



## LATE EFFECTS: THE LASTING IMPRINTS OF CHILDHOOD CANCER



## **Late Effects: The Lasting Imprints of Childhood Cancer**

### **Education, funding and support are keys to survivors' long-term quality of life**

A seventh-grader is suffering fatigue and chronically forgetting his homework. His teacher tells his dad that his son is “lazy.”

A high school student making A's in advanced placement classes continually performs poorly on tests because she has trouble processing the questions and writing the answers in the time frame allotted.

A young man working in a manufacturing job observes that his coworkers get irritated with him toward the end of the day. Standing all day at an assembly station on feet that suffer from painful neuropathy, his late afternoon fatigue slows down the line and forces his peers to leave work well past quitting time.

Down the street, a young bank teller continually forgets how many five and 10-dollar bills her customers ask for when they cash a check.

These four young people have something in common that is hidden from their teachers, fellow students, coworkers and customers: they are all childhood cancer survivors. Their physical, cognitive and emotional struggles aren't by chance, but connected to, and actually caused by, the treatments that saved their lives.

“Many of these young people say to me, ‘But I’m cancer free! What are you talking about?’” explains Courtney Dauwalder, an occupational therapist at St. Louis Children’s Hospital. She works with adolescent, teen and young adult childhood cancer survivors who have physical and cognitive problems linked to their cancer treatment. She commonly sees young people with issues like neuropathy in their hands or feet, difficulty remembering, planning and organizing schoolwork or job tasks, chronic fatigue, weight issues, and physical challenges created by surgery.

Families who have survived the heart-stopping news that their child has cancer and the subsequent journey through treatment aren't prepared when they leave the oncologist's office for the last time and hear the chilling words, “Your child will likely have problems down the road.”

“It’s heartbreaking when you hear parents say, “We thought we were done!”” says Marnie Hauff, school liaison for the Late Effects Clinic at St. Louis Children’s Hospital. “But this is a life-long issue.”

Post-treatment medical, intellectual or emotional problems are a reality for most childhood cancer survivors, often haunting them in their teens and into their adult years. Called “late effects,” these health and developmental issues can occur months or even years after treatment has ended and a child’s life has returned to normal.

### **Late effects are common and varied**

More than two-thirds of young adult survivors of childhood cancer eventually experience at least one late effect, according to the National Cancer Institute at the National Institutes of Health. Late effects can occur in any organ or system of the body and vary from person to person. Some late effects may be serious or life threatening. Late effects can be influenced by a number of factors, including:

- The original cancer diagnosis, age at diagnosis, gender, treatment, family history, aging process and overall health.
- Where the tumor is located in the body and how the tumor affects the way tissues and organs work.
- The type of surgery; chemotherapy type, dose, and schedule; or type of radiation therapy. Also, the use of two or more types of treatment at the same time, and the length of treatment.
- The child's gender and changes in the child’s genes.
- Health problems the child had before being diagnosed with cancer.
- Family history of cancer or other conditions.

More information is continually being discovered about late effects caused by various cancers and treatment protocols. Unfortunately for parents and survivors, there is no one predominant problem doctors can advise them to be on the lookout for down the road.

