

FEATURE STORY

A New Survivor's Club

BY JENNIFER HAUPT

Unique programs give gratitude and support to co-survivors.

At first glance, Patricia Newton, 71, and Kim White, 45, don't appear to have much in common. But during the past four years, the two women from Warren, Arkansas, have become as close as mother and daughter. "Kim was just a casual acquaintance, but when she heard I was diagnosed with breast cancer she called me right away, and she's been there for me every day since," says Newton, who discovered during that first phone call that her newfound friend had a lumpectomy just a month before and was going through radiation treatment. "My life changed drastically after meeting Kim. She became so much more than my caregiver—she's my best friend, companion, and faith teacher. She's my co-survivor, my co-everything."

Though seemingly a simple extension of the caregiver definition, a new term has entered the cancer vocabulary to define people who care for cancer patients—co-survivor. "Just as we honor the lifelong fight of cancer patients by calling them survivors, we are now also honoring the continuing role of nonmedical caregivers—the spouse, parent, friend, neighbor, co-worker—anyone who provides the support that is so critical for recovery, as well as maintaining emotional and physical well-being of the patient," says Wendy Mason, director of project management for the Susan G. Komen Breast Cancer Foundation, which recently launched a co-survivor program.

"We've always provided a helpline and educational tools for caregivers, but we got to a point where we wanted to formally put a structure around the co-survivor program to really legitimize their needs," says Mason. The Komen co-survivor program consists of, among other things, a collection of co-survivor stories that illustrate the program's key objectives: strength, support, love. The goal is one easy-access area for co-survivors to be informed and connect with each other.

✕ Caregivers have major unmet needs—concerns about handling daily life, their emotions, and their sense of social identity. Supporting these needs is an integral part of overall patient care. ✕

—Ronda C. Talley, PhD

Though the term “co-survivor” has been employed for some time in other settings, the recent extension into oncology has led cancer centers and support organizations to diversify support services to provide a broader foundation for those who are the backbone of strength for cancer patients.

Caring for Mind, Body, and Spirit

Medical advances coupled with changing health policies mean shorter hospital stays for cancer patients and more strain on those who care for them at home. “Ninety percent of cancer care is delivered in outpatient settings, and caregivers bear the major responsibility for this home care,” says Ronda C. Talley, PhD, former executive director of the Rosalynn Carter Institute for Caregiving. “Caregivers have major unmet needs—concerns about handling daily life, their emotions and their sense of social identity. Supporting these needs is an integral part of overall patient care.”

A growing body of studies confirms Talley’s position that support for caregivers is key throughout the entire process of coping with cancer. A recent study in the journal *Psychooncology* reported that husbands of women with breast cancer had lower quality of life independent of the time since diagnosis or stage of illness compared with men with healthy wives.

Experts are finding that co-survivors need the same integrated approach to wellness as their partners. “Co-survivors are often so overwhelmed with concern for the patient that they forget to eat, lose sleep, skip exercise, and generally let their own physical and mental health slide,” says Mitch Golant, PhD, vice president of research and development for The Wellness Community, a non-profit dedicated to providing support and education for survivors and co-survivors. “Co-survivors take part in all of our mind, body and spirit classes—whether it’s counseling groups, nutrition classes or meditation and exercise programs.”

Phydd Kettler, a psychiatric advanced practice nurse who runs a weekly support group for caregivers at M.D. Anderson Cancer Center, says caregivers often are hesitant to ask for help or feel too guilty taking time for themselves. “But it is vital that they do so in order to combat physical and mental fatigue,” she says. Like many first-rate cancer treatment centers, M.D. Anderson offers a growing variety of mind-body programs for survivors and co-survivors, including massage, nutrition, yoga, Pilates, and weekly educational forums presented by staff members.

An innovative laughter program used by Gilda’s Club, the national support program named after Gilda Radner, is being adopted by an increasing number of hospitals and cancer centers. “Laughter is one of the best remedies for the depression and anxiety that can rob both survivors and co-survivors of the energy needed to fight cancer,” says Gloria Nelson, a senior oncology social worker who runs laughter sessions for cancer survivors and co-survivors at Albert Einstein/Montefiore Cancer Center in New York.

Edward Haczynski, a 74-year-old former police officer, and his wife, Phyllis, have attended Nelson’s laughter sessions since he was diagnosed with multiple

myeloma four years ago. “We’re all taking a stand that even though we have this horrible disease, we’re still going to enjoy life and even have a good laugh once in awhile,” says Haczynski, who often tells Jay Leno jokes. “I think my wife likes to see me making people laugh. It’s in my nature and the cancer isn’t going to take that away from me.”

