

# CANCER

# Survivorship

When treatment ends, the healing begins

By Julie A. Jacob

**A**fter Carolyn Nugent was diagnosed with stage 2B invasive ductal carcinoma, the 33-year-old physical therapist underwent a mastectomy, eight rounds of chemotherapy, 33 radiation treatments and breast reconstruction surgery. Following her radiation treatments, she celebrated with her extended family by taking a New Year's cruise. That's when she realized that she was just beginning the healing process.

"I was anxious for the clock to strike 12 and put the awful year of 2014 behind me," Nugent recalls. "We celebrated at midnight, and I went to bed. I woke up the next morning and looked in the mirror: intense burns from the radiation that were painful to the touch and deep scars across my chest. I was still bald with no eyelashes and no eyebrows. I realized that a new year may be the beginning, but the pain of what I had gone through was still very much with me."

For Nugent and countless other

cancer survivors, the end of treatment does not mark the end of their cancer journey but the beginning of the healing process.

Over the past several years, great strides have been made in treating many types of cancer. Immunotherapy drugs like ipilimumab, for example, are revolutionizing cancer treatment by unleashing the immune system to attack tumors. Targeted therapies, such as trastuzumab for treating breast cancer, hone in on specific molecules in cancer cells. Faster and easier techniques for genome sequencing of tumors are helping oncologists tailor treatments to a tumor's genetic profile.

Thanks to advances like these, many people who years ago may have died from cancer only a few months after diagnosis are being successfully treated and living long and active lives.

The National Cancer Institute and American Cancer Society estimate that 15.5 million cancer survivors are living in the United States. This

includes everyone who's ever had cancer, from the newly diagnosed to the long-term survivor. Two out of three people diagnosed with cancer now live at least five years after their diagnosis.

While cancer survivorship is something to be cheered and celebrated, the recovery process isn't always a smooth slide back into normal life, say patients and clinicians. Often, recovering physically and emotionally from cancer is a long and arduous process.

The medical community is beginning to pay closer attention to the concerns and challenges of cancer survivors. On the American Society of Clinical Oncology website, for instance, the number of abstracts on survivorship issues jumped from 23 in 2009 to 332 in 2016, highlighting growing interest in the subject.

"It's really long overdue to formally address patient survivorship concerns," says Sheetal Kircher, MD, an oncologist and medical co-director of the Cancer



Survivorship Institute of the Robert H. Lurie Comprehensive Cancer Center of Northwestern University.

A cancer survivor is anyone who has been diagnosed with cancer, whether or not the cancer is ultimately curable, Kircher explains. Cancer survivorship services, like those offered at the Lurie Cancer Center, are commonly used by people who are dealing with the physical and emotional after-effects of treatment.

## SIDE EFFECTS OF TREATMENT

Numerous short- and long-term side effects can occur after treatment. Chemotherapy, for example, "can affect almost every organ in the body," Kircher says. "It can impact your bones, your fertility and your sexual function."

An impaired immune system is another common side effect of chemotherapy, notes Kelley Elizabeth Kozma, MD, an oncologist at Presence Saint Joseph Hospital. Cancer survivors may also experience peripheral neuropathy, which is nerve damage that causes tingling and pain in the hands and feet. The neuropathy can last for months or even years, she says.

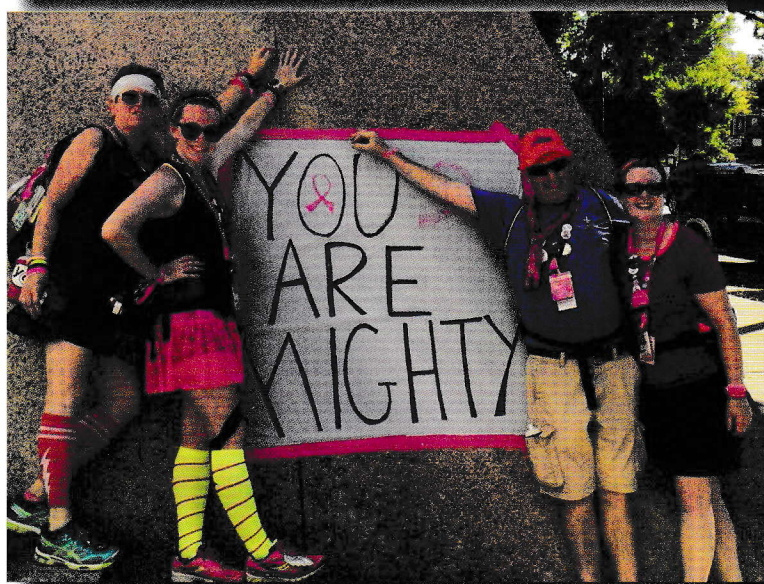
Sometimes, chemotherapy can cause cognitive problems, says Megan Slocum, a physician assistant at Lurie Cancer Center who cares for cancer survivors. Fatigue is another common lingering side effect.

"[Cancer-related] fatigue can be chronic and debilitating," Slocum says. "We don't have a great understanding of the mechanism at this point. Even patients who haven't had chemotherapy or radiation can experience it."

Endometrial cancer survivor Sharon Meyer, for instance, struggled with fatigue for months after completing eight months of treatment that included surgery, radiation and chemotherapy.

"I would get up, shower, get dressed, and all I wanted to do was go back to bed," says Meyer, an office coordinator at Presence Saint Joseph Hospital. It wasn't until about six months after her treatment ended that she began to feel normal, she says.

Breast cancer survivor Laura Davis also struggled with fatigue after completing 20 weeks of chemotherapy and 28 radiation sessions to treat her stage 2 breast cancer. ►



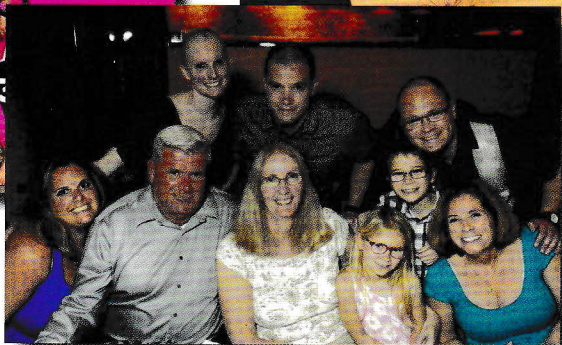
FROM TOP TO BOTTOM: SHARON MEYER WITH ART SHE CREATED FOR A PRESENCE SAINT JOSEPH SURVIVOR CELEBRATION. LAURA DAVIS AT THE AMERICAN CANCER SOCIETY'S MAKING STRIDES AGAINST BREAST CANCER WALK. CAROLYN NUGENT CELEBRATING HER LAST DAY OF CHEMO. PHOTOS PROVIDED BY LAURA DAVIS, CAROLYN NUGENT AND SHARON MEYER.



DAY 3. 60 MILES.



PHOTOS ON THIS PAGE FROM LEFT TO RIGHT: LAURA DAVIS AND FRIENDS AT THE 2016 SUSAN G. KOMEN 3-DAY IN CHICAGO. CAROLYN NUGENT WITH FRIENDS AND FAMILY. SHARON MEYER ENJOYING TIME IN THE PARK. LAURA DAVIS HIGH-FIVING SUPPORTERS DURING A RUN/WALK FOR CANCER. PHOTOS PROVIDED BY LAURA DAVIS, CAROLYN NUGENT AND SHARON MEYER



A friend threw a party for her after she completed her treatment, Davis says. But, often, well-meaning friends did not understand that being finished with treatment wasn't the same as being healed.

"It took me a full year to get to the point where I could do things on a Friday night and a Saturday night," she says. "For a year, I could do one or the other, but not both."

There are physical challenges during recovery, too. Nugent had ongoing joint pain and muscle imbalance problems. Davis underwent physical therapy to regain strength in her arm. Meyer developed urinary incontinence due to side effects from her radiation treatment and also experienced peripheral neuropathy.

### SURVIVORSHIP PLANS

Many options are available to help cancer patients recover once their treatment ends, and those options are discussed at survivorship care plan meetings. At the Lurie Cancer Center, survivors meet with an advanced practice nurse about three months after completing treatment to develop such a plan. Treatment approaches can include physical therapy, cognitive therapy, counseling, exercise and dietary changes.

"The [advanced practice nurse] goes

over exactly what happened, what cancer they had, how they will be followed in the future and strategies to manage their specific needs. All this information is shared with their primary care doctor," Kircher explains. The cancer survivors come in at least once annually to review and update their care plan.

While not every cancer survivor is interested in such an approach, "the overwhelming response has been positive," Kircher says. "They crave that hour to slowly and quietly process what happened to them and go over it in a systematic way."

