

# 10

## SCHOOL



Children benefit from continuing their education after a cancer diagnosis. School and learning helps children maintain a sense of normalcy. Inform your child's school teachers, nurses and guidance counselors about your child's diagnosis as soon as you can. Talk to a member of the healthcare team, such as a child-life specialist or social worker, about the options available for your child to continue his or her education. Many children's hospitals have education (school) liaisons. Education liaisons are professionals who can work with you, your child's healthcare team and the school to coordinate continuing education and his or her return to school.

**Education Needs While Your Child Is Out of School.** If your child is unable to go to school during treatment, there are resources available to help your child continue to receive an education so that he or she will not fall behind in his or her studies.

**Inpatient Education.** Many children's hospitals have part or full-time teachers available to work with students while they are hospitalized. If the hospital or treatment center does not have in-house teachers available, work with a child-life specialist or social worker to arrange for a teacher from the local school district to visit your child. While your child is in the hospital, school time tends to be about an hour a day.

**Homebound Education.** If your child is not in the hospital but isn't yet well enough to return to school, homebound instruction is an option. Your child's school district can provide a teacher to come to your home on a regular schedule to teach your child. Programs and rules differ by state and school district. A child who will be out of school for 3 to 4 weeks or longer may be eligible for a homebound teacher. Homebound teachers typically coordinate with your child's regular classroom teacher to plan similar lessons and assignments.

**Adaptive Interactive Virtual Technologies (AiVTs).** If your child is homebound, AiVTs may provide new ways to help continue your child's education. With AiVT, your child can receive an education that is as close as possible to the education he or she would be getting if he or she was actually present in the school. One example is an AiVT device that is similar in size to a computer monitor and provides high quality input/output with a wide field of vision. The device is put on a cart and moved between classrooms. The use of AiVT is becoming a more accessible and practical option to connect homebound and hospitalized children to their classrooms. When health permits, your child can attend school from the home or hospital and interact with his or her peers in real time, during regular school hours.

### TIP:

Even if your child is not attending school full time, if approved by the healthcare team, he or she may be able to visit the classroom for special events to stay connected with classmates and teachers.

**Returning to School.** School is a place for learning and fun so children benefit from returning to their classrooms as soon as medically possible. Most children who have cancer will attend school at least some of the time during their treatment. Yet, returning to school after a diagnosis of cancer can be a tough adjustment. Your child may have reservations about returning to school, including fears about

- The reaction of friends and other children at school
- Missed schoolwork and social activities
- Changes in his or her abilities
- Changes in his or her appearance

Discuss any fears your child may have before he or she goes back to school. Help him or her develop coping strategies for situations that he or she might face.

Talk to the school administrators about adjustments to schedules and other options available for your child. If your child has been out of the classroom for an extended time, it may be helpful to ease him or her back into full-time school slowly. For example, your child may attend school for half days or every other day during the first weeks back.

Take the following steps to ensure that your child gets the support that he or she needs at school:

- Meet with school administrators, teachers, counselors and the school nurse to discuss your child's medical condition, and address any special needs or concerns with them. Discuss any evaluations that may need to be done to provide your child with extra support, such as neuropsychological testing (see **Neuropsychological Testing** on page 3) or other educational interventions needed (see **Individualized Education Plan [IEP]** and **Section 504** on page 4). Ask that school staff members inform you if any new issues arise.
- Work with the healthcare team and the school nurse to create a care plan that addresses your child's medical needs during school hours. For example, your child may need to take medication at school. These may be daily medications or medications taken as needed (for example, if your child feels nauseated). If your child has a catheter in place or some other medical device make sure the school nurse knows how to care for the device. The care plan should also include a list of issues that can come up, reasons to contact you, and when to call emergency care. Fill out any paperwork required by the school. For example, you may need to sign a permission form to allow school staff to give medications to your child.
- Ask your child's doctor to write a letter outlining your child's physical limitations or medical needs, such as the need for an extra snack or cool drink, extra bathroom breaks, and/or a safe place to rest, as needed. Your child may also need modifications for recess or physical education (PE) classes. Meet with school administrators and teachers to discuss these needs and how they will be accommodated. Ask your child's healthcare team for expertise in explaining this information.
- To reduce your child's anxiety, arrange meetings with his or her teacher(s) before he or she goes back to school.
- Ask about providing an age-appropriate class presentation, either before or after your child returns to school, to educate friends and classmates about the illness. Ask the healthcare team for assistance. Some treatment centers have healthcare professionals available who can lead these presentations or have versions of these presentations available. Ask your child if he or she would like to be present for the presentation. If so, your child can participate in ways that are comfortable for him or her.



