

Health



future imperfect

Breast cancer survival rates are on the rise. But life after a diagnosis is still tough, and not just on your body—your relationships, mental health and body image can suffer, too. Here's how two women are rebuilding their lives.

BY JILL BUCHNER & STACY LEE KONG

ILLUSTRATIONS, GETTY IMAGES (BRA); SHUTTERSTOCK (BACKGROUND)





HELP WANTED

Three resources for women who have completed treatment.

CARING VOICES

An online community and support group, this site connects women across the country with other survivors, medical experts and a resource library of expert-vetted info. caringvoices.ca

AFTER BREAST CANCER

A Toronto-based organization focused on improving quality of life for women who have finished treatment, After Breast Cancer helps those who've had a mastectomy or a lumpectomy and can't afford to buy bras and prostheses. afterbreastcancer.ca

MOVING FORWARD

This free three-hour session, a partnership between the Canadian Cancer Society and provincial organizations, provides information about followup care and emotional health, as well as exercise and nutrition tips. For more information, contact your regional Canadian Cancer Society office.

WHEN JOANNA, WHO ASKED US not to use her last name, thinks back on her 20s, they're divided into two distinct eras: Before and After. Before, she was living in a Vancouver apartment with her boyfriend, preparing to take the exam that would earn her a certified human resources professional designation and getting ready to launch her career. Then, she found a lump in her breast, and she was irrevocably pushed into After.

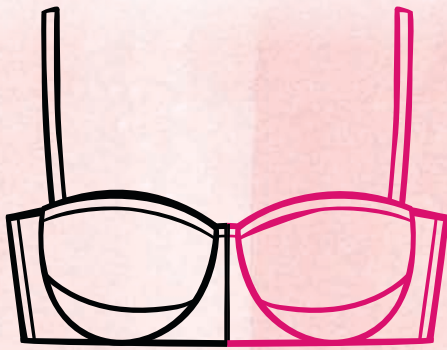
"I truthfully don't remember what I was doing when I felt it," says Joanna. "I didn't even suspect it might be cancer; I was 26 and I had no family history, so I didn't have the impression that there was concern for my health. I just wanted to understand why there was a lump and how I could have it removed."

When she went to the doctor, there was nothing to indicate she was wrong. Pointing to Joanna's age, her doctor said the lump was almost certainly a cyst. (According to the Canadian Breast Cancer Foundation, 82 percent of new breast cancer diagnoses happen in women 50 or older.) While initially relieved, Joanna wanted to be absolutely sure, so she asked for a mammogram. Doctors believe the possible risks of the procedure (such as radiation exposure or unnecessary biopsies) usually outweigh the possible benefits, so they don't tend to OK mammograms for women under 40 who don't have any risk factors. But, after convincing, her doctor eventually relented, and Joanna had a mammogram on Christmas Eve. When the results came back negative, a weight was lifted. "I thought it was just a cyst, but I wanted someone to operate on it, to get it out," she says.

Her doctor didn't think surgery was necessary, but Joanna kept pushing for one. Finally, after four months of back-and-forth, Joanna persuaded him to refer her to a breast cancer specialist, who was worried enough to expedite a biopsy. That's when Joanna found out it wasn't a cyst, after all. She had HER2-positive invasive ductal carcinoma.

The most recent stats say 25,000 Canadian women are diagnosed with breast cancer every year, but millions of dollars in research funding, improved screening methods and awareness campaigns have led to a steady rise in survival rates since the 1980s. Though breast cancer remains one of the most common cancers among Canadian women, it's also one of the most survivable: Today, the five-year survival rate is 88 percent.

Now 33, Joanna finished treatment—a bilateral mastectomy, chemotherapy and radiation—five years ago. After her last radiation appointment, she and her boyfriend travelled to Iceland to celebrate and, when he proposed, shifted their focus to the future. "The trip signified a fresh chapter, one where I wouldn't be defined by being a cancer patient," says Joanna. But returning to normal wasn't easy. "I felt relieved to be finished with chemo, radiation and surgery, but I also suffered from anxiety and depression," she says. In fact, family and friends might not realize just how difficult life as a breast cancer survivor can be; for many women, emotional upheaval, body image issues and uncertainty about the future linger well after treatment is over. ◻



MIXED FEELINGS

Many, if not most, women experience at least some anxiety, fear and depression following a breast cancer diagnosis, but some are surprised to find that the end of radiation or chemo doesn't always bring relief. In one study, which followed more than 500 women for three years, many breast cancer survivors reported significant levels of stress after the end of treatment; their support network suddenly changed or disappeared, they didn't know what to expect for the future or they were scared the cancer would return.

