



Women & Living with Breast Cancer Today

When Arlene Dobren's mother was diagnosed with breast cancer 30 years ago, the cancer had already spread to her liver. She died a year later at age 62. Conversely, when Ms. Dobren herself was diagnosed with breast cancer in 1995 during a routine mammogram, she underwent a breast-conserving lumpectomy followed by chemotherapy and radiation and remained cancer-free for nine years.

When the cancer recurred last year—picked up during a routine chest X-ray—doctors quickly eased Ms. Dobren's panic, telling her that these days, metastatic breast cancer can be treated as a chronic disease. While she would have cancer for the rest of her life, they said, life could be expected to go on for many years.

"That was quite a concept for me," recalls Ms. Dobren, 58, a retired New York City guidance counselor. "They talk about partial remissions and full remissions, and all I could think about was that remissions had to do with leukemia. Now that a year has passed, I'm beginning to understand it. I'm still being treated, and I'll always be treated. But I still feel good."

"Things have progressed drastically in the last 20 years," says Margaret C. Kirk, CEO of the support and advocacy group, Y-ME National Breast Cancer Organization. One example: When her organization was created by two breast cancer survivors in 1978, "cancer" was known as the "big C," and no one ever said the words "breast cancer" out loud, she says.

Today, millions of Americans proudly display pink ribbons on their cars, women's magazines devote entire sections to breast cancer coverage during October, and breast cancer research receives more government funding than any other cancer.^{1,2}

New treatment options, solid research and women willing to participate in clinical trials to identify better ways of screening, diagnosing and treating the disease have led to a significant drop in the breast cancer death rate in recent years, even though the incidence remains about the same.

Specifically, while the death rate increased by 0.4 percent a year between 1975 and 1990, it dropped 2.3 percent a year between 1990 and 2002.³

Women also are surviving longer with breast cancer, with 88 percent of women still alive five years after their diagnosis, and 63 percent still alive 20 years after their diagnosis. Those figures are undoubtedly higher now, notes the American Cancer Society, since they were based on women diagnosed before more recent treatment advances.³

However, the disease is still the most common cancer in women, and the second most common cause of cancer death in women (behind lung cancer). This year, breast cancer is

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expected to affect an estimated 270,000 women, killing about 40,410, according to the American Cancer Society.³

"There are still tremendous challenges around diagnosis and screening tools," says Ms. Kirk. "Other challenges include more effective, less toxic treatments, better translation of science into the clinic and ensuring that all women with breast cancer receive quality care based upon accepted medical guidelines and standards," she adds.

Targeted Treatments

Every time Ms. Dobren pops another chemotherapy pill into her mouth or spends a couple of hours at the oncologist's getting a Herceptin infusion, she's aware of just how far breast cancer treatment has come since she was first diagnosed 10 years ago.

The drug she swallows used to be given only by time-consuming injection. And Herceptin (trastuzumab), a biological drug that targets a specific protein on breast cancer cells, didn't even exist outside the laboratory.

Today, both keep her cancer at bay while enabling her to live a full life, complete with trips to Las Vegas with her husband, an evening glass of wine, weekends at her country home in the mountains of Pennsylvania, and regular workouts.

Indeed, breast cancer treatments have become not only more targeted, but easier to bear, says Funmi Olopade, MD, a breast cancer specialist and professor of medicine at the University of Chicago Medical Center. "We've come a long way since I started in oncology," says Dr. Olopade. "Today, we're all about having people live well, have a good quality of life and be able to manage a normal lifestyle even when they're in the midst of treatment."

For instance, she says, many of her patients receive chemotherapy along with drugs to minimize nausea or receive

oral chemotherapy or hormone treatment with very few side effects and are able to work during treatment. She and her peers also have new tools to treat the low blood counts and fatigue that come with chemotherapy, such as erythropoietin to treat or prevent anemia, and hormone growth factors to stimulate the production of immune system cells.

Plus, newer chemotherapies like capecitabine (Xeloda) can be taken as a pill alleviating the need to come to the hospital for an intravenous infusion, says Toni K. Choueiri, MD, a hematology and medical oncology fellow at the Cleveland Clinic Foundation in Ohio, reducing the risk of infection.

