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## BEYOND TREATMENT



After active treatment ends, you may begin to recognize that there is no one set point at which your child's cancer experience ends. Resuming old routines and creating new ones is a gradual process. Even as your child returns to regular life, follow-up care is very important. In addition to practical changes to your and your child's daily lives, there may be emotional changes as well. You, your child and your family members will all need to learn to adjust to these changes.

**Post-treatment Care.** Once your child's disease is in remission, the pediatric hematologist-oncologist will continue to monitor your child's response to treatment and check for signs of relapse. Members of the healthcare team can also help manage any side effects that continue after treatment. It is very important to keep all follow-up appointments, even if your child is feeling well.

During the first year after treatment, your child will see members of the healthcare team frequently, but as time goes on, your child may need to be seen less often. Two years after the end of treatment, many childhood cancer survivors transition to receiving long-term, specialized care at a survivorship clinic (see **Survivorship Clinics** on page 5). However, the timeline can differ based on your child's unique needs and medical history.

Your child's healthcare team should also recommend a schedule for having your child's learning skills assessed. If your child appears to struggle with learning, special education accommodations can help.

**Appointment Anxiety.** Follow-up doctor visits may cause anxiety for both you and your child. Before doctor's visits, you are likely to worry that you will be told that the cancer has returned. Anxieties should lessen as time passes. Talk to members of the healthcare team or a child-life specialist about ways to cope with anxiety around follow-up visits.

### TIP:

When a person is diagnosed with cancer, they are considered a "survivor" at the time of diagnosis until the end of life. After a cancer diagnosis, some people feel empowered by the word "survivor," and use it to describe themselves. Some people may not feel comfortable using the word until after treatment ends. Others may prefer to use different words. You and your child may each have different feelings about using the word. The different opinions and feelings people have about using the term "survivor" are all valid. You may encounter the term used in different ways.

## Questions to Ask Members of the Healthcare Team

- Will you provide me with a written survivorship care plan?
- Which members of the healthcare team will be responsible for which aspects of my child's follow-up care?
- What should my child's pediatrician be watching for during appointments?
- Whom should I contact when I have questions?
- What are the signs and/or symptoms that may indicate a relapse or recurrence?
- What are the possible long-term and late effects of my child's treatment?
- What can be done to manage these side effects?
- Does my child need any immunizations?
- Are there any restrictions or precautions we should take at home, in activities or at school?
- What can I do to promote my child's well-being and encourage healthy lifestyle habits?
- Once my child becomes an adult, who can help with the transition from pediatric to adult healthcare?

**Immunization Schedule.** Immunizations help the body to build up a resistance to specific diseases. Most immunizations work by introducing a small, safe amount of the disease into the immune system. If the person has ever been exposed to the disease, the body's immune system already knows how to fight it. Most immunizations are vaccines given as either a shot or a series of shots.

Your child's vaccination schedule may have been interrupted due to cancer treatment. It is not safe to receive some vaccines during cancer treatment. Chemotherapy and other cancer treatments can weaken the immune system and may decrease the effectiveness of vaccines.

Children treated with an allogeneic stem cell transplant, which uses stem cells from a healthy donor, will need to be revaccinated, even if the child received the vaccines in the past. Children who did not receive an allogeneic stem cell transplant may not need to repeat all of the vaccines that they received in the past, but they may need new vaccines or boosters to complete the recommended vaccination schedule for their age-group.

**Antibody Titer Test.** After completing cancer treatment, the healthcare team may order an antibody titer test for your child. This test checks for the presence of antibodies in the blood. Antibodies are proteins that help the body fight against infection. The presence of specific antibodies in the blood can show whether or not your child has immunity to a certain disease. The results of the antibody titer test help the healthcare team to determine which vaccines or boosters your child needs.

The healthcare team will create a catch-up schedule for your child to receive the necessary vaccines. Depending on the treatment, some children can begin vaccinations 3 to 6 months after treatment ends. A child who has received a stem cell transplant may need to wait longer. The healthcare team that administered the stem cell transplant should be consulted to create an appropriate vaccination schedule for your child.



