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Learning & Living with Cancer

Advocating for your child's educational needs



A Message from Louis J. DeGennaro, PhD

President and CEO of The Leukemia & Lymphoma Society

The Leukemia & Lymphoma Society (LLS) is the world's largest voluntary health organization dedicated to finding cures for blood cancer patients. Our research grants have funded many of today's most promising advances; we are the leading source of free blood cancer information, education and support; and we advocate for blood cancer patients and their families, helping to ensure they have access to quality, affordable and coordinated care.

Since 1954, we have been a driving force behind nearly every treatment breakthrough for blood cancer patients. We have invested more than \$1 billion in research to advance therapies and save lives. Thanks to research and access to better treatments, survival rates for many blood cancer patients have doubled, tripled and even quadrupled.

Yet we are far from done.

Until there is a cure for cancer, we will continue to work hard—to fund new research, to create new patient programs and services, and to share information and resources about blood cancer.

This booklet has information that can help you understand your finances, prepare questions, find answers and resources, and communicate better with members of your healthcare team.

Our vision is that, one day, all people with blood cancers will either be cured or will be able to manage their disease so that they can experience a better quality of life. Today, we hope our expertise, knowledge and resources will make a difference in your journey.



Louis J. DeGennaro, PhD

*President and Chief Executive Office
The Leukemia & Lymphoma Society*

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Introduction

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 treatment. After treatment ends, all children return to school. Because school is a place for learning and fun, children benefit from returning to school as soon as medically possible. Your child may experience both short- and long-term side effects of treatment that can affect his or her education. Talk with members of your child's medical team to learn about the possible effects your child may experience that can impact the school experience. Understanding these potential issues and how they relate to your child will help you and your child's school personnel in planning for a successful school reentry and any long-term supports your child may or may not need to ensure positive educational outcomes.

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 include

- Hair loss
- Mouth or throat sores that can be painful
- Nausea and vomiting
- Diarrhea or constipation
- Neuropathy (numbness, tingling, weakness and pain most often in the hands and feet)
- Anemia
- Fatigue
- Social and emotional concerns, such as anxiety, depression, or fear
- Patients receiving steroid therapy may also experience
 - Weight gain
 - Acne
 - Swelling of the face
 - Mood swings.

Parents should notify their child's teacher when their child is on steroids so that the teacher can understand the intense mood swings and behavioral problems that may occur during this time.

On pages 10 through 13, you will find suggested ways school personnel can help your child manage these effects should they occur and be problematic at school.

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 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. Additionally, stressing normalcy is a critical component in the classroom presentations. Reminding peers that the child with cancer is still a normal child is best accomplished by discussing what the children knew about their classmate before the cancer diagnosis and suggesting that much of what they knew remains the same. Practicing dialogue and brainstorming topics for conversations are especially helpful for classmates who may be feeling anxious about talking with their classmate.

Keep in mind the ages of the children in the classroom. Classroom presentations that are age appropriate are most effective. Here are some ideas to consider and address in the classroom presentation.

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.

During a classroom presentation, keep in mind that some of the children may have a family member or another friend with cancer. While the classroom presentation should be specific and address their classmate's situation, some children in the class may draw their own conclusions from the discussion and then come up with unexpected questions. Thinking through responses to the following examples may help you to respond to these or similar questions.

- My (insert relative) had (insert type of treatment), will (insert name of classmate) receive (insert type of treatment)?

Answer to consider: Doctors make decisions about how to treat each patient with cancer. Some treatments work best with specific kinds of cancer. Right now, we know that (insert name of classmate) will receive (insert type of treatment). His or her doctors may decide to try other treatments as time goes on, but for now (insert name of classmate) will be receiving (insert treatment).

- My (insert relative) died from cancer, will (insert name of classmate) die too?

Answer to consider: I am sorry to hear your (insert relative) died. There are many different kinds of cancer and sometimes people do die from cancer, but many people survive cancer. The doctors and nurses are doing everything they can to help (insert name of classmate) get well.

- What is the worst type of cancer?

Answer to consider: A cancer that is untreated. It is very important to see a doctor when you are not feeling well. The worst type of cancer is a cancer that someone ignored.

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 such as

- 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)
- Neuropathy (numbness, tingling, weakness and pain, most often in the hands or feet).

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

For additional information, please see the free LLS publication *Long-Term and Late Effects of Treatment for Childhood Leukemia and Lymphoma Facts*.

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. Ask the psychologist to explain what typically happens during an evaluation to minimize any fears your child may have about receiving “another test.”

When testing is complete, schedule time for the neuropsychologist to explain the results and make any recommendations for adjustments to be made at school. This type of approach will benefit the child and limit the frustration and struggle due to cognitive late effects. If needed, ask the neuropsychologist to help explain the recommendations to the school staff. Keep in mind that even if the results of the first evaluation are normal, at some point in the future your child may experience cognitive late effects, such as slow processing speed and/or problems with visual memory. At academically challenging times, such as transitions into elementary, middle, or high school or during precollege planning, periodic evaluations may be needed. Ask members of your medical team to suggest a follow-up care program that includes such periodic evaluations.