For more information about returning to school, visit [www.LLS.org/booklets](http://www.LLS.org/booklets) to view **Learning and Living with Cancer**.



Use **Worksheet 15: Information for School Staff** to help you communicate your child's needs to his or her teacher, school nurse, and/or school administration.

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**The Trish Greene Back to School Program for Children With Cancer.** This LLS program offers free information and materials to parents and educators that can help ease a child back into school. The program was developed to encourage communication among parents, patients, healthcare professionals and school personnel to assure that children have a smooth transition from undergoing active treatment to returning to school. Call an LLS Information Specialist at **(800) 955-4572** to learn more.

**Long-term and Late Effects and Their Impact on Learning.** Cancer treatment can cause side effects that are ongoing or that appear years after treatment ends. These can include changes to your child's mental abilities (cognitive effects), which can impact learning. Children who receive central nervous system-directed therapy, such as intrathecal

chemotherapy (drugs injected directly into the spinal fluid) or radiation to the brain, are at the highest risk for cognitive effects. Children who receive cancer treatment at a young age are also at higher risk.

**Learning (Cognitive) Effects.** Cognitive effects affect mental abilities such as thinking, concentration and memory. Areas of learning that may be affected include

- Organizing materials—the student may often misplace homework assignments or leave school materials in disarray.
- Organizing thoughts—it may be difficult for the student to write or speak in clear and accurate sentences.
- Reading decoding and/or reading comprehension
- Processing speed—the student may work more slowly than peers.
- Retaining visual memory for things that are new—the student may struggle to decode letters and numbers or read music.
- Understanding math concepts or remembering math facts
- Following instructions, especially those for multistep projects or activities
- Staying focused or paying attention for long periods of time

**Physical Effects.** Some physical late effects may also affect schooling, including

- Fatigue
- Problems with eyesight or hearing
- Mobility issues or problems with fine motor skills
- Neuropathy (numbness, tingling, weakness and pain, most often in the hands or feet)

**Psychological Effects.** There can also be psychological late effects of cancer treatment such as changes in mood, feelings or behavior, including depression or posttraumatic stress disorder (PTSD). Changes in mental health can impact a student's ability and motivation to do well in school.

**Neuropsychological Testing.** Any child who is at risk for cognitive effects or is having difficulty in school should have neuropsychological testing done by a licensed pediatric psychologist or neuropsychologist to check for possible learning challenges. Ask your child's healthcare team for a referral. Find out if neuropsychological testing is covered by insurance as it can be expensive. When testing is complete, schedule time for the neuropsychologist to explain the results and make any recommendations for adjustments or accommodations that can support your child at school. If needed, ask the neuropsychologist to help explain the recommendations to the school staff. These recommendations will also be used to help determine if your child needs a formal education plan such as an Individualized Education Plan (IEP) or 504 Plan. These plans are explained in the following sections.

**School Psychological Assessment.** If neuropsychological testing is not an option, a school-based assessment may help to determine your child's educational needs or may be required by the school. These assessments are usually performed to determine if your child is eligible for special education programs. Generally, school-based assessments are less effective at linking cancer treatment with learning or behavior problems. Ask your child's school administrators for more information.

### Questions to Ask Members of the Healthcare Team

- Can you refer my child for neuropsychological testing?
- Will insurance cover the cost? If so, under what conditions? (For example, testing may be covered while a child is inpatient.)
- Who will help me explain the results to teachers and staff at my child's school?
- When would it be appropriate for my child to be retested?

**Legal Protections.** Children affected by cancer treatment may have physical, social/emotional or learning disabilities. The following federal laws help protect the rights of students with disabilities, including those with educational needs resulting from cancer treatment.

**The Individuals With Disabilities Education Act (IDEA).** This law protects students (aged 3 to 21 years) by ensuring that public schools, colleges and universities provide a free and appropriate education for disabled students, just as they do for other children. Part C of IDEA outlines early intervention services for children (birth to 2 years old) and their parents.

**Individualized Education Plan (IEP).** An IEP under the Individuals With Disabilities Education Act (IDEA) outlines a plan for public schools to accommodate a student's individual needs. To create an IEP for your child, you must request one in writing. A member of your child's healthcare team, such as the doctor, nurse practitioner, social worker or psychologist, can help you with the process. The IEP will be created by a group of people. It may include the principal; teachers; a school counselor; a school nurse; a healthcare team member; and anyone else that you choose, such as a friend, family member or advocate. The plan will need to be evaluated and updated periodically as your child's needs change.

**Section 504.** This is a civil rights law that protects the rights of individuals with disabilities in programs and activities that receive federal assistance from the Department of Education. A 504 Plan covers students with eligible disabilities, including cancer. The disability must substantially limit one or more major life activities. An evaluation is needed to determine eligibility and the plan is updated periodically as your child's needs change. A 504 Plan can follow your child into college.

