LEUKEMIA &
LYMPHOMA
SOCIETY®

PROVIDING THE LATEST INFORMATION
FOR PATIENTS & CAREGIVERS

Learning & Living with Cancer

Advocating for your child's educational needs

Revised **2020**

A six-word narrative about living with blood cancer from patients in our LLS Community

Stay strong and keep moving forward. Find the positive in every day. Be your own best patient advocate. Changed my life for the better. Accept, learn and focus on present. Learning to live a different life. Sudden and life changing—be positive. Waiting, worrying, anxiousness/happy I'm alive! Embrace a new normal each day. 5 years, 41 infusions, constant fatigue. Patience, positive attitude, hope and faith. Test to test, I will survive! Treatment, fatigue, treatment, fatigue and survival. Love life, live better every day. I don't look back only forward. So far, so good, live life. Meditation, mindfulness, wellness, faith, nutrition and optimism. Finding the joy while living with uncertainty. Watch, wait, treat, regroup, rest, re-energize. Blessed to be doing so well! Eye opening needed learning and healing. Feel great: uncertain travel plans annoying. Renewed faith, meditation, diet, mindfulness, gratitude. Watchful waiting can be watchful worrying. Scary, expensive, grateful, blessings, hope, faith. Thank god for stem cell transplants! Do not know what to expect. Extraordinarily grateful, I love my life. Diagnosed; frightened; tested; treating; waiting; hoping. I'm more generous, impatient less often. Embrace your treatment day after day. Live today, accept tomorrow, forget yesterday. Strength you never realized you had. Challenging to our hearts and minds. Life is what we make it. Live life in a beautiful way.

Discover what thousands already have at **www.LLS.org/Community**

Join our online social network for people who are living with or supporting someone who has a blood cancer. Members will find

- **Thousands of patients and caregivers sharing experiences and information, with support from knowledgeable staff**
- **Accurate and cutting-edge disease updates**
- **The opportunity to participate in surveys that will help improve care.**

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Acknowledgement

The Leukemia & Lymphoma Society appreciates the review of this material by

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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 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 can I go 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. Fortunately, your child's medical team and school personnel will support you in shaping and carrying out your plan. You should know that you are not in alone in this endeavor.

Education Needs While Out of School. While out of school, your child should still be receiving an education. Federal and State law require that if children are out of school due to illness (typically ten school days or more) they must receive hospital/home instruction so they do not fall behind in their academics. Many children's hospitals have part-time or full-time teachers to work with students while they are admitted in the hospital.

In fact, across the United States there are approximately 230 children's hospitals, many of which have educational and medical professionals who work with local school districts to help children with cancer. They can help children receive their education while they are hospitalized and also help with the transition back to school. These programs are often referred to as School Re-entry Teams or Educational Liaison Services. Start by checking with your pediatric oncology social worker to see if your treating center has this type of program. If your center does not have this service, there is a professional organization called *Hospital Educator and Academic Liaison Association (HEAL)* that may be able to help connect you with professionals in the area. See page 22 for more information. You can also contact our Information Specialists at (800) 955-4572.

How this booklet can help you. Whether your treating hospital has an Educational Liaison Program or not, this booklet can help 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

Feedback. Visit www.LLS.org/PublicationFeedback to give suggestions about this booklet.

Returning to School — Addressing the Now and Planning for the Present and Future

Most children with cancer will attend school at least some of the time during their treatment. After treatment ends, children return to school. Because school is a place for learning and socialization, they benefit from returning to school as soon as medically possible.

Your child may experience both short-term and long-term side effects of treatment that can affect his or her education experience. 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 re-entry
- Any long-term support your child may 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 and school nurse when their child is on steroids, so the teacher can understand the intense mood swings and behavioral changes that may occur in the child during this time.

In the rest of this booklet, you will find ways that school personnel can be expected to help your child manage these effects should they occur and be problematic at school.

