



HELPING CHILDREN

Adjust to School After Cancer Treatment

By Andrea Greif

For children with cancer, returning to school during or following treatment presents an array of challenges. Teachers, school nurses, guidance counselors and other school personnel can make a huge difference in helping children make the transition.

While great progress has been made in treating childhood leukemia and other pediatric cancers in recent years, cancer therapy is hard on children, and many are left with serious long-term physical and emotional scars. As an increasing number of teachers and school personnel are discovering, many patients are also leaving treatment with significant learning disabilities and cognitive impairments that need to be addressed in the classroom. Helping these children readjust and flourish depends in large part on how well teachers, parents, and healthcare workers function as a team.

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“Children with cancer face many obstacles when they try to transition back into daily life,” says Hildy Dillon, Senior Vice President of Patient Services for The Leukemia & Lymphoma Society. “The return to school can be fraught with physical, learning, and social challenges for children. There are often very specific accommodations that can be made in the classroom that will help the child have a more positive and successful experience.”

Most child cancer patients who return to school do so within 4 to 6 months of their initial, and most intensive,

period of treatment. While they may be in remission, the children are literally carrying the physical and emotional scars of their experience. They may have no hair, be overweight or underweight depending on treatment, are easily fatigued and may have a

central line catheter that limits their physical activity. In addition, they may suffer from nausea, headaches, mood swings and chemo-induced neuropathy in the hands and feet.

“Peers may avoid them, fearing that cancer is contagious or they may not know how to support their friend,” adds Dillon. “The patient may feel sad or isolated.”

About 40 percent of children with acute lymphocytic leukemia (ALL), the most common form of childhood cancer, will have cognitive impairment. The percentage is highest among



Craig's Story

EDITOR'S COMMENTS



Not all stories end in successful treatment and not all school staff will have time to deal with a child's illness and subsequent death. When Craig's grandmother registered him for kindergarten she simply put "cancer" on his medical health history. I called to introduce myself and gather more information. I found out that Craig was a 5-year-old with a Hickman catheter, in remission from cancer but still under the care of his oncologist. His grandmother felt he might not be able to start school, and neither of Craig's parents, currently separated, felt he should attend. I offered to have them come in and meet me and the class during the first week of school to help them make their decision.

Craig loved school. The children he knew were cousins and cancer patients. He found kindergarten fascinating. He had a great smile and everyone loved him. His Hickman catheter was safely hidden under a mesh net vest beneath his clothing. He began school with few restrictions. His classroom teacher and I monitored his activity tolerance. We called his father regularly. (His mother was not able to handle his school experience, and chose not to be a part of it.)

Craig fell out of remission before the end of September and by mid-October his family felt the need to keep him at home to spend every possible moment with him. His teacher and I were able to make very much happen in those few weeks. Each child created a page for a booklet we would present to him during the class Halloween celebration describing in words and pictures what Craig meant to them. The Home-School Association had a fund raiser. The parents of all the children were told what was happening and we shared suggestions of books and stories to help young children cope with death.

Best of all was that Craig's father brought him to school one final time, to attend the class party for 20 minutes. Not only was he able to see his friends, but Craig's father was able to feel the close relationships he had formed and see the lives he had touched in his brief time as a classmate. When he was ready to read the booklet much later, he would know who each child was and be able to remember their smiles and care.

After his death, both the classroom teacher and I were excused from our work day to attend the services for Craig. We met his oncologist, who sat right behind us. We met his grandmother. We signed his memory book and hugged his mother. And as the year went by, whenever someone talked about Craig, we were able to remember him with great tenderness.

~Deb Ilardi

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those who have been treated with radiotherapy to the brain. Some of the late effects include: a marked slowing in processing information, attention problems, memory and fine motor coordination difficulties, reduced skill in planning and organizing tasks and materials, and poor handwriting, reading comprehension and mathematical skills.

“Peers may avoid them, fearing that cancer is contagious or they may not know how to support their friend,” adds Dillon

There are methods to help children overcome some of the obstacles. Some examples might be oral instead of written tests, untimed tests, tutoring in math and reading, reduced homework demands, limited handwriting requirements, large-print or audio books, and assignment of a classroom aide or a peer buddy.

To begin, teachers and parents should reach out to organizations like The Leukemia & Lymphoma Society (LLS), which offers a number of programs and materials to help. They include:

- *Trish Greene Back to School Program for Children with Cancer* distributes published materials and videos to help inform the school staff and classmates about cancer and what to expect when the child returns to school. The materials help explain how children with cancer feel, why they may look different, the type of treatment they’ve undergone, and the special needs they may have on their return.
- *Welcome Back: Facilitating the Return to School for Children with Cancer* is specifically designed to teach school personnel ways to help ease a child’s return to school after cancer treatment. The program helps them to recognize the short- and long-term effects of cancer treatment; accommodations to help overcome educational obstacles; and specialized education plans and laws that protect children’s rights. The program is taught by local medical experts and educators.
- LLS also offers the booklet *Learning & Living with Cancer: Advocating for Your Child’s Educational Needs*, which addresses the short- and long-term effects of cancer treatment; suggested classroom presentations; neuropsychological testing for cognitive effects; and laws to protect children with special educational needs, and accommodations for these children. 🐾

RESOURCES

Information about all of these programs and materials can be found at www.LLS.org or by contacting LLS’s Information Resource Center, (800) 955-4572.

ABOUT THE AUTHOR

Andrea Greif is the Director of Public Relations for the Leukemia & Lymphoma Society.

Disease Information

All of the following and more is available at the LLS web site. Why not go there, look around and bookmark the site for future information? I have found everyone associated with LLS to be approachable, informed and eager to share information with school nurses in order to help their students and families cope with their diagnosis, treatment and consequences.

~Deb Ilardi

Facts & Statistics - Read the latest incidence, survival and other up-to-date statistics and facts about blood cancers.

Leukemia - Leukemia is divided into four major categories: acute myelogenous, acute lymphocytic, chronic myelogenous, and chronic lymphocytic.

Lymphoma - Learn about the different forms of lymphoma, including Hodgkin’s disease.

Myeloma - Some 19,900 new cases of myeloma were diagnosed in the United States in 2007.

Myelodysplastic Syndromes - Learn about myelodysplastic syndromes, their diagnosis and treatment.

Myeloproliferative Disorders - Learn about this group of blood diseases characterized by chronic increases in some or all of the blood cells.

Childhood Blood Cancers - Families face uncertainty when they are told that their child has leukemia or lymphoma. It is a time filled with new people and situations, worries and change. It may help to learn that cancer survival rates for children have improved significantly during the last several decades due to new treatments.

Treatment & Clinical Trials - This segment provides information to assist people in choosing treatment options.

National Education Programs - Live and archived presentations by the experts for patients, care givers and health professionals, available to the public. All programs listed here are provided free of charge.

Free Materials - The most popular publications are available on this Web site. They can be read online, downloaded or ordered by mail.

Signs and Symptoms - Learn more about the signs and symptoms of leukemia, Hodgkin’s and non-Hodgkin’s lymphoma, myeloma, myelodysplastic syndromes, and myeloproliferative diseases.