



LIFELONG HEALTH: SELF-CARE IS CRITICAL FOR CHILDHOOD CANCER SURVIVORS



Lifelong Health: Self-Care is Critical for Childhood Cancer Survivors *Clinics Around Country Help with Education, Screenings & Record Keeping*

Caitlin Adkins was a playful 8-year-old when doctors discovered a football-size tumor in her sacrum. A whirlwind of tests produced a frightening and life-changing diagnosis: Caitlin had Ewing's Sarcoma, an aggressive childhood bone cancer. The second-grader immediately began a difficult journey of chemotherapy and radiation. After two years, she completed treatment and refocused her life on growing up, graduating from high school and starting college.

Throughout treatment and the years following, Caitlin's parents managed her healthcare needs. But now 21 and a junior attending a university distant from her rural hometown, the responsibility for everything from regular checkups to managing late effects caused by her treatment drugs falls on Caitlin's shoulders.

"I've always had all my care at St. Jude's Hospital. When I left there for the last time after turning 21, it was very bittersweet," explains Caitlin, a pre-pharmacy student at the University of Virginia. "But they gave me a portfolio of all my scans, and all their notes and all my medical reports, and now I give them to my new doctors. It helps with communicating with them – it makes them more educated on what I've gone through."

Long-term health monitoring is increasingly on the forefront among those who treat pediatric cancer patients. Educating families about late effects – medical, intellectual or emotional problems that can develop as a result of treatment drugs and surgeries – are now a routine part of childhood cancer treatment. But going beyond that, more oncology hospitals are creating survivor clinics specifically to help young adults keep careful records and manage their regular screenings once they are out from under their parents' protective wings.

"We expect 80 percent of children are going to be long-term survivors, so we hope 80 percent of the kids will eventually come to the survivor clinic," explains Dr. Lillian Meacham, a pediatric endocrinologist, professor of pediatrics at Emory University, and chair of the Survivor Program at the Aflac Cancer and Blood Disorder Center of Children's Healthcare of Atlanta.

Nearly two-thirds of all childhood cancer survivors will face a chronic health condition and at least 25 percent will live with a severe, disabling or life-threatening condition, according to an article published in the June 2013 issue of the *Journal of the American Medical Association*. The paper asserts that among adult survivors of childhood cancer, the prevalence of adverse health outcomes was high, and a systematic risk-based medical assessment identified a substantial number of previously undiagnosed problems that are

more prevalent in an older population. “These findings underscore the importance of ongoing health monitoring for adults who survive childhood cancer,” the paper concludes.

“You can’t be an ostrich and stick your head in the sand if you had childhood cancer,” says Dr. Meacham. “Our goal is to help these survivors thrive ... that’s the point of survivor care.” She added that survivors should always consult with their pediatric oncologist before entering a survivor healthcare program.

For survivors unsure about problems that may be linked to their cancer treatment, [The National Children’s Cancer Society](#) offers a [free Late Effects Assessment Tool](#) that survivors can use to learn about the long-term medical impact of their specific diagnosis and treatment.

Caitlin said she was well educated by St. Jude’s about her late effects, follow-up care protocol, and even the importance of non-cancer related screenings such as regular eye and dental exams. The hospital also connected her to an endocrinologist near campus for treatment of hormone and thyroid issues that are part of her late effects.

But Caitlin’s responsible control over her healthcare is not the norm among adult survivors of pediatric cancer. Childhood cancer survivors typically do not adhere to American Cancer Society’s guidelines on healthy living, according to a National Cancer Institute-funded study known as the “Chicago Healthy Living Study” and reported in [Medical News Today](#). Investigators found that childhood cancer survivors rarely adhere more closely to guidelines on healthy eating than their cancer-free peers. Their casual attitude persists despite the reality that they face different healthcare challenges and are more susceptible to dying earlier than the general population. Pediatric cancer survivors have a higher risk of second cancers, heart disease, body weight disorders and psychosocial problems.

Guidelines from the American Cancer Society (ACS) offer science-based advice to survivors for eating better and staying active, two keys to healthy living. The report, called *Nutrition and Physical Activity Guidelines for Cancer Survivors*, is [available for free](#) from the ACS website.

American Cancer Society Guidelines On Nutrition And Physical Activity For Cancer Survivors
▶ Achieve and maintain a healthy weight.
<ul style="list-style-type: none">• If overweight or obese, limit consumption of high-calorie foods and beverages and increase physical activity to promote weight loss.
▶ Engage in regular physical activity.
<ul style="list-style-type: none">• Avoid inactivity and return to normal daily activities as soon as possible following diagnosis.• Aim to exercise at least 150 minutes per week.• Include strength training exercises at least 2 days per week.
▶ Achieve a dietary pattern that is high in vegetables, fruits, and whole grains.
<ul style="list-style-type: none">• Follow the American Cancer Society Guidelines on Nutrition and Physical Activity for Cancer Prevention.
<small>SOURCE: Nutrition and Physical Activity Guidelines for Cancer Survivors (2012)</small>

Source: American Cancer Society

Because so little is known about how well cancer survivors adhere to these guidelines, the University of Illinois medical research team selected data from the “Chicago Healthy Living Study” participants. Structured health-focused interviews were conducted with 431 childhood cancer survivors and 361 people who never had the disease. The survivors, between 18 and 59 years old, were all diagnosed with a malignant cancer before their 21st birthdays.