Doctors also are getting better at treating hormone-receptive cancers, which make up the majority of breast cancers. These cancers rely on estrogen to grow, so anti-estrogen therapies aim to cut off their fuel supply. The oldest anti-estrogen, tamoxifen, has been used for more than 20 years to treat and, more recently, prevent breast cancer. Today a new class of anti-estrogen drugs called aromatase inhibitors seems to work even better.^{4,5,6}

Unlike tamoxifen, which works by blocking estrogen receptors on cells, the aromatase inhibitors anastrozole (Arimidex), exemestane (Aromasin) and letrozole (Femara) work by preventing androgen hormones from turning into estrogen in the first place.

Down the road are new and existing drugs packaged as nanoparticles, microscopic materials that hitch a ride on the back of common proteins in the blood to target cancer cells. One laboratory study evaluating nanoparticles loaded with paclitaxel (Taxol), found the particles worked better at killing cancer cells than Taxol alone.⁷

Researchers are also working on vaccines to supercharge the immune system so it can destroy cancer cells.

One such vaccine for metastatic breast cancer currently in clinical trials at the University of Pennsylvania and at Johns Hopkins University stimulates the immune system to create special white blood cells that target an enzyme found in more than 90 percent of breast cancer tumors. When the white blood cells go after this enzyme and destroy it, they also destroy the cancer cells.⁸

Genetic Screening Important

Doctors are also getting better at targeting therapies to a woman's individual tumor. For instance, Herceptin doesn't work for everyone; only the 20 to 30 percent of women whose tumors over-express the HER2 gene. But thanks to genetic testing of women's tumors, doctors can tell if the drug should be used.

That's particularly important with Herceptin. Currently approved only for metastatic breast cancer, it's expected to become a first-line treatment after surgery for women with primary breast cancer since studies presented at this year's American Society of Clinical Oncology meeting showed adding it to chemotherapy during adjuvant treatment could halve the risk of recurrence.⁹

Doctors also can use a screening test called Oncotype DX to identify 21 genes the tumor expresses. This enables them to predict the risk of recurrence in women with newly diagnosed, early stage invasive breast cancer and, in turn, determine if chemotherapy is needed, said Dr. Choueiri.

Of course, medicine is also getting better at predicting a woman's risk for breast cancer, particularly if

she had a close relative with the disease. Researchers already know that mutations on two genes, called the BRCA1 and BRCA2, significantly increase a woman's risk of the disease. Now they're learning how to take that knowledge a step further, ensuring the cancer is caught early with advanced screening techniques like MRI, or preventing it altogether with prophylactic mastectomy.

But those genetic mutations account for only a tiny percentage of breast cancers. The vast majority occur with no evidence of family history, prompting researchers to look for other clues to a woman's individual risk.

One tool is called the Gail model, a computer program that uses personal and family history to estimate a woman's chance of developing breast cancer. It takes into account such things as when a woman started menstruating, how many children she's had and how early she had them, whether or not she breastfed, her race, age, weight and family history—all factors that play into a woman's risk of developing the disease. The Gail model does not, however, recognize certain risk factors that may influence the degree of risk in some women.

Better Radiation Therapy

Radiation treatment has changed too, notes Carol L. Kornmehl, MD, a radiation oncologist at Valley Hospital in Ridgewood, NJ, and author of *The Best News about Radiation Therapy*.

Nearly anyone who's had ductal carcinoma in situ (DCIS) or invasive cancer will need radiation, she notes. Why? How about

a 30 percent risk of a local recurrence without it versus less than a 10 percent risk of recurrence with it? Not only that, she notes, but if you choose not to receive radiation, any recurrence could be much more serious and invasive than the original cancer. "So it's a risky business not to treat breast cancer with radiation," she says.

The good news? "We're so much better at targeting the radiation to just the tiny area of the breast that has the cancer," she says, using CT scans to exclude as much normal tissue as possible.

Doctors and radiation oncology nurses are also much more aware of how to manage and even reduce skin-related side effects, like redness, tenderness, blistering and ulcers.

"We give patients a break about halfway through their treatment to help minimize or even prevent a nasty reaction," explains Dr. Kornmehl. In the

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African-American women are more likely to be diagnosed with more advanced, larger tumors, and their cancer is more likely to be estrogen-receptor negative, a classification that means that many of today's most effective drugs don't work.