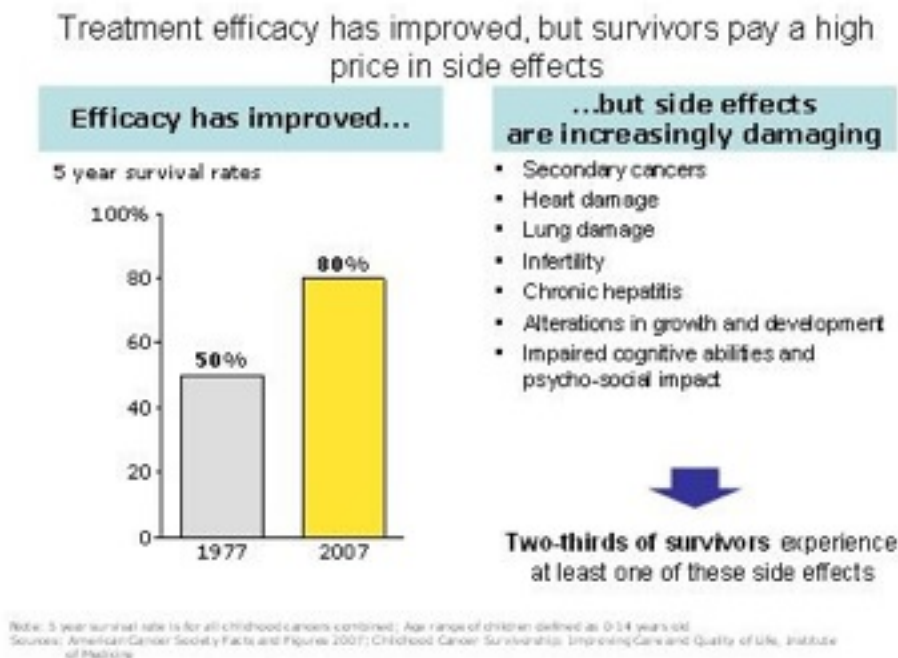
“The scope of a patient’s problems reflects the specific nature of their treatment: whether they had surgery or not, whether they had radiation or chemo, and the specific chemo drugs they received,” says Dr. Robert Hayashi, director of the Division of Pediatric Hematology/Oncology at Washington University School of Medicine, an attending physician in Hematology/Oncology and General Pediatrics at St. Louis Children's Hospital, and director of the hospital’s Late Effects Clinic. Hayashi also led the development of a Late Effects Assessment Tool that is offered free of charge to all survivors and families by The National Children’s Cancer Society. The tool ([thenccs.org/late-effects-cancer-tool](http://thenccs.org/late-effects-cancer-tool)) helps identify which late effects may occur based on a child’s specific diagnosis and treatment.

“Most of the problems we see in this population are relatively invisible, such as intellectual function or emotional conditions,” adds Hayashi. “We define late effects broadly because we see all these issues as important and requiring monitoring and treatment.”

Cancer treatments, including chemotherapy, radiation, surgery and stem cell transplants can harm the body's organs, bones or tissues. In children who are still physically developing while they are undergoing treatment, the drugs can have long-term effects on a number of body systems. Those include organs, tissues, and body function; growth and development; mood, feelings, and actions; thinking, learning and memory; social and psychological adjustment; and risk of secondary cancers.

### Late effects rate is increasing

While the death rate for pediatric cancer has continually declined due to improved treatment, the rate of late effects in childhood cancer survivors is increasing. That’s due to several factors: the higher rate of survivorship, better research linking treatment to future health problems, and because doctors, occupational therapists and other medical providers are becoming more skilled at connecting problems during the teen and young adult years to a child’s cancer history.



Source: American Cancer Society

“This is a relatively new area of medicine where we continue to learn new things each and every year,” says Hayashi.

Body organs and systems subjected to chemotherapy and radiation wear down faster than they would during regular aging, so childhood survivors often deal with regular life problems at a younger age. For example, a female survivor of pediatric cancer may experience menopause in her 30s instead of her 50s.

Chemotherapy and radiation, which kill cancer cells, can damage the cells of a child's still-growing organs. Both boys and girls are at risk for not only cognitive and emotional problems as they grow older, but also reproductive, hormonal and sexual development problems. Radiation therapy and chemotherapy agents like cyclophosphamide and ifosfamide can affect puberty and sexual function in boys and cause infertility in girls. Detailed information about reproductive late effects is available at [Cancer.Net](#).

Cancer treatments also can affect hormone-producing glands (the endocrine system) that control body functions, such as growth and energy. Radiation therapy near the brain, eyes, or ears can affect the pituitary gland, which helps control growth. Pituitary gland radiation has also been linked to a higher risk of being obese and overweight. Radiation therapy given to bone can lead to reduced or uneven growth and bone conditions such as scoliosis, a sideways curvature of the spine. Steroids such as prednisone and dexamethasone, and other drugs such as methotrexate, have direct effects on bone formation and can lead to osteoporosis.

Some late effects can be as simple as regular hand cramps that affect note- and test-taking in the classroom. "One of the drugs used all the time is a nerve toxic drug, so survivors' hands cramp up and that can be a long lasting effect," says Dauwalder.

