

FEATURE STORY

Taking Control

BY BEVERLY A. CALEY

Cancer survivors deal with fear.

Marshall Ramsey was afraid of cancer most of his life. As a child, he watched his mother battle breast cancer. “I didn’t understand it exactly, but I knew cancer was a monster,” Ramsey remembers. “It caused people to cry and get upset.” In 2001, when he was diagnosed with melanoma at age 32, it was “a total freak-out,” he says.

The freak-out Ramsey experienced probably came from fears often associated with cancer—and there are many things a rational person could be afraid of following a cancer diagnosis. Death tops the list for most, but another fear may be that even if treatment works, the cancer will come back. Fear of an unknown future may persist, including what will happen to the people one loves and cares about. Also on the list is fear of alienation—not being treated as normal by other people.

Fear associated with cancer is at least partly caused by the fact that we don’t have all the answers as to why some people get cancer, says Julia Rowland, PhD, director of the National Cancer Institute’s Office of Cancer Survivorship. “Cancer is often equated with the other big C: loss of control,” she explains. “It causes anxiety, because if you don’t know what caused you to have cancer, you don’t know what to do to keep it from coming back.” Although fear is common, there are strategies for coping with it, and help is available.



Marshall Ramsey, a melanoma survivor, uses humor to manage his fears about cancer. Photo by Barbara Gauntt.

Families, Friends, Fear

Kristen Doyle went to a doctor with what she thought was a simple sore throat. At the end of the day, her doctor told her to come in to talk about blood test results first thing the next morning. “I’ve seen enough episodes of ER to know that wasn’t good,” she recalls. During that first evening, friends and co-workers told her stories about people who had news from a doctor that turned out to be nothing. “All these people were speaking out of a place of caring,” she says. “But I felt, ‘I’m really worried and telling me about your aunt’s experience is not helping me.’ ” The next day she found out she had leukemia.

Frank Baker, PhD, director of the Behavioral Research Center at the American Cancer Society, encourages patients to communicate with their loved ones and doctors. People who have difficulty communicating with their families, friends and healthcare providers are more likely to experience higher levels of anxiety. According to Dr. Rowland, families and friends can help by acknowledging that cancer is very stressful, for both the patient and their loved ones. Another important thing families and friends can do is to acknowledge that at times their love and support might not be enough, and when this happens, to encourage the patient to seek additional help elsewhere.

Certain situations can also increase fear and anxiety. Disease progression or a change in treatment regimen may increase fear of death or fear of the future. Anxiety about recurrence may increase after treatment, as the time approaches for a checkup. Aches, pains or other bodily problems can also trigger fear of recurrence.

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—Julia Rowland, PhD

Personal Fear Management

In addition to being a professional expert on coping with cancer, Dr. Baker has firsthand experience, as his wife recently died from kidney cancer. For him and his wife, focusing on the things they could control was key to coping with their situation. “One of the ways to deal with fearful situations is to do active coping by changing our behavior,” Dr. Baker says.

Take good care of your body by eating a healthful diet and exercising when you are able. Many people find that knowledge about cancer helps to alleviate the fear. Ramsey reports that the more he learned about melanoma, the easier it became to deal with it. Others deal with cancer in practical ways, such as taking care of wills and other legal issues, and emotional ways, such as talking with loved ones about unresolved problems.

Some people use humor to help manage their emotions. A Pulitzer Prize-nominated editorial cartoonist by profession, Ramsey is a natural for using humor to cope. He recalls an incident that was a turning point for him in dealing with anxiety about how others would react to him. About two months after his surgery, he went to the beach. His experience with melanoma had made him cautious about sun exposure, but in the evening he decided to go for a swim. Out on the beach, he encountered a woman with two little girls who noticed the 8-inch scar on his side and back. The woman pointed at him, and the little girls started to look at him. Ramsey told the woman that the scar was from a shark attack “and it happened just about where your little girls are.” The woman grabbed her girls and ran out of the surf. Ramsey says he decided that from that point, “I’m just going to laugh about this. I’m not going to get offended; I have to put as much humor into it as I can.” It is important, though, for friends and family members to realize that humor can be distressing to some people, and to be sensitive to the needs of the individual patient.

Doyle found help for herself in finding help for her young son, Cason. In her hometown of Austin, Texas, she found Wonders & Worries, a program for families dealing with potentially terminal illnesses (www.wondersandworries.org). To help Cason get through the experience of being without his parents while she was in Dallas for a bone marrow transplant, she took pictures of where she was going to be and taped stories for him to hear before he went to bed at night. In addition to all the Wonders & Worries program did for Cason, the staff talked with Doyle about her many concerns about her son, and gave her both practical advice and reassurance. “I would talk with them about my fear that I would die and he wouldn’t remember me, and they would talk with me about that,” she remembers.

You Don't Have to Go It Alone

Dr. Rowland emphasizes that a cancer diagnosis is an enormously stressful event for anyone, and few people successfully manage it all by themselves. Many people find help in a cancer support group. Others seek advice from clergy, nurses or social workers.

Sometimes people become so fearful that they fall into despair or become depressed. Dr. Rowland advises that if a person feels overwhelmed by fear, it is time to get help from a mental health professional. Symptoms of fear that may indicate a need for mental health care include anger and irritability, difficulty with concentration and problem solving and physical symptoms, such as muscle tension, dry mouth, trembling, shaking or restlessness. Some people find that medication is appropriate in helping them get through the most stressful periods.

Although nearly all cancer centers have some psychosocial support available, cancer survivors report a significantly greater unmet need for mental health services than do people who have never had cancer. Nationwide efforts are currently under way to make screening for emotional problems routine, and to make referrals so that people who need help can get help.

Every person dealing with cancer is unique, and their beliefs, experiences and factors, such as economic and marital status, can have a profound impact on their experience with cancer. For Doyle, the best coping strategy was to get her life back to normal. “I love my job, I love my life, I love my family, and all I wanted to do while I was sick was get back to it.”

What is helpful in the early phases of diagnosis and treatment may be different from what is needed by survivors trying to get on with their lives. Ramsey’s experience led him to become active in the cancer community. He helps organize an event called Run from the Sun (www.runfromthesun.com) in Jackson, Mississippi, that helps fund a melanoma researcher, and supports educational efforts in elementary schools about sun safety. He also does cartoons for the Melanoma Research Foundation newsletter and for posters about sun safety, and he speaks publicly about the importance of humor in cancer. His way of taking control is to do all the work he can to tame the cancer monster, motivated by his desire that he and his children will never have to face that monster again.