Classroom Presentations About Cancer – All Ages. The outward signs of illness can be especially hard for children with cancer regardless of age, because of their need to fit in with peers. Classroom presentations about cancer can help peers understand what to expect when the child who has cancer returns. Common 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 age-appropriate, straightforward and reassuring answers to children's questions can help turn anxious classmates into supportive friends. Additionally, focusing on normalcy is a critical component in all classroom presentations. Reminding peers that the child with cancer is still a typical 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. Considerations and suggestions by age group begin on the next page.

Children 5 to 8 years old

- May think that cancer happened because the child or the family did something "bad"
    - Explain that neither the child nor the family did anything wrong.
- May think that they can "catch" cancer
    - Explain that cancer is not contagious (and explain what the word "contagious" means). This helps the children relax and makes it easier for everyone to play together.

Children 9 to 12 years old

- May be able to empathize with the child who has cancer
    - Ask classmates: "What do you think (insert name of classmate) wants? Or "What are some ways we could be a good friend to (insert name of classmate)?" These are great ways to get peers thinking about how they can be supportive.
- 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 who has cancer the same as others
    - For returning adolescents, it may be helpful for teachers, coaches, or the school nurse to meet with the student's sports team, club, or other co-curricular group of students who know the student with cancer well. Helping 10 to 20 close friends better understand what a child with cancer is going through is typically more effective than an all-grade or all school assembly for this age group.

During a classroom presentation, keep in mind that some of the children may have a family member or another friend who has 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 relative had (type of) treatment; will my (insert name of classmate) receive the same?
  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 (type of treatment). His or her doctors may decide to try other treatments as time goes on.

- My (relative) died from cancer; will (insert name of classmate) die too?
  Answer to consider: I am sorry to hear your relative died. There are many different kinds of cancer and sometimes people die, 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 is the worst. 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.

Common School-Related Challenges. When children and adolescents return to school, it is an exciting and scary time. Social dynamics and friend groups can change significantly in a short time and children returning to school are often trying to catch up with the academic, physical, social, and emotional aspects of being back at school. Some common school-related challenges to watch for include:

- Gaps in content knowledge
- Missed academic skills (in reading, writing, and particularly in math)
- Fatigue
- Being more distant socially
- Being overwhelmed and anxious

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 (cognitive means affecting thinking and memory) include problems such as

- Organization of materials—homework assignments may often be misplaced; school materials can be jumbled
- Organization of thoughts—students might experience more difficulty creating clear and accurate sentences in writing or in speech
- Reading decoding and/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:

- 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)
- Seizures

Some behaviors to watch for in children who have cancer include anxiety/depression and risky decision-making by adolescents. There are also psychological late effects, such as posttraumatic stress. The term posttraumatic stress describes a person's response to trauma. If symptoms continue for more than a month and there is difficulty with daily routines, going to school, or doing important tasks, the child may have post-traumatic stress disorder (PTSD). If this is a concern, get help from a mental health professional experienced in treating PTSD.

Parents and teachers will also want to keep an eye on the siblings of their child who has cancer. Siblings can also experience academic, emotional and social issues.

Visit www.LLS.org/FamilyWorkbook to find additional information about long-term and late effects in the chapter, *Beyond Treatment.*

Risk Factors for Late Effects. Not all children who are cancer survivors will develop late effects. Factors that increase the risk for learning problems in school include

- Cancer diagnosis at a very young age (under age 5)
- Cancer treatment involving the central nervous system (the spinal cord and brain)
- Certain types of cancer, such as
  - Acute lymphoblastic leukemia (ALL)
  - Acute myeloid leukemia (AML)
  - Non-Hodgkin lymphoma (NHL)
  - Hodgkin lymphoma (HL)
  - Brain or spinal cord tumors
  - Tumors in the eye, eye socket, head, or facial area
- Brain surgery
- Radiation to the total body or to the head
- 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 who is having difficulty in school should have neuropsychological testing done by a licensed pediatric psychologist or neuropsychologist. A neuropsychological evaluation (or test) is a comprehensive assessment of skills and abilities as they relate to different aspects of brain functioning. Where a traditional psycho-educational evaluation conducted by a school district includes intelligence testing (IQ) and academic skills (reading, writing, and math), a neuropsychological evaluation usually also measures attention, memory, language, visual-spatial skills, cognitive processing, and social-emotional functioning.

