

After BREAST CANCER

Working through pain and fear toward a new normal.

BY SARA AASE

Five years after undergoing chemotherapy and radiation treatment for breast cancer, Darlene Maxwell, 53, still experiences fatigue and memory loss. “Chemo brain is the most frustrating,” says Maxwell, who lives in Mound. “Right after chemo, I would lose words and have trouble completing a sentence. And my short-term memory is still gone.”

Maxwell’s complaint is common among breast cancer survivors—one of a litany of physical indignities, setbacks, and daily griefs most women aren’t prepared for when treatment ends.

Some suffer swelling of the arm, reduced feeling in their breasts, and early menopause. Chemotherapy and hormone treatment can affect fertility and heighten the risk of osteoporosis. Emotionally, breast cancer survivors work through anger, grief, depression, and ultimately come to terms with the biggest fear of all: That the cancer could come back.

“Breast cancer is one of the few cancers that can come back many years after the original diagnosis,” says Dr. Harold Londer, medical director of North Memorial Hospital’s Humphrey Cancer Center in Robbinsdale. “You’ve got that hanging over you and that is a fear that some women have enormous trouble getting past.”

With more than 2 million breast cancer survivors in the United States, treatment programs are now focusing on the fact that for some patients breast cancer is never really over. “As people are living longer and doing better with breast cancer, survivorship programs help address the need to talk about and plan for long-term issues,” says Dr. Steven Rousey, an oncologist with Minnesota Oncology Hematology and chair of Ridgeview Medical Center’s Cancer Care Committee.



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DARLENE MAXWELL

GRIEVING THE CHANGES

Because breast cancer is one of the few cancers that is disfiguring, women often have questions about how they will handle dating, sex, childbirth, or the lack of ability to conceive. “With breast cancer you’ve got a lot of physical and psychological issues revolving around your body image and your sexuality,” says Londer.

At St. John’s Hospital/HealthEast Cancer Care Center, patients work with an oncology psychotherapist and a “patient navigator” to help them through treatment and its aftermath. “They are so relieved when they come in for surgery to see a familiar face,” says registered nurse and patient navigator Nancy Welty. “I go over their prognosis with them and do a lot of postoperative care and education.”

Breast cancer offers a crash course in the grim minutia of surgical procedures and aftercare, including the emptying of blood and lymph fluid from drains from the breast or armpit. Patients learn which foods to avoid, when they can wear a bra or prosthesis, and how to do arm exercises to prevent stiffness. Some will live with chronic feelings of pinching or tingling. Others deal with periods of swelling of the arm that will leave it feeling heavy and useless.

Years after treatment ends, the scars are a daily reminder. Kelly Moore of Lino Lakes had two lumpectomies to remove tubular cancer when she was 32 and has since had reconstructive surgery with implants. “I’m extremely lucky just to be alive and also to still have sensation in my breasts,” she says. “But I need a special fitter when I shop for bras because I’m lopsided. It’s no

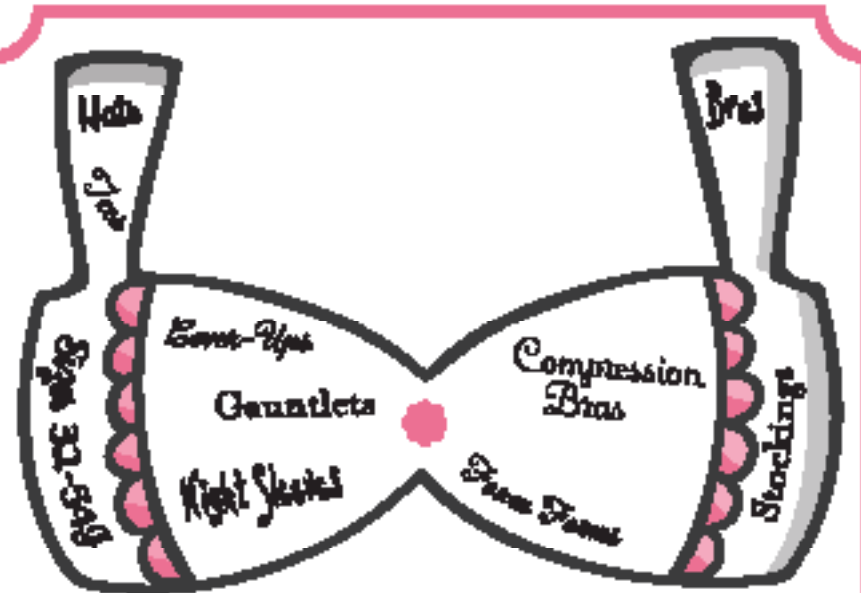


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Breast Cancer

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big deal, but it's not the same."

