

## FEATURE STORY

# The Long-Term Survivor

As cancer survivors move further and further away from treatment, they enter what both Fitzhugh Mullan, MD, and Kenneth Miller, MD, call “permanent survivorship.”

In the best scenario, the survivor has resumed a fulfilling life of joy and accomplishment with few of the lingering physical or emotional long-term effects addressed in "Getting Well After Cancer." They have a good quality of life, which researchers determine by looking at physical, emotional, spiritual, and social well-being, which includes issues such as family, work, finances, and relationships.

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### **Late Effects**

With advances in treatment and the development of new drugs, more people diagnosed with cancer are finishing treatment and living long lives. Yet, some survivors have lingering physical and emotional effects, called long-term effects, which were explored in the article [“Getting Well After Cancer.”](#) Among long-term effects are pain, neuropathy, anxiety, sleep disturbances, cognitive function, and, in some cases, fatigue.

Other survivors may have issues related to cancer or its treatment that emerge months or years after treatment has ended, which are called late effects. Late effects include such issues as secondary cancers or heart, bone, or lung problems.

Research on late effects has only just begun as the survivorship movement has emerged, and in adults the issue becomes complicated by the fact that, as people age, they develop other medical problems, or comorbidities, making it more difficult to determine if the problems are related to prior cancer treatment, aging, or an interaction between the two.

“Some of the drugs we give for certain diseases like lymphomas or breast cancer

can weaken the heart muscle,” says Craig Earle, MD, director of Health Services Research at Odette Cancer Centre in Toronto. “That may not be a problem initially. But over time as people age and other things affect the heart, they can end up with congestive heart failure.”

For example, one class of medications, known as anthracyclines, create free radicals that help the drug kill the cancer cells. While other cells in the body can neutralize the free radicals, the heart muscle lacks this capacity, leaving the free radicals available to hurt the heart muscle. “It’s dose-dependent,” Earle says. “The more of the drug you have, the more likely this is to be a problem.”

Patients younger than 18 or older than 65 when treatment starts have an increased risk. An underlying heart condition also increases the chance of cardiac complications in the future.

Radiation presents another risk since beams aimed at the chest to fight lymphoma, breast, or other cancers also can reach the heart and lungs. Radiation can weaken or scar the heart muscle or damage valves in the heart, research shows. Radiation also can accelerate coronary artery disease, creating rough spots in the lining of the arteries where fatty plaque can accumulate. Patients who have received such therapy may be more prone to suffering a heart attack at a younger age.

Recently, the American Society of Clinical Oncology set out to develop guidelines for survivor care in this area but decided more research was needed, leaving experts with little advice to offer survivors beyond the basics: get regular medical care, fully inform your health providers about your medical history (your survivorship care plan should list which drugs you had), and make appropriate lifestyle changes. Stop smoking. Eat a healthy diet. Drink alcohol only in moderation. Maintain a normal weight. Exercise. Control blood pressure.

“All that will help,” Earle says. “There’s no downside to healthy living.”

## **Secondary Cancers**

If cancer returns, it is considered a recurrence of the primary cancer. When a survivor is diagnosed with a new primary, it may not be connected to treatment for the first diagnosis, or it may be a secondary cancer, one caused (or whose risk may have been increased) by treatment for the initial cancer.

A second cancer can occur for a variety of reasons, the majority not related to past cancer treatment. For example, it is well known that breast cancer survivors with BRCA mutations are at higher risk for ovarian cancer, and current or former smokers who have survived other cancers may have an increased risk of lung cancer.

Many of those diagnosed with secondary cancers, researchers know, received high doses of radiation in certain areas or particular types of chemotherapy. For example, receiving radiation in the chest area for Hodgkin disease has now become a risk factor for breast cancer.

Radiation can result in solid tumors, usually near the radiation field, while chemotherapy may lead to blood cancers, such as leukemia.

Andrea Ng, MD, PhD, associate professor of radiation and oncology at Harvard

Medical School, researches the late effects of lymphoma treatment. She says chemotherapy-linked secondary cancers usually appear within the first 10 years after treatment, while it may take up to 30 years for a radiation-related solid tumor to emerge.

“Patients we treated here 10 or 15 years ago are surprised to hear they have an increased risk of cancer,” Ng says.

She recommends that survivors ask their physicians for a survivorship care plan that includes monitoring for late effects, such as secondary cancers. “Some patients walk away after their five-year checkup and don’t go to see anybody for years,” Ng says. “They should see a health care provider once a year at least.”

## The Right to Work

Barbara Hoffman, JD, legal research and writing professor at Rutgers University School of Law and a Hodgkin disease survivor, explains that four federal laws govern discrimination in the workforce for cancer survivors. The Americans with Disabilities Act (ADA) and the Family Medical Leave Act (FMLA) provide the primary help, with further coverage for some under the Employee Retirement Income Security Act (ERISA) and the Federal Rehabilitation Act.

“Before the ADA and FMLA, many employers assumed that workers who were diagnosed with cancer would be unable to perform their jobs. Survivors were fired, demoted, and denied benefits more often than their co-workers,” Hoffman says.

In January 2009, the ADA was revised to better protect survivors by expanding the definition of “disability” to include an actual or perceived impairment, such as a cancer survivor who has been discriminated against by an employer.

But, as with any similar situation, there are survivors who these laws don’t cover. Companies with fewer than 15 employees don’t have to adhere to ADA rules. And for those survivors who want to keep their medical history secret, advocates say it may keep you from getting the accommodations that you’re entitled to.

For example, the 12 weeks of unpaid leave a year allowed under the FMLA can be taken one hour at a time for medical issues, shortened workdays due to fatigue or chronic pain, or other accommodations needed post-treatment. Companies must also continue group health benefits as if the employee continued to work. Pension or other retirement plans also continue during FMLA leave for purposes of vesting and eligibility to participate.

Despite this, some survivors would rather their company not know about their cancer experience. For survivors whose cancer returns, Hoffman recommends being up front with employers.

“If you’re working when you are diagnosed and need some kind of accommodation, you must tell your employer why you need an accommodation,” she says. “Try to work out a reasonable plan with your supervisor or with the person in charge of your human relations department.”

Communication, supported with documentation of health-related requests from a health care provider, is key to using the laws for post-treatment needs. For more information, go to [www.dol.gov/esa/whd/fmla](http://www.dol.gov/esa/whd/fmla) or [www.ada.gov](http://www.ada.gov).