Some children with lasting effects of their disease and treatment are victims of bullying. Bullying can happen when classmates do not understand why a child is different in some way. In these situations, it helps to have the teacher or guidance counselor talk with the other children in the class and remind them of their classmate’s journey with cancer and to explain the reasons why their classmate may be different. Often, once children understand the unique needs or situation of their classmate, the bullying stops. See *Resources*, on page 16, for more information.

Laws That Help Protect Children Who Have Educational Needs

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

- **The Americans With Disabilities Act (ADA)**
Protects people with disabilities against discrimination in employment, transportation, communication, government and public accommodations. It may be especially useful to students who are seeking employment or going to public colleges or universities.
- **The Individuals With Disabilities Education Act (IDEA)**
Protects students (aged 3-21 years). Ensures that public schools, colleges, and universities provide a free and appropriate education for disabled students, just as they do for other children. Part C of IDEA outlines early intervention services for children (birth to 2 years of age) and their parents.
- **The Rehabilitation Act of 1973 – Section 504**
Requires all educational institutions receiving federal funding to provide accommodations (adaptations) for students with physical or mental impairment, or a record of impairment, that limits one or more major life activities.

Which Law Can Help My Child the Most?

Many childhood cancer survivors qualify for intervention or adaptations under one of these laws. Some children only require assistance during active treatment while others need help years beyond treatment. The table on the facing 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 criterion. 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*

*Adapted with permission from *Our Child Has Cancer: What Do We Do About School?*

by Carla Hart, MEd. To order, call (602) 300-0831.

	Individuals With Disabilities Education Act (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 schools	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 <i>other health impairment</i> which may qualify cancer survivors	All eligible disabilities, including cancer. Disability must <i>substantially limit one or more</i> major life activities.
Safeguards	Parent participation, consent and notification needed	Notice to parent required
Evaluation of eligibility	An evaluation needed	An evaluation needed

Types of Accommodations

The next few pages list examples of accommodations (adaptations) that children with cancer may need. The accommodations are divided into two 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 in the *Resources* section on page 16.

Physical Accommodation	Rationale
The student will be given two sets of books — one for use at home and one for use at school.	The student may miss school often because of hospital stays and feeling poorly. Having an extra set of books at home makes it easier for the student to keep up with assignments, especially when absences are unexpected. Also, children experiencing fatigue need lighter backpacks.
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.

Physical Accommodation

Rationale

The student will not be required to participate in physical education activities that involve contact sports, strenuous exercises and distance running.

Many students return to school with port-a-cath or other central lines in place. They also may be extremely tired from treatment or be at risk for internal bleeding if they suffer from a low platelet count. Strenuous physical activity can tire the student, causing problems with concentration and school performance. For those students with neuropathy in the feet and legs, an exemption from physical activity may be necessary, especially when it requires a lot of running or walking the track.

The student will not be required to participate in the Presidential Youth Fitness Program.

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 five 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 or may need to avoid the inevitable physical contact in a busy school hallway. For those students with neuropathy in the feet and legs, an elevator pass may be needed, if available.

The student will be allowed to have a midmorning and afternoon snack, if needed.

Treatment (especially with steroids) can cause weight loss and increased hunger. A child experiencing weight loss needs snacks to add calories and nutrients to his or her diet.

Physical Accommodation

Rationale

The student will be given a shortened school day or rest period, if needed. Intermittent homebound instruction should be offered to make up classes missed due to the child's inability to attend for a full day.

"Intermittent homebound instruction" is the term used when the child can attend school on some days, but gets instructed at home intermittently on the days when he or she is in clinic, hospitalized or just not feeling well. Fatigue is common, but a rest period and/or shortened school day may make it possible for the student to attend school.

The student will be given a locker close to his or her classes, or two 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 for him or her 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 to avoid fine motor fatigue and to make assignments easier to read.

The student will be provided a desk suitable for his or her body size and frame.

A child's body weight on steroids can fluctuate. The child may feel uncomfortable in the initial desk assigned to him or her and too embarrassed to say anything.

Cognitive Accommodation

Rationale

The student will be given extra time for classwork, homework, quizzes and tests.

During and following chemotherapy and/or radiation treatment, the student may process information and respond more slowly. Students who experience neuropathy in their hands often have difficulty taking notes for long periods.

The student will have a homebound teacher (a licensed teacher, provided by the public school) who comes to the child's home to help with assignments.

The student may miss school often because of hospital stays and feeling poorly. 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 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.

Developed with Alma Morgan, MEd, Educational Consultant, VCU Medical Center, Richmond, VA.