Many women say losing their hair during chemotherapy is one of the worst blows. "It's a shock," says Victoria Thurs of New Hope. "I was sitting in a restaurant and I scratched my head and a chunk came out." That night, Thurs went home and pulled out the rest. "You look at yourself then and that's when it hits you that you have cancer. It's a vain thing and it's not a vain thing. It's devastating."

Hair loss is emotional not only because of the change to one's physical identity, says HealthEast oncology psychotherapist Mary Hughes, but also because it's the first tangible sign that the patient is in the grip of something beyond her control. "We encourage them to prepare for it and take control of it themselves—to cut their hair shorter, put some pink dye in it, or shave their heads," she says.

Maxwell bought a couple of straight, auburn wigs after she started chemotherapy to try to match the hair she lost. "You kind of want things to stay as normal as you can," she says, "because what you're going through is so abnormal."

For many women, another blow is the ongoing fatigue and memory loss even after their cancer treatment has concluded. Doctors point to many potential causes, from the emotional trauma and depression that can affect memory, to estrogen loss in menopause, to the side effects of the hormone therapies that women take in recovery to lower their risk of recurrence. "It's difficult to make a clear association to the cause, but the symptoms are very real," Rousey says.

"I can't believe what it did to my brain," Maxwell says. "Whenever my boss wants to run something by me, I say, 'Let me get my notebook first.' I used to be able to remember what he told me from the time I left his office to walk to mine, but not now."

ACCEPTING THE NEW NORMAL

Breast cancer patients soon learn that fear is an ongoing battle. There is fear of not being able to work or do the hundreds of things you take



"I was so angry. Every day after radiation I would go and whack golf balls to get it out."

KELLY MOORE

for granted, fear of dealing with your own and other people's emotions. The hazy outer edges of mortality everyone faces are suddenly thrown into sharp relief: You fear losing the ability to have children, losing a physical part of yourself, losing your sexuality, losing, ultimately, your life. "I was so angry," Moore recalls. "Every day after radiation I would go and whack golf balls to get it out."

One of the biggest fears is the specter of chemotherapy, which often leaves patients nauseated and out of commission for a day or two after each treatment—not to mention the accompanying hair loss that proclaims to the world: I have cancer.

"I thought maybe I could get by with just radiation, but when my oncologist started talking about chemo, I went white," says Maxwell, who started treatment on New Year's Eve 2004. "They put a port in my chest with a tube that went into a vein. At that point I thought, 'I no longer have control over my own body.'"

UNPREPARED FOR THE LETDOWN

It can take six months to a year to complete treatment for breast cancer and it is a bewildering, isolating time. What nobody is prepared for is the letdown after the treatment is over.

"They are so focused on the physical part of survivorship and the busywork of treatment that some of those emotional issues don't hit until they're done," Hughes says. "Right after treatment is when a lot of the intense emotions start to sink in."

On top of that, many patients are fatigued for months afterwards. They have also lost a critical support system—the doctors and nurses who



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shepherded them through treatment. "It's finally over, but they don't feel good yet and they're on their own," Hughes says. "People think they should be celebrating, but they're not ready yet."

Ultimately, most breast cancer survivors thrive. They reevaluate their life goals, professions, and relationships. They talk about how differently they see and experience the world.

Moore, a former Minnesota Vikings cheerleader, found an outlet in Treasured Chests, a nonprofit she started to raise money for local cancer research and treatment efforts. The group's biannual fundraiser uses dancers, models, cheerleaders, and martial artists to represent the stages of denial, fear, anger, and acceptance that survivors experience.

"The show is dedicated to people we've lost to breast cancer," she says. "I needed this to make sense for me and I wanted other people to feel it. I figured



Terminal is a funny word—we're all terminal. There's nothing you can do but go on with life and enjoy it.

VICTORIA THURS

if I tell the story through music, dance, and art, they would get it."

WILL IT COME BACK?

"The thing they don't tell you," Moore says, "is that you may get out of breast cancer, but you're never quite sure it's done."

The fear of recurrence is real; the challenge is to push ahead in spite of it. Maxwell found a ministry in volunteering with other survivors, but mysterious physical changes can still cause panic. "Just in the last month, I had a deep

bone ache in my hip," she says. "I was walking with a limp and my chiropractor urged me to call my oncologist. They did a MRI and an X-ray, and I was scared to death that it was bone cancer. It turns out it was arthritis."

When the worst does happen, women are able, finally, to move beyond the last fear. Thurs was first treated for breast cancer more than 15 years ago when she was 38.

Now 54, her cancer has returned and metastasized into her bones. "Did I expect to get it back? No, but in my subconscious I never really ruled it out," she says.

Thurs takes a daily oral chemotherapy medication to slow or stop the growth of cancer cells. Since her cancer is considered terminal, the emphasis is on quality of life. "I don't live scared of cancer or unhappy about it," she says. "Terminal is a funny word—we're all terminal. There's nothing you can do but go on with life and enjoy it." ●

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