Breast Cancer Glossary

- **Adjuvant therapy.** Chemotherapy and/or radiation given after surgery to prevent cancer recurrence.
- **Ductal carcinoma in situ (DCIS).** A noninvasive form of breast cancer in which cancer cells are found in the lining of a breast duct and limited to only this area. In some cases, it may become invasive and spread to other tissues.
- **Metastatic disease.** Cancer that has spread to another part of the body.
- **Mammogram.** X-ray of the breast to screen for breast cancer.
- **Mastectomy.** Removal of the breast to treat known breast cancer or prevent breast cancer in high-risk women.
- **Prophylactic mastectomy.** Removal of the breasts in high-risk women to prevent future breast cancer.

Instead of a cure, doctors talk about survival rates and long-term remission, pointing to the ways in which most cancers are being treated as chronic diseases like diabetes.

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past, radiation oncologists might have continued to treat until the reaction occurred. There are also creams available to help protect the skin during treatment.

Plus, today women can receive internal radiation, also called brachytherapy, as well as external radiation. Brachytherapy involves placing radioactive tubes or even a wire within a balloon (called Mammosite) within your breast in the same

spot as the tumor to supplement or instead of regular external radiation treatment.

Some institutions also offer accelerated radiation delivered through external beam, which is completed in two to three weeks.

Radiation therapy can also be an important part of any treatment for metastatic cancer, as Ms. Dobren learned when an MRI revealed the cancer had spread to her brain. She underwent a gamma knife treatment, also called stereotactic radiosurgery, in which a special form of radiation therapy delivers high-energy radiation rays directly to the cancer in the brain. The results, she says four months after the treatment, “look promising.”

Hoping for the Best

Mention the word “cure” around cancer doctors, and they cringe just a bit. The word is politically incorrect in the medical field; instead of a cure, doctors talk about survival rates and long-term remission, pointing to the ways in which most cancers are being treated as chronic diseases like diabetes.

“Cure is very important but it is difficult to prove,” says Dr. Choueiri. “Cancer can return 10 or 20 years after an initial occurrence. For instance, if a woman diagnosed with breast cancer at age 50 lives without any symptoms of recurrence until she dies of a heart attack at age 80, and then an autopsy finds signs of a recurrence that never bothered her while she was alive, was she really cured? We would rather speak about long-term remissions.”

Ms. Dobren no longer thinks about a cure. Instead, she thinks

ahead to the next MRI, the next CT scan, the next Herceptin treatment. And she focuses on the fact that, despite the rogue cancer cells in her body, she feels really good. She never stops counting her blessings—like great doctors and nurses and great health insurance. And she focuses on what she can control, rather than what she can’t.

“You either live the rest of your life being miserable and being negative and berating your doctors and all the healthy people in the world and moaning, ‘why me, why me,’” she says, “or you just say, ‘look on the bright side and at all the things you’re so lucky to have.’” ✕

Racial Disparities in Breast Cancer

At first glance, the declining death rate for breast cancer looks great — until you break it out by race. While the death rate dropped 2.4 percent in Caucasian women between 1990 and 2002, it only dropped 1.8 percent in Hispanic women and one percent in African-American women.³

In fact, overall death rates are 37 percent higher in African-American women than in Caucasian women, even though the incidence of breast cancer in African-American women is lower than in Caucasian women (141 cases per 100,000 Caucasian women compared to 122 per 100,000 African-American women).¹⁰

Overall, just 76 percent of African-American women survive five years after diagnosis, compared to 90 percent of Caucasian women.

What’s going on? Numerous factors, say experts. For one, African-American women are more likely to be diagnosed with more advanced, larger tumors, and their cancer is more likely to be estrogen-receptor negative, a classification that means that many of today’s most effective drugs don’t work.¹⁰

They are also less likely than Caucasians to get mammograms and less likely to have health insurance, and more likely to have lower incomes, unequal access to medical care and disparities in their treatment.¹⁰

“Racial disparities are always an issue in any cancer, whether it is breast cancer, leukemia or other cancers,” says Toni K. Choueiri, MD, a hematology and medical oncology fellow at the Cleveland Clinic Foundation in Ohio. “Future research needs to more specifically target the area of cancer and race.”

Resources

American Cancer Society

1-800-227-2345

www.cancer.org

The American Cancer Society offers vast resources on diagnosis, treatment and prevention for a wide range of cancers, as well as support and advocacy for the disease.

