

# 3 WHEN YOUR CHILD HAS CANCER

Visit [www.LLS.org/CaregiverWorkbook](http://www.LLS.org/CaregiverWorkbook) to access all chapters and worksheets.

Hearing that your child has cancer is terrifying for any parent. Today, most childhood cancer patients can expect to have full and productive lives. Many childhood cancer survivors return to school, attend college, enter the workforce, marry and become parents. Nevertheless, being vigilant about follow-up care, being aware of long-term and late effects of treatment, helping your child return to school and even dealing with your emotions are all things you'll need to manage.

**Managing Your Emotions.** You are likely to experience a wide range of emotions from the time your child is diagnosed with cancer, throughout treatment and beyond. These emotions may include shock, denial, fear, anger, guilt and sadness. You may feel that life for your child and family will never be the same. Allow yourself to feel sad. Understand that you are not to blame for your child's diagnosis. Over time, you'll find ways to adapt and gradually develop a new sense of normalcy for you and your family.

All of these feelings are to be expected, but if you feel consumed by feelings or are unable to function, seek professional help. Psychologists, social workers and spiritual advisers may also help you come to terms with your child's diagnosis. It's important to work through your feelings so you can help your child to cope and you can continue to manage other aspects of family life and work.

**Talking to Your Child About His or Her Diagnosis.** Regardless of age, children are usually aware when their health causes their parents concern. Your child may experience a variety of emotions, such as anger, guilt, fear, anxiety and sadness, all in quick succession.

Some parents wish to shield their child from information about the illness and its treatment. Keep in mind that your child will use his or her imagination to fill in what he or she perceives as gaps of information. Sharing information about the illness and treatment helps your child build trust in both you and the members of the treatment team so that he or she feels comfortable talking about fears and concerns. Encourage your child to talk about his or her concerns and ask questions.

Introduce your child to treatment team members who provide psychosocial support, such as a psychologist, nurse, social worker and child-life specialist. In addition to helping you explain the illness and its treatment to your child, they can help your child better understand his or her disease through play or other activities.

**Age-Appropriate Discussion.** Keep the discussion age appropriate when you talk to your child about his or her diagnosis. Consider the following guidelines by age.

## TIP:

For children of any age, if you notice troubling changes in mood or behavior, reach out to the healthcare team for help.

### **Baby/Toddler (0 to 3 years)**

- Children this young do not have an understanding of illness or cancer. However, they are aware of changes to routines and the feelings of people around them.
- Children in this age-group may be afraid of the medical staff and medical procedures.
- They may be afraid of abandonment or being left at the hospital. Offer physical and verbal reassurance.

### **Preschool/Kindergarten (4 to 6 years)**

- Children may have some understanding of an illness like a cold, but not grasp the implications of a serious illness.
- Children's primary focus will be the symptoms they are experiencing in any specific moment.
- Children in this age-group may be afraid of pain, so explain tests or treatments to them in advance.
- Assure your child that he or she did nothing wrong to cause the cancer.

### **Elementary/Middle School (7 to 12 years)**

- Children in this age-group may have a better understanding of serious illness, but not specifically cancer. They may have heard things about cancer at school, from friends, on TV or they may have found information on the Internet. Ask your child what he or she knows and correct any misunderstandings, especially those that cause distress.
- Explain tests, treatments, and other medical procedures in advance. Your child may be afraid of pain and resist some tests or procedures. Be honest. If a procedure might be painful, work with the healthcare team and decide how to explain what will be done to lessen pain and why the procedure is important.
- Talk to your child, in advance, about possible changes to his or her physical appearance.
- You may see signs of regression in a child's behavior, such as thumb sucking, bed wetting or tantrums.
- A child may use play to process the information, play-acting doctor/patient scenarios, for example.
- If the cancer treatment will result in any changes to the child's daily routine, explain them ahead of time so that the child knows what to expect.

### **High School/Teenagers (13 to 18 years)**

- Teenagers understand more about cancer and may want to know more. You may still need to correct any misinformation your teen has heard about cancer from school, friends, TV, movies or has found online.
- Teenagers may want to participate in decisions about their treatment. Include them in discussions with members of the healthcare team, as appropriate. You may need to discuss fertility preservation with teenagers. Some cancer treatments can affect fertility. Fertility preservation, such as egg or sperm banking, needs to be done before treatment that can harm fertility begins. Enlist members of the healthcare team to help with this sensitive discussion.
- People in this age-group may also be very concerned about changes to their physical appearance, such as hair loss and losing or gaining weight, as well as worrying about how their peers will react to the changes.
- As teenagers struggle to find independence, a cancer diagnosis may feel like a setback that can lead to feelings of frustration and anger. They may try to test their boundaries or engage in risky behaviors like drinking, drug use, or sex.