Unfortunately, many childhood cancer survivors do not receive the recommended follow-up care and screening they need after leaving treatment. The Children's Oncology Group, a network of pediatric oncologists that treat about 90% of American children with cancer, reports the following:

- Only 88.8% of survivors reported receiving some form of medical care after completing treatment.
- Only 31.5% reported receiving care that focused on their prior cancer (survivor-focused care).
- Only 17.8% reported receiving survivor-focused care that included advice about risk reduction and discussion or ordering of screening tests.

Surveillance for new cases of cancer was very low in survivors at the highest risk of colon, breast, or skin cancer, suggesting that survivors and their physicians need education about the risk of subsequent tumors and recommended surveillance.

“Our greatest challenge is to identify what the patient’s risks are, counsel them to make decisions to optimize their full potential, and educate them about life in the future so they can take steps to be independent and successful,” explains Hayashi.

### **Research is ongoing, but challenging**

Research into late effects is challenging, as government support is shrinking for all facets of cancer research. Also, since late effects can onset many years after a child’s cancer is cured, survivors require long-term monitoring. Funding for those lengthy studies is hard to find.

“Late effects doesn’t elicit the same passion as acute cancer care, but it’s something the public needs to have increased awareness of and passion about, because adult survivors have very few options and venues to receive services in existing pediatric facilities,” says Hayashi, noting that the Late Effects Clinic at St. Louis Children’s Hospital is one of only a handful of programs nationwide dedicated to providing therapy and guidance to survivors well into their adult years.

Research generally focuses on studying how late effects evolve, developing interventions to minimize the development of late effects and optimally manage those that arise, and understanding the genetics of late effects. “We can have two pediatric cancer patients with the same therapy, and one may have profound late effects and the other one doesn’t,” says Hayashi. “It’s quite likely that the genetic composition affects that.” The St. Louis Children’s Hospital has a sophisticated genomic research program. As part, it actively collects tissue samples on all cancer patients in an effort to characterize the genes connected to various late effects conditions. The goal is to identify who’s at greatest risk, and hopefully develop therapies to prevent those late effects from happening to patients in the future.

“Genetics also will allow us to identify the patients at highest risk, so if there are options for therapy, we can choose the one with the least risk,” adds Hayashi.

Lexi Chopp didn’t have many options for therapy when she was diagnosed at age 5 with Ewing’s Sarcoma. Over a fast seven months, she had chemotherapy, surgery to remove three ribs and the surrounding muscle and tissue, radiation, a bone marrow transplant with her own marrow, and more chemotherapy.

Now 23, and working fulltime in the public relations department of a major corporation based in Wisconsin, she has a list of late effects that started with social/emotional challenges at age 12, manifested into cognitive problems during college, and continue today by wreaking havoc on her thyroid and reproductive organs.

“Some doctors understand late effects, and some don’t,” she says. “With my thyroid, I had a hard time getting doctors to listen to how I was feeling as opposed to just reading the lab numbers. Sometimes people tell you ‘It’s just in your head.’”

Lexi still lives in the area she grew up in, so she’s familiar with most of the doctors and medical centers. However, she wishes there were a central hub for late effects, so they could be managed by a variety of doctors working together under one roof. “All my late effects are being managed by different doctors, so it’s hard to connect all the pieces.

### **Education and health monitoring are critical**

Acceptance, education and follow-up are critical for childhood cancer survivors. Knowing ahead of time that there is a risk for future emotional, physical and cognitive problems – and that help is available if they need it – are crucial to their long-term quality of life.

“There are two overarching issues we are attentive to in childhood cancer survivors,” explains Hayashi. “One is their quality of life. We want to optimize the function of the child and their potential so they can have as full a life as possible and achieve goals comparable to their peers. The second is that they can achieve a state of independence, so that they are positioned to make good educational and career choices.”

Good health habits also are important for childhood cancer survivors. Exercise, a healthy diet, and regular medical and dental checkups can lessen the severity of late effects and lower the risk of other diseases they might be more susceptible to because of their compromised organs. Along those lines, avoiding dangerous activities like smoking, sun exposure, alcohol and illegal drug use are also critical to their long-term well being, including lowering their risk of having cancer a second time.

Some tips for childhood cancer survivors that can improve overall health include:

- Eat a healthy diet
- Exercise regularly
- Choose not to smoke
- Avoid risky behavior
- For women: do monthly breast self exams and annual gynecological exams
- Men: Do monthly testicular exams
- Avoid drugs and alcohol
- See your dentist every six months
- See your primary care physician once a year
- Limit your sun exposure and always use sunscreen
- Care for your mental health

## Maintain up-to-date medical insurance

Source: St. Louis Children's Hospital Late Effects Clinic

### **Government and medical help is available**

Dauwalder said many childhood cancer survivors are not aware that there are provisions in the [Americans with Disabilities Act](#) for meeting the educational needs of anyone identified as having “cellular alterations.” These include functions of the immune system, normal cell growth, digestive, bowel, bladder, brain and nervous system, respiratory, circulatory, endocrine, and reproductive systems. The 2008 ADA revision states: “These changes can help people with cancer, because in the past they often had a hard time meeting the definition of disability.”

“This allows them to have accommodations at school, such as a longer time than other students for taking a test, and at work as well,” says Dauwalder. “There are many compensatory strategies – ways to make it better. It’s our job in the Late Effects Clinic to work with the survivor to identify what those are and help them implement them so they can be efficient and effective at school and at work.”

Meanwhile, Hauff works directly with teachers and parents to address the cognitive struggles of cancer survivors that are affecting their ability to perform in school.

“We know that some of the therapy for cancer actually changes the way the brain connections work, so with neuro-cognitive testing we can identify and document those challenges,” she explains. “For the typical students I see, it will be having trouble with concentration, focus, processing speed and memory. They have trouble retrieving things that they learned, and trouble with short-term memory.”

Educational intervention has been critical for 16-year-old Brian Ott, who was diagnosed at age three with a cancerous brain tumor and has been on and off treatment ever since. Today, he gets help with writing and other tasks through special education classes and a full-time personal aid. But he and his parents had to pursue that help.

“The schools had no idea what to do with Brian, because his strength is verbal, so if you talk to him you assume he is age appropriate,” says his mother, Erin Ott. “But he has cognitive delays, memory loss and a reading disorder. He told me once, “If I’m not bald (from chemotherapy) they assume I’m healthy.”

Hauff says many schools might see only a handful of cancer survivors over several years and not understand or even know about the connection between their illness and their learning problems. Part of her job is to educate school staff and parents about services available to survivors. The 2008 revisions to the Americans with Disabilities Act included a provision, known as the 504 Plan, that guarantees help to students with disabilities



connected to cancer treatment. “Some students just need a longer test time or a quiet place to work; others need special education services,” explains Hauff.

At the [Late Effects Clinic](#) at St. Louis Children’s Hospital, survivors are provided a broad array of screenings to identify all the issues that are impeding their progress in normal life activities. A cadre of specialists, including pediatric oncologists and nurses, a neuropsychologist, school liaison, registered dietician, occupational and physical therapists and social workers provide a team approach to helping each survivor find and implement strategies to manage their challenges.

The clinic also is addressing such needs as fertility preservation through egg harvesting. “Our goal is to harness the tremendous resources and talents of this medical center and utilize them effectively for the late effects patients,” says Hayashi.

Many insurance companies will cover the expenses incurred at the clinic as long as the patient can demonstrate that their problems are a direct consequence of their cancer treatment. There are more challenges, however, for patients on Medicaid or without insurance, who eventually age out of coverage when they reach adulthood, or without insurance altogether.

That speaks to another reason late effects care is critical: to help young adults manage their problems so they can find and keep fulltime jobs with health benefits. “Because of the unclear future of health care today, we aggressively counsel our patients to choose career pathways that will allow them to maintain stable employment,” says Hayashi.

The clinic also refers families to nonprofit organizations like the National Children’s Cancer Society, whose Beyond the Cure Program <http://www.beyondthecure.org> ensures that childhood cancer survivors and their families have access to survivorship information, and to the CureSearch Children’s Oncology Group <http://www.curesearch.org> for long-term follow-up guidelines for survivors of childhood, adolescent, and young adult cancers.

### **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](http://thenccs.org). For information and resources for survivors, including a Late Effects Assessment Tool and college scholarship opportunities, visit [beyondthecure.org](http://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.