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 develop a strategy 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 (Child Study Team) that may include the principal, teachers, school counselor, school nurse, a treatment team member, and anyone you choose, such as a friend, family member, or advocate. The team may suggest strategies that can be tried for a period of time (about four weeks).

Parents may find that receiving training about the accommodations process may help them understand and be better prepared for next steps. State Parent Training and Information Centers are funded by the US Department of Education, Office of Special Education Programs and are authorized to train parents in these laws. Contact your State Parent Training and Information Center or visit ED.gov.

Step 3. If the strategies are not successful, request in writing that your child be evaluated for either an Individualized Education Plan (IEP) under IDEA or a Section 504 plan (see page 8 and 9 for more information about these plans). A member of your treatment team (the doctor, 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 pay close attention and keep track of all the time it takes for referral, eligibility and development of IEPs, as well as reviews, in order to keep the process moving along. The timelines for these evaluations are specified under federal and state regulation.

Step 5. Ask for a meeting with the Child Study Team 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 should you disagree with the first evaluation results.

Step 6. Watch your child closely to see how the accommodations are working. If different accommodations are needed, talk with the Child Study 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 important times for your involvement. One very critical juncture is the transition to adult life. Transition to adult life could include college; vocational, technical, or adult education; internships; apprenticeships; employment and independent living.

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.

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 Individualized Education Plan (IEP) or Section 504 plan in high school, he or she may qualify for accommodations 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 to obtain accommodations.

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.

LLS Resources

Consult with an Information Specialist. Information Specialists are master's level oncology social workers, nurses and health educators. They provide accurate up-to-date disease, treatment and support information and are available to speak with callers Monday through Friday, 9 a.m. to 6 p.m. ET at (800) 955-4572. You can email infocenter@LLS.org or chat live at www.LLS.org.

Co-Pay Assistance Program. This program offers assistance for financially eligible patients with certain blood cancer diagnoses to help pay for private or public health insurance premiums and/or co-pay costs for prescription medications. Check www.LLS.org/copay or call (877) 557-2672 to speak to a Co-Pay Assistance Program specialist for eligibility information.

Other Helpful Organizations. Our website, www.LLS.org/resourcedirectory, offers an extensive list of resources for patients and families about financial assistance, scholarships, counseling, transportation, summer camps and other needs.

School Reentry. *The Trish Greene Back to School Program for Children With Cancer* is a program designed to increase communication among healthcare professionals, school personnel, parents and patients to assure children with cancer a smooth transition back to school. For more information, visit www.LLS.org/backtoschool.

Telephone/Web Education Programs. LLS provides a number of free, live telephone and web education programs presented by experts for families, parents of children with cancer and healthcare professionals. Visit www.LLS.org/programs for more information.

Resources

ED.gov

(800) 872-5327

The US Department of Education's mission is to promote student achievement and preparation for global competitiveness by fostering educational excellence and ensuring equal access. Information about Parent Training and Information Centers by state can be found through the US Department of Education.

National Dissemination Center for Children with Disabilities

(800) 695-0285 (Toll-free, Voice/TTY)

www.nichcy.org

NICHCY provides information to the nation on disabilities in children and youth; programs and services for infants, children, and youth with disabilities; IDEA, the nation's special education law; and research-based information on effective practices for children with disabilities. You can also find the guide, *Developing Your Child's IEP*.

Stopbullying.gov

StopBullying.gov provides information from various government agencies on what bullying is, what cyberbullying is, who is at risk, and how you can prevent and respond to bullying.

www.wrightslaw.com

Wrightslaw.com is a helpful website for parents, educators, advocates, and attorneys with reliable information about special education law, education law and advocacy for children with disabilities.



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REACH OUT TO OUR **INFORMATION SPECIALISTS**

The Leukemia & Lymphoma Society's (LLS) Information Specialists provide patients, families and healthcare professionals with the latest information on leukemia, lymphoma and myeloma.

Our team consists of master's level oncology social workers, nurses and health educators who are available by phone Monday through Friday, 9 am to 9 pm (ET).

Co-Pay Assistance

LLS's Co-Pay Assistance Program helps blood cancer patients cover the costs of private and public health insurance premiums, including Medicare and Medicaid, and co-pay obligations. Support for this program is based on the availability of funds by disease.

For more information,
call **877.557.2672** or
visit **www.LLS.org/copay**.



For a complete directory of our patient services programs, contact us at

800.955.4572 or **www.LLS.org**

(Callers may request a language interpreter.)

For more information, please
contact our Information Specialists
800.955.4572 (Language interpreters
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Our Mission:

Cure leukemia, lymphoma, Hodgkin's disease and myeloma, and improve the
quality of life of patients and their families.

LLS is a nonprofit organization that relies on the generosity of individual,
foundation and corporate contributions to advance its mission.

