

# after breast cancer

THERE'S HELP ON THE JOURNEY TO FEELING IN CHARGE OF YOUR LIFE AGAIN.

BY RACHELLE VANDER SCHAAF

**B**reast cancer can turn a woman's life upside down. For months, her illness and treatment are front and center, consuming her time, thoughts and energy. Finally, she receives a clean bill of health. The cancer is gone, and she has her normal life back.

Or does she?

"You've been so focused on the specifics—getting the right surgeon and medical oncologist, dealing with treatments and their side effects," says Richard Michaelson, M.D., chief medical officer for oncology at St. Barnabas Medical Center in Livingston. "But suddenly it's over, and you're struck by the enormity of what you've faced. Instead of the trees, you see the forest—and it can be overwhelming and terrifying."

Fortunately, research shows that most women report a good adjustment to the post-breast-cancer life within a year. "Over time, in general, women begin to settle into a routine—we call it the 'new normal,'" says Ellen Levine, LCSW, acting manager of the social work department at the Cancer Institute of New Jersey in New

Brunswick. Still, it can take time to get there especially when you're feeling your way on your own, guided by only a few dos and don'ts for daily issues, such as diet and exercise.

"Many women hate the visits and the treatments while they have cancer, but at least they're getting attention. Now, they wonder, 'What do I do? How do I manage on my own?'" says Levine. At the Cancer Institute, experts offer cancer survivor resources to help former patients deal with day-to-day emotional and physical concerns.

## EMOTIONAL ISSUES

"Cancer free" doesn't mean "worry free." Most survivors fear a recurrence. "You have to regroup and find out how not to be cancer-phobic, and not worry about every ache and pain that might actually be typical of aging," says Levine.

Meanwhile, survivors may be plagued by mood swings and mental fuzziness as a result of hormonal therapy. "Tamoxifen throws the body into menopause, hitting you with all the attendant emotional upheavals related to

surviving and thriving

Dr. Ann Stock knows what it's like to emerge successfully from a bout with breast cancer. She's been there.

Stock is a professor in the Department of Biochemistry at UMDNJ-Robert Wood Johnson Medical School, Center for Advanced Biotechnology and Medicine. Diagnosed with breast cancer at age 39 in 1996, her life was immediately altered as she was spun into rounds of chemotherapy, radiation therapy and a lumpectomy.

To cope, Stock tried to maintain an upbeat attitude. "Don't worry about those things you can't control. Worry about the things you can control," she says. Not feeling the need for a cancer support group, Stock was nourished by the support of family and friends. "There's an amazing support network of people who have been through it. It's great to hear stories of how others have coped with their ups and downs." She also credits the supportive environment of the Cancer Institute of New Jersey (CINJ). "They make it easy for you to keep your spirits up," she says.

Keeping busy at work was a way to maintain her emotional equilibrium. "If you're able to keep up a relatively normal life and activities, that's the positive way to go,"

she says. "On the other hand, you learn you don't have to do everything. Give others the opportunity to help. Usually, you don't even have to ask."

Now, Stock says, her life is back to the way it was before she was diagnosed. She has returned to her former exercise and diet routines. The only thing different is that she has become a contact for others who are going through cancer battles. "Suddenly you belong to a club of people, part of a network to give advice."

What advice does Stock give?

"Play an active role in decision-making on your treatment," she says. "Then, once you make a decision, don't look back."

On Oct. 25, Stock will receive the Cancer Institute's 2003 Award of Hope. The award, CINJ's highest honor, was established in 1997 to publicly recognize extraordinary service, untiring leadership and deep commitment to serving the health care needs of New Jersey. The 2003 Award of Hope Gala and Benefit Auction will be held at Ellis Island. For information, contact Rosemarie Franchini at (732) 235-7076.

—Sandra Lowich

hormonal changes," says Levine.

Chemotherapy may also have lingering side effects, such as fatigue and problems with concentration and memory. "Women have long complained of 'chemo brain'—trouble focusing after treatment," says Michaelson. The change isn't drastic—women can still perform complicated mental tasks—but it can be frustrating.

At the same time, others may expect a breast cancer survivor to reflect only the glow of good health and happiness, and may not notice—or understand—the cloud hanging overhead. "Everyone's there to help when breast cancer is diagnosed, but once it's over, they think she's fine," says Michaelson. "She loses the support of people who think she should be back to normal, who don't understand that without treatment, she feels unprotected."

