

# A School's Guide For Children With Cancer

2024 Edition



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This publication is designed to provide accurate and authoritative information about the subject matter covered. It is distributed as a public service by The Leukemia & Lymphoma Society (LLS), with the understanding that LLS is not engaged in rendering medical or other professional services. LLS carefully reviews content for accuracy and confirms that all diagnostic and therapeutic options are presented in a fair and balanced manner without particular bias to any one option.

# Introduction

In the past 30 years, advances in the treatment of childhood cancer have greatly increased the number of pediatric and adolescent patients who are surviving their illness and entering adulthood. If diagnosed today, 85% of children with cancer survive 5 years or more.

**In previous decades, the main goal of childhood cancer treatment was curing the disease. Now the emphasis is on survivorship and quality of life.**

This shift in attitude and expectation makes it critical for the family, school and larger community to assist young people with cancer in maintaining continued involvement in normal life activities.

Most children with cancer will have to balance attending school while undergoing intensive medical treatments. These children can easily fall behind in their academic pursuits due to absences and/or fatigue. The child or teen may experience visible side effects caused by the illness or treatments, such as hair loss, weight gain or surgical disfigurement. The child or teen may also experience **invisible** side effects from treatment: physical pain, changes in social interaction, memory or cognition difficulties, and emotional/psychological symptoms (mental pain and/or fatigue, anger, depression, worry about the risk of cancer's relapse, stress, and anxiety). Often these changes are temporary. However, there are also side effects that can surface years later that impede learning and social integration.

For children and adolescents, school provides the opportunity to master social skills and the educational competence necessary to actively contribute to society. Partnerships between the school, the hospital and the family will ensure children who have faced cancer receive an education that will prepare them to be productive and well-adjusted adults.

**MYRA**  
Leukemia survivor



▶ Throughout this book, there will be references to **Staying Connected®: Facilitating the Learning Experience During & After Cancer Treatment**, an online course with video modules created by The Leukemia & Lymphoma Society for professionals to learn more about children who have been diagnosed with cancer and their return to school. Please use the **Staying Connected®** program for examples, explanations and additional information to supplement the content found in this book.

# What You Should Know About Childhood Cancer



## What is Cancer?

The human body is made up of trillions of cells. Normally these cells grow and multiply in an orderly fashion, but every so often something goes wrong. Cancer is the process in which abnormal or damaged cells grow and reproduce in an uncontrolled manner. These cells form tumors, which are masses of tissue.

Cancer is classified as either solid tumor cancer or blood (liquid) cancer. Solid tumors are cancers of body organs or tissues (such as the breast or lung) and create a single mass or many masses. At its earliest stages, solid tumor cancer cells grow in their original, or primary site, when the disease is most treatable. If the cancer is left unchecked, it will invade surrounding tissue and organs (metastasize), spreading by way of the bloodstream or lymph channels.

Blood cancers are cancers of the blood cells (such as leukemia or lymphoma) which circulate throughout the body via the bloodstream. Blood cancers start in the blood, bone marrow or lymphatic system and crowd out healthy cells.

Children tend to get cancers of developing organ systems such as the blood, nervous system and bones. As a group, children respond much better to treatment than adults. In the United States, more than 15,000 new cases of cancer are diagnosed each year in children between birth and 19 years of age. Average survival rates for childhood cancers are about 85%, with some cancers having an even better outcome. Some types of cancer, even when first diagnosed at an advanced disease state, can be curable.


## How do Children Get Cancer?

Cancer is caused by changes to genes that control the way cells function. Cancer can happen due to:

- Errors that occur as cells divide
- Damage to the DNA of cells caused by harmful substances in the environment (such as chemicals in tobacco smoke or ultraviolet rays from the sun)
- Genetic changes inherited from parents

Lifestyle factors, such as being overweight or having an unhealthy diet, are not thought to play a major role in childhood cancers, as lifestyle factors take many years to influence cancer risk.

## What Types of Cancer Affect Children?

 Visit [www.LLS.org/booklets](http://www.LLS.org/booklets) to read additional information about leukemia and lymphoma. Visit [www.cancer.org](http://www.cancer.org) for more information about solid tumor cancers.

**Leukemia.** Leukemia is a blood cancer that starts in blood-forming tissue, such as the bone marrow. Leukemia causes large numbers of abnormal blood cells (most often white blood cells) to be produced and enter the bloodstream. These abnormal cells accumulate in the bone marrow and blood stream and crowd out the normal cells causing them to not function properly.

There are several types of leukemia. Two of the most common types in children are acute lymphoblastic leukemia (ALL) and acute myeloid

leukemia (AML). Acute lymphoblastic leukemia is the leukemia in which hematologists-oncologists (doctors specializing in blood diseases and cancer) can achieve the highest remission and cure rates.

The primary treatment for leukemia is chemotherapy. Treatment may also include radiation, stem cell transplant, targeted therapy, immunotherapy and chimeric antigen receptor (CAR) T-cell therapy.

**Lymphoma.** Lymphoma is a blood cancer that starts in the lymphatic system (made up of the lymph nodes, spleen, thymus gland and bone marrow), the body's disease-fighting network. The two main types are Hodgkin lymphoma and non-Hodgkin lymphoma. Hodgkin and non-Hodgkin lymphoma both have subtypes. PTLN (post-transplant lymphoproliferative disorder) is a lymphoma-like disease found in patients after organ transplant and subsequent immunosuppression and can also be diagnosed in children and adolescents.

Non-Hodgkin lymphoma is more common in younger children, and Hodgkin lymphoma is more common in older children, teens and young adults. Currently, Hodgkin lymphoma represents one of the most curable cancers, with 5-year survival rates approaching more than 90%.

Treatment for lymphoma may include chemotherapy, radiation, stem cell transplant, targeted therapy, immunotherapy and chimeric antigen receptor (CAR) T-cell therapy.

**Brain Tumors and Other Cancers of the Central Nervous System.** Brain and spinal cord cancers are the most common solid tumors found in children under the age of 15. Some tumors are benign (non-cancerous), but the malignant (cancerous) types frequently seen in children are medulloblastoma and astrocytoma.

Medulloblastoma starts in the part of the brain (the cerebellum) that affects muscle coordination, balance and movement. Astrocytoma is formed by astrocytes, star-shaped cells that support the nerves in the brain and can cause growing pressure inside the skull.

Treatment for these types of cancer may include surgery, radiation therapy, chemotherapy, targeted therapy, steroids, immunotherapy and stem cell transplant. Supportive care is used to assist with side effects and rehabilitation is used to regain motor skills and muscle strength.

**Neuroblastoma.** Neuroblastoma is a rare cancer that develops in immature nerve cells and occurs most often in infants and children under age 5. It is often found in the adrenal glands but can also develop in the spinal cord, abdomen, chest, bones, or neck.

Treatment for neuroblastoma is highly variable based on staging. There are some forms in infancy which can resolve on their own without any treatment and are just followed with surveillance. Other forms may necessitate surgical removal only, while still others may need chemotherapy, radiation, immunotherapy, and even autologous stem cell transplant(s).

**Sarcomas.** Sarcoma is a rare type of cancer that begins in bone or in the soft tissues of the body, including cartilage, fat, muscle, blood vessels, fibrous tissue or other connective or supportive tissue. There are more than 70 subtypes of sarcoma.

Osteosarcoma is the most common primary bone tumor found in children, often occurring in adolescence, and affecting the fast-growing long bones of the legs or arms. Ewing sarcoma is the second most common tumor of the bone. It can develop in any bone in the body, but is most commonly found in the pelvis, ribs, and long bones of the arms and legs. Treatment may include surgery, radiation, chemotherapy, targeted therapy and immunotherapy.

Other sarcomas include soft tissue sarcomas like rhabdomyosarcoma, synovial sarcoma and others. These tumors originate from the supporting structures of the body, such as muscle, cartilage, ligaments and tendons. The soft tissue sarcoma most commonly seen in children is called rhabdomyosarcoma, which affects muscle tissue. About half of the cases occur in the head and neck, less often in the urinary and reproductive organs and the limbs. Treatment options vary based on the type of sarcoma; it may include surgery, chemotherapy, radiation, targeted therapy, immunotherapy, and in specific circumstances, autologous stem cell transplant.

**Wilms Tumor.** A rapidly developing cancer of the kidney, Wilms tumor is most commonly diagnosed in children from two to four years

of age. The prognosis for children with Wilms tumor is excellent due to effective new therapies. Treatment may include surgery, chemotherapy and radiation.

**Retinoblastoma.** Retinoblastoma is a rare type of eye cancer that develops typically before the age of 5. It is a tumor of the membrane at the back of the eye, called the retina. This cancer may be inherited or arise spontaneously. If detected early, it can be cured, and vision can be preserved. Treatment may include cryotherapy (the use of extreme cold to destroy abnormal tissue), thermotherapy (the use of heat to destroy cancer cells), chemotherapy, stem cell transplant, radiation, surgery and targeted therapy.

**Hepatoblastoma.** Hepatoblastoma is a rare malignant tumor that develops from the cells of the liver and is most often seen in children under three years old. Not all patients who develop hepatoblastoma have risk factors, but some children with certain genetic syndromes are at an increased risk for this disease and are thus monitored until age 4. Treatment for this type of cancer includes surgical resection (removal of liver in-part or whole, which, in some cases may necessitate liver transplant), and can also include chemotherapy, and radiation therapy.

**Germ Cell Tumors.** Germ cell tumors arise from reproductive cells and most often include testicular and ovarian cancers. These tumors can be either malignant or benign, and typically occur in the testicles or ovaries themselves, but can also arise in other locations such as the brain, chest or abdomen. Treatment most often includes surgical removal of the tumor and may also include chemotherapy and/or radiation therapy.

## Where do Children with Cancer Get Treated?

Since children and adolescents have unique physical and emotional needs compared to adults, the best place for children to get treatment for cancer is at a major medical center that has a specialized program for young people with cancer. Many times, this is at a regional children's hospital. It's at these tertiary facilities that young people have access to the newest treatment innovations as soon as they are available.

Treatment of childhood cancers requires the combined efforts of a multidisciplinary healthcare team, comprised of doctors, nurses, social workers, psychologists, psychiatrists, child life specialists, teachers, laboratory staff and other specialists. All of these specialists are necessary to ensure that young people with cancer receive the comprehensive care they need to continue normal life activities, like attending school.

**Once treatment has been completed, children will continue lifelong follow up appointments with their oncology team to address any concerns with their physical and psychological wellbeing as they continue to grow.**

## What are the Phases of Cancer Treatment?

Cancer treatment generally moves through different phases, depending on how extensive the disease is and how the child is responding to treatment. Certain phases involve more intensive medical treatments. Children will receive a treatment protocol which is commonly referred to as a “road map” because it helps everyone keep track of all the complex components of treatment. Knowledge of the “road map” can help a teacher prepare for upcoming medical events that may

affect school attendance and/or participation. Parents and healthcare team members can help teachers and school support staff (school nurse, administration, office staff, school psychologist) understand these treatment schedules.

**With the success of new treatments, most children’s cancer journey will result in living a long, healthy life.**

1. **Diagnosis** may have been brief or drawn out, and is marked by intense anxiety, pain and grieving. Many medical tests and procedures may be needed to establish the diagnosis.
2. **Induction/Start of Treatment** is a very busy and stressful period of time as children and families must cope with frequent medical appointments as well as complicated and intense treatment protocols. They must also incorporate the new demands of their child’s illness and treatment into family life

and come to terms with their “new normal.” The goal of induction therapy is to “induce,” or encourage, remission or a state where there is no evidence of disease (NED).

