

You've Survived Cancer. What Comes Next?

As more patients are treated successfully, doctors and researchers are focusing more on helping people navigate the difficult, often

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As more patients are successfully treated for cancer, a daunting new challenge awaits: navigating the physical and emotional challenges of being a survivor.

When the treatment ends, the patients' next journey is just beginning. They are left with new health issues often caused by the treatment itself, such as damage to the heart and other organs, or worsening high blood pressure and diabetes. Studies show many struggle with depression, fatigue and nagging fear that the cancer will return. Sexual function and personal relationships may suffer.

Compounding it all, survivors often feel alone and adrift as they face those challenges. According to [a new survey](#) of cancer survivors by the nonprofit National Coalition for Cancer Survivorship, few feel very prepared for the transition to posttreatment, nor informed about how to manage their health going forward.

Their oncologists are focused on treating new cases, and their primary-care doctors have neither the time nor expertise to deal with the complexities of survivor needs.

"Your life in treatment is easy, because doctors and nurses are always telling you what to do next, but as soon as you are released, you wonder, 'What do I do now?'" says Marissa Vickers, 26, who began radiation and chemotherapy treatments at age 18 for Ewing's sarcoma, a type of cancer that grows in bones or the soft tissue around them.

Fortunately for cancer survivors, providers are starting to answer that question. Rather than leaving patients to fend for themselves, providers are beginning to take a much more active role in helping patients deal with their life after treatment. They're looking for new treatments that won't take the punishing long-term physical toll that today's regimens take. They're focusing on how to help younger patients who will have the longest to live. And they are coming up with plans to figure out exactly what all patients need in those difficult years after treatment, and putting structures in place to help providers and patients stick to the strategies.

The urgency of such actions, of course, is the result of good news: There are growing numbers of cancer survivors. Nearly 40% of men and women will develop an invasive cancer in their lifetimes, with men at slightly higher risk. But thanks to medical advances in detection and treatment, there are close to 17 million cancer survivors in the U.S.—and with an aging population, that number is expected to rise to about 22 million by 2030.

The health-care industry is facing increasing pressure to adapt to such success. In 2015, the [Commission on Cancer](#), a program of the American College of Surgeons, began requiring that, as a condition of accreditation, hospitals provide patients with a survivorship-care plan. But studies have since concluded that outcomes aren't improved by just offering patients a one-time survivorship-care plan when they end treatment. Starting next year, hospitals will be encouraged but not required to provide the plans, and instead will have a new, broader mandate to create formal long-term follow-up programs that provide ongoing assessment and interventions to manage survivor issues, according to Lawrence Shulman, chair of the Commission on Cancer and deputy director for clinical services at the University of Pennsylvania's Abramson Cancer Center.

"We continue to learn more about the short- and long-term effects and complications of therapy, and patients' problems today may be very different in a year or in five years," Dr. Shulman says.

[A bill](#) recently reintroduced in the House of Representatives may help by enabling doctors to bill Medicare for the time they spend developing comprehensive care plans from active treatment through survivorship.

Here's a closer look at how health-care programs are increasingly focused on helping cancer survivors navigate the years after their treatment.

Changing treatment itself

For starters, doctors are learning how to make cancer treatments less toxic in the first place, to reduce aftereffects and recurrence risks.

For example, chemotherapy plus radiation was long the standard treatment for a type of Hodgkin lymphoma. But as evidence emerged that radiation can lead to new cancers and other complications, doctors have reduced or in some cases eliminated radiation as studies suggest chemotherapy alone improves the rate of overall survival for certain patients.

Researchers [are now studying](#) whether a type of radiation known as proton therapy, which exposes less of the heart to radiation, is as effective in treating breast cancer as the standard photon therapy and may cause fewer heart problems down the road. And studies in the field of pharmacogenetics and personalized medicine are also helping doctors identify which medications are likely to be most effective for individual patients based on their genetic variations—and which patients might be at risk for severe or toxic side effects from certain drugs.

At the same time, uncertainty remains about the risks of newer approaches to treatment. [A recent study](#) found that women who had minimally invasive surgery for cervical cancer had higher odds of recurrence than those who had traditional open surgery. Novel immunotherapy drugs, which harness the immune system to find and eliminate cancer cells, hold great promise for some cancers, but there are still many unknowns about long-term effects and recurrence risks.

Providing specialized care

There are a variety of cancers, and that means a variety of necessary treatments for patients—and then a variety of follow-up needs for survivors. So, it is crucial for survivors to be monitored by specialists who can assess their individual risk of recurrence and know the aftereffects of specific chemotherapy and radiation regimens.

That's the idea behind a fast-growing model of care at hospitals around the country—matching survivors with caregivers trained to deal with their particular form of cancer.