Ask your medical team for a referral. A neuropsychological evaluation 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 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 to make any recommendations for adjustments 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 your child’s first evaluation are normal, he or she may still experience cognitive late effects at some point in the future. During 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.

Social and Emotional Effects. 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 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 *Other Resources* on page 22 for more information.

Laws That Help Protect Children Who Have Educational Difficulties

Children affected by cancer treatment may have physical, social/emotional (such as an anxiety disorder) or educational difficulties. The following three federal laws help protect the rights of students with disabilities, including students with educational difficulties resulting from cancer treatment.

- **The Individuals With Disabilities Education Act (IDEA)**
  Protects students (aged 3-21 years). Ensures that public and private schools provide a free and appropriate education for disabled students, just as they do for other children; this also applies to children who are home-schooled. (However, if your child is enrolled in a private school, there may be fewer comprehensive services.) Part C of IDEA outlines early intervention services for children (from birth to age 2) and their parents. IDEA also outlines transition plannning, which coordinates the transition from school to post-school activities (eg, education, employment, etc).
- **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.
- **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.

Which Law Can Help My Child the Most? Many childhood cancer survivors qualify for intervention or adaptations under one of these laws. Some children require assistance only during active treatment, while others may need help for years beyond treatment. The table on the next page (see page 10) compares IDEA and Section 504. With IDEA, most students are eligible under the "other health impairment" category. If a child is eligible for IDEA, the tool used to implement the law is an Individualized Education Plan (IEP). 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 meet one or more of these 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		
	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 *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 needed	Notice to parent required
Evaluation of Eligibility	An evaluation needed	An evaluation needed

Types of Accommodations – Physical, Cognitive and Social/Emotional. The next few pages list examples of accommodations (adaptations) that children may need. The accommodations are divided into three 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

- Social/emotional – those that help students cope with social and emotional effects of cancer to make sure the student feels included

To help you advocate for your child when working with school staff members, the table below 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 *Other Resources* section on page 22.

Types of Accommodations

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 not feeling well. Having an extra set of books at home makes it easier for the student to keep up with assignments, especially when absences are expected. Also, children who experience fatigue need lighter backpacks.
The student will be allowed to carry a water or juice bottle throughout the school day.	Students being treated with chemotherapy or other medicines may need to drink extra fluids to prevent dehydration and dry mouth.
The student will be given bathroom, guidance counselor and clinic passes.	A laminated pass to use when needed allows the student to leave the classroom without drawing attention to himself or herself.
The student will not be required to participate in physical education activities that involve contact sports, strenuous exercises or distance running.	Many students return to school with a port-a-cath or other type of central line in place. They also may be extremely tired from treatment or be at risk for internal bleeding if they suffer from a decreased 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 the activity requires a lot of running or walking.

Physical Accommodation	**Rationale**
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 as most of one's body heat is lost through the head. 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.
The student will be given an elevator pass.	When a student is struggling with neuropathy in the feet, climbing stairs can be very difficult. The elevator pass will allow the student to avoid stairs and the possibility of falling, making it easier to get from class to class.
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.
The student will be given a shortened school day or rest period, if needed. Intermittent homebound instruction should be provided at home on the days when the student is in the clinic, hospitalized or just not feeling well.	"Intermittent homebound instruction" is the term used when the child can attend school on some days, but not all days. The child can make up school classes at home when unable to attend school full-time. 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.

Physical Accommodation	Rationale
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 to his or her body size and frame.	If the child is on steroids, his or her body weight may 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 of the 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 not feeling well. 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 day of school, 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 in order 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.