Breastcancer.org

www.breastcancer.org

Web site provides in-depth, easy-to-understand information about breast cancer screening, detection, treatment and living with cancer.

National Cancer Institute

1-800-422-6237

www.cancer.gov

Government agency devoted to research and providing information on cancer. Offers information on clinical trials.

Y-ME National Breast Cancer Organization

1-800-221-2141

www.y-me.org

Advocacy and support organization for women coping with breast cancer. Offers toll-free hotline 24 hours a day staffed by breast cancer survivors and print and online information.

Reconstruction after Mastectomy

Ellen Parker* has always taken pride in her breasts. So after her breast cancer diagnosis in 1991, when she learned she'd need a mastectomy, she was pleased to hear she could have an immediate reconstruction.

And, indeed, she woke up in the recovery room with a tissue expander in place of the missing breast, the first step in the two-step reconstruction procedure using a breast implant.

On the advice of her doctor, Ms. Parker, now 58, who lives in Arlington, VA, opted for a silicone implant.

But instead of the cosmetic results she had hoped for, the implant sat stiff and high on her chest, looking little like her other breast. By the time it ruptured 14 years later (a common occurrence with older saline and silicone implants)¹¹, she was relieved. "I was never happy with it," recalls Ms. Parker.

Soon after her implant, the U.S. Food and Drug Administration (FDA) limited silicone-gel implants to controlled clinical studies involving cases of mastectomy, replacement of ruptured silicone implants or correction of congenital deformities. Earlier this year two manufacturers of silicone implants received "approvable with conditions letters" from the FDA for their products. Once the conditions are met, silicone implants likely will be available again in the U.S. Meanwhile, most reconstructions are done with saline implants.

Ms. Parker's experience isn't entirely unusual—studies find that about one in three women receiving an implant for reconstruction, regardless of the type of implant used, required another operation within five years.^{12,13}

However, today's implant shells are nearly twice as thick as those

of the old silicone-gel implant.

Additionally, manufacturers have added a barrier between the inner and outer layers of the implant to prevent silicone from leaking from the implant if it ruptures. Also, the outside of the implant shell is usually textured, which studies find results in fewer incidences of contracture, a condition in which fibrous tissue grows around the implant.¹¹

Nonetheless, Ms. Parker didn't want another implant. Instead, in September 2005 she underwent a new type of breast reconstruction that uses fat and tissue—but not muscle—from her abdomen to shape a realistic-looking and feeling breast. One month later, still recovering from the surgery, she was ecstatic.

"I'm so excited I can hardly stand it," she says. The heft, the droop, everything about her new breast matches the untouched breast, she says, and under clothes you can't tell the two apart.

That's the goal, says her doctor, Maurice Nahabedian, MD, associate professor of plastic surgery at Georgetown University in Washington, DC.

He is one of only a handful of specialists in the U.S. using this new reconstruction technique, called the DIEP (deep inferior epigastric perforator) flap. The procedure is a variation of the most commonly performed breast reconstruction surgery method, the TRAM flap, in which muscle, tissue and fat are removed from the transverse rectus abdominis muscle (TRAM) in the lower abdomen.

In both operations, the lower abdomen is the principle source of tissue. During a TRAM flap, the surgeon removes the tissue, fat and the muscle to preserve the major blood supply that runs through the muscle for use in the new breast. With the DIEP flap the surgeon doesn't remove the muscle, so there's very little change in abdominal strength and a faster recovery time, says Dr. Nahabedian.

In the traditional TRAM flap, women lose up to 40 percent of abdominal strength for a single breast reconstruction; up to 70 percent if both breasts are done. With the DIEP flap, they can do everything they're used to doing, even sit-ups, Dr. Nahabedian explains.

The downside is the complexity of the procedures. Surgeons carefully tease blood vessels away from the muscle, preserving the nerves. During reconstruction, they painstakingly connect those tiny blood vessels via microscopic surgery to vessels in the chest, providing the new breast with its own critical blood supply.

Because the surgery is so complex, he says, it's critical to find a specialist in the procedure. If it isn't performed properly, the breast tissue could die and become infected, putting a woman's overall health at risk.