Verna Siteman-Burns knows exactly what that's like. At the age of 49, she was vacationing in Barbados when she noticed her left breast was swollen on one side. She discovered a lump not long after she returned to Canada, and her doctor sent her for a mammogram. But before her results had come back, Verna started noticing other symptoms: Her breast had become sore and inflamed, and she developed a rash that looked like hives. It turned out she had inflammatory breast cancer, a rare and aggressive form of the disease. After chemo and a surgery to remove her breast, chest wall and all of her lymph nodes, she was given a 50 percent chance of survival.

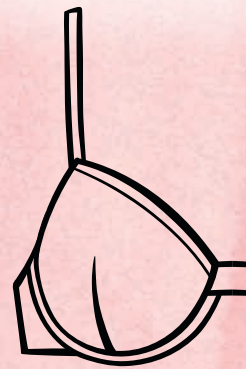
Verna is normally an upbeat person ("I believe in positive thinking," she says—which is why she informed the surgeon that she'd be part of the other 50 percent), but she admits that cancer sometimes took her to a dark place. "I was angry and could not for the life of me figure out why this had

happened to me," she recalls. When her treatment finally ended, she was overcome with fear. "The day I was released from seeing my oncologist, I sat in my car in the parkade and bawled. As long as they were giving me treatment, I felt protected. Once it was over, I felt alone," she says.

This reaction, called deprofessionalization, is very common. "During treatment, women are seeing professionals sometimes daily. This confers a sense of security," says Anne Katz, a certified sexuality counsellor at CancerCare Manitoba in Winnipeg. Once that care is over, a fear of recurrence sets in. "With every headache, you think, The cancer is going to my brain," says Verna. "With every ache, you think, It's going to the bone."

There's also the impact of hormone-suppressing drugs to consider. Because mood and hormones are tightly intertwined for many of us, women on post-treatment courses of drugs like tamoxifen, an estrogen-blocker prescribed to prevent recurrence, can experience mood swings or depression, says Dr. Tallal Younis, a medical oncologist at Queen Elizabeth II Health Sciences Centre in Halifax and professor of medicine at Dalhousie University.

However, Katz says there are resources available to women both during and after treatment. "Talking about these issues is really important—you shouldn't hold everything inside," she says. "Every cancer clinic across Canada has psychosocial clinicians who help people cope with the reality of having cancer and support them coming through the other side."



BODY BLOW

It's especially difficult to get back to your old self when, every time you undress, you're faced with a physical reminder of what you've been through. Sue Roberts, breast-health nurse coordinator at IWK Health Centre in Halifax, says even when health-care professionals explain what a woman's body will look like, or a patient views postmastectomy photos on the Internet, looking down to find her breasts gone can provoke a new wave of grief that lasts months. "A breast is much more than a body part; it's how we identify as a woman, a source of physical pleasure, how we nourish children. The scar that's left behind after a mastectomy is a constant reminder that you've had breast cancer," she says.

Less invasive treatments can also leave their mark. After a lumpectomy, one breast may be smaller than the other, and the dimpled scar can look like a crater. Removing lymph nodes can cause lymphedema, or long-term swelling, particularly in the breasts, arms and hands. Chemo can cause weight gain and, of course, hair loss; when your hair grows back, it might be different, for example, newly grey or curly instead of straight. Some chemo drugs can, in rare cases, cause hyperpigmentation, an uneven darkening of the skin or mucosal membranes (like the tongue), especially in women of colour. These dark patches can take months to fade and can occur anywhere on the body—for some women, the reminder is right there on their faces.

Seven years after finishing treatment, Verna says she still feels self-conscious about how her body has changed. In addition to her scars, she has lymphedema in her upper arms. "I want to minimize the fact that things happened under this clothing," she says. "There are scars. There are war wounds. I would be lying if I said I didn't shed tears more than once." She does try to keep perspective, though: "You still want to feel sexy, but your hair is thinner, your eyebrows are thinner, your eyelashes are barely there anymore. But it's a trade-off, and I wouldn't change anything." ◦