The Abramson Cancer Center Survivorship Program at the University of Pennsylvania was founded in 2001 with clinics for breast and testicular cancer and young-adult survivors of childhood cancers. It has added new clinics over the years, and in 2016 expanded to offer specialized survivorship clinics for any type of cancer.

Follow-up care often begins right after patients complete treatment. They are referred to clinics specific to their type of cancer managed by nurse practitioners and physician assistants. Board-certified in oncology and expert in different types of cancer, these providers work closely with oncologists and manage individualized follow-up schedules for each disease, order recommended labs and scans, and focus on health promotion and disease prevention. They also make sure patients are receiving routine surveillance for other diseases they may be at risk for.

Without such surveillance, “long-term cancer survivors get lost to follow-up and may return years later with a new cancer that went unrecognized,” says Linda Jacobs, a clinical professor of nursing at Penn and founding director of the cancer-survivorship program. Primary-care doctors generally aren’t familiar with what is recommended for follow-up, she notes, and don’t necessarily recognize when someone presents with a symptom that would warrant further specific testing.

In one case, a patient who had received radiation for a brain tumor 30 years earlier was treated by a primary-care doctor for what was assumed to be a recurrent infection. In fact, it was a sinus tumor caused by the long-ago radiation. An oncology nurse practitioner would have known to order a head CT scan or MRI, which would have revealed the tumor, Dr. Jacobs says.

Among the patients followed through the survivorship clinics at Penn is Dennis Patterson, a professor of law and philosophy at Rutgers University, who was originally treated for testicular cancer in 2001. Testicular-cancer patients must be followed carefully for possible recurrence, long-term side effects of treatment and new cancers, with specific screenings such as tests that look for certain tumor markers. “Oncology providers notice subtle changes in lab values and subsequently order other testing,” says Dr. Jacobs, and patients continue to see their oncologists as needed.

Eight years later, during a follow-up appointment, Dr. Patterson says, his oncologist David Vaughn noticed his spleen was enlarged, and follow-up tests found a rare form of lymphoma, which was successfully treated with an immunotherapy drug and surgery to remove his spleen. Then, two years ago, during another follow-up visit, Dr. Jacobs noticed his levels of PSA—for prostate-specific antigen—were slowly rising. Referred to Penn’s urology department for further evaluation and management, he was diagnosed with prostate cancer, and is pursuing a strategy of watchful waiting.

“I go in every six months and meet with one of my oncologists, and Linda monitors everything,” says Dr. Patterson, 63. “It’s great to have complete confidence that she is looking at every test result and nothing will go wrong that she doesn’t notice.”

A focus on young survivors

Things have gotten a lot better for survivors of childhood cancer—but also much more complex. Thanks to advances in treatment, more than 83% of children treated for cancer can expect to survive five years or longer, compared with 58% in the mid-1970s, according to the National Cancer Institute.

Yet because cancer treatment can damage organs, impede growth and learning ability, and lead to later cancers, patients need lifelong support and follow-up. And the problems aren't just medical. Young survivors have a daunting medical history to keep track of as they grow and move away from or outlive the doctors who originally treated them.

Now some providers are trying to make life simpler for young survivors—and their caregivers—as they age. The Children's Oncology Group, a clinical-trials organization supported by the National Cancer Institute, puts out regular long-term guidelines that help pediatricians and other clinicians determine what physical, emotional and developmental issues can arise as survivors of childhood cancer mature.

The group's Passport for Care [website](#), developed by Texas Children's Cancer Center and Baylor College of Medicine, uses an algorithm that generates information on long-term side effects and risks of different treatments and recommends screenings and tests that doctors can use to follow patients once they've completed treatment. Patients or family members can go online to check treatments that a survivor has received in the past to learn about potential late effects and get tailored recommendations for follow-up care.

"Even if it's been years and you've lost contact with your physician, if you remember the therapies you received as a child, you can get information on your potential risks for late effects and the type of screening you may need and other important recommendations," says Dr. David Poplack, a developer of the Passport program and associate director of Texas Children's Cancer and Hematology Centers. If survivors don't remember details of treatment, he adds, there is still guidance on issues unique to their type of cancer.

The University of California, San Francisco UCSF Benioff Children's Hospitals in San Francisco and Oakland offer a program focused on young cancer survivors—including those treated elsewhere—who have been in remission at least two years after treatment, according to Robert E. Goldsby, director of the program at the San Francisco hospital.

Dr. Goldsby says secondary cancers may occur more than 20 years after the initial cancer has been cured, and survivors are at risk of diseases not expected in teens or young adults, such as osteoporosis, coronary artery disease and infertility.

Ms. Vickers, who was treated for the cancer in her upper right arm and shoulder socket in the young survivors' program at UCSF, initially returned there every three months for tests including scans and chest X-rays. Her visits were cut back to once every six months, and then at the five-year mark, she was told she should follow up in the survivor program. Dr. Goldsby and his team explained the future concerns she might face from her treatment, including damage to internal organs, and the importance of screening for other malignancies such as skin or breast cancer.

Ms. Vickers will start work next year as a pediatric nurse with plans to become a pediatric oncology nurse practitioner. She met and married an Air Force officer, moved with him to Florida and, despite warnings that she might have fertility issues, gave birth to twins earlier this year. They also recently made another move to the Washington, D.C., area.

A longtime swimmer, she participates annually with Dr. Goldsby in Swim Across America in San Francisco Bay, a charity event to benefit the UCSF children's cancer program. Her local doctors can consult with UCSF if need be; a spot appeared on an MRI two years ago and turned out to be nothing to worry about, but Ms. Vickers says she is vigilant and knows what to look out for.

"If I have consistent pain for a month or more, that's when I need to get it checked out—I know the difference between just a tweak and something deep in the bone," Ms. Vickers says.

She also believes surviving cancer has changed her life for the better in unexpected ways—without it, she never would have moved to San Francisco, where she met her husband, or had her children.

"It made me face my own mortality, realize what's important and not wait for tomorrow," Ms. Vickers says.

In addition to making her cherish activities like swimming and igniting a passion to swim for the cause of cancer research, it led her to a rewarding career "and purpose-filled life making

other people's treatment journeys better," she says. "Although I wish all these things could have happened without cancer and chemo, I wouldn't change it now if I could."

To expand its existing follow-up services for adult cancer patients, UCSF just opened a new Cancer Survivorship and Wellness Institute, which offers regular oversight by a medical team to help with symptoms and watch for signs of recurrence. It also offers experts in nutrition, exercise, reproductive health, spiritual care and psychological and social issues. And UCSF has a number of research projects on the impact of lifestyle on patients' prognosis after treatment, such as the use of mobile messaging to steer colorectal-cancer patients to better dietary choices.

Providing emotional support

The emotional and psychological toll of treatment often go untreated as survivors seek care. Now more organizations are working locally to support survivors as they try to manage those burdens.

One program, Elevate Survivorship, from the National Coalition for Cancer Survivorship, is using survivors as a main part of its effort: The group is recruiting and training them as ambassadors to improve care in their community with projects at hospitals, oncology practices and local organizations. Meanwhile, the [Cancer Support Community](#)—formed by the merger in 2009 of the nonprofit Wellness Community and Gilda's Club, founded in honor of the late comedian Gilda Radner, who died of ovarian cancer—offers patients who have completed treatment within 24 months a free program called Cancer Transitions.

The program—available through health-care providers including hospitals, and at local Gilda's Clubs and Cancer Support Community affiliates—includes six weekly 2½-hour group sessions covering a range of issues, from practical aspects of medical management to emotional well-being and coping concerns, as well as exercise programs and training in stress management.

Teresa Saltsman, diagnosed in 2012 with breast cancer in three sites, had a bilateral mastectomy, lymph node removal surgery, chemotherapy and radiation over nearly a year. In addition to continuing pain from the surgery, she had a flare-up of an old rotator-cuff injury, muscle spasms in her upper torso, and tightening of tissues under her arms and in her chest.

The side effects of the anticancer therapies prescribed after treatment were so intense that she eventually discontinued their use. Although happy to be alive, Ms. Saltsman asks: “How do we manage this posttreatment crap that can go on for years?”

She turned for help to the Cancer Transitions program at the Gilda’s Club Quad Cities near her home in Rock Island, Ill., which has helped her connect to other survivors dealing with the same issues, and “bring calm and peace to a chaotic situation.” She attends regular yoga sessions there tailored to patients with physical limitations from pain and swelling after breast-cancer surgery, which has helped reduce muscle spasms and ease tightness, and takes classes in meditation, painting and music.

In Silicon Valley, hospitals can refer patients after cancer treatment to a local nonprofit, [Cancer Carepoint](#). A six-week program, with a maximum of 14 people per session, includes seminars on how to manage emotional distress, move forward in life after the trauma of cancer and deal with social changes after treatment.

Hannah Haworth, who writes young-adult thrillers under the name Hannah Jayne, was referred to the Silicon Valley program by the hospital where she was treated for breast cancer. Diagnosed three years ago after her newborn daughter had just turned one, she had been through several surgeries, chemotherapy and radiation, and was in considerable pain and discomfort, and felt her brain was in a fog. She admits she was skeptical at first, as some of the material seemed too touchy-feely, including questions about what joy cancer had brought her.

But as the 12 women in the group met for the sessions each week and talked about their fears and concerns, “they became my lifeline, and brought me through it,” says Ms. Haworth, 43. The group keeps in touch through texts and occasional dinners.

“It was everything I didn’t know I needed—being able to talk to people who know exactly where you are and realizing you are not alone,” she says.

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