk for recurrence.

While Fish focuses on the physical long-term and late effects, he also does a psychological evaluation and refers patients to staff psychologists.

Adolescents may express their guilt as anxiety. Some parents report seeing their teens become oppositional. Often, that’s because the teens don’t want to think about having had cancer. Or, they may engage in high-risk health behaviors such as smoking and drinking to mask anxiety about not fitting in with their peers.

He cites the instance of one 14-year-old who underwent treatment for leukemia at age 2, relapsed, and was treated again, finishing treatment at age 8. As part of a family where there were many siblings, he had required significant parental time and energy.

“When he came to the survivorship center, it was clear that there were school behavioral and performance issues,” Fish says. “When pursuing what was going

on in school, it came out that he had a lot of guilt about feeling he had destroyed the family."

The parents assured him it wasn't true, and the issue was resolved by having open communication in the family and involving appropriate counseling, Fish says. Research indicates that about 16 percent of childhood cancer patients meet the diagnostic criteria for post traumatic stress disorder, Fish says.

"So, if 16 percent meet the diagnostic criteria, there is a large percentage who are anxious but not to the point that it is pathological and interfering with life," Fish says.

## The Self-Blame Game

Brad Zebrack, PhD, associate professor of social work at the University of Michigan, researches adolescent and young adult survivors, describing them as a population that has fallen through the cracks. It's an omission he knows too well as a 25-year survivor of Hodgkin lymphoma that was diagnosed when he was 25.

Guilt comes up as a finding in research studies on quality of life, Zebrack says, with issues of self-blame included on the list. Smokers who get lung cancer often blame themselves as do those who take a fatalistic approach to cancer, he says. "I sinned or did something, and God is punishing me for it." In these instances, Zebrack says survivors can face serious repercussions, such as not adhering to drug regimens, because at some level, they may believe they do not deserve treatment.

Zebrack recounts, as an example, the story of one woman who, at age 31, continues to live at home and care for her parents because she believes they compromised their own health during the time they had to take care of her earlier in her life. Her self-imposed sense of obligation has prevented her from going away for weekends with friends or getting a job.

> I got all the things we both wanted out of life, and for me to watch her not get them was hard.
>
> —Rich Davila

Zebrack found anger and guilt emerging in his own life when he and his wife, Joanne, attempted to have a child six years after his treatment ended. Joanne was required to go through numerous invasive procedures. "I remember feeling angry and guilty," Zebrack says. "It was my cancer that was now subjecting my wife to painful, mood-altering drugs and procedures, and there wasn't anything I could do about it." They ultimately adopted a daughter, who is now 8.

Experts agree that the solution to survivor guilt lies in recognition of the issue and open communication. They also advise working with mental health professionals who have training and experience dealing with the issues of cancer

patients and their families.