

SPIRIT

v2n2 - Facing down the fear

BY LORI HOPE

Anxiety is common after cancer, but how do you cope?

Five years cancer-free, and I'm feeling blissfully normal as I glance over the greeting cards at my neighborhood bookstore — until a 1950s illustration of a furrow-browed brunette clutching a handkerchief to her cheek catches my eye. "On the bright side," the card reads, "she no longer had to worry about getting old." Ignoring the italics, my heart races with fear as I think, "Cancer! What if my cancer returns and kills me before I'm old?" Then I laugh. "I get it, she's already old!"

I wasn't just being dense that day. Cancer changed me; I see things differently, and, although I've been what feels like my old self for years, I will probably always battle bouts of what I call post-cancer anxiety.

Comprising a range of feelings from mild angst to intense dread, this fear of cancer returning can render survivors not just anxious, but hypersensitive, depressed and irritable. And it can show up without warning.

"It's the most common shared experience of cancer survivors across all diagnoses," says clinician and researcher Karen Syrjala, PhD, director of biobehavioral sciences at the Fred Hutchinson Cancer Research Center in Seattle, who says that some cancer patients bounce back emotionally quite quickly, while others find their fear lasts longer. Her study of lymphoma and leukemia patients who underwent stem cell transplants, published in *The Journal of the American Medical Association* in 2004, found that this group of survivors had a particularly long emotional recovery, sometimes five years or longer, because the treatment is so aggressive. This information, she says, allows her to give them realistic expectations of emotional recovery.

"If your house falls in an earthquake, your first task is to put it all together," Syrjala says. "But it's really the feelings of loss and worry afterwards that cause most of the trauma. Being unpredictable and uncontrollable — those are the two hardest aspects of anything stressful."

Most survivors have recognizable triggers for the onset of anxiety — such as a new body ache, a celebrity's death from cancer, cancer-related anniversaries, upcoming medical tests or even references to death in other contexts that can be extrapolated to cancer — like my greeting-card moment. The feelings can last

from moments to days or months. But no matter those feelings' intensity, duration, cause or moniker — fear of recurrence, adjustment disorder or, in extreme cases, post-traumatic stress disorder — virtually all cancer survivors experience anxiety.

The good news is studies show that anxiety lessens with time, and we can learn our triggers and prepare to cope — and even use the anxiety to live a richer life.

Scanxiety

Amy Bartlett, 36, of Portland, Ore., steels herself for a PET scan, her first since completing treatment for non-Hodgkin's lymphoma. Though not as severe as the anxiety that interrupted her sleep for months after radiation, her fear still comes in waves. "Your mind easily goes back to the place where you were when you had cancer. I'll imagine having to call everyone again and tell them I have cancer, and then I'll start crying. It's like breaking a heart every time you tell someone."

As more survivors have begun to communicate with one another, especially online, a new lexicon has emerged. Indeed, the anxiety that precedes scans has acquired its own name: scanxiety.

"That's an appropriate description of an emotion we routinely encounter in our practice of oncology," says Brian Lawenda, MD, clinical director of radiation oncology at Naval Medical Center San Diego. "Usually this classification of anxiety is secondary to a patient's known medical condition, i.e., their history of cancer."

Lawenda says he sees anxiety in patients every day and attempts to assuage it.

One such patient of Lawenda's, 51-year-old Jacki Campbell of San Diego, was treated for a rare form of cancer, Burkitt's lymphoma, three years ago, but she still gets CT scans two to four times a year. When medications and breathing exercises fail to calm her before upcoming scans, she visits Lawenda — this time for acupuncture.

During his residency in radiation oncology at Harvard Medical School, Lawenda says, he had little exposure to complementary therapies but heard anecdotally that patients were using acupuncture to help alleviate symptoms and side effects of cancer treatment, so he decided to study it.

"I was convinced that it was merely acting as a placebo," Lawenda says. "However, after I started integrating acupuncture into my practice, I found it extremely effective. Now I am convinced that the effects go much further than might be expected of a placebo."