Cognitive Accommodation	Rationale
The student will be provided oral and written directions, with clarification of understanding.	After chemotherapy and/or radiation, a student may have difficulty with multi-tasking and understanding the multi-step directions that are often provided in the classroom. Providing both oral and written directions, as well as having the teacher clarify directions in a one-on-one setting, will help the student get answers to questions he or she may have.
The student will be given a hard copy of notes, Power Point presentations, and study guides.	When students are assigned computers rather than textbooks and the class notes and study guides are posted on the computer, it can take longer to pull up the individual screens and complete the work, particularly if a student's processing is affected.
The student will be given both assignments and tests in small sections.	When a student is dealing with fatigue, low stamina, or anxiety following treatment, he or she may feel overwhelmed or anxious when taking tests or completing lengthy assignments. Having smaller segments of the assignment or test, and taking one test at a time, helps reduce this anxiety.
The student will take tests and quizzes in a quiet place, free of distractions.	The ability to focus and concentrate is often difficult for students following treatment. Taking tests in the counseling office, library, or other designated quiet place may enable the student to concentrate and focus.
The student will be given a word bank or formula bank when having difficulty with word-retrieval and memory.	Difficulty with word retrieval and short-term memory is often an issue following treatment with chemotherapy and/or radiation.

Social/Emotional Accommodation	Rationale
The student will be assigned a case manager to help keep him or her informed of class and school activities such as Picture Day, field trips, yearbook orders, etc.	With school attendance often interrupted because of medical appointments and not feeling well, the student often misses important notices of upcoming school events. A case manager can keep a student informed, so he or she feels a part of the class and the school.
The student will be assigned a peer buddy when unable to participate in physical education class or recess.	In order to keep the student from feeling left out when unable to participate in physical education class or recess, a "peer buddy" will be assigned so that the student and buddy may play board games, complete art activities, visit the library, or participate in other recreational activities.
The student will be assigned an instructional aide or peer buddy when transitioning between classes.	Due to low stamina, fatigue, neuropathy, and difficulty walking, the student may have trouble transitioning from class to class. An instructional aide or peer buddy can assist with carrying the student's backpack as well as being of service if the student needs other help.
A qualified student may be assigned the role of team manager when unable to participate in school sports.	For the student who has played school sports and is no longer allowed to play due to diagnosis and treatment, he or she may find comfort in being named team manager and thus be able to participate in team events.

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

Process/Steps for Accommodations and Services

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 Child Study Team that may include the principal, teachers, school counselor, school nurse, a treatment team member, and anyone else 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 these centers are authorized to train parents in applicable laws. Contact your State Parent Training and Information Center, the Hospital Educator and Academic Liaison Association, or visit ED.gov. See *Other Resources* on page 22.

Step 3. If the strategies are not successful and your child needs accommodations to succeed in school, make a request in writing that your child be evaluated for either an Individualized Education Plan (IEP) under IDEA or a Section 504 plan (see pages 9-10 for more information about these plans). A member of your treatment team (the doctor, social worker, or psychologist) can help you write this letter. The letter should be given to the school principal and also the Director of Special Education (or the equivalent of that role in the school).

Step 4. Within approximately 60 days, schools are supposed to set up and conduct an evaluation of your child. Be sure to pay close attention and keep track of 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 hear 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. Transitioning to adult life could include planning for 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 as he or she makes decisions for the next phase of life.

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 Law(s) Protect My Child? It is important to know the disability law that has protected your child throughout school will change, regardless of what your child is planning to do after high school. Up until the time your child graduates from high school or turns age 21, The Individuals with Disabilities Education Act (IDEA) protects your child in his or her elementary and secondary school environment. In fact, according to the IDEA, the school district is responsible for the child's educational plan, including transition planning. The Americans with Disabilities Act (ADA) is the governing law once IDEA no longer protects your child. In addition, the burden of responsibility switches from the parents to the individual with the disability. The child (not the parent) must disclose the disability to the post-secondary school or workplace, if he or she wants protections and accommodations under the ADA.

