Democracy Dies in Darkness

More kids are beating cancer. Improving the rest of their lives is next.

Pediatric cancer survivors can face lifelong complications from their treatments.

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By Amy McHugh

When oncologists gave my 5-year-old daughter the all-clear from high-risk neuroblastoma in 2010, I breathed a sigh of relief.

But her health needs were just beginning.

Fifteen years later, the intense and often toxic treatments that saved Emily's life have left her with a host of lifelong health challenges — hearing loss, stunted height, endocrine and kidney dysfunction, and permanent hair-thinning — issues no one talked about during her 18 months of cancer treatment.

The National Cancer Institute says 85 percent of children diagnosed with cancer are alive at least five years later and that there were nearly 496,000 pediatric cancer survivors in the United States in 2020. While the good news is encouraging, long-term survivor care brings its own challenges — something pediatric oncologists are working to improve.

"Kids with cancer are beating a disease we never beat 30, 40 years ago," says Greg Armstrong, who chairs the department of epidemiology and cancer control at St. Jude's Children's Research Hospital and is also the principal investigator of its Childhood Cancer Survivor Study. "There's an entire population of kids who didn't exist before. Now we need to figure out how to best support them."

Unique childhood challenges

The National Cancer Institute estimates that about 15,000 children and adolescents 19 and younger were diagnosed with a form of pediatric cancer in 2024. While nearly 1,600 died last year, many more survive cancer today than in the past, but survival can mean enduring toxic treatments.

By age 50, childhood cancer survivors have almost twice as many chronic health conditions as the general population, according to a St. Jude Life cohort study.

Unlike their adult counterparts, children with cancer are going through growth spurts and puberty while they're getting medication, chemotherapy, radiation treatments and new targeted therapies.

"A 70-year-old treated for cancer doesn't have to worry about what happens in 50 years," says Stephanie Smith, pediatric oncologist and survivorship expert at Stanford Medicine Children's Health. "It's very different when you're treating a 5-year-old."

"When a kid is diagnosed it's always going to be, 'We gotta win,'" Armstrong says. "Cures and survivorship are a hard thing to balance."

Childhood cancer is rare, which translates into limited government funding, enrollment for trials and incentive for pharmaceutical companies to develop less toxic, more effective treatments. A lack of targeted drug therapies for children has required pediatric oncologists to tweak protocols and therapies developed for adults. But kids aren't mini-adults.

"Pediatric cancers aren't a result of lifestyle decisions like smoking or sun exposure," says Melissa Hudson, director of the Division of Cancer Survivorship and St. Jude's principal investigator of the Lifetime Cohort Study. "They're extremely complicated and unique."

Post-treatment issues like organ damage, stunted growth, hearing and vision loss, infertility, premature aging, post-traumatic stress disorder, insomnia, breast cancer risks, sexual dysfunction, secondary cancers, skin and teeth problems, and early rates of comorbidities pose significant challenges for pediatric cancer survivors as they age.

Translating data into practice

The Childhood Cancer Survivorship Study, funded by the National Cancer Institute since 1994, set out to better understand these post-treatment effects, increase survival rates and minimize harm. The multi-institutional study followed more than 38,000 children and teens diagnosed between 1970 and 1999 who survived five or more years after their childhood diagnosis.

The self-reported questionnaires revealed that childhood cancer survivors have shorter lifespans, an increased burden of chronic diseases and a high risk for new and secondary cancers.

The data has informed randomized control intervention trials and helped to create tools that assess the risk of future diseases based on the kind of cancer a patient had, and the medications and therapies used to cure it.

"Without a doubt, the data has changed the way we treat new cohorts of children," Armstrong says.

In 2000, the Children's Oncology Group (COG), a member of the National Clinical Trials Network, created best-practice guidelines for survivors' ongoing care based on clinical research and the type of treatment a child received.

In 2023, COG added recommendations for health-care professionals, including school nurses, primary-care doctors and pediatricians, who work with survivors but often haven't treated many — if any — children with cancer.

COG guidelines also inform survivorship care plans that are tailored to address a patient's unique physical and mental condition post-treatment and designed to help them make healthy lifestyle choices to mitigate later risks.

At Primary Children's Hospital in Salt Lake City, Douglas Fair, the founder and director of the Childhood, Adolescent and Young Adult Cancer Survivorship Program, breaks down which post-treatment scans, appointments and screenings are necessary because such details often overwhelm survivors and keep them from continuing with care.

Despite abundant evidence on the value of follow-up care, many survivors don't get it.

"We're playing catch-up," says Fair. "For years, you were a survivor if you cleared your five-year mark. Now, survivorship starts day one [of diagnosis], and we weren't trained in survivorship care."

Doctors acknowledge that persuading older childhood cancer survivors that it's not too late to begin survivorship care might be difficult.

"By the time survivors are 25, they've already established patterns and a way to get through life," says Lisa Diller, director of the David B. Perini Jr. Quality of Life Clinic for Childhood Cancer Survivors at the Dana-Farber Cancer Institute. "But if they're 7, we have a better shot to get them to accept that follow-up care is going to be a part of the rest of their lives."

New tools and access

Passport for Care, an online resource that provides accurate, timely information for individual patients, was designed by Texas Children's Hospital to help survivors, many of whom are uncertain of the details of their treatment protocols. They can draw on this detailed information during an emergency room visit or an appointment with a new practitioner.

Soon, St. Jude will launch ARIA (Adapted Resource and Implementation Application), a web platform that will enable survivors and clinicians worldwide to access videos, best practices and guidelines for all pediatric cancers.

Doctors are also working on what quality of survival looks like for all pediatric cancer survivors by measuring and identifying where and how they can improve care.

"You can't just have survival," Hudson says. "You have to have quality of survival."

A success story

Doctors are optimistic they can improve protocols of care as they did with acute lymphatic leukemia (ALL), the most commonly diagnosed childhood cancer. Once a death sentence, ALL cure rates went from below 10 percent in the 1960s to 94 percent today.

Through the use of clinical trials, doctors ended up removing ALL treatments such as brain radiation that caused significant cognition issues in most patients, and discovered the patients fared as well without it.

"We figured out how to cure [ALL] without overusing toxic therapies," Diller says. "We're looking to do the same for all childhood cancers."

For 15 years, Emily has followed her survivorship care plan, which dictates annual medical visits and specific tests and scans. Neuroblastoma remains one of the trickiest cancers to treat, so doctors are forced to continue to use "big gun" therapies that can cause significant post-treatment issues.

Emily was one of the first kids enrolled in a neuroblastoma trial that tested the efficacy of one stem cell transplant vs. two. Doctors believed two transplants would give kids a better shot of survival. They were right, and the study was stopped early and the protocol changed to two stem cell transplants because the kids who received two transplants relapsed less. But the physical and mental fallout of two transplants, separated by only a few weeks, is significant.

Emily doesn't want to be known as "the girl who had cancer," but her body tells the story of a kid who traded vital parts of it to be cured. With support, she continues to manage her survivorship care, acknowledging that while she may wish to be "done with it," she never truly will be.

"There's a lifetime cost for kids treated for cancer," Armstrong says. "It's time for us to advocate for better outcomes. This demographic has been through so much and deserves more."

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