Campbell started having acupuncture a year ago and noticed results the first day. "It really worked. I was so calm I went home and took a nap, and I'm not normally a napping person."

Campbell sought help for her anxiety, but those who don't may find that normal feelings of fear can overpower logic, sometimes resulting in unwise decisions, says David Spiegel, MD, director of Stanford University's Psychosocial Treatment Laboratory. For example, Spiegel says that while most people hear the term "PSA" and think of the test to diagnose prostate cancer, he also uses it to refer to

“prostate-specific anxiety.” Spiegel explains that some men are so anxious about cancer recurring that they choose aggressive surgery — with possible bad consequences such as impotence or incontinence — just to take care of their anxiety.

A Known Reaction

Literature on fear of recurrence dates back to 1981, when psychologist and Harvard University professor Gerald P. Koocher, PhD, co-authored *Damocles Syndrome*, a book about those who had survived childhood cancer and their feelings of the cancer sword dangling above their heads.

The first study about mastectomy patients and fear of recurrence was published in the journal *Cancer Nursing* the same year, but it wasn't until more recently, when cancer survivors began to live longer (and be heard more) and survivorship issues began to surface, that the subject has gained more widespread attention.

Spiegel recommends numerous ways to deal with fear of recurrence, including group support. His 1989 study of women with metastatic breast cancer who attended a support group showed that they fared better emotionally than women who did not attend such a group, a finding that has been confirmed by numerous studies.

Support outside what is seen as a traditional support group can also be helpful. Seven months after lung cancer treatment, Barbara Coman, 68, of Savannah, Ga., was shopping for fabric when a saleswoman offered her help. “She had very short hair and looked like she might have had chemo, so I said that I'd been sick with cancer and she said, ‘Me, too!’ Then she invited me to a group of survivors that gets together once a month.”

The five women gather to not talk about cancer. “The rule is to not mention our problems. We just laugh and have fun. Just knowing we've all had cancer creates an instant bond.”

Though they don't share emotional issues collectively, they do support one another, Coman says, explaining that when Celine, a member whose cancer had recurred, called Coman in a teary mood, Coman couldn't talk because she was getting on a plane to go out of town. “So I called [group member] Jean and said, ‘Celine is in trouble. Can you talk to her?’ And she did.”

Extreme Distress

While most survivors can work their way through fearful emotions as time begins to heal, some can't, and they might begin showing symptoms of post-traumatic stress disorder, PTSD, defined as the development of specific symptoms after a

mentally stressful event that involves actual death or the threat of death, serious injury or a threat to oneself or others. Symptoms can include insomnia and feeling continuously afraid or on alert in addition to irritability, angry outbursts, difficulty concentrating, hypervigilance and an exaggerated response when startled.

Syrjala says cancer survivors with PTSD may find themselves going out of their way to avoid reminders of cancer, including the place they were treated or even words as basic as cancer, which can make their hearts pound or leave them feeling like they hit a wall.

Although PTSD is most often associated with combat veterans, studies show that the disorder affects as many as one-third of people who experience an extremely upsetting event, including cancer. While there is no explanation why some cancer patients get PTSD and others don't, it is known that having advanced or recurrent cancer, being hospitalized longer and having lower income can be factors. In addition, research shows that childhood cancer survivors (particularly girls) and their mothers are at greater risk for the disorder.

A 2008 study of PTSD by the Dana-Farber Cancer Institute in Boston, published in the International Journal of Gynecologic Cancer, indicated that 26 percent of early-stage ovarian cancer survivors who were tested had mental health scores suggestive of PTSD.

More research is needed to determine the prevalence of PTSD across all cancers and to develop assessment tools and treatment options, which now include anti-anxiety and antidepressant medications, other psychiatric treatment, counseling that offers strategies to refocus disturbing thoughts, and organized support groups.

Lori Hope is an author, speaker and freelance writer based in Oakland, Calif.