

FEATURE STORY

Conquering Cancer & the Classroom

BY SCOTT WILLIAMS

Children with cancer still have to get an education.

For most kids, the phrase “back to school” suggests challenges no more serious than which supplies—and which of the latest fads—are necessities. But for youngsters who have survived cancer, the challenges of returning from a life-and-death struggle to the day-to-day rhythms of childhood or adolescence can be daunting. It’s a happy problem to have, given that 40 years ago the five-year survival rate for all childhood cancers was 28 percent compared with almost 80 percent today, according to National Cancer Institute statistics.

Being glad she has leukemia now instead of 40 years ago is still a hard sell for 14-year-old Louise Flournoy, who recently completed the first phase of her treatment after being diagnosed in July 2008 with acute lymphocytic leukemia (ALL) before beginning eighth grade. Nina Flournoy says that when her daughter was diagnosed, Louise’s questions were all about the upcoming school year, when she would be a cheerleader and would be applying to high schools from the Catholic school she had attended since first grade. Would she be able to keep up and graduate from eighth grade with her friends?



Louise Flournoy photographed in April at her school in Dallas. Photos by Wes Wolfe.

“She was not just desperate for school itself but also for the friendships that are

so important at school,” says Flournoy. “One of the most difficult things for her to take was that she would lose touch, and life would pass her by.”

Louise, who her mother says has always loved school, attended 50 percent of her classes during the acute treatment phase and recovery, which lasted nine months. By March 2009, Louise carried only 80 pounds on her 5-foot-1-inch frame and had difficulty walking as she entered the maintenance phase of her treatment—another year and a half of oral chemotherapy and a close watch on blood counts.

“Even though she feels like she has lost touch, she is very intuitive and doesn’t really worry about it because she understands that this (leukemia) is going to go away, and eighth grade leads to high school, so there is a separation that everyone will go through,” Flournoy says.

Growing Up With Cancer

As the survival rate for childhood cancers has increased, so has the attention paid to the physical, social, and cognitive consequences for the more than 270,000 childhood cancer survivors in the U.S. The severity, specifics, and duration of the issues each child will face as they continue their education can depend on a number of variables, including age at diagnosis, type and stage of cancer, gender, the type of treatment received, and the support provided.

Indeed, when discussing the effects of cancer treatment, Robert B. Noll, PhD, chief of the child development unit at Children’s Hospital of Pittsburgh, says pediatric cancer survivors must be divided into those with primary tumors within the central nervous system (such as the brain) and those with other types of cancer. Research shows, he says, that primary brain tumor survivors not only have more learning issues but also have more social and cognitive problems compared with children treated for other forms of cancer or the general population.

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—Nina Flournoy

Noll says radiation to the brain impacts the child’s cognitive functioning and behavior based on dose and age. “Typically, larger doses of radiation and a younger age when the radiation is received are associated with more challenges later,” Noll says.

Anna T. Meadows, MD, director of the Cancer Survivorship Program at The Children’s Hospital of Philadelphia, agrees. “The problem is that if you treat the brain of a young child, it affects the child’s ability to learn,” she says. “And so as that child grows up and goes through the normal school years, while other children are learning, that child is learning less well, so such children get further

and further behind.”

Meadows has spent the past three decades researching the cognitive and intellectual changes that occur in children following treatment for leukemias and brain tumors. The American Cancer Society estimates that more than 10,000 children under age 15 are diagnosed with cancer each year; leukemias and brain and other central nervous system (CNS) tumors account for more than half of the diagnoses. Treatment options for childhood cancer include surgery, chemotherapy, and radiation therapy, which is a primary treatment for brain and CNS tumors.

Shawna L. Palmer, PhD, a research psychologist and member of the pediatric brain tumor team at St. Jude Children’s Research Hospital in Memphis, Tennessee, says the younger a CNS patient is at the time of radiation, the greater and more immediate the decline in intellectual ability and academic function. “Children younger than 7 or 8 experience immediate declines,” she says, “while older children start to experience declines two to three years after treatment, a time when many find their academic curriculum also increases in difficulty.”

She says it’s not a loss of previously acquired information, but rather not being able to acquire new information or skills at the same rate as their healthy peers. Palmer says research has found children treated for brain tumors struggle most with reading and spelling, and research in recent years has looked at the day-to-day effects of cancer treatment. “What we believe is that the earlier changes in working memory, processing speed, and attention lead to later changes in intellect and academic achievement,” Palmer says.

Resilience and Recovery

Noll says his research indicates that survivors of childhood cancer, other than brain tumors, actually do better with their peers and are more well liked and less aggressive or disruptive.