How to Decide What to Do After High School. Deciding what to do after high school is a different decision for each individual family and should be based on a number of factors. Families should consider the following factors as a starting point:

- Academic ability and motivation
- Cognitive functioning
- Family and community support
- Financial goals and responsibilities
- Physical health and stamina
- Social and emotional well-being

There is no one right way to go about this process. However, working closely with the school transition team and the psychosocial team from the treating institution is highly recommended. Working with experts who have dealt with these types of decisions before is very helpful, but in the end, the decisions are up to the individual and the family.

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)

State Vocational Rehabilitation Agencies. Every state has a vocational rehabilitation agency to help individuals with disabilities meet their employment goals. Vocational rehabilitation agencies assist individuals with disabilities to prepare for, obtain, maintain, or regain employment. The Job Accommodation Network (JAN) provides a list of state agencies. Visit https://askjan.org/concerns/State-Vocational-Rehabilitation-Agencies.cfm to find your local agency.

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 to find out what documentation is required to obtain accommodations. Some accommodations for testing include extended test time and extra or extended breaks.

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.

Resources and Information

LLS offers free information and services to patients and families affected by blood cancers. This section lists various resources available to you. Use this information to learn more, to ask questions, and to make the most of the knowledge and skills of the members of your healthcare team.

For Help and Information

Consult With an Information Specialist. Information Specialists are master's level oncology social workers, nurses and health educators. They offer up-to-date disease and treatment information. Language services are available. For more information, please

- Call: (800) 955-4572 (Monday through Friday, 9 am to 9 pm EST)
- Email: infocenter@LLS.org
- Live chat: www.LLS.org/InformationSpecialists
- Visit: www.LLS.org/InformationSpecialists

Clinical Trials Support Center (CTSC). Research is ongoing to develop new treatment options for patients. LLS offers help for patients and caregivers in understanding, identifying and accessing clinical trials. When appropriate, patients and caregivers can work with Clinical Trial Nurse Navigators who will help find clinical trials and personally assist them throughout the entire clinical trial process. Please visit www.LLS.org/CTSC for more information.

Free Information Booklets. LLS offers free education and support booklets that can be either read online or ordered. Please visit www.LLS.org/booklets for more information.

Telephone/Web Education Programs. LLS offers free telephone/Web and video education programs for patients, caregivers and healthcare professionals. Please visit www.LLS.org/programs for more information.

Financial Assistance. LLS offers financial assistance to individuals with blood cancer. Please visit www.LLS.org/finances for more information.

Co-Pay Assistance Program. LLS offers insurance premium and medication co-pay assistance for eligible patients. For more information, please

- Call: (877) 557-2672
- Visit: www.LLS.org/copay

LLS Health Manager™ App. This free mobile app helps you manage your health by tracking side effects, medication, food and hydration, questions for your doctor, and more. Export the information you've tracked in a calendar format and share it with your doctor. You can also set up reminders to take medications, hydrate, and eat. Please visit www.LLS.org/HealthManager to download for free.

One-on One Nutrition Consultations. Access free one-on-one nutrition consultations with a registered dietitian who has experience in oncology nutrition. Dietitians assist callers with information about healthy eating strategies, side effect management, and survivorship nutrition. They also provide additional nutrition resources. Please visit www.LLS.org/nutrition to schedule a consultation or for more information.

Podcast. The *Bloodline with LLS* is here to remind you that after a diagnosis comes hope. Listen in as patients, caregivers, advocates, doctors and other healthcare professionals discuss diagnosis, treatment options, quality-of-life concerns, treatment side effects, doctor-patient communication and other important survivorship topics. Please visit www.LLS.org/TheBloodline for more information and to subscribe.

Suggested Reading. LLS provides a list of selected books recommended for patients, caregivers, children and teens. Please visit www.LLS.org/SuggestedReading to find out more.

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.

Continuing Education. LLS offers free continuing education programs for healthcare professionals including *Staying Connected: Facilitating the Learning Experience During and After Cancer Treatment*. Please visit www.LLS.org/ProfessionalEd for more information.

Community Resources and Networking

LLS Community. The one-stop virtual meeting place for talking with other patients and receiving the latest blood cancer resources and information. Share your experiences with other patients and caregivers and get personalized support from trained LLS staff. Please visit www.LLS.org/community to join.

Weekly Online Chats. Moderated online chats can provide support and help cancer patients to reach out and share information. Please visit www.LLS.org/chat to join.

LLS Chapters. LLS offers community support and services in the United States and Canada including the *Patti Robinson Kaufmann First Connection Program* (a peer-to-peer support program), in-person support groups, and other great resources. For more information about these programs or to contact your chapter, please

- Call: (800) 955-4572
- Visit: www.LLS.org/ChapterFind

Other Helpful Organizations. LLS offers an extensive list of resources for patients and families. There are resources that provide help with financial assistance, counseling, transportation, patient care and other needs. For more information, please visit www.LLS.org/ResourceDirectory to obtain our directory.

Advocacy. The LLS Office of Public Policy (OPP) engages volunteers in advocating for policies and laws that encourage the development of new treatments and improve access to quality medical care. For more information, please

- Call: (800) 955-4572
- Visit: www.LLS.org/advocacy

Additional Help for Specific Populations

Información en español (LLS information in Spanish). Please visit www.LLS.org/espanol for more information.

Language Services. Let members of your healthcare team know if you need a language interpreter or other assistance, such as a sign language interpreter. Often, these services are free.

People Suffering from Depression. Treating depression has benefits for cancer patients. Seek medical advice if your mood does not improve over time—for example, if you feel depressed every day for a 2-week period. For more information, please

- Call: The National Institute of Mental Health (NIMH) at (866) 615-6464
- Visit: NIMH at www.nimh.nih.gov. Enter “depression” in the search box

Other 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.

Center for Parent Information & Resources
www.ParentCenterHub.org
(973) 642-8100
Center for Parent Information & Resources provides family-friendly information and research-based materials on key topics such as disability laws, IDEA and more; where to find your State Parent Training and Information Center; private workspaces for parents to exchange resources, discuss high-priority topics and solve mutual challenges; coordination of parent training efforts throughout the network; a twice-monthly e-newsletter, and more.

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.

Hospital Educator and Academic Liaison Association (HEAL)
https://www.HealAssociation.org/
HEAL's vision is a world where students with medical and mental health needs are embraced and supported to help them reach their full potential. HEAL's mission is to support and connect professionals who work to improve the educational outcomes for students with medical and mental health needs.

Understood.org
This organization focuses on making a real, positive impact in the lives of people who learn and think differently by offering tools, support, and community. Some of its resources and goals include empowering your child, partnering with your child's school and your child's rights, explaining evaluations (including information with video on IEP and 504 plans), and offering live chat experts who discuss different topics.

NOTES

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LEUKEMIA &
LYMPHOMA
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Get support.
Reach out to our
INFORMATION SPECIALISTS

The Leukemia & Lymphoma Society team consists of master's level oncology social workers, nurses and health educators who are available by phone Monday through Friday, 9 a.m. to 9 p.m. (ET).

- Get one-on-one personalized support and information about blood cancers
- Know the questions to ask your doctor
- Discuss financial resources
- Receive individual clinical-trial searches

Contact us at
800-955-4572 or
www.LLS.org/informationspecialists
(Language interpreters can be requested)

LEUKEMIA &
LYMPHOMA
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For more information, please contact our Information Specialists **800.955.4572** (Language interpreters available upon request).

**BEATING
CANCER
IS IN
OUR BLOOD.**

National Office 3 International Drive, Suite 200 Rye Brook, NY 10573

The mission of The Leukemia & Lymphoma Society (LLS) is to cure leukemia, lymphoma, Hodgkin's disease and myeloma, and improve the quality of life of patients and their families. Find out more at **www.LLS.org**.

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