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Men Behaving Boldly

BY MARC SILVER

Male cancer caregivers defy clueless and powerless stereotype.

They are men with huge hearts. And, on occasion, sore feet. Some of them have deep pockets and freely dig in. Others are potent persuaders, convincing family members, friends, even strangers to support the cause. A few even do the unthinkable—for guys, that is. They share their feelings!

They are not cancer survivors. They are cancer husbands (and boyfriends and sons). And after a wife's or girlfriend's encounter with the disease, they have gone on to become cancer activists.

Finding A Mission

Paul Boulanger's "aha moment" came in 2001, the year after his then-wife was diagnosed with breast cancer. The couple signed up for the Avon Walk for Breast Cancer in Boston, a fund-raiser for research and treatment. In a crowd of 3,000-plus women, Paul was one of 88 men.

"That was a sad testament to male participation as it relates to this disease," he says. "It's common for the male to be the support coordinator on the home front. Yet when it comes to the larger picture, where were the men?"

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—Paul Boulanger

He knew he had found a new mission: to convince more guys to plunge into the sea of pink. Boulanger created the nonprofit group Men with Heart to recruit male walkers. A financial officer at monster.com, he used his tech know-how to build his own website. Men with Heart now has 125 members. In subsequent walkathons, Paul and his pals have logged thousands of miles, suffered countless blisters and raised more than \$600,000.

In the world of cancer husbands, men like Boulanger are the exception. After a

wife finishes treatment for cancer, “I think most men just want to put it behind them,” says Jim Zabora, dean of the National Catholic School of Social Service at Catholic University of America and a veteran of 20 years counseling cancer patients at Johns Hopkins Hospital. But while the number of husband activists is small, they definitely make a difference, raising dollars as well as consciousness.



Paul Boulanger (front right) with fellow members and supporters of the Men with Heart group at the 2006 Breast Cancer 3-day in Boston.
Photo Courtesy of Men with Heart.

Indeed, John Nickoll’s generosity has been a boon for lung cancer patients and their families. Grateful for the counseling they received at the Ted Mann Family Resource Center at UCLA’s Jonsson Comprehensive Cancer Center, Nickoll and his wife, Ann, wanted to make sure others were as fortunate. Ann died of the disease in 2001, but Nickoll has gone on to give well over \$1 million to support the Ann and John Nickoll Family Lung Cancer Support Program, which helps patients at Jonsson and trains counselors, and to fund research into new treatments. “I’ve been lucky in business,” says the 72-year-old Los Angeles retired CEO. “I think Ann would be very thankful and very proud.”

Post-traumatic Success

In the lingo of psychology, activist husbands are examples of “post-traumatic growth.” Simply put, after a brush with disaster, some people take stock of their life. “It’s quite common that people take on new causes, and what’s more important than helping others who have suffered the trauma you experienced?” says Tzipi Weiss, DSW, assistant professor of social work at Long Island University.

In the arena of cancer, the patient isn’t the only one eligible for post-traumatic growth. In two studies, Weiss looked at how couples respond to breast cancer. In a study of 41 survivors and their spouses, published in the *Journal of Psychosocial Oncology* in 2002, 98 percent of the women reported “significant positive changes” after treatment. So did 88 percent of the husbands. A subsequent study in 2004 of 72 couples published in the *Journal of Social and Clinical Psychology* revealed that breast cancer survivors are more likely to experience post-traumatic growth if they perceive their husbands as supportive.

Dave and Pam Olson represent that kind of hand-in-hand activism. After Pam was diagnosed with colon cancer in 2005, Dave was struck by the symbolism in the American Cancer Society’s dusk-to-dawn Relay for Life walkathon. “You’re living your life, you get a diagnosis, and you have to go through the dark and search for the light,” he says. An assistant grocery store manager, Olson, 41, and his wife are co-chairs of the Relay in Woodbury, Minnesota, and have participated together in Celebration on the Hill, which brings cancer survivors and family members to Washington, D.C., to urge legislators to fund cancer causes. When it comes to his activism, Olson says in addition to his wife, his daughters, ages 11 and 7, are front and center in his mind: “I don’t want my kids to have to deal with cancer.”

Why Guys Get Involved

While it's clearly not the norm, cancer husband activism isn't an anomaly, either. "It really doesn't surprise me," says Anne Coscarelli, PhD, the psychologist who directs the Ted Mann Family Resource Center at Jonsson. "I see so many men who are so dedicated to their wives through [treatment] and who'll do anything they can"—including advocacy work.

The "Mr. Fix It" mentality is most likely part of the motivation. But Coscarelli believes there's more to it than that. Cancer activism has a "healing quality for the men," she says, whose emotional depth defies stereotypes.

The men themselves often say activism gives them a sense of control after being buffeted by cancer. Kevin Murray, 34, a banker in Cleveland, didn't like being "at the mercy of medicine" after his wife's diagnosis with non-Hodgkin's lymphoma in 2002. Because her symptoms are mild—"aches and pains and psychological doubt"—Kelly Murray is in a "watch and wait" stage. But Kevin isn't waiting around. An experienced fund-raiser, he's redirected his energies to the local Leukemia & Lymphoma Society. As president-elect, he notes, "I can try to do something rather than just sitting back and being passive. I can't go out and be a researcher myself but I can try to raise and direct the money."

Bob and Karen Strickland agree activism restores a sense of balance. "It makes him feel he's doing something instead of just sitting back and letting everything happen," says Karen, 52, who was diagnosed with breast cancer seven years before she married Bob, who is a regular walker with the Men with Heart team. "It feels like he's in there with me and we're fighting for the same thing," says Karen. "It means a lot to me that he cares about doing it." Bob, who wasn't much of a volunteer before he met Karen, believes "too many people are willing to pay their money and let someone else do the work." Walking the walk sends out a "greater message" about the need to find a cure for cancer, says the 54-year-old New Hampshire architect.

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—Karen Strickland, About Her Husband, Bob

Activism can also satisfy a primal impulse for revenge. "The only way I can get back at cancer is to do what I'm doing," says Robert Marraro, 39, of Corpus Christi, Texas, whose girlfriend, Rebecca Esparza, was diagnosed with ovarian cancer in 2001 and is now in remission. The two founded a support group for patients and their caregivers and have lobbied for cancer causes. Marraro has even stayed up into the early morning hours fashioning awareness ribbons for a Christmas tree decorating contest.

Breast Cancer Boom

Much of this spousal activism is set in the world of breast cancer, where men are often inspired by the vibrant organizations set up by survivors. In the Avon and Susan G. Komen for the Cure walkathons in the Boston area, the Men with Heart contingent walk en masse. Wearing yellow T-shirts, they hand out Band-Aids, chocolate and (if asked) tampons while serenading the women with goofy songs.

To Boulanger, the group's role is similar to that of the breast cancer husband: serving as a caregiver for the women who walk. He is now divorced from his wife but remains committed to the group. "The reason I continue is because it's bigger than me," says Boulanger, 36. "I need to keep doing it. I don't think it's any more complicated than that."

Guys also gave birth to the group Men Against Breast Cancer, which teaches men to be better caregivers. The cofounders have a personal stake in the organization, which they launched in 1999. For Stephen Peck, 61, it's a way to remember his wife, Gayle, who died of the disease. For Marc Heyison, it's a way to pay tribute to his mother, Gloria, a breast cancer survivor.

Men Against Breast Cancer presents workshops around the country, teaching men to be effective caregivers. At its first-ever national conference for caregivers last summer, 50 men came for the weekend crash course. Some participants were motivated to reach out beyond their family, expressing interest in setting up local chapters of the group.

Expressing Themselves

The conventional wisdom is that men have a hard time talking about their feelings. But some men are happy to speak up if they can find the right forum. After Doug Drake's wife, Janet, was diagnosed with breast cancer in 2000, he started Partners in Breast Cancer Survival, a support group for men that is thriving today. An oncology nurse planted the idea. "So many men feel lost," she told him. Drake wanted to "give back to the community," so he forged ahead, consulting with the nurse and three other breast cancer husbands.

"Men seem to do well with food and a beer," he says. So they set the meeting place: Kelsey's restaurant in New Albany, Indiana, where the Drakes live. The group meets on the fourth Tuesday of the month. Speakers include oncologists, nurses and other medical professionals, discussing everything from chemotherapy to sexuality. Guys can just sit and listen or join the conversation. "We don't set any outlandish goals," says Drake, 50, who is the executive director of a counseling center. "We just wanted to reach a few guys locally. I'm surprised that men talk more openly than I ever imagined."

When the women they love are diagnosed, these men are afraid, but they aren't paralyzed by fear. "I think fears get smaller if you face them," says Judy Kasey Houlette, program director of the Friend for Life Cancer Support Network in Louisville, Kentucky, which trains survivors and their spouses to support newly

diagnosed women and their partners.

Nor do these hands-on husbands let anger and frustration get the upper hand. Stephen Peck recalls how he wanted to “pick up a gun and shoot breast cancer” after his wife’s diagnosis. But it turns out that activism is a far more effective way to blast away at cancer.