3. **Post-Remission or Consolidation Therapy** is continued treatment even if a remission is attained because many cancers can reoccur. Most children will respond favorably to treatment and will attain a period of illness plateau or the complete absence of detectable cancer.
4. **Maintenance Treatment** is usually not as intense as the initial treatment period. A child with acute lymphoblastic leukemia, for example, will typically have maintenance therapy consisting of lower doses spread out over a longer period of time (about 2 years).
5. **Completion of Treatment** is reached when the healthcare team is comfortable the child is in a long-term remission and has received adequate treatment. Depending on the type of cancer and how widespread it was at the time of diagnosis, treatment may be over a period of months or may need to continue over several years.
6. **Long-Term Survivor** is a person who has survived 5 years in a disease-free condition after the completion of therapy. This person is considered cured. Every year after completing therapy that a person survives disease-free, their chance of long-term survival increases dramatically. Long-term survivors require life-long health surveillance by their oncology team and primary doctor to monitor for late side effects, relapse and secondary cancers due to their cancer treatment.



7. **Relapse/Disease Progression** is the return of the disease. Some children who have had an initially favorable response to treatment may have a relapse and will need to have additional treatment. Even after a relapse, a child can be cured of their disease, but their chances for long-term survival decrease. Sometimes, a child's disease may have been controlled for a long period of time, but it was never eliminated completely. For reasons yet unknown, cancer cells can become resistant to once-effective therapy and start to grow once again. If conventional treatments are no longer helpful for a child, the family and healthcare team may decide to seek alternative treatments including a clinical trial. See *Clinical Trials* on page 8.

8. **Terminal Illness/Death** generally refers to a child who is in the final few months-weeks of life. Focus of care for the patient shifts to emphasis on enhancing quality of life. Early engagement of palliative care and/or hospice services can be beneficial in helping the patient be as comfortable and pain free as possible.

When death is imminent, social support, family, friends, and school experiences continue to be very important to most children. In general, a child will deteriorate gradually over time, and may still be able to attend school or participate in school-sponsored activities periodically.



**LOXLEY**  
Leukemia survivor,  
with his mother

▶ For more information, see *Coping with a Medical Crisis or Declining Health* on page 26 and visit [www.LLS.org/EndOfLife](http://www.LLS.org/EndOfLife) to read more about end-of-life care.

## What are the Common Treatments?

▶ For additional information about treatments and common procedures, see page 59.

- **Chemotherapy** is the use of potent drugs or chemicals, often in various combinations, to kill or damage cancer cells in the body.

**During and after chemotherapy, children will have lower resistance to normal childhood illnesses than other children. This is called being immunocompromised. Even if they received vaccines prior to diagnosis, they should not be exposed to any communicable illnesses, including chicken pox, shingles, COVID, flu, etc.**

**Inform the child's parent and the school nurse if any child in your class develops a communicable illness so they and the child's doctors can decide how to best handle the situation. Encourage all students to wash their hands frequently, stay home if feeling sick, and get fully vaccinated.**

- **Chimeric antigen receptor (CAR) T-cell therapy** involves engineering a patient's own immune cells to recognize and attack cancer cells.
- **Clinical trials** are carefully controlled research studies conducted by doctors to improve the care and treatment of people

who have cancer. In the United States, the FDA requires all new drugs and other treatments be tested in clinical trials before they can be used on the general public. At any given time, there are thousands of cancer clinical trials taking place. Doctors and researchers are always looking for new and better ways to treat cancer.

- **Immunotherapy** is the use of substances to stimulate or suppress one's own immune system to help the body fight cancer.
- **Radiation** is the use of high energy x-rays or other types of radiation to kill cancer cells.
- **Stem cell transplantation**, also referred to as bone marrow transplantation, is a procedure in which the patient receives healthy stem cells to replace damaged stem cells. Transplant is an intensive treatment approach for children with resistant types of cancer that do not respond to chemotherapy alone.
- **Surgery** is a procedure to remove or repair a part of the body or to find out whether disease is present.
- **Targeted therapy** is the administration of drugs or substances that block the growth and spread of cancer by interfering with specific molecules such as enzymes and proteins. Targeted therapy generally causes less harm to normal cells than other treatments like chemotherapy or radiation and may have fewer side effects.

▶ Visit [www.LLS.org/ClinicalTrials](http://www.LLS.org/ClinicalTrials) for more information about clinical trials.

▶ See [www.LLS.org/StayingConnected](http://www.LLS.org/StayingConnected) to see the module on *Treatment and Side Effects of Childhood, Adolescent, and Young Adult (AYA) Cancers*.

# The Emotional Impact of Childhood Cancer



**JELIEN**  
Leukemia  
survivor

## How Does Cancer Impact the Child?

The diagnosis of cancer in a child or teenager can be a frightening experience. Adjusting to the reality of a life-threatening illness is difficult for the child and family.

The developmental level of the child will influence their ability to comprehend the nature of their illness and treatment. Young children are focused on the immediate worries of pain and discomfort, along with the anxiety of being separated from parents and familiar surroundings during hospitalizations.

Older children are better able to comprehend the serious nature of their disease and may feel isolated and alone if they are unable to participate in their usual activities, such as school. For teens, the fear of dying may be very strong. The physical changes in appearance brought on by their illness and treatment can be extremely distressing to any child struggling to fit into their peer group. Kids of all ages are very sensitive to the reactions and behaviors of family and friends and need the opportunity to feel as “normal” as possible.

## How Does Cancer Affect Family Members?

Parents will usually go through a “roller coaster” of emotions as they adjust to the reality of their child’s illness. Parents typically experience various stages of grief including shock, denial, anger, despair and eventually acceptance; they may find their feelings alternating from moment to moment. Parents must make critical decisions about their child’s care. They often feel anxious about their choices and uncertain about what the future holds. Parents may feel some relief and sense of regaining some control of the situation once a plan is in place and treatment starts.

Juggling the needs of a child affected by cancer with the needs of siblings, self and spouse can exert tremendous pressures. Extended family and friends can be very supportive and helpful but can also add stress through well-intended advice.

Many parents experience loneliness and isolation when friends stop including them in regular activities due to scheduling problems or discomfort over talking about the child with cancer.

Siblings are often and unintentionally overlooked with all of the commotion and treatment-related demands surrounding their ill brother or sister. Relevant school staff are encouraged to create a confidential, safe, space for check-ins with the siblings to assess how they are coping and offer support. The emotional needs of the siblings are just as important as those of the patient; when possible, school staff is encouraged to help families keep the siblings involved in their normal educational and extracurricular activities. Depending on their age & developmental level, siblings can be encouraged to visit the hospital and participate in the child’s care. It is common for siblings to experience a range of emotions, from jealousy and anger at the special attention



**ELIOT**  
Lymphoma survivor,  
with his mother



**HUDSON**  
Leukemia survivor,  
with his sister

the ill child receives, to fears they will also get sick, or worries their sibling may die. Even though parents and family members may be preoccupied with the child affected by cancer, siblings must be encouraged to feel connected and important.

▶ Visit [www.LLS.org/StayingConnected](http://www.LLS.org/StayingConnected) for additional resources from **Staying Connected**®.

There are resources specifically designed for children and adolescents who have a sibling with cancer. These interactive web sites, cancer camps and hospital-based activities provide an outlet for the sibling to express their emotions in a safe and supportive environment.

Invariably families coping with childhood cancer are impacted financially and experience employment changes and challenges.

Visit [www.LLS.org/booklets](http://www.LLS.org/booklets) to share helpful publications with parents such as:

- *Cancer and Your Finances*
- *The Caregiver Workbook*
- *Navigating Life During and After a Blood Cancer Diagnosis: A Workbook for Parents, Children and Adolescents*
- *Each New Day – Ideas for Coping with Blood Cancers*
- *Managing Stress*

▶ See also the **Staying Connected**® module *Psychosocial Concerns of a Cancer Diagnosis in Children, Adolescents, and Young Adults (AYA)* at [www.LLS.org/StayingConnected](http://www.LLS.org/StayingConnected)

## How Does Cancer Affect Peers and Classmates?

The acceptance and support of classmates and the wider school community is critical to the successful school reintegration of a young person with cancer. The child may feel very self-conscious and be hurt by unkind comments and

behaviors, like teasing and name-calling. Many times these behaviors can be avoided if peers are informed of what the person with cancer is going through ahead of time.


Kids who are undergoing cancer treatment may look and feel differently compared to their peers. Healthy classmates and their parents may be nervous about having a seriously ill child in the class unless they are provided with accurate and sensitive information about the illness and treatment.

Classmates may find it hard to figure out ways to be supportive. Suggestions such as sharing homework assignments when the child with cancer is absent, or inviting the child to play with them during recess can help.

**Peers and classmates need to know that cancer is a treatable disease, it is NOT contagious, and that we are hopeful their friend will do well and be cured.**

Here are some ideas for teachers to help classmates stay connected to the child with cancer from **How to Support a Student with Leukemia** by The Leukemia & Lymphoma Society of Canada:

- Arrange a video call or an in-person visit.
- Schedule periodic “Mystery Calls” where a different classmate calls the student-patient each week (at a prescheduled time) and the student-patient has to guess who the caller is.
- Record video or audio messages and send them to the student.
- Make cards, drawings, banners, etc. to give to the student.
- Encourage classmates to send text messages, emails and letters to the student.
- Place a bag on the student’s desk so classmates can put notes and messages in it whenever they want; give the notes to the student.
- Organize a childhood cancer awareness campaign at school.

 Visit [www.LLS.org/StayingConnected](http://www.LLS.org/StayingConnected) to watch a sample classroom presentation on how to talk to children about their classmate with cancer. We encourage you to provide this presentation in person by partnering with members of the child’s healthcare team or your school nurse.

## What are the Implications of How Teachers and Staff React?

Teachers and school personnel are subject to the same myths and misconceptions about cancer as the rest of society. They may not realize children can get cancer, or that the different types of childhood cancer may have more favorable outcomes than cancer in adults. Teachers may wonder if a child with cancer is capable of being in school or may inadvertently treat the child as “fragile”, adding to the child’s sense of being different.

When a teacher has a personal experience with cancer it is not unusual for them to project thoughts, feelings, and even their own fears onto the child affected by cancer. Before a teacher can help support a child’s return to school, they need to understand their own personal bias and reactions to cancer and become educated about the facts.

# Preparation for Return to School



**CAYDEN**  
Leukemia survivor,  
with his mother

## Communication, Partnership, and Flexibility

Once a child has been given the go-ahead by their healthcare team to return to school, it is crucial the child's re-entry be as smooth as possible. Based on their pre-illness experience, some children will be very eager to go back, while others may not want to be separated from their parents or support system. Similarly, some parents may also be nervous about allowing their child to return to a "non-clinical" setting such as school; they may worry the school staff will not know how to keep their child safe. The resumption of school, however, is an activity that signals to everyone the child's life is moving forward.

One of the first challenges to face when a child is diagnosed with cancer is how to form a partnership between the hospital, school and family. Through a coordinated effort by a multidisciplinary school support team, the child has a greater chance of maintaining the social and academic skills necessary to successfully return to school life.

Unfortunately, schools and hospitals are both very complex systems, each involving many different professionals, perspectives, and protocols. It can be daunting for parents, students and school staff alike, as they try to make their way through this unfamiliar terrain.

The most effective way to achieve this partnership goal is by having someone take the lead and serve as the school liaison for the child. This individual will facilitate communication regarding school and medical needs between the child, family and medical team.


A young person's needs are typically best met when **their parents assume the primary role in monitoring their child's school experience and serve as their advocate.** Many parents feel comfortable assuming this role, especially those who have already established relationships with their child's teachers and have mastered the intricacies of their child's illness and treatment. For those parents who do not speak English, or who may not feel comfortable communicating with doctors and school personnel, a school professional (such as the school nurse or counselor) or a hospital professional (such as a social worker, psychologist, nurse or school intervention specialist) can assist. **Many times, the best school professional for this role is the school nurse.** Your school nurse is a professional versed in both the intricacies of the medical and educational worlds and can "speak both languages" allowing them to help bridge the gap between the hospital and school, ensuring a safe and productive return to school.