Use **Worksheet 8: Immunization Record** to keep up with your child's vaccines.

**Life After Treatment.** Many people refer to the adjustment after cancer treatment as finding a “new normal.” The new normal is a time of adjustment for parents and children. Although follow-up visits are important and will continue for life, when active treatment is over, a child is usually expected to return to typical childhood activities. This means readjusting to the home routine, social activities and school. Although the transition may go quite well overall, there are likely to be stressful times as your child deals with the challenges of multiple tasks and responsibilities.

**Emotional Challenges.** You may see changes in your child’s self-esteem during the return to normal life. A child who may have felt competent and secure prior to illness, or even during active treatment, may now feel insecure and more dependent. They may feel embarrassed because of changes in appearance and the responses of some friends or classmates. Your child may become more aware of the stresses they have experienced due to the illness and may begin to process the changes and losses that have occurred. Some childhood cancer survivors experience survivor’s guilt if they know someone for whom cancer treatment was not successful. After treatment, the child may also experience changes in attention from family members, caregivers and school staff as they begin to resume the roles of child, sibling, student and friend.

**Helping Your Child Transition.** Support at home will help your child navigate the challenges they may encounter on the road back to normal life. Provide structure for your child by establishing a routine to help their return to previous activities and cope with new experiences. You can help your child to cope with these challenges by:

- Establishing an after-school routine, such as doing their homework at the same time every day, a time for relaxing with a favorite show or activity, or dinner at a regular daily time
- Setting up a nightly bedtime routine that helps your child to get the proper amount of sleep and helps to make them feel safe
- Helping your child to identify goals as they resume daily home and school activities
- Reinforcing your child’s efforts to work toward achieving their goals
- Helping your child to recognize the progress that they are making
- Observing and recognizing changes in your child’s behavior, when and if they occur
- Talking to your child about their feelings and letting your child know that it will take time to adjust to all the changes that have taken place
- Providing your child with support and encouragement, and obtaining extra support from a therapist if problems persist. Feelings of anxiety, depression and recurrent thoughts or fears regarding the illness and its treatment should be explored.
  - Is your child anxious about going back to school and worrying about the reaction of their peers?
  - Are they having difficulty sleeping or frequent nightmares?
  - Is your child quick to have tantrums and are they frequently tearful?
  - Is your child spending more time alone?
- Letting your child know that you love and are proud of them

If your child seems to be having difficulty in these areas, they may need some additional support. Reach out to members of the healthcare team, such as a child-life specialist or psychologist as well as to teachers, coaches or guidance counselors, for help.

**Siblings.** Siblings may also struggle to adjust to life after a sibling has undergone treatment for cancer. Family dynamics between siblings can be complex and a cancer diagnosis for a sibling can complicate these relationships, and continue influencing them, even after treatment ends. During treatment, the child with the cancer diagnosis was likely to have been the focus of attention from parents, relatives and friends. The reactions of siblings may be different and will depend on their ages and understanding of the situation. However, the impact of feeling as though they were/ are a “secondary consideration” may stay with siblings into adulthood. Siblings may also be affected by the experience in other ways, such as wishing to pursue a career in healthcare. The suggestions in **Helping Your Child Transition** on page 3 can also be used to help siblings cope.



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

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**Challenges for Parents.** When your child finishes cancer treatment, you and your co-parent may feel a mix of emotions including happiness, relief, hope, anxiety and fear for the future. Fear of the cancer returning or a secondary cancer are universal fears among parents. You may miss the sense of security that seeing the healthcare team during treatment provided. You may worry that any change in your child’s well-being or mood is a sign of disease relapse. To help manage these feelings, talk to members of your child’s healthcare team about any of your fears.

- Ask your child’s healthcare team about the risk of relapse and what signs and/or symptoms may indicate a relapse.
- Ask who on the healthcare team you can call with questions and concerns.
- Try to fill the time that was once taken up with appointments and treatments with new activities for both you and your children.
- