Learning & Living With Cancer

Advocating for your child's educational needs

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THE TRISH GREENE
BACK TO SCHOOL PROGRAM
FOR THE CHILD WITH CANCER
The Leukemia & Lymphoma Society

The Leukemia & Lymphoma Society®
Fighting Blood Cancers

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Building hope for the future

For children with cancer and their parents, returning to school builds hope for the future. Attending school is a big part of feeling normal and productive. Yet, going back to school also brings new challenges to families whose main focus has been getting through treatment. You may wonder:

- What challenges will my child face?
- What help is needed for my child to be successful?
- What laws protect my child?
- Where do I turn for help?

As the parent of a child returning to school during or after cancer treatment, you will need to be the mobilizing force behind your child's education plan. You are the person who will need to see that a plan is started and maintained, or changed as needed. Your child's medical team and school personnel will support you in shaping and carrying out the plan.

How this booklet can help you

This booklet is written to guide you in this endeavor. It is a starting point to give you:

- Insights about the challenges your child may face and what can be done
- Information about the laws that protect your child's educational needs
- Specific ways that schools can help meet your child's educational needs

Returning to school — Planning for the future

Most children with cancer will attend school at least some of the time during and after treatment. Because school is a place for learning and fun, children benefit from returning to school as soon as medically possible. Your child may experience side effects of treatment both in the short and long term that can affect his or her education. By being aware of possible effects, you can work with the school to help your child.

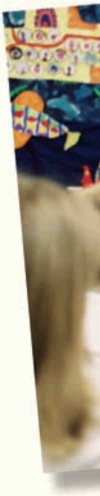
Short-term effects of cancer treatment

Short-term effects are the side effects that happen during and shortly after cancer treatment.

Possible short-term effects of treatment

- Hair loss
- Mouth or throat sores that can be painful
- Nausea and vomiting
- Diarrhea or constipation
- Anemia
- Fatigue
- Social and emotional concerns, such as anxiety, depression, or fear

On pages 8 through 12, you will find suggested ways school personnel can help your child manage these effects of cancer treatment should they occur.



Ideas for classroom presentations

The outward signs of illness can be especially hard for children with cancer because of their need to fit in with peers. Classroom presentations can help peers understand what to expect when the child with cancer returns. Questions other children may ask include:

- Is cancer contagious? How did my classmate get cancer?
- Will the cancer go away? Will it ever come back?
- Does my classmate still have to do homework?
- What can we do to help?

Providing straightforward, reassuring answers to children's questions can help turn anxious classmates into supportive friends.

Be sure to keep in mind the ages of the children in the classroom. Classroom presentations that are age appropriate are most effective. Some ideas to keep in mind are listed below.

Children 5 to 8 years old

- May think that cancer happens because the child did something "bad"
- May think that they can "catch" cancer

Children 9 to 12 years old:

- May be able to empathize with the child with cancer
- May want to know about the probability of getting cancer

Teens 13 to 17 years old:

- May want to know about the scientific basis for the disease
- May understand the need to treat their classmate with cancer the same as others

Young people who are educated about cancer may grow up to be compassionate adults who will reach out to others in times of need.

Types of late effects

Many parents are surprised to learn that the effects of cancer treatment may continue after treatment ends. These effects of cancer treatment — called *late effects* — can impact schooling for years. Sometimes late effects are noticeable right away. Others may take years to show up. Some **cognitive** late effects (those affecting thinking and memory) include problems with:

- Organization (homework assignments may often be misplaced; school materials can be jumbled)
- Reading or reading comprehension
- Processing speed (children may work more slowly than their peers)
- Visual memory for things that are new (such as decoding letters and numbers or reading music)
- Understanding math concepts or remembering math facts

Other late effects can be **physical,** including:

- Seizures
- Problems with eyesight or hearing
- The need for a wheelchair or prosthesis (an artificial arm or leg)

There are also **psychological** late effects, such as posttraumatic stress. The term ***posttraumatic stress*** describes a person's response to trauma.

Risk factors for late effects

Not all childhood cancer survivors will develop late effects. Factors that increase the risk for learning problems in school include:

- Cancer diagnosis at a very young age
- Cancer treatment involving the central nervous system (the spinal cord and brain)
- Certain types of cancer, such as:
  - Brain or spinal cord tumors
  - Tumors in the eye, eye socket, head, or facial area
  - Acute lymphoblastic leukemia (ALL)
  - Non-Hodgkin lymphoma (NHL)
  - Hodgkin lymphoma
- Brain surgery
- Radiation to the total body or to the head
- Female gender — Girls may be more at risk for cognitive late effects

Should my child be evaluated for late effects?

Any child who is at risk for late effects or is having difficulty in school should have neuropsychological testing done by a licensed pediatric psychologist or neuropsychologist. Ask your medical team for a referral. The tests may be available free of charge from major medical centers or universities. You may want to tell your child that these tests are painless.

When testing is complete, be sure to schedule time for the neuropsychologist to explain the results and any recommendations for adjustments at school that the child may require. If needed, ask the neuropsychologist to help explain the recommendations to the school staff. Keep in mind that even if the first evaluation is normal, at some point in the future your child may experience certain late effects, such as slow processing speed and problems with visual memory. Periodic evaluations may be needed at academically challenging times, such as entry into elementary, middle, or high school or during precollege planning. Ask your medical team to suggest a follow-up care program that includes periodic evaluations.

Laws that help protect children with educational needs

Children affected by cancer treatment may have a physical or learning disability. The following 3 federal laws help protect the rights of students with educational needs resulting from cancer treatment.

The Americans With Disabilities Act (ADA)

Protects against discrimination in employment, transportation, communication, government, and public accommodations. It may be especially useful to students seeking employment or going to public colleges or universities.

The Individuals With Disabilities Education Act (IDEA)

Protects students (aged 3-21 years). Ensures public schools, colleges, and universities provide a free and appropriate education, just as for other children.

The Rehabilitation Act of 1973 – Section 504

Requires all educational institutions receiving federal funding to provide accommodations for students with physical or mental impairment, or a record of impairment, that limits at least one major life activity.

Which law can help my child most?

All childhood cancer survivors qualify for intervention or accommodation under one of these laws. The table on the next page compares IDEA and Section 504. With IDEA, most students are eligible under the "other health impairment" category. If the child does not meet IDEA eligibility, Section 504 accommodations could be considered. Under Section 504, the child qualifies if he or she has a record of impairment that substantially limits one or more major life activities, such as learning, walking, or climbing stairs. Most children who have or had cancer will meet this criteria. To find out which approach is best for your child, work closely with your child's medical team and school staff.

Comparing the IDEA and Section 504*

	Special Education (IDEA)	Section 504
Type of law	An education law	A civil rights law
Who is in charge	Special education director	Section 504 coordinator
General purpose of the law	Each child with a disability is guaranteed a free and appropriate education Includes preschool, elementary, and secondary	Protects the rights of individuals with disabilities in programs and activities that receive federal assistance from the Department of Education
Name of tool(s) used to implement the law	Individualized Education Plan (IEP)	Accommodations (504 Plan)
Types of disabilities	13 disabilities, including *other health impairment*, which may qualify cancer survivors	All eligible disabilities, including cancer Disability must *substantially limit* one or more major life activities
Safeguards	Parent participation, consent, and notification is needed	Notice to parent is required
Evaluation of eligibility	An evaluation needed	An evaluation needed

*Adapted with permission from *Our Child Has Cancer: What Do We Do About School?* by Carla Woyak, MSEd. To order, call 602-300-0831.

Types of accommodations

The next few pages list examples of accommodations that children with cancer may need. The accommodations are divided into 2 types:

- **Physical** – those that help students cope with physical effects of treatment, such as fatigue and hair loss
- **Cognitive** – those that help students cope with effects of treatment on thinking and memory

To help you advocate for your child when working with school staff members, the table also includes a rationale for each accommodation. For every accommodation, the child's individual needs, as well as his or her age, are key considerations. To learn more, be sure to consult the organizations listed on the back cover of this booklet.

Physical accommodation	Rationale
The student will be given 2 sets of books — one for home and one for school.	The student may miss school often because of hospital stays and feeling poorly. By having an extra set of books at home, the student can better keep up with assignments. Lighter backpacks are easier for fatigued children to carry.
The student will be allowed to carry a water or juice bottle throughout the school day.	Students on chemotherapy or other medicines may need to drink extra fluids to prevent dehydration and dry mouth.
The student will be given bathroom, guidance, and clinic passes.	A laminated pass to use when needed allows the student to leave the classroom without drawing attention from the other students.

Developed with Alma Morgan, MEd, Educational Consultant, Pediatric Hematology/Oncology, Virginia Commonwealth University Medical Center.

Physical accommodation	Rationale
The student will not be required to participate in physical education activities that involve contact sports, strenuous exercises, and long distance running.	Many students return to school with PORT-A-CATH® Systems or other central lines. They also may be extremely tired from treatment. Strenuous physical activity can tire the student, causing problems with concentration and school performance.
The student will not be required to participate in the Presidential Physical Fitness Testing.	This testing can take too much energy from the child who is physically fragile.
The student will be allowed to wear a hat or scarf throughout the school day.	A student with hair loss may feel uncomfortable. Because most schools have a "no hat" rule, an accommodation should be made.
The student will be allowed to leave class 5 minutes early to get to the next class.	The student may have classes at opposite ends or on different levels of the school building. Hallways can be crowded. The student may need extra time to get to the next class.
The student will be allowed to have a mid-morning and afternoon snack, if needed.	Treatment can cause weight loss and increased hunger. Snacks are needed to add calories and nutrients to the student's diet.
The student will be given a shortened school day or rest period if needed.	Because fatigue is common, a rest period and/or shortened school day may make it possible for the student to attend school.