Many childhood cancer survivors qualify for intervention or adaptations under one of these laws. Some children only require assistance during active treatment while others need help years beyond treatment. If your child does not meet IDEA eligibility, Section 504 accommodations could be considered. To find out which approach is the best fit for your child, work closely with your child's healthcare team and school staff.



For a detailed comparison of IDEA and Section 504 and examples of the types of accommodations that may benefit your child, visit [www.LLS.org/booklets](http://www.LLS.org/booklets) to view *Learning and Living With Cancer*.

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**Preventing Illness at School.** Even if the healthcare team has cleared your child to return to school after cancer treatment, he or she may still be especially susceptible to illness and infection. Talk to your child's teachers and the school nurse about ways to help reduce the risk of infection and illnesses that can be picked up in the classroom. The following measures can help prevent the spread of infection at school:

- Request that the school administration and teachers
  - Provide frequent opportunities for students to wash their hands. Teach students how to wash hands with soap and warm water for 20 seconds. Students should always wash their hands after using the restroom, before eating, and after recess or physical education (PE).
  - Make gel or liquid hand sanitizer available in the classroom. Ask if your child can keep a bottle at his or her desk.
  - Use disinfecting wipes to wipe down desks and school supplies.
- If another student is sick, ask the teacher if your child may sit in another area of the classroom.
- Pack your child's lunch safely to decrease the risk of foodborne illness. Tell your child not to share foods or drinks with others.
- Ask the healthcare team if your child may participate in recess or PE. Let the school know of any restrictions.

- Make sure your child’s teacher and the school nurse have the correct phone numbers to contact you and/or your co-parent. Provide a list of reasons for why you should be contacted immediately (for example, if your child has a fever of 100.4°F or greater or if your child may have been exposed to chicken pox, shingles, pink eye, strep throat, lice or other illnesses). You can ask members of the healthcare team to provide a list of reasons.
- Remember your child’s annual flu shot. Your child should receive the flu shot, not the nasal spray vaccine. The nasal spray vaccine contains the live virus. The live virus can be dangerous for immunosuppressed patients. Ask the healthcare team what other immunizations your child needs.

**Bullying.** Some children with lasting effects of their disease and treatment are victims of bullying. Bullying can happen when a child is different in some way from his or her classmates or if a child changes physically or socially. In these situations, it helps to have the teacher or guidance counselor talk with the other children in the class and remind them of their classmate’s journey with cancer and to explain the reasons why he or she may seem different. Often, once children understand the unique needs or situation of their classmate, the bullying stops.



Visit [www.stopbullying.gov](http://www.stopbullying.gov) for bullying prevention resources.

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**Preparing for Adulthood.** Your child’s transition to adult life could include college; vocational, technical, or adult education; internships; apprenticeships; employment and independent living.

Ask your child about his or her interests, career goals, hopes and dreams. When you plan ahead, you can explore options and gather the support your child needs.

**College.** If your child plans to attend college, his or her high school guidance counselor can help identify colleges that fit your child’s needs and goals. Your child also may be eligible for scholarships or financial aid.

When researching different colleges, your child may want to keep in mind the following questions:

- Does the school have a good track record of serving the needs of students with disabilities?
- Does the school offer online classes? (Online classes can be a good alternative to physically attending class.)
- Is the school located near a cancer treatment center and/or cancer survivorship clinic that will make it easy to continue follow-up care?
  - Will the health insurance plan cover care provided by the center or clinic?
- What financial aid or scholarships are available?
- Would a community or technical college offer similar programs?

**Entrance Exams.** If your child has an Individualized Education Plan (IEP) or 504 Plan in high school, he or she may qualify for accommodations for college entrance examinations, such as the Scholastic Aptitude Test (SAT), and for additional accommodations at the postsecondary level. Work closely with a guidance counselor to determine when to apply for accommodations and what documentation is required to obtain them.

**Scholarships.** To help childhood cancer survivors offset the costs of education, scholarships and grants are sometimes available. Visit [www.LLS.org/scholarships](http://www.LLS.org/scholarships) to view a list of potential scholarships.

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

For more career resources for your child, visit

- Triage Cancer: <https://triagecancer.org/>
- Cancer and Careers: [www.cancerandcareers.org](http://www.cancerandcareers.org)



To learn more about all school topics, visit [www.LLS.org/booklets](http://www.LLS.org/booklets) to view ***Learning and Living With Cancer.***

For more resources, call an LLS Information Specialist at **(800) 955-4572** or visit [www.LLS.org/BackToSchool](http://www.LLS.org/BackToSchool) for information about available programs and materials.

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