**Ways to Help Your Child Cope.** It will help your child cope with his or her diagnosis if you:

- Provide structure to increase your child’s sense of control. Children crave structure in their environment. Make things as consistent as possible. For example, plan a regular routine that you will follow during your time together in the hospital or clinic.
- Acknowledge and praise your child when he or she is doing difficult things. Intermittent praise is the best way to reinforce the desirable behaviors that you want to see in your child.
- Use the same consequences for bad or inappropriate behavior as you did before your child was diagnosed with cancer. Consistency will maintain structure and normalcy.
- Show that you respect your child’s anger, worry, sadness or fear. Give your child appropriate outlets for expressing these feelings, such as drawing or keeping a journal.
- Keep your child busy with activities during treatment to take his or her mind off difficult and unpleasant experiences.
- Help your child to stay connected with friends from home and school with phone calls, emails, or visits, if possible.
- Ask for professional assistance for your child if he or she is having an especially difficult time adjusting to the cancer diagnosis and its treatment.

**Siblings.** When a child is diagnosed with cancer, everyone in his or her family is affected by the experience, including the child’s brothers and sisters. Siblings can feel angry, anxious, lonely, sad, guilty, or even resentful of the new attention their sibling receives. You can help your children cope with a sibling’s diagnosis in some of the following ways:

- Give them the chance to talk about how the experience is affecting them.
- Be open and willing to answer questions about their brother or sister’s cancer and treatment.
- Reassure younger siblings that they cannot “catch” cancer from their brother or sister.
- Explain that their brother or sister didn’t do anything that caused the cancer.
- Warn siblings that their brother or sister may have less energy or lose his or her hair.
- Explain that other concerned family members and friends may ask them about their sibling’s diagnosis. Talk about appropriate responses.
- Remember that brothers and sisters still have their own problems, unrelated to their sibling’s cancer. Their problems are real and require your attention.
- Provide consistent, fair discipline to all your children, even though it may be more difficult right now.
- Let all your children know that you love them and are proud of them.

Siblings need to continue to go to school and participate in their usual activities, as much as possible. Ask friends, family, other parents, and teachers for help. However, disruptions to routines are inevitable, and siblings may feel lost or overlooked. Arrange for regular “alone time” with each child.

Make sure the school is aware of the diagnosis. Talk to the sibling’s teacher. Ask your hospital’s social worker or psychologist or your school psychologist whether your community offers any programs for siblings of children who have cancer.



SuperSibs, a program of Alex’s Lemonade Stand Foundation, provides programs and support for the siblings of children with cancer. Visit [www.alexlemonade.org/supersibs](http://www.alexlemonade.org/supersibs) to learn more.

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**School.** Most children who have cancer will attend school at least some of the time, both during and after their treatment. Let your child’s school teachers, nurses and guidance counselors know what’s happening. School is a place for learning and fun so children benefit from returning to their classrooms as soon as medically possible.

Yet, returning to school after cancer treatment can be a tough adjustment for young survivors. 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 he or she might face.

You'll need to ensure that your child's education is started, maintained or changed as needed. Take the following steps to ensure that your child gets the support that he or she needs at school:

- Meet with school administrators, teachers and counselors as soon as possible after diagnosis 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 physical therapy, occupational therapy, or other educational interventions needed.
- Ask school staff members to promptly identify any issues that arise and provide you with relevant information.
- Let your child meet with his or her teacher(s) before returning to school to reduce anxiety.
- Ask your child's doctor to write a letter outlining your child's physical limitations or medical needs, such as the need for extra snacks, water or bathroom breaks. Meet with school administration and teachers to discuss these needs and how they will be accommodated. Ask the treatment team for expertise in explaining this information.
- Ask to give an age-appropriate class presentation, either before or after your child returns to school, to educate friends and classmates about the illness. Ask the treatment team for assistance. Some treatment centers have healthcare professionals available to lead these presentations or have versions of these presentations available.



Staying Connected is an educational program provided by LLS that walks school personnel and parents through the effects of cancer treatment that children may face, and introduces numerous resources that can help childhood cancer survivors flourish in the educational environment post-treatment. Call **(800) 955-4572** for schedule information.