**Medical emergencies rarely happen at school. If the child is going back to school, that generally means the doctors and parents feel it is safe and appropriate for the child to be there. Upon the return to school, it is always a good policy to create a health plan with prearranged protocols so the school staff knows when to call parents if the child isn't feeling well. Please speak to your school nurse for more details and see page 39.**

## The Teacher's Role in Helping Children with Cancer

If you have a child in your class who has cancer, you don't need to become an "expert" about cancer or its treatment. But, by being well informed about your student's illness and treatment protocols, you will find it easier and less stressful to help them succeed and continue with their school program.

Beginning at the time of diagnosis, it is important to establish open lines of communication between the school, the child, the parents, and the healthcare team. Questions may surface for you or other children in the class that may need to be addressed. A teacher's support and encouragement will reinforce the child's ability and desire to continue participating in school during this very difficult time of life.

 See *Parent and Survivor Stories* on page 32 to read a note from David, the father of a child with cancer and a school nurse.




## Multidisciplinary School Conferences

School conferences include members from a multidisciplinary team consisting of parents or guardians, an oncology healthcare team member, and key school staff (classroom teacher(s) including physical education teacher, school nurse, administration, counselor, school psychologist, special education representative, and office staff likely to interact with the child) working together. This team is comprised of relevant staff that can offer their unique perspectives when developing a plan.

The multidisciplinary team is essential to discuss a child's condition and invaluable in helping to minimize the difficulties of re-integration and to maximize the student's safety and success. Such conferences are informative, reassuring, and allow for the development of good communication, planning and cooperation between all those who care for the child.

In preparation for the conference, the school liaison should assess teacher concerns to gauge their level of knowledge and their emotional reactions to the material being discussed.

 Visit [www.LLS.org/StayingConnected](http://www.LLS.org/StayingConnected) to watch a panel discussion for practical tips on transitioning your student back to school from *Staying Connected®: Facilitating the Learning Experience During & After Cancer Treatment*.

## The Major Components of Conferences Include:

- A presentation of the child's illness and treatment, including specifics about scheduling of appointments and an estimated timeframe for treatments, treatment side effects and prognosis. The material should be presented in a manner and language easily understood by all team members.
- Discussion on how information about the child affected by cancer will be disseminated to school personnel who may not attend the conference. Keep privacy rules and the parent/child's comfort levels in mind.
- Distribution and discussion of up-to-date printed materials on childhood cancer.
- Identification of any current special academic, medical, or social needs and planning for interventions. For example, student may benefit from special education services or accommodations under Section 504 and the team may need to start the discussion soon.
- Discussion and development of an individualized emergency health plan or putting emergency protocols in place. Speak to your school nurse for more information.
- Consideration of the child's long-term school needs and establishment of a follow-up plan to ensure progress.
- Any unique or specific concerns the parents/student or staff members have about reintegrating back into school.
- Deciding on what (and how) information will be shared with student-patient's classmates and their parents.

## Checklist: Information Teachers Need from Parents

- ☑ **Materials from the Child’s Medical Team and Parents Regarding the Child’s Illness and Treatment.** These materials should include basic information on diagnosis and treatments along with possible physical and emotional side effects that may be anticipated. (See *Back in the Classroom* on page 17 and the sample *Return to School Guide for Pediatric Oncology Patients* on page 39.)
- ☑ **Emergency Phone Numbers.** This should include family and medical emergency numbers, including the primary healthcare team. You can list the numbers on the form on page 49.
- ☑ **Instructions on How to Handle Specific Medical Conditions.** For example: Medications to be given at school must be in the original prescription bottle (labeled with directions on how they should be administered), notes to physical education teachers, care of catheters, and precautions as to the danger of the child being exposed to infectious diseases such as chicken pox, shingles, COVID, and influenza. Note, this information is typically included in a health plan written by your school nurse.
- ☑ **Practical Information.** Many schools do not permit students to wear hats in the school building. If a child returns to school and wishes to wear a hat because of hair loss, accommodations should be made, and all of the need-to-know school personnel must be alerted. Often children with cancer are needlessly singled out in front of classmates when teachers are unaware of their special circumstances. See a list of *Examples of IEP Services and Accommodations* on page 35 and an example of a *Hall Pass* that the child could use on page 51.
- ☑ **Information to Prepare Classmates for the Child’s Return.** The teacher can be given an example of a classroom presentation, appropriate to age and grade level. See *How Does Cancer Affect Peers and Classmates* on page 11.

# Back in the Classroom



**HENRY**  
Leukemia survivor

## Common Behaviors and Side Effects to Look for in the Classroom

Children returning to the classroom may do so while continuing to receive treatment. The following is a list of some, but not all, of the possible side effects that the student may experience:

- Susceptibility to infection (immunocompromised)
- Nausea or vomiting
- Hair loss
- Weight loss or weight gain (and either lack of appetite or increased appetite depending on regimen)
- Mouth sores
- Sensitivity to the sun
- Forgetfulness
- Sleepiness
- Poor concentration or changes in cognition
- Irritability
- Hyperactivity
- Inappropriate reactions
- Regressive behaviors both socially and academically
- Acting out
- Controlling behaviors
- Other physical symptoms (stomach aches, headaches, body aches, frequent urination)



**NIK**  
Leukemia survivor,  
with his father

**Dealing with Fatigue.** A child with cancer can struggle with fatigue due to the treatment. Their energy level may fluctuate from day to day, and this will dictate just how much they can do. This is often very frustrating for the child since they are often excited to “jump right in.” By maintaining flexibility in dealing with children with cancer who are returning to school, expectations can be kept high and be realistic. **The child should be allowed to participate in activities as tolerated.**

**Concerns About Anxiety and Fear.** The child and their parents may have many worries and fears about school that need to be addressed directly and sensitively. These may include fears about contagious diseases at school, teasing, and the challenges of keeping up with their peers both physically and academically. Teasing may be a particular concern as kids at school may tease and make unkind remarks when they don’t understand why their peer with cancer looks or acts differently. Developing children’s social and emotional skills can help them better handle negative experiences like teasing and name-calling.

▶ Visit [www.LLS.org/booklets](http://www.LLS.org/booklets) to view the free fact sheet *Cancer-Related Fatigue*.

## Tips for Teachers and Families

### Helping Kids Cope with Teasing and Name Calling

- Provide basic information to the child about why they look different, so the child can then to be able to explain it to others. Example: “I’m bald because I’m taking strong medicine that made my hair fall out. When I finish the medicine, my hair will grow back.”
- Prepare the child to ignore comments from people that are cruel or inappropriate. Explain to the child that some comments don’t even deserve a response.
- Teach the child to be assertive. The child should let people know that they don’t like the way they are being treated. Explore options to walk away or get help.
- Make sure the child knows whom they can turn to at school. Come up with a list (close friends, teachers, school nurse or a counselor) of people who can help with especially bothersome kids.

Most times, if the peers are educated in advance as to why the child with cancer looks or behaves differently, they won’t tease or give them a hard time to begin with.

### Misconceptions About Children with Cancer by their Peers

In the absence of accurate and timely information, children and teens will often believe rumors. When a child is out of school because of a

potentially life-threatening illness, experience indicates that rumors begin circulating almost immediately, and these rumors are usually far worse and more frightening than the truth. It is essential that teachers and school staff understand their students’ perspectives, provide straightforward answers that are reassuring and dispel any rumors.

The table starting on page 20 provides information about how different age groups understand cancer. This information can help teachers anticipate students’ questions.

▶ Please visit [www.LLS.org/SuggestedReading](http://www.LLS.org/SuggestedReading) for suggested reading for younger children.

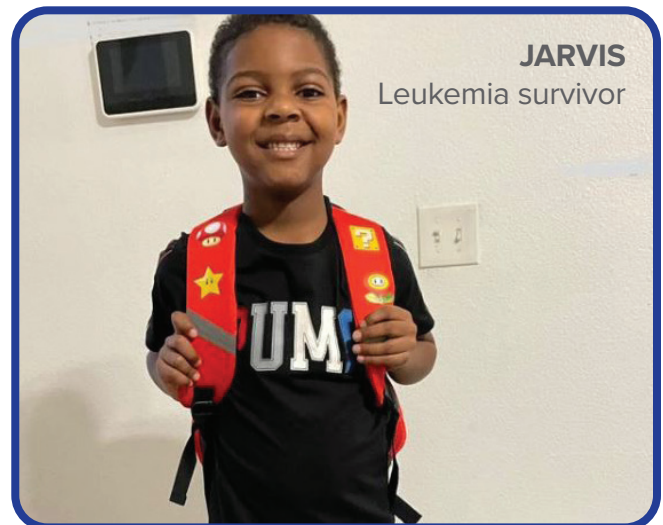


**KYLE**  
Lymphoma survivor,  
with his teammates

Age Group	Developmental Attribute	Interaction Suggestion
5-8 Year Olds (Kindergarten through 3rd Grade)	May believe the patient did something “bad,” which in turn caused the illness.	Explain that cancer is not caused by anything a person thinks or does. Kids do not get cancer because they did something wrong.
	May believe they can catch the disease “like a cold.”	Explain that cancer is not “caught” or contagious like a cold or the flu. It is ok to be friends with, sit next to, share books and play with classmates who have cancer.
	May believe that the diagnosis of a disease “changes” the child. The patient goes from one character to another.	Explain that while a classmate might look different, they are still the same person inside with the same likes. Use an example of a favorite sport, activity or team that a student will continue to like after a diagnosis.
9-12 Year Olds (4th Grade through 6th Grade)	Understands and applies logic.	Explain the difference between cancer (a disease of a cell’s internal mechanism and is NOT contagious) and COVID (a virus which infects the cell and IS contagious).
	Often judge ideas in absolutes.	Discuss choices with them. Does the patient have the choice to refuse treatment? What would happen if the patient refused treatment?
	Capable of discussing and sharing feelings, emotions and fears.	Ask the classmates how they might feel if they were in a similar situation.
	Has a better understanding of complex language.	Explain the difference between probability and possibility. It is possible that other children in the school could be diagnosed with a similar disease, but the probability is very low.



**SHAMEEL**  
Leukemia survivor,  
with his sister



**JARVIS**  
Leukemia survivor

Age Group	Developmental Attribute	Interaction Suggestion
13-17 Year Olds (7th Grade through High School)	Often does not wish to disclose their personal situation to all students.	They may instead wish to speak privately with a few students. The child’s wishes should be respected and honored.
	May be more concerned with peer acceptance.	Children at this age should be urged to have at least one “safe person” on campus. This can be a teacher, counselor, school nurse or staff person who is aware of the child’s medical condition and can offer guidance and support.
	Develops more complex thinking.	A scientific and factual explanation and approach that is understandable is appreciated for this age group.
	Capable of understanding the perspective of others.	Social support and the positive impact of friendships should be emphasized.
	Compares self to peers.	Teens with cancer do not want to be perceived or treated differently. Classmates can assist in their friend’s recovery by treating them the same as they did prior to the illness.



# What You Need to Know About Teens with Cancer

## Normal Adolescent Development

- Development of autonomy from parents
- Increased involvement with peers and concerns for acceptance
- Experimentation with different social roles
- Identity formation
- Preparation for adulthood: education, vocation, family

## Special Issues Facing Teens with Cancer

- Social isolation such as separation from peer group and normal activities caused by diagnosis and treatment
- Challenges maintaining open communication lines between teen and family, school and medical team
- Possibly less time for learning when homebound or in the hospital
- Limited energy and concentration to do schoolwork and move around campus
- Multiple teachers and subjects in middle school and high school make it challenging to keep pace when out of school
- Sensitivity to getting “special” treatment if returning to school and requiring modifications or accommodations in academics or physical education
- Myths and misconceptions by peers and teachers regarding cancer and treatment in adolescents

- A regression in their development of independence (autonomy from parents); may be student-patient or parent initiated

## What Can We do to Help Facilitate School and Social Reintegration for Teens

- Help inform teens, parents, medical teams and school personnel about the many benefits of continuing a structured school program soon after diagnosis.
- Facilitate connection to hospital or homebound educational programs for all students required to be out of school for 4 weeks or more (home/hospital teaching, virtual learning, etc.).
- Encourage students with cancer to access social and emotional support available at school, such as a social worker or counselor. Inform the student the names of staff that they can reach out to and the best way to reach them. If needed, IEP and 504 plans can assign scheduled social emotional support sessions with available school staff.
- Strongly suggest that throughout treatment and beyond, the student keeps in touch with friends and classmates through text, phone and any other way they previously communicated to peers prior to the diagnosis.
- Allow the teen the option to attend school and social events if approved by the medical team.
- Set educational goals aligned with high school requirements. Speak with guidance counselors to set a realistic schedule and course load.