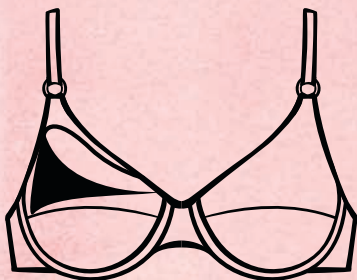


CONNECTION PROBLEMS

Though support groups abound, it can be profoundly isolating to go through breast cancer treatment. It's difficult for loved ones, especially males, to understand what a woman is feeling, and romantic relationships can be strained by the shift from a partnership between equals to a caregiver/charge dynamic. The emotional impact of this experience is often coupled with a physical one: A 2010 study published in *The Journal of Sexual Medicine* found that 70 percent of partnered breast cancer survivors experienced sexual problems after treatment. "Some women report that they lose sexual interest. There might be vaginal dryness because chemo has put them in early menopause or they're taking other drugs that decrease hormone levels. Sex can become extremely painful, which often leads to avoidance, and this can be difficult for the couple to talk about," says Katz.

For Verna, who says her husband was totally supportive, intimacy during her treatment became more about holding hands and cuddling. "You kind of revert back to the early romance that you started off with, and you find greater feeling in it," she says.

Roberts agrees that those small loving gestures are key to rekindling intimacy. "You have to try to introduce romance back into the relationship because, for a while, the partner is the caregiver, and when you're switching from a caregiver back to a sexual partner again, it can create a little bit of unease," she says.

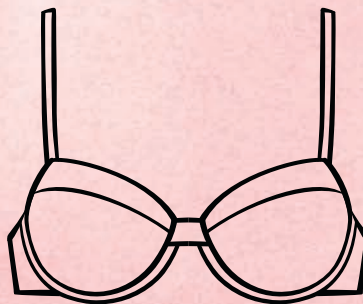


BABY STEPS

And then there's the fertility issue. For couples who aren't finished having children, or who haven't started, for that matter, the diagnosis can be particularly devastating. After Joanna was diagnosed, she read that many women have fertility issues following cancer treatment. Not only can chemo put patients into early menopause, but drugs that prevent

recurrence, like tamoxifen, can cause birth defects if a woman gets pregnant while she's taking it. Since these endocrine treatments are often recommended for five to 10 years after treatment, women can miss out on most of their reproductive years. "On top of all the treatment, you feel like your hopes and dreams are kind of in limbo," says Joanna. She spoke with her doctor about her concerns and asked to see a fertility specialist so she could freeze embryos before her treatment began.

Three and a half years into her five-year course of tamoxifen, she spoke to her oncologist about temporarily coming off the drug to try to have a baby. She was supportive, a fact Joanna is grateful for, as she says many doctors rush to treatment. "I always knew I wanted a family. Learning that I might not be able to have children was harder to process than the cancer diagnosis," says Joanna.



EMBRACING THE AFTER

Five years to the day of her diagnosis, Joanna brought her newborn son home for the first time, and now she's talking to her doctor about having a second child. (Her husband's already on board.) "It's the least romantic way to grow a family," she admits, laughing. But she thinks of her son, and any future kids, as the "ultimate celebration," not just of life, but also of her femininity. "Breast cancer took my hair, my eyelashes, my breasts—things that made me feel

like a woman," she says. Having a baby didn't make life "normal" again (she's back on tamoxifen and continues to worry about recurrence), but he is a constant reminder that she has a bright future.

Though it might not look that way on the surface, Verna's experience was similar. She, too, had to let go of what she used to think her life would be and to accept a new reality. A former workaholic who kept going to the office throughout treatment (her employer was supportive, and it helped her feel like she wasn't sick), she finds that she's taking more time for herself, spending more quality time with family and friends and even anticipating a day when she'll retire. But she needed some help to get there. She started attending meetings with the Pink Panther Support Group, a survivor group hosted by Breast Cancer Action Nova Scotia (BCANS), where she met several women who were diagnosed with Stage 3 cancer around the same time as Verna. "I knew I had to decide if I wanted to sit and worry or live my life with the determination to survive," she says. "Talking openly about our fears and realizing that we were all doing very well helped me change my thought process to a more positive one." Now a volunteer cochair with BCANS, Verna still sees her Pink Panthers, but now she's the survivor giving support to newly diagnosed women.

Like Joanna and Verna, every woman who has made it through treatment must find a way to look forward if she's going to fully embrace her own After. Her body might not look the same, the fear of recurrence will likely always be at the back of her mind, and her relationships may have undergone tremendous strain, but she's made it through the hard part, and she's facing a future full of possibility. ●

➔ FOR MORE ON BREAST CANCER, FROM DIAGNOSIS THROUGH TREATMENT AND BEYOND, VISIT canadianliving.com/breastcancer.