As for Ms. Parker, she's excited about being able to work out at the gym without stuffing a towel into her sports bra, and being able to wear the bright, sexy tops she's been saving for her new breast. "It's just a miracle," she says. ✕

New treatment options, solid research and women willing to participate in clinical trials to identify better ways of screening, diagnosing and treating the disease have led to a significant drop in the breast cancer death rate in recent years.

*Not her real name

Mammography & Beyond

The American Cancer Society recommends a yearly mammogram beginning at age 40 and continuing “for as long as a woman is in good health.”

The U.S. Preventive Services Task Force, however, recommends all women “over 40” get a mammogram “every year or two,”¹⁵ while the National Cancer Institute recommends women in their “40s” get a mammogram “every year or two.”¹⁶

Why the variation?

“This is more a political and a public health policy issue than a medical debate,” says radiation oncologist Marisa Weiss, MD, president and CEO of the non-profit Web site breastcancer.org. “The bottom line is you should have a mammogram once a year from age 40 on, unless you have a history of breast cancer at young ages in your family, in which case, earlier is probably more appropriate.”

Unfortunately, too few women heed that advice.

A Harvard study of 72,000 women found that only a fraction of those who need mammograms get them every year, with just six percent of those screened in 1992 returning for another mammogram every year during the next decade. That’s despite the hospital’s “aggressive reminder program.”¹⁷

“This suggests that women are either reluctant to comply with recommendations, are not being counseled appropriately by their physicians or are not going for routine preventive health care,” says Carol L. Kornmehl, MD, a

radiation oncologist at Valley Hospital in Ridgewood, NJ, and author of *The Best News About Radiation Therapy*.

Other reasons, notes a 2004 Institute of Medicine report on the topic, range from a lack of health insurance coverage to a fear of breast cancer to the fact that some find the procedure painful.¹⁸

Yet there’s no doubt that mammograms identify breast cancers at an earlier stage, when they’re most treatable and less likely to spread.¹⁹

However, mammograms are not perfect. They carry a high risk of false-positives, meaning women may undergo needless worry, expense and biopsies only to find that they don’t have cancer. Overall, one study found, a 50-year-old woman having annual mammograms for 20 years has a one in five risk of receiving a false-positive report.²⁰

Mammograms also don’t work well in women with dense breasts, common in younger women.

Still, for women with a low risk of breast cancer, they’re an excellent screening tool. For women with a high risk of breast cancer, or those whose mammograms show an abnormality, there are other options, such as MRI. One major study of 1,909 women with a high risk of breast cancer found that MRI worked better than mammography at detecting tumors.²¹

So why not offer it to all women?

“MRI is a useful tool as a supplement, but not as a replacement to mammograms,” says Dr. Kornmehl. “Besides being an expensive test that many insurance companies are reluctant to pay for, it can open a ‘Pandora’s box’ by leading to false-positive findings and the need for stressful procedures, such as biopsies.”

Another, less expensive option, particularly for younger women with dense breasts who feel a breast lump, is ultrasound, which sends sound waves through the breast to create a picture on a screen. It’s often used to tell if an abnormality is solid or filled with fluid, but it isn’t specific enough to be used alone as a screening technique.

When choosing a mammography center, Dr. Kornmehl recommends looking for the following:

- An American College of Radiology-accredited facility.
- Radiologists who spend the majority—if not all—of their time reading mammograms in a set-aside block of time known as “batch reading.” One study found it could significantly reduce the number of women who have to return for additional mammograms.
- A center with immediate readings and follow-up. One study of more than 8,500 women found those who received immediate screening results and underwent follow-up tests within the same office visit had significantly less anxiety than those who had to wait several days for results. ✕

Commonly Asked Questions About Reconstructive Surgery

Q I'm scheduled for a mastectomy. When is the best time to have reconstructive surgery?

A When to have reconstructive surgery depends on your own situation. Most women can have immediate reconstructive surgery and wake up with a breast, because we're catching tumors at such an early stage. So in those situations, immediate reconstruction is safe and acceptable and should be offered to the majority of women.

In cases where the tumor is more advanced, and we know for certain that a woman is going to have radiation or prolonged chemotherapy, we sometimes recommend you delay reconstruction until the treatments end, because we don't want to do anything that might interfere with the treatment or vice versa. For instance, radiation therapy could affect the reconstruction, causing an implant to fail prematurely or a flap to harden or even shrink a bit.