- As a stakeholder, allow a teen diagnosed with cancer to have a voice in their transition back to school. Provide frequent checkups with the student on how the transition is going. As new issues may arise, less or more support may be needed.

## Setting the Student up for Success

Here are ideas to consider for a student's return to school:

- Location of the student's desk
  - Convenience of student's locker
  - Physical education requirements
  - Exceptions to the "no hat" & "no food/drink at desk" rules (allow access to water and snacks as needed)
  - Distance between classes
  - Time allotted for changing classes
  - Length of school day: a truncated school day focusing on core classes may be necessary
  - Weight and number of textbooks
  - Provide outlines/study guides
  - Emphasize quality vs. quantity of student's work
  - Modify assignments or allow for extra time with assignments
  - Use multisensory methods
  - Allow for a variety of student responses: i.e., oral vs. handwritten vs. typed assignments
- Consider alternative assignments and assessments as needed
  - Arrange a time before or after school when the student can meet with their teacher
  - Schedule regular communication between parent/teacher/student to prepare for the upcoming week's learning and medical needs (e.g. teacher can provide/explain that week's assignments early, so student-patient can complete them during that week's prolonged medical appointment)
  - Utilize virtual learning platforms and learning management systems, such as Google Classroom, for providing the student access to instructional materials, remote check ins, lessons and assignments

## Addressing Special Academic Needs

The process of re-integrating a child with cancer (especially if learning problems have developed because of treatment) needs to include the entire multidisciplinary team – hospital staff, teachers and other key school staff and parents. A return-to-school program must begin at the time of the child's diagnosis and continue until formal education is completed.

## Conditions that Lead to a Child Being at Risk for Educational Difficulties

- Being diagnosed with cancer before mastering basic academic skills (generally prior to age 6)
- Numerous or lengthy hospitalizations
- High rate of school absences
- Prior history of developmental and educational delay or difficulties
- Neurological impairments or having had radiation of the brain
- Brain tumors
- Family history of school difficulties or special educational services
- Family in financial need
- Major family discord
- Non-English-speaking family

Children may have school and learning needs because of their illness and treatment that necessitate special help. They may have a learning disability associated with having a brain tumor or radiation treatment to their head, a visual impairment, or they may have mobility problems because of a surgery or amputation. Special education services are available through the public schools to help students from preschool through college receive the specialized help they may need to be successful at school.

## Special Education Services

### Laws that Protect Children’s Educational Needs

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. ADA may be useful to students seeking employment or going to public colleges or universities.

#### **The Individuals with Disabilities Education Act (IDEA).**

Under IDEA, public school children with disabilities may receive an Individualized Education Plan (IEP) that modifies the curriculum and outlines a formal plan to accommodate a child’s individual needs. IDEA also outlines transition planning, which coordinates the transition from school to post-school activities (such as education and employment).

Federal laws PL 94-142 (also known as the Education for All Handicapped Children Act or “EHA”) and 99-457 (reauthorizing and amending the EHA to provide services to handicapped children from birth through age 2) require that every public school must provide Free and Appropriate Public Education (FAPE) in the least restrictive environment to all disabled individuals from birth through 21 years. These laws were refined and extended by the Individuals with Disabilities Education Act (IDEA). The law requires the development of an

Individualized Educational Plan (IEP) for each child that establishes exactly which special services the child needs and how those needs will be met. Services may be needed soon after diagnosis or anytime thereafter; even long after treatment may have been completed.

These laws protect students, including students with cancer, whose medical problems adversely affect their educational performance, under the category known as “Other Health Impairment” (OHI). Special education services are available under OHI whenever the child’s medical condition limits their strength, vitality, or alertness, and adversely affects their educational performance. Although many students with cancer attend school without the need for specialized assistance, special education services may be an important bridge for those children who need extra help to do their best at school.

#### **The Rehabilitation Act of 1973 – Section 504.**

The act requires all educational institutions receiving federal funding to provide accommodations (adaptations) for students with physical or mental impairment, a record of such an impairment, or be regarded as having such an impairment, that limits one or more major life activities. The purpose of the 504 Plan is to allow for accommodations to help the student access free public education as general education students. Accommodations can be long term, short term or episodic. The accommodations are put in place to counter the negative impact cancer and its treatment has on the student’s ability to perform their major life activities. Examples of Major Life Activities that may impact the school experience can include, but are

not limited to the following: reading, focusing, thinking, communicating, learning, working, walking, seeing, hearing, speaking, eating, sleeping, standing, lifting, bending, breathing, doing tasks with one’s hand, caring for oneself and other major bodily functions.



**MYLES**  
Leukemia survivor

- ▶ See [IDEA/504/ADA Comparison Chart](#) on page 55.
- ▶ Visit [www.LLS.org/booklets](http://www.LLS.org/booklets) to view *Learning & Living with Cancer: advocating for your child’s educational needs*.
- ▶ See [www.LLS.org/StayingConnected](http://www.LLS.org/StayingConnected) for the module on *The Education Journey During and After Cancer Treatment: Approaches to Dealing with These Challenges*.

## Coping with a Medical Crisis or Declining Health

Although the outlook for most children with cancer is hopeful, the reality of medical complications or declining health cannot be overlooked. When complications are encountered, the importance of clear communication between family, medical team and school becomes critical. Rumors must be replaced by facts and knowledge. Extended absences may require that home or hospital teachers be used until resumption of the regular school program becomes possible. Every effort should be made to help the child remain emotionally connected to his or her peer group through various forms of communication such as email, text messages, letters, cards, telephone calls, and visits, whenever appropriate.

If the child's condition worsens and survival is uncertain, it is important to remember that continued school participation is vital to the child's self-worth, community connectiveness, and overall sense of wellbeing. Every effort should be made to include the child in school activities, with modifications as needed. Staff may need assistance with their own emotional reactions to the painful possibility of a child's death. Peers need to know why a child may look different or is absent more than before. Discussions with peers at school should emphasize that efforts continue to help the child, but complications are being encountered that add doubt to what will happen in the long term. Questions about the possibility of a child's death should be answered honestly, and age

appropriately, while at the same time remaining hopeful that treatments will help stabilize the situation. Classmates need to know they can help by maintaining their friendships and remembering that the child affected by cancer is still the same child they have always been.

If death is imminent, teachers and school personnel may need additional support from school and hospital professionals to understand and cope with the complex emotions experienced by everyone. Many school districts and county office of education have mental health professionals on staff that can assist. Children with cancer who are declining in health do not die at school, as the close medical supervision they receive ensures they are only at school if they are physically able to be. If a death occurs, teachers and staff should receive mental health services so they can also then help classmates understand what happened and can grieve. If the teacher is uncomfortable having that conversation with their class, please partner with a mental health professional in your school district or from the hospital that can facilitate the conversation with the students.

When a student dies, friends, peers and classmates will grieve and understand the death in different ways depending on their experiences, age and maturity. Consider celebrating the life of the child through a memory board, sharing letters or pictures of school experiences with the family, or a fundraiser in honor of the student. Allow students to express normal feelings of grief and ensure social emotional support services are available at the school.

Appropriate school memorial programs such as writing a bereavement letter to the family or planting a tree in honor of the child can sometimes be extremely beneficial. However, please keep in mind that “permanent” memorials can also be painful for many siblings, classmates and staff when trying to move forward. Partnering with the family and respecting their wishes is also an important component. Please speak to your mental health professional to discuss what is appropriate for your situation.

## If the Death of a Child or Teen Occurs

- The death of a child affects the entire staff of a school, not just the immediate teachers involved.
- School staff may need to grieve separately from their students, perhaps devoting some portion of a staff meeting to reviewing what has occurred and the impact it has had on the school.
- Plans should be made to provide emotional support to all involved, including siblings, classmates, or relatives of the deceased child that attend the school and staff members.
- Consider how the school might maintain contact with the child’s family, if they are agreeable, and when they are comfortable to do so.
- Many parents find it very comforting to know their child’s school continues to be a source of support even after their child has died.



AVA  
In memory

▶ Visit [www.LLS.org/StayingConnected](http://www.LLS.org/StayingConnected) to see the module on *Coping with Grief, Loss, and Bereavement throughout the Treatment Continuum*.

# Survivorship

**ANNA**  
Leukemia survivor



## The Road Ahead

For the children who are cured, there are often unexpected hurdles to overcome many years after their treatment has ended. The treatments used to cure children can greatly affect developing minds and growing bodies.

Even though the visible signs of the disease and/or side effects of treatment may be gone, there are physical, emotional and social ramifications of surviving cancer. These residual effects are often overlooked as the child's parents and school staff focus on "putting it behind us" and "getting back to normal." Though these are realistic goals, the challenge of survivorship is accepting a "new" normal, assimilating the changes and becoming well-informed as to the options available to the survivor.

The survivor and those who care about them must forge ahead, all the while staying attentive to the possible long-term effects brought on by their illness. Survivors need experienced help and advice from their healthcare team to make the most of their life after cancer. Appropriate intervention (such as medical care, psychological or vocational counseling) can positively influence the path of the survivor's life. Often the parent must advocate for the services the survivor requires.

The success of the child's future—educational achievements, career goals and engagement in life—depend on active participation from the whole team (the parent, the child, healthcare team, school and community) beginning the moment of diagnosis and continuing into adulthood.

## Late Effects of Childhood Cancer

The journal *Pediatrics* published an article in September 2021 summarizing the need for follow-up care for childhood, adolescent and young adult survivors:

*Virtually every organ system can be affected by the chemotherapy, radiation, surgery, and/or immunotherapy required to achieve a cure. Late complications of treatment may include problems with organ function, growth and development, neurocognitive function and academic achievement, and the potential for additional cancers. Cancer and its treatment also have psychosocial consequences that may adversely affect family and/or peer relationships, educational attainment (both formal and practical knowledge gained from real-world experience), vocational and employment opportunities, and insurance and health care access.*

*In addition, survivors may experience troubling body image changes or suffer from chronic symptoms (eg, fatigue, dyssomnia [sleep disorders], pain) that adversely affect emotional health and quality of life.*

A teacher may be the first to observe the childhood cancer survivor encountering learning difficulties, psychological or physical issues. It is important for the teacher to communicate their observations with the young person, their parents, and their current healthcare team to plan effective assistance strategies. The teacher can also direct the survivor and family to [www.survivorshipguidelines.org](http://www.survivorshipguidelines.org) to get advice on how to help themselves.

**FAITH**  
Leukemia survivor



▶ See *Parent and Survivor Stories* on page 33 to read *A Survivor's Story*.

## Possible Late Effects

Some possible late side effects from treatment are included in the following list. This list is not all-inclusive, and a patient's late effects may vary.