### EMOTIONAL CARE

In addition to physical issues such as fatigue and joint pain, cancer survivors often must cope with the emotional fallout of surviving the disease. Cancer survivors may experience depression and anxiety, as well as a fear of reoccurrence, Kozma notes. About 10 percent of cancer survivors report poor mental health compared with only 5.9 percent of adults without cancer, according to a 2010 National Health Interview Survey.

"Survivorship is a very scary time for patients," Kozma says. "During treatment, people are 'go, go, go' to get through." But once treatment is finished, emotions such as depression

and anxiety that were held in check during the active treatment phase may bubble to the surface. Worrying about cancer coming back is stressful, she says, particularly until patients reach the crucial five-year mark of no reoccurrence, when they're considered cured.

"You're done, but you're not done," Meyer says. "Your new normal doesn't seem so normal now. When you have an ache, you wonder, 'Is it cancer? Should I tell my doctor? Should I get it checked out?'"

Kozma regularly screens cancer patients for depression and often prescribes antidepressants during or after treatment.

Nugent says that she sunk into a depression after completing her breast cancer treatment.

"I personally struggled with admitting that I was depressed because I felt like I should be happy to be alive," Nugent says. "But I was depressed and too tired to spend time with friends and in too much pain to resume the activities I used to love."

Talking to a therapist helped, she says, as did joining a Facebook group for cancer survivors.

Meyer found support by joining a cancer support group at Presence Saint Joseph. It's comforting and cathartic, Meyer notes, to talk with other people

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PHOTOS ON THIS PAGE FROM LEFT TO RIGHT: CAROLYN NUGENT CELEBRATING HER LAST DAY OF RADIATION. LAURA DAVIS AND HER DOG HENRY. SHARON MEYER WITH FRIENDS. CAROLYN NUGENT CROSSING THE FINISH LINE OF THE CHICAGO MARATHON IN 2016. PHOTOS PROVIDED BY LAURA DAVIS, CAROLYN NUGENT AND SHARON MEYER

who have gone through the same experience.

"I hadn't talked too much during my treatment. I thought it would make me vulnerable if I gave in to that," Meyer says. "At the support group, I was the one crying for things I thought were behind me. The support group has been phenomenal."

Support groups are often available through hospitals as well as through organizations like Gilda's Club Chicago, which runs a monthly cancer survivor support group at both its Wells Street office and Advocate Christ Medical Center. The meetings include presentations, networking and exercises such as yoga or tai chi.

"The lectures have included a variety of topics focused on post-treatment issues such as managing nutrition, optimizing physical function and sexuality after cancer," says Jamie Mazer Wiener, the organization's program director.

Although cancer survivors often feel a new sense of purpose and gratitude for life, they also may grapple with feelings of guilt when they become irritated by life's everyday stresses, whether a bad day at work or a fight with a spouse.

"It's very interesting when patients talk about it," Kircher says. "They say, 'I should be grateful. I shouldn't feel frustrated.' But that is part of life."

The key to coping with life after cancer is to celebrate every step forward, cancer survivors say.

"I am doing much better than I was six months ago, and I hope six months from now I will be better than I am today," Nugent says. "I just keep telling myself there are good days and bad days, but every day that you get up and keep going, you win."+

## TIPS FOR SURVIVING AND THRIVING

Patients and clinicians offer these tips on how to address the physical and emotional issues of cancer survivorship.

**EXERCISE.** "Exercise can help with energy and joint pain, and it has been shown to lower your risk of cancer recurrence," says physician assistant Megan Slocum.

**MAINTAIN A NORMAL ROUTINE AS MUCH AS POSSIBLE.** "I tell most of my patients to try to get back to life as quickly as possible," says Kelley Elizabeth Kozma, MD. "Get back to work; get back to the gym; see your friends."

**KNOW THAT YOU ARE NOT ALONE.** "It's my personal mission to share my post-cancer struggle so the next person out there who feels the same way knows they are not alone," says survivor Carolyn Nugent.

**DON'T BE AFRAID TO ASK FOR HELP.** "When I saw the support I got from my family and friends, it made me more grateful for what I have," says cancer survivor Sharon Meyer.

**SHARE INFORMATION ON YOUR CANCER SURVIVORSHIP PLAN WITH YOUR PRIMARY CARE DOCTOR.** The survivorship plan serves as a bridge that will help your primary care doctor assume the central role in your healthcare, says Sheetal Kircher, MD.

**DON'T COMPARE YOUR RECOVERY TO ANYONE ELSE'S JOURNEY.** "Everyone is different and everyone recovers differently," says survivor Laura Davis.