Building A Village

When it comes to caring for a child with cancer, it’s important for the entire family to be on the same page with treatment as well as making sure that siblings, friends and teachers are clear about what’s going on with the young patient. “It’s best to present everyone with the facts, otherwise the imagination takes over and that can be worse than reality,” says Carol Benefield, a counselor at Texas Children’s Hospital in Houston, who runs weekly support groups for parents and siblings of pediatric cancer patients. The Child and Life Program at the University of Michigan Comprehensive Cancer Center even takes its support services directly to the patient’s school to help teachers and classmates understand how the disease works and the symptoms.

When children are involved, survivors and co-survivors especially need to fuel up on laughter, exercise and other stress-reducing activities. Family camp programs, like the three-day Camp CLIFF at Camp for All in the Texas Hill Country, take families away from the demands of fighting cancer.

“When our invitation to the camp came in the mail, my son was going through a grueling four-month chemo treatment, and I was driving him an hour to the hospital every other day,” says Susan LeBlanc, whose 9-year-old son Andrew was diagnosed with non-Hodgkin’s lymphoma in June 2004. “Camp was three days of pure freedom. The moms were in one cabin, the dads were in another, and the kids were grouped by sex and age, so the support just came naturally. To see my son running around bald-headed with a central line running out of his chest, feeling like a normal little boy at summer camp—that was the best medicine for all of us.”

☒ I was so honored to be able to help Pat through her cancer and to get to know this incredible woman. ☒

Survivors and co-survivors gain enormous strength in numbers through camps and retreats, patient/caregiver partnerships, small groups sharing emotional support, and practical tips, and growing communities networking through nationwide conferences and online communities.

When Bobbie Ragan of California was diagnosed with lung cancer, the 75-year-old couldn’t always express herself to her husband Rex because she was either too tired or didn’t quite understand it herself. But for the past year, she and her husband have attended a support group for couples. “Going to a support

group together has taken some of the stress off our relationship because Rex learns from the entire group what I'm going through and how he can help." Now, when Bobbie has chemotherapy treatments, Rex knows to encourage her to nap and fixes meals she can eat even when she has no appetite.

The safe environment also helped the couple open up to each other. "Sometimes, it's easier to tell your partner something in the supportive group atmosphere," Rex explains. "One time, Bobbie told me, 'I wish you'd go to the beach by yourself sometimes,' and other patients chuckled and chimed in that they'd like to have more time away from their spouse. My feelings might have been hurt if she told me that at home, but it wasn't as threatening when I could see that other couples were going through the same thing."

Honoring Co-Survivors

Sharing stories is a way for survivors to honor the people who provide support and inspiration through their diagnosis and treatment. Last year, a number of local Komen chapters and cancer centers initiated essay contests for breast cancer survivors to honor their co-survivors. The Arkansas affiliate of Komen teamed up with a local television station to feature five winning survivor/co-survivor teams on a local talk show in addition to honoring the co-survivors at a luncheon following the affiliate's annual Race for the Cure event.

Patricia Newton and Kim White were among the winning teams. "I was so honored to be able to help Pat through her cancer and to get to know this incredible woman," says White. "I had no idea she was writing this essay about me, so when we were picked, it was an amazing surprise. Just one more gift I've received from Pat."

Newton and White are known around the small town of Warren as the "Dynamic Duo." When they saw a need for a breast cancer support group, they organized one. They also published a cookbook entitled Potlucks, Parties, and Pink Ribbons as a fundraiser and handed over a \$16,000 check to both the American Cancer Society and Komen last year.



Patricia Newton [right] and Kim White are known around the small town of Warren as the "Dynamic Duo." Photo by Robert Camp.

Georgia-Pacific and its Quilted Northern Ultra bath tissue brand teamed up with NASCAR's Kyle Petty to host a "Time for Thanks" weekend at Victory Junction Gang Camp in North Carolina last November. Of the more than 450 essays submitted by survivors honoring their co-survivors, 32 survivor/co-survivor teams won a weekend of spa treatments, horseback riding, and other activities.

Terri McClain and her husband Herbert were among the winners. "During 33 years of marriage, I've always been the one doing most of the cooking and caring for my husband, but while I was going through months of chemo and recovery, our marriage did a 180," says 54-year-old Terri, who was diagnosed with breast cancer in 2001. "Herbert did whatever I needed him to do. He went to all of my doctors' appointments and chemo treatments. He nursed me through the nausea

and drained my tubes. He held me all night when I was scared. He has been my rock. We're both living with cancer and he's a true survivor.”