Q I had a mastectomy 20 years ago but never had reconstruction. Is it too late?

A It's never too late for breast reconstruction, and you're never too old. As long as you're healthy and willing to undergo the operation, you can get great results. In fact, studies in women over 65 find a very high rate of satisfaction.

Q Which is better, a breast implant or a reconstructive flap?

A It really depends on you. For many women, implants are a very good option. It's a shorter operation, a speedier recovery and provides a very good cosmetic result. The downside is that implants won't last forever—studies find that one in three women receiving an implant for reconstruction, regardless of the type (silicone or saline), require another operation within five years.^{12,24}

However, if you've had radiation to the breast area, I recommend avoiding an implant. After radiation, the tissue loses some

of its elasticity, making it more difficult to create a natural looking breast.

While the flaps are a more difficult operation with a more prolonged recovery, they last forever and get better with time as the scar tissue softens and the effects of gravity serve to make the breast look more realistic.

Q I don't have health insurance. What are my options for breast reconstruction?

A While the Women's Health and Cancer Rights Act of 1998 requires all health insurance providers who cover mastectomy procedures to also cover the cost of breast cancer reconstruction, there is no such law for women without health insurance. The best I can suggest is to talk to your surgeon and the hospital; sometimes the surgeon will waive the fee for the procedure, and the hospital may offer a discount if you're paying cash.

—Maurice Nahabedian, MD, FACS
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Life During and After Breast Cancer Treatment

The shock is subsiding. You may even surprise yourself one day soon and find you're thinking less about your diagnosis and more about living with breast cancer.

You'd be right: Your focus now should be on maintaining as normal a life as possible during and after your treatment. One area you may be grappling with is sexual intimacy. Between the sexual connotations associated with a woman's breasts, side effects of treatment, plus the emotional distress of having cancer, it's no surprise that research finds that about half of all women who have had breast cancer experience long-term sexual problems.²⁵

One study of 558 women in the year after their breast cancer treatment found about one-fourth simply weren't interested in sex, particularly if they'd had chemotherapy.²⁶ Other reasons for a lack of sexual interest include menopausal symptoms like vaginal dryness and hot flashes that can result from cancer therapies.

And yet, now perhaps more than any other time in your life is when you need to be close with someone, both physically and emotionally.

So here's what I suggest: Forget about sex for the moment. Instead, focus on intimacy. Massage one another, hold hands, go on spontaneous dates. Find ways to bring sensuality into

your life—beautiful negligees (several companies make lingerie for women who have had a mastectomy), romantic music, low lights. Spend one evening slowly touching each other. Ask your partner to gently touch your scar.

And if your desire for intimacy is affected by negative feelings about your body, try turning out all the lights before you start.

Communication is essential during this time. Talk about why you may not feel desire right now. Get your partner to talk about how your diagnosis and treatment has affected him or her. If you feel too uncomfortable talking, try writing letters in which you tell each other how you feel.

And share your concerns with your health care team who may be able to recommend strategies to help you regain the intimacy you've lost.

Other Lifestyle Issues

Fatigue is also a major problem, particularly if you're undergoing chemotherapy. Many women also complain about "chemo brain," in which they feel like they can't remember anything.

That's why you must take care of yourself first. That means

napping instead of volunteering; working a shorter schedule during and after treatment; hiring out certain chores, if you can afford it; and even asking the student down the street to do your grocery shopping.

It's also a time when I urge you to call upon the people in your life who love you. Most people want to help—they just don't know what to do. So tell them.

Ask a close friend to organize a dinner brigade, assigning neighborhood families a night to bring your family dinner. Call on a friend to drive if you feel too tired to drive yourself. I know one woman whose greatest fear was getting the laundry done for her large family—a friend came to her house and made sure it was done and put away every week.

And seek out other women with breast cancer, either in a formal or informal support group, in person or online. Numerous studies find such support can improve your overall quality of life.²⁷

Finally, make time for some form of exercise every day to help you regain energy as well as confidence in yourself. It may even help your long-term survival. One study of 3,000 women with breast cancer found those who got a few hours of exercise a week were less likely to die of their cancer than women who got less than an hour a week.²⁸ ✕



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To learn more about breast cancer, visit www.healthywomen.org.
See Take 10 for Breast Cancer Awareness.