### Cognitive

- Math abilities
- Problem solving
- Attention span
- Concentration
- Handwriting
- Processing information
- Memory
- Planning/organizing skills
- Reading
- Spelling

### Social and Emotional

- Underdeveloped social skills
- Post-traumatic stress disorder
- Depression related to physical changes
- Fear of relapse
- Isolation
- Anxiety disorders, including obsessive compulsive disorder or panic disorder

### Physical

- Fatigue
- Thyroid problems
- Vision impairment
- Hearing impairment
- Lung/breathing issues
- Growth delay
- Bone issues
- Infertility
- Early or delayed puberty
- Secondary cancer
- Endurance impairment
- Other organ damage

#### **AIDEN**

Leukemia survivor,  
with his mother





## Follow-up for Children and Teens Affected by Cancer

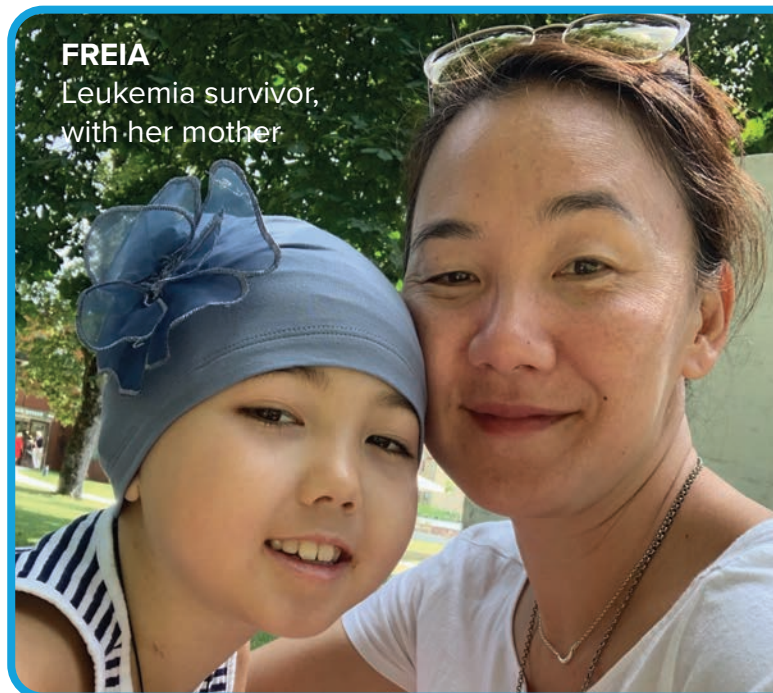
### Tips for Teachers to Give to Survivors

*Please discuss these resources with parents and guardians before providing them to students.*

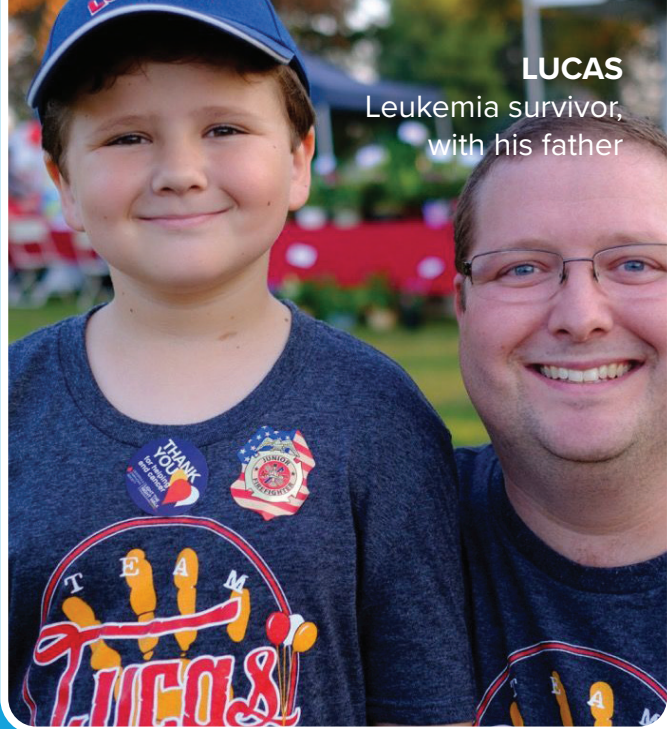
- If they ask for assistance, help the student find another cancer survivor in their school to talk to, or help them locate a survivor support group in their community or online.
- Suggest students or parents contact reputable cancer organizations or check online for survivorship materials in various formats. Visit [www.LLS.org/StayingConnected](http://www.LLS.org/StayingConnected) to find a resource list.
- Review educational goals.
- Offer older students resource information on vocational training programs and career forums.
- Encourage the survivor to think of their cancer experience as a meaningful life event. Suggest they keep a journal of their thoughts and feelings.
- Often survivors will want to help other children with cancer. This is an important step toward healing the trauma of their illness.
- When the student-patient is preparing to move up a grade or change schools, encourage them and their parents to inform the new school staff of the student-patient's experience, the supports they will need,

what worked and didn't work etc. Often a conference in advance of the transition between the current teacher/academic team and future teacher/academic team can be very helpful.

- Teachers can inform students that accommodations provided in 504 Plans and IEP's can also apply to standardized college entry examinations, such as the ACT, AP and SAT examinations, and placement tests. Usually, a request is submitted to the testing agency, with documentation, for approval in advance of each examination.



- ▶ For survivorship information, visit [www.LLS.org/SurvivorshipWorkbook](http://www.LLS.org/SurvivorshipWorkbook) to view the free LLS booklet *Navigating Life During and After a Blood Cancer Diagnosis* for children and adolescents.



**LUCAS**  
Leukemia survivor,  
with his father

## A Parent's Story: David

**“When parents and a dedicated academic and healthcare team work together, children can go on to have positive educational experiences and thrive after cancer.”**

At the age of seven months, my son, Lucas, was diagnosed with acute lymphoblastic leukemia (ALL). He was treated at UCLA

Mattel Children's Hospital over the course of a year. It was a very difficult time for us as a family. But thanks to the wonderful team of doctors, nurses and staff, Lucas is in remission and thriving! Even now, Mattel Children's Hospital continues to monitor Lucas's health as he grows up, attends school and navigates the possible long-term effects of his cancer.

We have been fortunate throughout the years that the team at the survivorship clinic at UCLA not only included a team of doctors, but also an education specialist who took the time to check in with Lucas to see how he was adjusting to school and if he was experiencing any challenges that may be related to his treatment.

When he was in elementary school, my wife and I noticed that Lucas was struggling to keep up with his peers on timed assignments and was complaining of leg pain and other physical discomforts. After discussing this with his healthcare team, we reached out to his teacher and decided to see what our options were to ensure that Lucas was successful in school. We set up a meeting with the school principal, his teacher and the school nurse, and determined that a 504 plan would be necessary to help Lucas meet his academic goals and make him comfortable at his desk in the classroom setting. Some accommodations were put in place, such as grading on accuracy as opposed to the number of questions answered and extra time on assignments and tests. Since then, Lucas has been making Principal's List and is now thriving as a high school freshman.

As a school nurse, I can see how vital it was for us as parents to advocate for our son early on. In my district, I draw on my own experiences to help families when they come to me with concerns about their child navigating the challenges of cancer treatment and possible long-term effects. Lucas is proof that when parents and a dedicated academic and healthcare team work together, children can go on to have positive educational experiences and thrive after cancer.

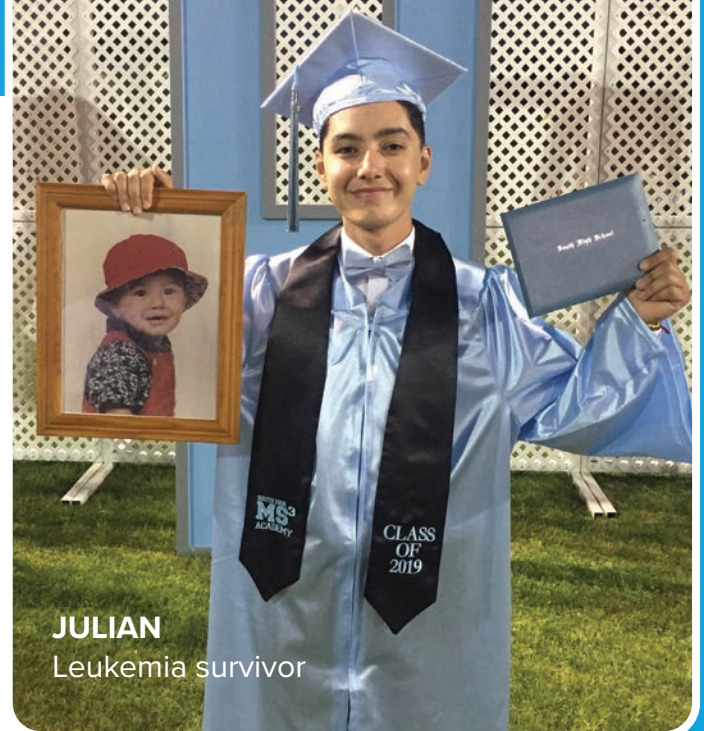
# A Survivor's Story: Julian

**“Your experience with cancer is just a chapter in your larger life story, not your entire identity. It’s OK if you write your story, at your own pace.”**

When I was 10, I was diagnosed with cancer and went through 3.5 years of chemo. I finally started to feel normal again, but then, during my sophomore year of high school, cancer came back. I had to leave school for a whole year and watching my friends on social media having fun without me hurt a lot. I felt left out, and like life was moving on while I was stuck in pause mode.

Going back to school was super weird. Whether it’s your first day of high school or you’re coming back after being sick, the whole place can feel super intense. For me, my body had changed a lot. I was weaker and my hair wasn’t all the way back. So, walking in, I felt like I was a whole new person. I felt all kinds of emotions: scared, worried, awkward, and out of place. But every day got a little bit easier. Teachers were helpful about helping me catch up, and I had learned what friends I could rely on and felt comfortable with. It took time, but slowly I started to feel more like the old me again.

If you’re going through something like this, it’s totally OK to feel all mixed up. Just take it one day at a time. Surround yourself with supportive people and focus on what you can control. High school has its own set of challenges, but you are much more than these temporary struggles. Your experience with cancer is just a chapter in your larger life story, not your entire identity. It’s OK if you write your story, at your own pace. I did.



**JULIAN**  
Leukemia survivor

*Julian delivering care packages with the nonprofit he founded, Bags of Love Foundation*



# Appendix



**LILY**  
Hodgkin  
lymphoma  
survivor

## Page 35 Examples of IEP Services and Accommodations

Examples of possible services or accommodations that could be implemented in a specific child's plan.

## Page 39 Return to School Form for Pediatric Oncology Patients

Parents and healthcare professionals can fill out this form for the teacher/school staff outlining side effects, information about medications, limitations on activity and details of when to call parents/healthcare professionals.

## Page 49 Helpful Contact Names/Numbers

### Page 51 Hall Pass

A sample hall pass allowing the child special permissions. You can laminate the hall pass once it has been filled out to make it last longer.

## Page 55 A Comparison of ADA, IDEA and Section 504

## Page 59 More Information About Common Cancer Treatments

## Page 62 Resources

## Examples of IEP Services and Accommodations

### The Individualized Educational Plan (IEP) May Provide the Following Services:

- Tutoring or Resource Specialist (RSP) teacher for subjects in which the child has fallen behind or is having special difficulties handling due to illness and/or treatment
- A liaison with general teachers to help them understand and plan for the impact of the illness and/or treatment on school performance
- Assistance of the school nurse in administering medications, performing medical procedures and/or monitoring health conditions during the school day under physician orders and parent permission, notifying staff of medical issues and physician recommendations, coordinating the monitoring of communicable disease outbreaks that could adversely affect the child
- Teaching services provided at home or at the hospital for prolonged absences or repeated short-term absences
- Mild/Moderate Special Education or Resource Specialist Program services for a child with a diagnosed learning disability requiring more than tutoring to succeed. Due to inclusion, “special day class (SDC) placement” is less likely for our patient/students.
- Educationally Related Mental Health Services (ERMHS) on school adjustment or emotional issues
- Adjustment of class schedules, independent studies, waiver of penalties for absences, or modification of graduation requirements
- Special modified physical education programs
- Transportation to and from school
- Special equipment or physical access to school facilities
- Specification of ongoing IEP goals and follow-up of the child’s progress and recommending additions/deletions to the program based on changing needs
- Testing accommodations on formal and informal examinations can include extra time, separate setting, questions read aloud, a scribe for written responses, as well as designated rest periods or breaks.
- Related services, such as physical, occupational, nursing, and speech therapies, if the child’s medical needs are impacting educational performance.
- Assistive technology that can support students with visual, mobility, reading, writing, or hearing challenges in the classroom.