No marked difference was found between how survivors and members of the control group adhered to the overall American Cancer Society guidelines. For example, only about one in every 10 survivors (10.2 percent) met fiber recommendations, while only 17.7 percent ate five fruits or vegetables per day. Survivors were better at meeting the goal of at least five hours of moderate activity per week (60.5 percent) than to sticking to any of the other guidelines, and on average scored under 50 percent for the quality of their diets. The 0.7 percent of survivors who actually adhered fully to the guidelines tended to be women, non-smokers and people with a good view of their own health.

"There is still much room for improvement in educating and encouraging survivors to follow healthier diets and lifestyles," says Dr. Chloe Berdan, a member of the team that conducted the study. "Adopting such behavior during early adulthood may have a lasting impact on their quality of life and overall survival."

It took 25-year-old Steven Dulin longer than Caitlin Adkins to take that message seriously. After suffering a sports injury at age 17, doctors discovered he had osteosarcoma, a childhood bone cancer that typically appears in teenage boys. He had 10 months of chemotherapy, broken up by surgeries to remove the tumor from his femur and secondary tumors from his lungs. Treatment ended in 2008, but since then Steven has had three recurrences of his cancer. His last treatment was completed in December 2012 and his scans have been clean since.

When Steven went off to college just after high school, he became the typical survivor talked about in the University of Illinois study. "I was pretty stubborn about not wanting help," he recalls of his freshman year at the University of North Carolina at Chapel Hill. "I had been athletic my whole life, so I could take care of the physical stuff, but the social and emotional effects of having cancer were hard for me. I felt different from everyone else, that I was no longer a typical 18 or 19 year old."

Steven got some counseling which helped him make a decision to quit school and move home to regroup. He has since enrolled in the civil engineering program at the University of South Carolina at Charlotte and has nurtured his leadership skills, becoming involved with the engineering fraternity on campus and doing volunteer work with Habitat for Humanity.

"I've changed," he explains. "I really thought about what I wanted to study, so I had a reason to go to college, a goal and a purpose, to get a degree in something I'm really interested in. It's turned out to be a much more rewarding and 'normal' college experience for me because of that." He also has made friends on campus who are fellow childhood cancer survivors, and that sense of community has had a positive impact. Because he took care of his emotional health, Steven is now attentive to his physical health.

"I follow a protocol for all CT scans of my chest and abdomen, and I have a really good relationship with my oncologist. I'm faithful about making my appointments, because that's

when I can ask my doctor about anything that's causing me anxiety, like, 'What is this bump on my leg' or 'What happens if I get the flu?'"

Because many patients end up like Steven, ignoring critical screenings and other healthcare needs, clinics around the country are being created to specifically address the long-term medical needs of teen and adult survivors of pediatric cancer. At the Aflac Center Survivor Program, patients start coming annually once they've been off treatment for two years. The multidisciplinary clinic provides them with a Survivor Healthcare Plan, or SHP, that includes three key components: their cancer history and treatment, their risk profile for late effects, and recommended surveillance to deter those late effects as early as possible. The clinic follows survivorship guidelines developed by the Children's Oncology Group (<http://www.survivorshipguidelines.org>).

"We also have a psychologist and a social worker," explains Dr. Meacham. "We call it one-stop shopping. All their tests are set up here – echocardiograms, pulmonary function tests, lab work ... plus they can see all the providers in one day." Once the SHP is created, it can be used as a guideline for optimum long-term follow-up care. Patients can get all the tests they need at the clinic every other year, and are urged to see their regular primary care doctor the years in between clinic visits.

The [Pediatric Oncology Survivor in Transition \(POST\)](#) program at Advocate Children's Hospital in Oak Lawn, IL, sees patients ages 5 into their 30s. However, many adult survivors in the area fail to utilize the clinic.

"There's a group out there who truly are lost to follow-up care, because they were treated years ago before the survivor clinic was even a thought," says Linda Rivard, a nurse and co-founder of the 11-year-old clinic. She helped start the POST program after her son was treated for childhood leukemia and the only survivor care program was out of state.

"The clinic gives survivors control over their healthcare and the issues that can come with having had childhood cancer. Even if future issues do happen, they still feel like they have control because they've learned about them ahead of time, before they're even out of treatment."