"If you find yourself feeling isolated, consider continuing to attend a support group—or join one now, even if it wasn't a priority during your

treatment," suggests Levine. To find one, seek recommendations from a social worker at a cancer center or an oncology nurse. Give a group at least two tries, says Levine. Attendance can vary, and if the first meeting didn't suit you, perhaps a different gathering will. While self-guided groups can work well, Levine admits to a personal bias toward groups with a professional facilitator, who makes sure no one monopolizes the discussion or treads into uncomfortable territory. The following organizations can help you locate a group or person to empathize with you and offer emotional support.

■ **Cancer Care**, a nonprofit organization based in New York City, offers professional help free of charge. It's staffed by oncology social workers who offer counseling over the phone or face-to-face at Cancer Care offices. Call the New Jersey main office in Ridgewood at (201) 444-6630 or log on to [www.cancercare.org](http://www.cancercare.org).

■ **Cancer Hope Network**, a New Jersey-based nation-

*Play an active role in decision-making on your treatment.*

—Dr. Ann Stock

al organization, sets up one-on-one conversations between patients and trained volunteers. Call (877) HOPE-NET or log on to [www.cancerhopenetwork.org](http://www.cancerhopenetwork.org).

■ The Cancer Institute of New Jersey in New Brunswick provides a variety of support groups that women can begin at any time during or after treatment. Call (732)235-6792 or log onto [www.cinj.org](http://www.cinj.org).

■ The Wellness Community provides professionally led support groups, workshops and mind/body programs for cancer patients and their families nationwide, with a center in Hillsborough. Call (908) 371-0844 or log on to [www.thewellnesscommunity.org](http://www.thewellnesscommunity.org).

You may also find emotional comfort through a community of faith, family and friends (you may need to state your needs explicitly) or short-term counseling. "Some people have a bias against therapy," Levine

notes, "but it's simply structured talk. It's a place where you can unload, vent and learn strategies for coping, such as relaxation techniques."

#### DIET DILEMMAS

The simple question, "What do you want to eat?" becomes a stumper in the wake of cancer. "People are bombarded with general information on diet and cancer, and it can be very confusing," says Maureen Huhmann, M.S., R.D., a clinical nutritionist with the Cancer Institute of New Jersey. "Things that were appropriate before as prevention may change during treatment, then change again after."

For example, vitamin C, abundant in citrus foods, is an antioxidant believed to help prevent cancer. But during treatment, the antioxidants may actually combat

helpful drugs. "After treatment, you could go back to taking vitamin C, so long as you don't go above daily recommended intake," says Huhmann. Or consider beta-carotene, another antioxidant found naturally in richly colored fruits and vegetables and touted as a particularly potent cancer fighter. Mega doses of beta-carotene appear actually to increase the risk of cancer, particularly among those who smoke and drink regularly.

But perhaps the most confusing food issue for post-breast-cancer patients is soy—it can prove either helpful or harmful, depending on the type of cancer. Soybean products contain phytoestrogens, weak plant versions of estrogen that studies suggest may help curtail hormone-driven diseases, including some types of breast cancer. In other cases, however, soy may increase the risk for breast cancer. "Phytoestrogens may stimulate tumor growth in breast cancer that's estrogen receptor positive," says Huhmann. "The research is inconclusive, but if you're a vegetarian who wants to eat soy for protein, limit yourself to just one or two daily servings. And if you don't know if your cancer was estrogen-receptor positive or negative, ask your doctor."

In general, cancer survivors should base food choices on the Food Guide Pyramid, suggests the American Cancer Society. But to help you sort out well-meaning but possibly misguided advice from friends, family and even the media, it's best to see a dietitian, Huhmann says. To find one, visit the American Dietetic Association's website at [www.eatright.org](http://www.eatright.org).

#### WORKOUT WORRIES

A person's level of commitment to exercise usually drops considerably when they face cancer. A new NCI-supported study found that breast cancer patients cut physical activity by about two hours a week after diagnosis. After the cancer is gone, though, it's time for cancer survivors to regain their lost footing, say researchers, who point out that less

activity may lead to greater weight and higher body fat, which has been linked to an increased risk of recurrence.

Exercise can also charge and cheer you up—assuming you can get past post-treatment fatigue and lack of desire to get moving. "It takes a monstrous effort, especially when you're not even sure what you should do," says physiologist Doreen Jones, M.D., a post-rehabilitation exercise specialist at the Pilates Center in Fairfield. Often, women are simply given a conservative list of post-treatment exercise guidelines. "Without medical supervision, things can get a little muddled," she says. "Usually a woman can do more within those restrictions than she realizes."

To help breast cancer survivors in workouts, Jones has developed the Pink Ribbon Program. "We work within the safety guidelines but take it to the next step, designing individual plans based on each woman's past treatment and current needs for physical therapy." (For more information on Jones' program, visit [www.thepilatescenter.biz](http://www.thepilatescenter.biz).)