“One reason for that might be that, if you’re a child who has a physical illness like cancer, and you’re just a little more tired and a little more frail, you might be a little more thoughtful about how you interact with your peers.”

Alex Potter, now 21, was 10 when he was diagnosed with rhabdomyosarcoma, a rare form of cancer that affects the connective tissues in the body. Tumors were found on his lung, spine, and the base of the carotid artery.

Potter’s cancer, diagnosed after he began having trouble breathing and staying awake, resulted in a year of treatment that included three surgeries, chemotherapy, and eight weeks of daily radiation.

“I think I’ve become a little stronger and more mature at my age because I went through a lot more than most 10-year-olds go through,” says Potter, who lives in the Philadelphia area. “I try to have a positive outlook and try not to get upset about a lot of things.”

Such outcomes are not unusual, say researchers, who have found that the experience of being treated for cancer at any age can result in positively

perceived changes in focus, a reordering of life priorities, increased resilience, and a greater appreciation of life and relationships.

Adolescents, however, may not cope as well as their younger counterparts, according to a study published in 2007 in the *Journal of Clinical Oncology*. The study evaluated the responses of parents of 2,979 survivors and 649 siblings to assess difficulty in six behavioral and social domains, such as depression/anxiety, attention deficit, and social competence. Survivors and siblings were similar in age, averaging around 14.

Researchers found that survivors were 1.5 times more likely than siblings to have symptoms of depression/anxiety and 1.7 times more likely than siblings to have antisocial behaviors. Adolescents treated for leukemias or CNS tumors had significantly elevated scores in the depression/anxiety, attention deficit, and antisocial domains; cranial radiation and/or intrathecal (injected into the spinal fluid) methotrexate were specific risk factors.

“Not every person who goes through cancer therapy has physiologic changes that interfere with their lives,” says Meadows, “but everybody who goes through that experience has some emotional change that takes place, or some psychological change.”

Teamwork Counts

Potter attended a small private Catholic school, which worked with him to make sure he kept up with his lessons while out for treatment.

“Every once in a while I would take a test to see if I was keeping up, and I was doing well,” he says. “After everything I had been through, it was good to get back and readjust to school life.”

Parents should check with their child’s school to see what is required by law and what is provided by the school district in terms of special education or other support for children undergoing treatment.

Like other top children’s hospitals, St. Jude has a school program that allows children to continue their education through homebound or hospital-bound services and provides services to make it easier for children to return to school.

“The way to make an impact on those children is the same way one makes an impact on all children with learning disabilities,” Meadows says. “That is, teach them ways of learning that may require one-on-one education, and that may require special help.”

Nina Flournoy met with the principal, assistant principal, counselor, and Louise’s homeroom teacher before school started in 2008. A journalist and college lecturer, Flournoy prepared handouts about ALL for the administrators. And, since she knew teachers had their hands full with school starting, Flournoy also included a letter that administrators could give Louise’s teachers about her condition. Flournoy says this was the first experience of this kind for the school, and they used all the information she brought to educate the teachers and others about ALL.

The experts agree that the parents, health care providers, and educators need to work together to diminish the negative consequences of any psychological, social, or intellectual effects of cancer treatment in kids. Another important component in minimizing the late effects of cancer, Palmer says, is to take baseline evaluations before cancer treatment begins and follow up with regular testing throughout and after treatment.

Flournoy says Louise has maintained good grades and was accepted to two private high schools, one coed and one for girls. In April, Louise chose the all-girls school, which will take the pressure off when it comes to her appearance, which bothers her, says Flournoy.

Flournoy says she never pushes Louise to do something when she doesn't feel like it, but if she doesn't want to do something because she's embarrassed about how she looks, Flournoy pushes back. "The more I encouraged her to face those fears and just do it, the more she realized [her friends] really don't care."

Teachers can use a number of strategies to help children learn, including providing information in a brief, concise manner, writing down instructions, and giving information that will be presented in class ahead of time. Other strategies include giving multiple choice tests, allowing more time to complete assignments, and decreasing the volume of homework. Smaller classes, front-row seating, and summarizing lessons also help.

"A team approach, I feel, is critical to the outcomes of the child and the family. That being said, it's important to continue as much as possible in supporting the child in keeping up with schoolwork," Meadows says.

In Louise's case, the school created a box for her where teachers put homework and where friends put their notes from classes so Louise could copy them. Flournoy says it has been a great way for Louise to get caught up when she isn't there, but also to get personal notes from friends or faculty that say, "Hi, how are you? We miss you."