Rivard emphasizes the need for kids to transition to the survivor clinic soon after finishing treatment. "The whole key to the clinic is to deal with possible late effects, but in a positive environment. We empower them with knowledge on how to prevent late effects or catch them early on so they don't become a major issue. Our patients can actually be healthier than their peers who haven't had cancer, because they typically don't become concerned about their health until they're in their 40s or 50s."

The POST clinic offers every patient a comprehensive treatment summary and personal attention from a dietician, school liaison, social worker and other specialists to help them with all possible challenges as they move forward in their life after treatment. "We also are in the planning stages for an adolescent/young adult clinic, so we'll bring on specialists in internal medicine and family planning who can see those patients in conjunction with our existing team," Rivard explains.

"The adult world is not educated about survivorship. We hope to change that."

While Steven is proactive about his healthcare today, he agrees with statistics that young adults survivors tend to be like he was when he ignored his healthcare.

“I do have friends who are cancer survivors and I cannot stress enough the need to stay on top of their regular screenings and get connected with doctors who understand their circumstances.”

Although the Children’s Oncology Group [Long-Term Follow-Up Guidelines](#) were developed as a resource for clinicians who provide ongoing healthcare to pediatric cancer survivors, most are easily understandable for survivors to read as well. They have several purposes:

- Provide recommendations for screening and management of late effects that may potentially arise as a result of the treatment for childhood cancer
- Increase awareness of potential late effects
- Standardize and enhance follow-up care provided to survivors

The website also includes a series of health links that provide more in-depth information about some of the more common late effects.

Seattle Children’s Hospital is another cancer treatment center with a concentrated focus on long-term survivor health through its [Quality of Life](#) program. Dr. Eric Chow, a physician-researcher and medical director of Children’s [Cancer Survivor Program](#), and program director Dr. Scott Baker, contributed to the Childhood Cancer Survivor Study – a landmark research project that started in 1993 and tracked the health of more than 10,000 people throughout the country. It found that the vast majority of cancer survivors suffer chronic health problems. It also detailed which health issues are likely to develop as a result of specific treatments. A second phase of the study began in 2007 to monitor thousands of new patients.

Chow and Karen Wilkinson, coordinator of the clinic, developed a personalized care plan that gives survivors – and their primary care providers – a road map of the health problems they might face. The plan provides a survivor’s doctors, along with school nurses and other healthcare providers, a quick, easy way to understand what a patient has been through and what they need to look out for.

Nonprofit organizations also are making strides in focusing on survivor care. The National Children’s Cancer Society, for example, has a comprehensive [Beyond the Cure](#) program to address the needs of survivors, from educational resources and workshops to college scholarships. Beyond the Cure also maintains a [list of survivor clinics](#) and offers free publications about surviving childhood cancer: [The View from Up Here](#) for survivors and [The Other Side of the Mountain](#) for parents of survivors.

Education is the key to long-term health of survivors, says Dr. Meacham. At Emory University, much research is devoted to how to best empower survivors to take control of their healthcare. One outcome has been the Cancer Survivor Link www.cancersurvivorlink.org. The site provides a comprehensive library for survivors and medical providers, allows survivors store their medical records and share them with healthcare providers.



Learn about the life-long healthcare needs of pediatric cancer survivors



Store your Survivor Healthcare Plan (SHP) and other healthcare documents



Share your documents with your primary and specialty healthcare providers

Source: CancerSurvivorLink.org

“It’s critical for young adults, because they’ve transitioned away from their pediatric cancer clinic and their parents, and are trying to assume responsibility for themselves,” Meacham explains. “They can store all their medical records so they don’t have to worry if they go on vacation or move to another state and don’t have them, They can also share them with any doctor who registers on the site, so a new doctor can read of up on their history and risks.

“Our whole goal is to help survivors have a safe transition to adulthood.”

The site also offers a list of survivor clinics around the country. Survivors who don’t live near a clinic should return to their treating clinic, advises Dr. Meacham. “They’ll have your records and know what your at risk for and what regular scans you need.”

That’s important, says survivor Caitlin. “It’s a blessing do leave treatment, but it’s also scary to go to different doctors than the ones who have been seeing you throughout childhood. To have all your records, and not have to go through every detail of your story every time, makes the transition so much easier.”

For Steven, being emotionally healthy and connected to communities with shared interests motivated him to taking his long-term healthcare needs more seriously.

“Belonging to a community is really valuable – it goes a long way toward making you feel less isolated and less different, and all of that leads to caring more about your health today and down the road.”

About the National Children’s Cancer Society

The mission of The National Children's Cancer Society is to provide emotional, financial and educational support to children with cancer, their families and survivors. To learn more about the NCCS, visit thenccs.org. For information and resources for survivors, including a Late Effects Assessment Tool and college scholarship opportunities, visit beyondthecure.org. The National Children’s Cancer Society is a 501C(3) organization that has provided more than \$61 million in direct financial assistance to nearly 37,000 children with cancer.