**An annual review of the IEP is required by law to make sure the child’s needs are being met and to plan for the coming school year. Any member of the IEP team, including the parent, has the right to call for an IEP meeting at any time that the child’s needs have changed, there are concerns and their school program needs to be adjusted.**

## Accommodation Options

Here is a checklist of possible accommodations. These are just suggestions. There may be additional accommodations that are included in the student's 504 Plan or IEP.

- ☑ Adjustment of attendance policy. Student will miss classes to accommodate various medical procedures/appointments and when Student is too ill to focus on schoolwork. The student's parent should provide a doctor's note to ensure Student is marked medically excused from school on these days.
- ☑ Send home class and homework assignments missed when Student is absent from school and allow extra time for completing these assignments.
- ☑ When Student is present (virtually) during remote classroom presentations, Student is exempt from being required to have the video "on". This is especially significant as we need to protect Student medical information.
- ☑ Student is exempted from grading based on 'class participation' requirements.
- ☑ Limit number of classes taken allowing for a shortened school day focusing on core classes.
- ☑ Student will require option to complete their work on a student driven pace. (or) Please allow extra time to complete homework assignments and for testing (when applicable) as Student may think and write more slowly due to fatigue or cognitive processing delays.
- ☑ Master-Learning. We request "demonstration of mastery" rather than repetition so that Student can be graded on the assignments Student turns in and not be penalized for the ones Student cannot complete. i.e. Student should be graded based on quality of work submitted not quantity of work completed.
- ☑ Use of assistive technology. For example: Permission to type assignments, or use voice to text, if neuropathy is an issue. (Side note: A Student may be on a medication called vincristine, which may lead to peripheral neuropathy in the fingers and toes. This may impact penmanship during class work, as well as gross motor skills during PE/recess. If you notice the student to be clumsier than usual or if they have numbness and tingling, please notify the parent and school nurse immediately. The parent should contact their healthcare team and the school team to let them both know if any additional interventions or evaluations are needed.
- ☑ Student should be allowed extra time as needed for testing; and in a separate location as needed.
- ☑ Student should have access to a set of books that remain in their classroom and a second set of books that remain at home so Student doesn't have to carry books from class to class.
- ☑ Rest periods as needed
- ☑ "Safety Net" grading - For High School students, in districts where this is available

- ☑ Questions read aloud and repeated if necessary for all local and standardized testing.
- ☑ Use of a computer or scribe if needed for tests and assignments that require writing
- ☑ Paraprofessional/fellow student to assist in escorting Student during passing period in the halls, and/or to assist in ensuring Student receives all assignments.
- ☑ Elevator pass as needed. Bathroom pass to keep with them so as not to disrupt class discussion.
- ☑ Allow Student to wear a head covering if they would like, as they have or will lose their hair due to chemotherapy (when applicable). It is helpful to provide Student with a pass to carry throughout the day (in case a hall monitor isn't aware of Student's circumstances).
- ☑ Dietary accommodations. For example: Allow Student access to snacks/water as needed at all times so Student can eat/drink, even during instruction time.
- ☑ Extra time for transitions (e.g. physical travel between classes, transitions between activities and assignments etc.)
- ☑ Preferential seating in a location where they can easily communicate needs (i.e. restroom break) to the teacher without calling undue attention to themselves or disrupting the class. Many teachers facilitate this process by agreeing upon a hand signal with eye contact with the Student ahead of time.
- ☑ Alternate program for physical education (Adaptive PE) OR may be able

to participate in PE class at this time with reasonable accommodations, "as tolerated."

- ☑ If student has a central line - for example: The student has a port-a-cath in place which allows for venous access in the hospital. The port is in the skin underneath the chest and is not visible to anyone. Care should be taken to prevent this area from being hit. No activities involving physical contact allowed (e.g. rough horseplay, contact football etc.).
- ☑ Provision of counseling and/or establish peer group support
- ☑ Peer tutoring
- ☑ Designate a person in the school to be a liaison with parents as a means of updating changing health status. The school nurse is a good person for this role.
- ☑ Development of a health emergency care plan. Note: health emergency care plans should be developed by the school nurse in conjunction with the student's medical team and appropriate physician orders. Allow access to the school nurse as needed. NOTE: if Student has a fever, or has other symptoms that are concerning, please contact their parent immediately (do not wait for end of the school day). Follow the established health emergency care plan for next steps if the parent cannot be reached or contact EMS via your local emergency phone number e.g. 9-1-1.
- ☑ Exemption from vaccination requirements. Follow your state/local public health guidelines to allow student to stay in school without fully completing immunization

requirements. This may require a doctor's note or formal medical exemption by the healthcare provider.

- ☑ Treatment, as well as the placement of a central line, may cause side effects that can be distracting and/or life threatening. Some may include fatigue, mood swings, excessive hunger/thirst, fever (100.4F or higher), or impaired memory, processing speed and/or executive functioning skills. Please let the parent know if you observe some of these treatment/learning side effects. Students who received intrathecal chemotherapy regularly as part of their treatment protocol will be at high risk for late onset cognitive effects down the road. In addition, this may be exacerbated by the missed instruction that occurs due to treatment intensity. Early intervention in any subject where Student appears to be falling behind or needing additional support is recommended.
- ☑ Due to the treatment, Student may be considered immunocompromised and easily susceptible to infections. The best and most effective way to prevent illness/infection is through good handwashing. School staff should allow the Student to wash their hands (or hand sanitize) as needed, and encourage all students to practice good hand hygiene by washing their hands thoroughly with soap and water, before eating, after using the restroom, and any time their hands are dirty. Additionally, we would advocate the

use of “creative seating” where needed. For example, if seats are assigned in their classrooms but Student is seated next to someone who is visibly ill, we would ask that they switch seats for the day to lessen exposure. Note: Chicken pox is an illness that can be very difficult on pediatric patients with cancer; if the child is exposed, the parents and medical team should be notified immediately so protective medical interventions can be initiated.

- ☑ If the Student is going to be outdoors at school for field trips, recess or physical education class (anything longer than 20 minutes in the sun), the use of sunscreen is recommended. The Student is at risk of secondary malignancies due to their chemotherapy treatment.



## Return to School Form for Pediatric Oncology Patients

Reentry into school is an important, yet complicated time in a patient's cancer journey. As the medical team, we hope to lessen that burden for the patient, family, and school staff. This guide will help educate the school nurse, teacher, and administration about the patient's needs as they transition back to school during or after cancer treatment.

When a child is medically able to attend school, we encourage the child to attend all school days and all school activities as tolerated. A child's school experience is critical for growth and development, as well as their confidence and social/emotional well-being. Accommodations will likely need to be made based on how the child is feeling that day or how their treatment has affected their body/energy level. We encourage you to have the same scholastic expectations for the student as you do for the entire class (unless otherwise noted by the medical team). The following pages outline considerations and side effects the child may experience during or after cancer treatment and guides the school staff on what procedures to follow to ensure a safe environment for the child.

Patient's Name: \_\_\_\_\_

Diagnosis: \_\_\_\_\_

Provider Name Completing this Form: \_\_\_\_\_

Name of Hospital: \_\_\_\_\_

Phone Number: \_\_\_\_\_

## Current/Planned Treatment Plan

Check appropriate:

- Chemotherapy
- Biotherapy/immunotherapy
- Radiation
- Surgery
- Stem cell transplant
- Other: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Anticipated school absences:

Check appropriate:

- Minimal (less than 5 days a month)
- Moderate (5-10 days a month)
- Significant (greater than 10 days a month)

## Possible Side Effects from Cancer or Treatment

- Increased chance of bleeding (gums, nose, bruising) or bruising
- Increased risk of infection
- Nausea or vomiting
- Hair thinning/loss
  - Please allow the student to wear a hat/wig or head covering if desired

*If your school has a policy against students wearing hats, it may be a good idea for the principal to sign a note or pass for the student/patient to show to school staff that may not be aware of their medical condition*

- Weight loss/gain caused by lack of, or increased, appetite (dependent on treatment)
- Mouth sores
- Sensitivity to the sun
- Decreased energy or hyperactivity
- Forgetfulness
- Sleepiness/fatigue
- Poor concentration
- Irritability
- Inappropriate reactions/lability
- Regressive behaviors
- Acting out
- Slowed or altered cognition
- Other physical symptoms (stomach aches, headaches, body aches)
- Other: \_\_\_\_\_  
\_\_\_\_\_

# Medications to be Taken at School

(School medication administration form to be completed and signed by medical team and parent):

Check appropriate:

- No medications in school
- Medications as follows:

<b>Medication</b>	<b>Medication form: pill/liquid/inhaler</b>	<b>Dose</b>	<b>Route</b>	<b>Timing or if as needed</b>

## Devices or Catheters

Central venous catheters are lines designed to administer long-term chemotherapy infusions, blood products, medications, nutrition, or hydration. Parents/guardians are taught to care for the central venous catheters outside of the clinical setting. There is a sterile dressing that covers any external catheters. You may see tubing outside the child's chest or arm.

*Note: Rarely, the child may discover a leak coming from the catheter or from the cap. If this happens make sure the clamp is closed and immediately call the parents/guardians or school nurse if parents/guardians are unavailable.*

Check appropriate:

- Mediport/Port-a-cath/"Port" – Internal line (under skin); typically in the chest
- Broviac®/Hickman – External line; exposed tube under a dressing, typically in the chest
- PICC Line – External line; exposed tube under a dressing, typically in the mid/upper arm
- VP shunt/cerebral shunt – Internal shunt along the scalp to drain cerebrospinal fluid, with internal catheter draining into the chest or abdomen
- G-tube/PEG/"Button"/J-tube – External tube in the abdomen for administration of fluids/nutrition or medications in those that cannot tolerate by mouth
- NG tube/Nasogastric Tube – Tube into the nose for administration of fluids/nutrition or medications in those that cannot tolerate by mouth
- No indwelling devices or catheters

## Limitations on Activity

Check where appropriate and provide start/end dates for limitations:

- No Limitations - unless parent notifies otherwise
- Non-contact sports (avoid certain activities in gym class/recess) with restriction start and end dates
  - \_\_\_\_\_
  - \_\_\_\_\_
  - \_\_\_\_\_
  - \_\_\_\_\_
  - \_\_\_\_\_
  - \_\_\_\_\_
- Limited contact sports with restriction start and end dates
  - \_\_\_\_\_
  - \_\_\_\_\_
  - \_\_\_\_\_
  - \_\_\_\_\_
  - \_\_\_\_\_
- No physical activity
- Special Accommodations and any durable medical equipment, ie. crutches/wheelchair with accommodation start and end dates
  - \_\_\_\_\_
  - \_\_\_\_\_
  - \_\_\_\_\_
  - Need for elevator pass
  - Need for peer buddy to carry bags between classes
  - Need for extra time passing between classes
  - Needs a second set of books to be kept at home so they will not have to carry heavy books between home and school. This also helps so that they can complete class work assignments on the days they have to miss school for medical appointments
  - Other: \_\_\_\_\_  
\_\_\_\_\_
  - Other: \_\_\_\_\_  
\_\_\_\_\_
  - Other: \_\_\_\_\_  
\_\_\_\_\_

## Comments:

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## Considerations

Parents should be notified of any acute illness, fever, or change in the child's condition or behavior.

### Fevers

Fevers can occur due to infection (minor or serious) or they can be related to a side effect of a drug.