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**Neuropsychological Testing.** Any child who is at risk for late effects or is having difficulty in school should have neuropsychological testing done by a licensed pediatric psychologist or neuropsychologist. Ask your medical team for a referral.

When testing is complete, schedule time for the neuropsychologist to explain the results and make any recommendations for adjustments that need to be made at school. This type of approach will benefit your child and limit frustration and struggles due to cognitive late effects. If needed, ask the neuropsychologist to help explain the recommendations to the school staff. As your child continues to grow, he or she may need to be retested, especially if you notice new cognitive changes or your child is struggling at school.

**Individualized Education Plan (IEP).** An IEP under the Individuals with Disabilities Education Act (IDEA) outlines a plan for public school children to accommodate their individual needs. To create an IEP for your child, you must request one in writing. A member of the treatment team, such as the doctor, 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 treatment 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 all eligible disabilities, including cancer. The disability must substantially limit one or more major life activities. An evaluation is needed for eligibility and updated periodically as your child's needs change.

**Adaptive Interactive Virtual Technologies (AiVT).** If your child is homebound, AiVT may provide new ways to help continue your child's education. One example of an AiVT device is a robot that can be controlled by a tablet or computer to move between the student's various classrooms. The use of AiVT is becoming a more accessible and practical option to connect homebound and hospitalized children to their classrooms. With AiVT, your child can receive as close to an equal education as possible, without actually being present in the school. 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.

**The Trish Greene Back to School Program.** The *Trish Greene Back to School Program* offers free information and materials to parents and educators that can help ease a child back into school after an absence. The program was developed to encourage communication among parents, young patients, healthcare professionals and school personnel to assure that children have a smooth transition from undergoing active treatment to settling back in school.



View, print or order the free LLS booklet *Learning and Living with Cancer* at [www.LLS.org/booklets](http://www.LLS.org/booklets) to learn more about neuropsychological testing and IEPs.



**For more information**

- Call an LLS Information Specialists at **(800) 955-4572** to learn more.
- Visit [www.LLS.org/backtoschool](http://www.LLS.org/backtoschool) for more information about these programs and available materials.

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**Long-Term and Late Effects of Childhood Cancer.** Treatment for childhood blood cancer involves risks for long-term and late effects that may affect

- Learning (cognitive effects)
- Physical development
- Fertility (ability to have biological children)
- Psychological development
- Risk of a secondary cancer.

Specific effects depend upon the child's age, gender, type of treatment and additional factors. The range and severity of potential long-term and late effects vary. Some children will have no significant effects or very mild effects, others may have serious complications.

However, early intervention and healthy lifestyle practices (not smoking, good nutrition, exercise, regular screenings and follow-up care) can help lessen the occurrence and/or severity of any late effects.

Ask your child's treatment team the following questions:

- What signs or symptoms indicate a long-term or late effect?
- Whom should I contact if my child develops any of these symptoms?
- What can we do to decrease the likelihood or severity of long-term or late effects?
- Can you provide printed lists of possible effects and signs or symptoms? What are the possible long-term and late effects my child may experience?
- Can you provide a list of routine screening tests and when they should start (for example, a mammogram)?

**Follow-up Care.** Follow-up care after treatment ends is a very important factor in your child's health and well-being. Even if your child is feeling well, keep all follow-up appointments with the oncology team.

Keep copies of all medical records, including dates and locations of treatment, specific drug and supportive therapies (such as blood transfusions), as well as dosages, specific sites and amounts of radiation therapy, if applicable. Keep copies of blood, marrow and imaging test (MRI, CT scan, x-ray) results. You and your child (when he or she is an adult) will need to share this information with future healthcare professionals.

Help your child develop and maintain a healthy lifestyle after treatment ends, including appropriate exercise, sun protection, good nutrition and not smoking. Enlist the help of health professionals, as needed.



If you would like to learn more about LLS's programs for parents and children or if you have any questions about blood cancer, you can contact an Information Specialist for much-needed support and information to guide you through your child's cancer journey. Call **(800) 955-4572**.



For more information, visit [www.LLS.org/booklets](http://www.LLS.org/booklets) to view, print or order the following free LLS booklets:

- *Back to School Resources brochure*
  - *Coping with Childhood Leukemia and Lymphoma*
  - *Learning & Living with Cancer: Advocating for Your Child's Educational Needs*
  - *Long-Term and Late Effects of Treatment for Childhood Leukemia and Lymphoma Facts*
  - *Pictures of My Journey Coloring Book*
  - *The Stem Cell Transplant Coloring Book.*
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