Jones favors Pilates-based movements to help restore full range of motion to the chest and arms, but points out that swimming offers similar benefits. Although breast cancer survivors are often urged to avoid heavy lifting because of the risk of lymphedema (swelling of lymph nodes), strength training using very light weights or while wearing a weighted vest should be safe, says Jones. "Try to find someone qualified to guide you, such as an exercise physiologist or a physical therapist," she says. "Ideally, that person will be certified as a cancer exercise specialist, or at least have worked with other patients." For printed guidance, she suggests *Essential Exercises for Breast Cancer Survivors* by Amy Halverstadt and Andrea Leonard (Harvard Common Press, 2000).

#### COSMETIC CONCERNS

You know your body is strong and beautiful—but even so, it can be hard to accept surgical changes. "Society puts so

much emphasis on breasts," says Levine. "Breast cancer survivors worry, 'Am I still a woman? Am I still desirable?' Plus, sensations in that area of your body may be different because surgery may affect the nerves."

Surgery isn't the only breast treatment that may have a drastic effect on a survivor's physical appearance. Hair can grow back a different texture or color after chemotherapy. Tamoxifen can cause weight gain.

At this point in her life, a woman may feel anything but fashionable. Dress the part anyway, advises Marisa C. Weiss, M.D., and Ellen Weiss in *Living Beyond Breast Cancer* (Time Books: 1997). "Clothes can make you feel good about yourself," write the authors. "Wear nice things at home, just for yourself, styles that flatter your figure, colors that suit you and trim you down."

A little makeup or a new haircut also can make a big difference in how you feel about yourself—and a little self-indulgence does wonders too. Treat yourself to a spa visit, suggests Michaelson, or make a date with Look Good...Feel Better, a program that offers cancer patients hands-on tips from makeup artists, hair stylists and other beauty professionals. "This is a really nice program that provides lots of pampering and attention, and you can use it later as well as during treatment," says Levine. For more information, call (800) 395-LOOK.

Finally, for inspiration, consider one of Michaelson's patients, a woman in her twenties who had a bilateral mastectomy and reconstruction. "She moved forward with diet and exercise, became interested in women's physique competitions and took second place in one contest's 'womanly figure' category," says Michaelson. "Women cope in incredible ways." **SL**

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Rachelle Vander Schaaf is the co-author of *The Doctor's Guide to Chronic Pain* (Reader's Digest Books.)

Can fly-fishing help you feel like yourself again after breast cancer—even if you've never touched a fishing rod in your life? Absolutely, says Maureen Kling, M.D., F.A.C.S., a breast surgeon in Mount Holly.

Dr. Kling volunteers with the Littoral Society of Manahawick, which sponsors fly-fishing retreats for breast cancer survivors in association with the national group Casting for Recovery. She first heard about the group through her husband, Craig Liskas, an avid fly fisherman. "I was intrigued by the idea of finding a new means of support for breast cancer survivors, beyond regular support group meetings," she says. "From tagging along with my husband I knew that, wherever you go fly-fishing, you're in God's country—and that's good for the soul."

The physical requirements of the sport—which calls for stretching, not power, strength or speed—involve a full range of motion for the shoulder, exactly what most post-breast-cancer patients need, says Dr. Kling. Equally important is the chance for a woman to stretch her idea of the range of possibilities for her life. "After you've battled with breast cancer, the opportunity to go off and explore something completely off the wall, like fly-fishing, is a joy in and of itself," she says. "It shows you that life goes on and there are whole worlds left to explore."

The groups are typically small (12 women or fewer) and include a medical expert, a social worker and experienced fly fishers to guide the novices. The retreats are all expenses paid, with funds raised by local sponsoring organizations.

While the breast cancer survivors on these trips are all technically

cured or in remission, they must learn to deal with uncertainty about the future. "I'll quote you a line from [renowned breast cancer expert] Dr. Susan Love, which I tell my patients: 'You only know that you are cured of breast cancer when you die of something else,'" says Dr. Kling. "That, harsh as it sounds, is the reality."

"But I tell my patients, 'If you work it right, cancer can be a gift,' she continues. "Generally that's when they look at me like I've lost my mind. I explain that we all have our mortality, but most of us go around pretending we don't. When you're facing a life-threatening illness, you have to deal with mortality, whether you want to or not."

"When you deal with it successfully, you won't be crippled by the fact that you're mortal, but you'll see how precious life is and will live it more fully and completely than the rest of us who don't deal with this. That is the gift of cancer: to truly live your life."

To learn more, visit [www.castingforrecovery.org](http://www.castingforrecovery.org).

—Lee Lusardi Connor

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