*What should I do if the child experiences a fever in school?*

- Call the parent/guardian immediately if their temperature is above 100.4 °F
- If you cannot reach the parent, please contact the oncology team at \_\_\_\_\_
- Contact the school nurse in the interim to assess the student when possible.
- If it is an emergency, please call 9-1-1 or your local emergency services number.

*Note: Sometimes an infection can occur without fever. Any time the child has chills or you are concerned that they do not look well, even if there is no fever, call the parents/guardians then school nurse immediately.*

### Nausea/Vomiting/Diarrhea

Gastrointestinal problems can be common side effects from cancer treatment.

*What should I do if these occur in school?*

- Call the parent/guardian if nausea/vomiting/diarrhea persists (child is at risk for dehydration). The child may need to be given medications to help with the side effects or hydration via an IV.
- Parents may have approved for anti-nausea medications to be administered as needed by the school nurse (see school medication administration form).
- Students should be able to eat and drink as needed throughout the day. They may need to keep snacks with them to help them remain focused on their schoolwork.

## Bleeding/Bruising/Petechiae

Bleeding, such as nosebleeds or gum bleeding, and bruising or small red/purple spots called petechiae may develop, if the patient's platelet count is low. A low platelet count can be due to their cancer or because of the side effects of treatment.

Staff should always follow universal precautions when dealing with blood and other bodily fluids.

1. Treat everyone as being potentially infectious.
2. Treat every body fluid as being potentially infectious.
3. Always use protective barriers (such as gloves).
4. Always clean contaminated areas.
5. Always wash hands thoroughly after. Please speak with your school nurse for more information.

*What should I do if this occurs in school?*

- Nosebleeds: Sit the child up and tilt their head forward, pinch both sides of the child's nose at the nostrils with constant pressure for 5 minutes. Try to squeeze consistently and not let go. It is important that the child does not blow their nose or stick their finger (nor anything else) up their nose, even after the bleeding has stopped.

- Do not tilt the child's head back; by leaning forward, it facilitates clotting, and the blood will be prevented from traveling to the stomach, avoiding discomfort/vomiting.
- If the nosebleed doesn't stop, continue to hold for 10 minutes.
- *If the bleeding does not stop after 10 minutes, or the child has more than 2 nosebleeds in 1 day, call the school nurse, and/or parents immediately. The child may have to go to the clinic/hospital to have a 'blood count' check and possibly receive a platelet transfusion.*
- General bleeding (cut or abrasion): Follow district standard first aid procedures but know that children in cancer treatment may take longer to stop bleeding due to low blood counts. Hold pressure for several minutes. Continue to monitor the area. If the bleeding does not stop after 10 minutes, see directions above.
- Bruising: If severe bruising or petechiae is observed, please contact the school nurse and/or parent/guardian immediately, as the child may need a 'blood count' check and possibly receive a platelet transfusion.

*Note: Do not allow the child to pick at a scab. Place a band aide over the area, as needed, to deter picking.*

## Pain

A child may experience pain due to their cancer, or because of their treatment.

*What should I do if this occurs in school?*

- Call the parent/guardian and notify them of the child's pain. The child may need to be given medication to help with the discomfort.
- Parents may have authorized for anti-pain medications to be administered as needed by the school nurse (see school medication administration form)
- **Patients receiving active chemotherapy should NOT receive ibuprofen or any NSAIDs, but typically are approved to receive acetaminophen if approved by the parent/guardian. Check with the healthcare provider.**
- If approved, the school nurse **MUST** check temperature **PRIOR** to administration of acetaminophen for pain, as it can mask a fever.
- As previously stated, please contact the parent/guardian for any temperature greater than or equal to 100.4 °F.

## Communicable Diseases

**IMMEDIATELY REPORT** any outbreaks of measles, chicken pox (varicella), COVID 19, or other communicable disease in the classroom to parents/guardians so you can reduce the chance of serious infection to the child with cancer.

**Varicella (chickenpox) immune status:** Check appropriate:

- Not susceptible - has immunity
  - Prior disease
  - Positive by titer
- SUSCEPTIBLE:** does not have immunity/immunity status unknown
  - **FOR SUSCEPTIBLE STUDENTS – IMMEDIATELY REPORT** any cases of chickenpox or other communicable disease in the classroom or in the sibling's classroom to parents.



## 504 or Individual Education Plan (IEP)

An IEP or a 504 Plan is a plan developed by the IEP or 504 team to meet the individual needs of a student. IEP or 504 teams are multidisciplinary teams and typically consist of the parent(s), the Student when appropriate, and various school professionals (i.e. the teacher, administration, school nurse, counselor and/or school psychologist).

- An IEP is recommended for this student due to their cancer/side effects as modifications to the student's school program. Specialized instruction and related services may be required.
- A 504 plan is recommended due to their cancer/side effects as accommodations to the student's school program may be needed
- An IEP and/or 504 plan is not recommended for this student at this time.

*Note: IEP/504 eligibility is determined, and the subsequent plan developed, by the IEP/504 team utilizing a multidisciplinary approach using assessment data (physician input can contribute to this assessment data) and is not determined solely by a physician note or recommendation. Most times the Student needs can be met through either a 504 plan or an IEP and both plans are not required at the same time. For instance the Student may start with a 504 and then qualify for an IEP at a later time. At that time, the accommodations in the 504 can be absorbed into the IEP and the 504 discontinued.*

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# Helpful Contact Names/Numbers

## Primary Physician

Name: \_\_\_\_\_

Phone number: \_\_\_\_\_

## Fellow Physician

Name: \_\_\_\_\_

Phone number: \_\_\_\_\_

## Nurse Practitioner

Name: \_\_\_\_\_

Phone number: \_\_\_\_\_

## Primary Nurse

Name: \_\_\_\_\_

Phone number: \_\_\_\_\_

## Social Worker

Name: \_\_\_\_\_

Phone number: \_\_\_\_\_

## Other Staff

Name: \_\_\_\_\_

Phone number: \_\_\_\_\_

## Hospital Information

Name: \_\_\_\_\_

Phone number: \_\_\_\_\_

## Parent/Guardian 1

Name: \_\_\_\_\_

Phone number: \_\_\_\_\_

## Parent/Guardian 2

Name: \_\_\_\_\_

Phone number: \_\_\_\_\_

## Emergency Contacts

Name: \_\_\_\_\_ Phone number: \_\_\_\_\_

Name: \_\_\_\_\_ Phone number: \_\_\_\_\_

**If there are any questions or concerns, please contact the parents immediately.**

**If it is an emergency, please call 9-1-1 or your local emergency services number.**

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perforated sheet

## Hall Pass

This student \_\_\_\_\_

Is allowed/has permission to:

- Go to the bathroom
- Go to the nurse
- Wear a head covering
- Carry a backpack/purse/bag
- Eat/drink as needed
- Access to technology/medical equipment as needed (e.g. cell phone)
- \_\_\_\_\_

Signed by Principal (or designee) \_\_\_\_\_

## Hall Pass

This student \_\_\_\_\_

Is allowed/has permission to:

- Go to the bathroom
- Go to the nurse
- Wear a head covering
- Carry a backpack/purse/bag
- Eat/drink as needed
- Access to technology/medical equipment as needed (e.g. cell phone)
- \_\_\_\_\_

Signed by Principal (or designee) \_\_\_\_\_

Blank - back of hall pass

## Hall Pass

This student \_\_\_\_\_

Is allowed/has permission to:

- Go to the bathroom
- Go to the nurse
- Wear a head covering
- Carry a backpack/purse/bag
- Eat/drink as needed
- Access to technology/medical equipment as needed (e.g. cell phone)
- \_\_\_\_\_

Signed by Principal (or designee) \_\_\_\_\_

## Hall Pass

This student \_\_\_\_\_

Is allowed/has permission to:

- Go to the bathroom
- Go to the nurse
- Wear a head covering
- Carry a backpack/purse/bag
- Eat/drink as needed
- Access to technology/medical equipment as needed (e.g. cell phone)
- \_\_\_\_\_

Signed by Principal (or designee) \_\_\_\_\_

Blank - back of hall pass



# Education: A Comparison of ADA, IDEA and Section 504

This document compares provisions of the Americans with Disabilities Act (ADA), the Individuals with Disabilities Education Act (IDEA), and Section 504 of the Rehabilitation Act (504).

	Americans with Disabilities Act (ADA)	Individuals with Disabilities Education Act (IDEA)	Rehabilitation Act of 1973, Section 504
<b>Type and Purpose</b>	This civil rights law prohibits discrimination on the basis of disability in employment, public services, and public accommodations.	This education act provides federal financial assistance to state and local education agencies to guarantee special education and related services for eligible children with disabilities.	This civil rights law prohibits discrimination on the basis of disability in programs and activities, public and private, that receive federal financial assistance.
<b>Who Is Protected?</b>	Any qualified individual who: (1) has a physical or mental impairment that substantially limits one or more major life activities; or (2) has a record of such impairment; or (3) is regarded as having such an impairment. Major life activities include walking, seeing, hearing, speaking, breathing, learning, working, caring for oneself, and performing manual tasks.	Children ages 3-21 in K-12 education who are determined by a multidisciplinary team to be eligible within one or more of 13 specific disability categories and who need special education and related services. Categories include autism, deafness, deaf-blindness, hearing impairments, intellectual disabilities, multiple disabilities, orthopedic impairments, other health impairments*, serious emotional disturbance, specific learning disabilities, speech or language impairments, traumatic brain injury, and visual impairments.  *Cancer typically falls under the OHI category when evaluating for special education	Any qualified person who (1) has a physical or mental impairment that substantially limits one or more major life activities; or (2) has a record of such an impairment; or (3) is regarded as having such an impairment. Major life activities include walking, seeing, hearing, speaking, breathing, learning, working, caring for oneself, and performing manual tasks.

This document, adapted from “A Comparison of ADA, IDEA, and Section 504” ([dredf.org/legal-advocacy/laws/a-comparison-of-ada-idea-and-section-504/](http://dredf.org/legal-advocacy/laws/a-comparison-of-ada-idea-and-section-504/)) by the Disability Rights Education Defense Fund (DREDF), is provided by:

**Mid-Atlantic**



**Center**

**Mid-Atlantic ADA Center**

Information, guidance, and training on the Americans with Disabilities Act in DC, DE, MD, PA, VA, WV  
Toll-free: 1-800-949-4232 | Local: 301-217-0124 | Online: ADAinfo.org

The Mid-Atlantic ADA center is operated by TransCen, Inc., and funded by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR, grant number 90DPAD0008). NIDILRR is a Center within the Administration for Community Living (ACL) in the U.S. Department of Health and Human Services (HHS). These contents do not necessarily represent the policy of NIDILRR, ACL, or HHS, and you should not assume endorsement by the federal government.

	Americans with Disabilities Act (ADA)	Individuals with Disabilities Education Act (IDEA)	Rehabilitation Act of 1973, Section 504
<b>Does It Provide for a Free, Appropriate Public Education (FAPE)?</b>	Not directly. However, ADA does cover all public schools and educational programs, as well as private nonsectarian schools. ADA requires covered entities to ensure access to facilities and programs; make reasonable modifications to policies, practices, and procedures; and provide auxiliary aids and services to ensure effective communication with individuals with disabilities.	Yes. A FAPE includes special education and related services. Special education means “specially designed instruction at no cost to the parents, to meet the unique needs of the child with a disability...” Related services (e.g., physical therapy, speech therapy, counseling*) are provided if students require them in order to benefit from specially designed instruction. IDEA requires the development of an Individualized Education Program (IEP) with specific participants.  *Related services may vary in different states.	Not directly. However, it does require that students with disabilities be provided an education comparable to that provided to students without disabilities. Development of a plan is required, although a written document is not mandated. An Individualized Education Program (IEP) may be used for the 504 plan. Amendments though the Workforce Innovation and Opportunity Act (WIOA) provide for enhanced vocational rehabilitation services to facilitate transition from high school and job readiness.
<b>Is Funding Provided to Implement Services?</b>	No, but limited tax incentives may be available for improving access. Also, many federal agencies provide grant funds to support training and to provide technical assistance to public and private entities.	Yes. IDEA provides federal funds under Parts B and C to assist states and local education agencies in meeting requirements to serve infants, toddlers, and youth with disabilities.	No. State and local jurisdictions have responsibility. IDEA funds may not be used to serve children found eligible only under Section 504.
<b>Procedural Safeguards</b>	The ADA does not specify procedural safeguards related to special education; it does detail administrative complaint procedures, and consequences for noncompliance.	IDEA requires written notice to parents regarding identification, evaluation, and/or placement. Written notice must also be given prior to any change in placement. The Act specifies the required components of the written notices.	Section 504 requires notice to parents regarding identification, evaluation and/or placements. Written notice is recommended. Notice must be given only before a “significant change” in placement. Following IDEA procedural safeguards is one way to comply with Section 504 mandates.