Developed with Alma Morgan, MEd, Educational Consultant, Pediatric Hematology/Oncology, Virginia Commonwealth University Medical Center.

Physical accommodation	Rationale
The student will be given a locker close to his or her classes, or 2 lockers if the classes are spread out on different floors.	So that the student can avoid carrying heavy books and notebooks throughout the day, a locker close to his or her classes can make it possible to change books between classes.
The student will be given a parking space close to the school entrance.	For the student who drives to school, a parking space close to the school entrance will make it easier to walk to class without getting tired.
The student will be provided a computer for note taking and assignments.	When handwriting is a challenge, the student can use a computer or other technology.

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Cognitive accommodation	Rationale
The student will be given extra time for class work, homework, quizzes, and tests.	During and following chemotherapy and/or radiation treatment, the student may process information and respond more slowly.
The student will have a homebound teacher (a teacher who comes to the home) to help with assignments.	The student may miss school often because of hospital stays and feeling poorly. And, the student may need extra help with assignments because of cognitive late effects. A homebound teacher will collect the missed work from school and help the child to complete missed assignments.
The student will be assigned a moderate workload that emphasizes quality versus quantity.	A moderate workload allows the student to show that he or she has mastered the concepts without feeling overwhelmed. After a full school day, the student may be too tired to spend a lot of time on homework.
The student will be permitted an extended school year (during winter, spring, and/or summer breaks) to allow more time to complete assignments and to stay at peer grade level.	As a result of learning difficulties arising from cancer treatment, students may need extra time during school breaks to complete schoolwork.

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How do I get started?

For parents whose children are undergoing cancer treatment or experiencing late effects of treatment, these steps can help you get started.

Step 1:	Talk with your medical team about possible short-term and late effects of treatment.
Step 2:	Work with your medical team to communicate your child's needs to the school staff. If your child needs accommodations to succeed at school, ask for a meeting with a team that may include the principal, teachers, school counselor, school nurse, a treatment team member, and anyone you choose, such as a friend or family member. The team may suggest strategies that can be tried for a period of time (about 4 weeks).
Step 3:	If the strategies are not successful, request in writing that your child be evaluated for either an IEP under IDEA or a Section 504 plan. Members of your treatment team (physician, social worker, or psychologist) can help you write this letter.
Step 4:	In a timely manner, the school must set up and conduct an evaluation of your child. Be sure to keep track of all dates in this process to keep it moving along.
Step 5:	Ask for a meeting to share the results of the evaluation and to develop a plan for accommodations. The law requires that you be informed of all results and recommendations. You must agree to any accommodation before it is put in place. You have the right to a second evaluation.
Step 6:	Watch your child closely to see how the accommodations are working. If different accommodations are needed, talk with the team members to change your child's IEP or Section 504 plan. These plans are "works in progress." As your child's needs and abilities change, the plans can be changed appropriately.

Transitions:
Advocating for the young adult

Your child's transitions throughout his or her school years are critical times for your involvement. One very critical juncture is the transition to postsecondary education and adult life. Transition to adult life could include college; vocational, technical, or adult education; internships; apprenticeships; and employment.

By planning ahead, you can explore options and help gather the support your child needs. For example, your child's high school guidance counselor can help identify colleges with a strong track record of serving the needs of students with disabilities.

Helpful Resource

Developing Your Child's IEP

This guide is available from the National Information Center for Children and Youth With Disabilities (NICHCY).

Call 800-695-0285, or go to www.nichcy.org/parents.asp.

What resources in high school can help with the transition?

Each high school has a Department of Rehabilitative Services (DRS) vocational counselor assigned to help students with disabilities. DRS services can include:

- Career guidance and counseling
- Diagnostic evaluations
- Supported employment and training
- Postsecondary Education Rehabilitation Transition (PERT)

If your child had an IEP or Section 504 plan in high school, he or she may qualify for accomodations for college entrance examinations, such as the Scholastic Aptitude Test (SAT), and for additional accommodations at the postsecondary level. Work closely with the guidance counselor to determine when to apply for accommodations and what documentation is required.

> *Use this transition as an opportunity to explore your child's interests, career goals, hopes, and dreams. There are many possibilities for your child. Do not hesitate to ask for the support your child needs to reach his or her goals.*

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The Leukemia & Lymphoma Society is the world's largest voluntary health organization dedicated to funding blood cancer research, education, and patient services. The Society's mission: Cure leukemia, lymphoma, Hodgkin's disease, and myeloma, and improve the quality of life of patients and their families. The Society provides written materials and videos to help ease the way back to school for children with cancer.

For more information, please contact:

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Founded by cancer survivor and champion cyclist Lance Armstrong, the Lance Armstrong Foundation (LAF) inspires and empowers people affected by cancer. Through advocacy, public health, and research, the LAF helps people with cancer live life on their own terms.

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