	Americans with Disabilities Act (ADA)	Individuals with Disabilities Education Act (IDEA)	Rehabilitation Act of 1973, Section 504
<b>Evaluation and Placement Procedures</b>	<p>The ADA does not specify evaluation and placement procedures. It does provide for accessible programs and services, effective communication, and reasonable modifications to policies, practices, and procedures. Examples may include redesigning equipment, assigning aides, providing written communication in alternative formats, modifying tests, reassigning services to accessible locations, altering existing facilities, and building new facilities.</p>	<p>A comprehensive evaluation by a multidisciplinary team is needed; parental consent is required. Reevaluations must be conducted at least every 3 years. For evaluation and placement decisions, more than one single procedure or information source must be used; information from all sources must be documented and carefully considered; the eligibility decision must be made by a group of people who know about the student, the evaluation data, and placement options; and the placement must serve the student in the least restrictive environment. An IEP meeting is required before any change in placement.</p>	<p>Section 504 requires only notice, not consent, for evaluation. It is recommended that districts obtain parental consent. Evaluation and placement procedures require that information be obtained from a variety of sources; that all data are documented and considered; and that decisions are made by a group of people who know about the student, evaluation data, and placement options. Students with disabilities must be educated with their non-disabled peers to the maximum extent appropriate. No meeting is required for a change in placement.</p>
<b>Due Process</b>	<p>The ADA does not delineate specific due process procedures. People with disabilities have the same remedies that are available under Title VII of the Civil Rights Act. Individuals may file a complaint with the relevant federal agency or a claim in federal court. Enforcement agencies encourage informal mediation and voluntary compliance.</p>	<p>IDEA delineates specific requirements for local education agencies to provide impartial hearings for parents who disagree with the identification, evaluation, or placement of a child.</p>	<p>Section 504 requires local education agencies to provide impartial hearings for parents who disagree with the identification, evaluation, or placement of a student. Parents must have an opportunity to participate in the hearing process and to be represented by counsel. Beyond this, due process details are left to the discretion of the local education agency. It is recommended that districts develop policy guidelines and procedures.</p>




## More Information About Common Cancer Treatments

**Chemotherapy.** Chemotherapy is a treatment for cancer using chemicals that are toxic to cells. Chemotherapy drugs are administered into the blood stream through a vein, injected into the muscle or under the skin, taken orally, or may be introduced into the spinal fluid by a lumbar puncture. These medications can be given alone, or a combination of them may be used. Based on the type of cancer a child has and where it is located, children may be assigned to a “treatment protocol” that is being used in a national or local program to improve care for that disease.

Many chemotherapy drugs can cause unpleasant side effects such as nausea, vomiting, fatigue, anemia, gastrointestinal symptoms, and hair loss. The recent development of new medications to treat these complications has greatly improved the quality of life for patients going through chemotherapy. Chemotherapy may also affect fertility; it’s important for the patient to talk with their oncologist to learn about the specific side effects their individualized treatment may have now and in the future.


There are various devices available to make the administration of chemotherapy medicines easier and less painful. These semi-permanent devices are commonly called “central line catheters”; they are long, thin, tubes placed into a larger vein and can remain there a lot longer than the typical IV. These devices are usually covered under clothing and require no special attention at school; though care should be taken to make sure the catheter is not hit or pulled on. Some examples of these catheters include:

- PICC line - often placed in the mid to upper arm. Some of the tubing “lumens” remain outside the body.
- Port-a-Cath - placed under the skin on the chest. There may be a small bump visible under the skin where the Port is.
- Broviac® - placed on the chest. Some of the tubing “lumens” remain outside the body.

 **Read more about methods of administration at [www.LLS.org/DrugAdmin](http://www.LLS.org/DrugAdmin)**

**Radiation Therapy (RT).** Radiation therapy, also known as “radiotherapy,” uses high energy x-rays or other types of radiation to kill cancer cells in a small, targeted area of the body. Since radiation can also harm healthy cells, whenever possible, RT is directed only at the affected areas where the cancer is, to reduce long-term side effects. To treat childhood cancers, radiation therapy is most often used in conjunction with chemotherapy.

Common side effects, such as fatigue, skin problems and hair loss, are temporary and generally disappear over time once treatment has ended. However, some side effects may appear months or years later. Depending on the location where the RT was administered, these late effects can include skin discoloration, cognitive changes, dental problems, hearing loss, less active thyroid gland, heart disease, infertility and secondary cancer. Radiation of the brain has also been associated with learning problems in many children.

 **Visit [www.LLS.org/booklets](http://www.LLS.org/booklets) to view *External Beam Radiation Therapy for more information.***

**Stem Cell Transplant.** To improve the chances of achieving remission (absence of disease) or cure (long-term or permanent remission), a stem cell transplant (SCT) may be recommended. A stem cell transplant (also called a bone marrow transplant) is the process of replacing unhealthy bone marrow with healthy bone marrow.

There are 2 main types of SCT:


- Autologous transplantation uses the patient's own stem cells. These cells are collected from the patient.
- Allogeneic transplantation uses stem cells from a donor. A donor may be a family member or someone who is not related to the patient.

Before SCT, the patient receives high doses of chemotherapy, and sometimes radiation therapy, to prepare the body for transplantation. This is called conditioning treatment. The conditioning treatment can be very hard on a patient's body and can lead to severe side effects and complications.

There are many immediate and long-term complications that can arise due to this procedure. The child may experience low blood cell counts (leading to a high risk for infection, anemia, easy bruising and bleeding), extreme tiredness, mouth sores, skin rashes, stomach upset and other effects. One potentially serious complication of an allogeneic transplant is called graft-versus-host disease (GVHD). GVHD occurs when the donor cells view the patient cells as foreign, and attack and damage them.

GVHD can be mild, moderate or severe and can involve a single organ or several organs.

A child who undergoes a stem cell transplant will face extended hospitalization, isolation and convalescence. Once allowed to return home, the child will likely have restrictions put in place to limit their exposure to infections. The child's immune system may take months, up to 1-2 years to fully recover; they may not be allowed to return to in-person learning during this recovery period.

 Visit [www.LLS.org/booklets](http://www.LLS.org/booklets) to view *Blood and Marrow Stem Cell Transplantation* for more information.

**Surgery.** Historically, surgical removal had been the primary treatment for solid tumor cancer. Surgery is performed:

- To determine if a tumor is malignant (cancerous) or benign (non-cancerous)
- To remove the tumor if cancer cells are found
- With the goal of preventing cancer cells from spreading to surrounding tissues or organs.

Surgery is often combined with radiation and chemotherapy. Some surgical procedures, such as limb amputation, can cause significant physical and psychological trauma in children. New surgical techniques and procedures continue to evolve, such as implants of artificial bones and advanced brain surgeries.

### **Targeted Therapy/Biotherapy/Immunotherapy.**

Cancer is a complex genetic disease. The staggering breakthroughs in molecular medicine and technology have given scientists the ability to work on the minute level of the human gene and many of the newest emerging cancer treatments are described as targeted, biotherapy or immunotherapy. Cancer researchers are beginning to understand the genetic underpinnings of a cancer cell. Scientists are decoding the abnormalities in the DNA that lead to the development of cancer, and by using this science (often in conjunction with other traditional treatments like chemotherapy) more challenging cancers are finding treatments all the time.

Biomarker testing (also called genomic testing or molecular profiling) is a way to look for genes, proteins and other substances in or on the surface of a person's cancer cells. This information helps doctors tailor treatment to the individual's cancer.

Targeted therapy can work by interfering with the molecules that control how cancer cells grow, divide and spread. Immunotherapy or biotherapy treatments use the body's own immune system to fight cancer cells by stimulating or suppressing parts of the immune system. The normal function of the immune system is to detect and destroy abnormal cells. However, sometimes cancer cells can avoid destruction. Immunotherapy can help by marking certain cancer cells to be easier to detect; blocking immune checkpoints to allow immune cells to respond more strongly; or by boosting the natural ability of certain cells to fight cancer. There are many types of these therapies. Their side effects can range from very mild to flu

like symptoms, injection site rash, or even more serious acute allergic-like or cytokine release syndromes.

## **Common Procedures Used in Cancer Care**

- ▶ See **Understanding Labs and Imaging Tests** at [www.LLS.org/booklets](http://www.LLS.org/booklets) for information on a number of diagnostic and monitoring tests used in cancer care, including bone marrow biopsy.
- ▶ Visit [www.LLS.org/3D](http://www.LLS.org/3D) to view 3D models that explain various tests, such as a bone marrow biopsy and cell development.

## LLS Resources

**The Trish Greene Back to School Program For Children With Cancer.** Free information and materials for parents and educators to help children have a smooth transition from active treatment back to school.

<http://www.LLS.org/SchoolResources>

**Staying Connected®: Facilitating the Learning Experience During and After Cancer Treatment.** This free 6.5 hour online continuing education (CE) course is designed for school nurses, social workers, teachers, school counselors and other school and college personnel. The purpose is to educate school and college personnel on the effects of childhood, adolescent and young adult cancer treatment to improve the learning experience during and after cancer treatment. Includes access to a resource list.

<http://www.LLS.org/StayingConnected>

**LLS Scholarship for Blood Cancer Survivors.** Provides up to \$7,500 to cover tuition for virtual or in-person vocational, two-year, or four-year undergraduate education for one year.

<https://www.LLS.org/Scholarship>

**Wiskurs Emotion Flipbook.** Kids can pick the “purrfect” Wiskurs image to express their mood.

Visit [www.LLS.org/Booklets](http://www.LLS.org/Booklets) to view or order the flipbook.

**Children’s Book Trilogy: *Stars Will Twinkle, The Sun Will Shine.***

Follow Olivia and her family in this 3-book series as Olivia is diagnosed with leukemia, goes to the hospital for treatment, and returns to school.

Visit [www.LLS.org/Booklets](http://www.LLS.org/Booklets) for a preview or to order.

## Other Resources

**American Cancer Society and American Society of Clinical Oncology.** The American Cancer Society (ACS) and the American Society of Clinical Oncology (ASCO) are collaborating to make it simpler for patients to find authoritative cancer information online.

[www.cancer.org](http://www.cancer.org)

**Livestrong at School.** When a parent, sibling, family member or friend is diagnosed with cancer, school age children need support. Livestrong has created a curriculum designed to help educators, parents and caregivers teach children about cancer in a way that is inspiring and empowering. Livestrong at School offers age-appropriate lessons for grades K-12 to help children understand the cancer journey.

<https://www.livestrong.org/school>



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Contact us at **800.955.4572** or **[www.LLS.org/InformationSpecialists](http://www.LLS.org/InformationSpecialists)**



The Leukemia & Lymphoma Society® team consists of highly trained oncology social workers and nurses who are available by phone, email and live chat 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 individualized clinical-trials searches
- Get connected to resources



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**JUDE**

leukemia survivor



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](http://www.LLS.org).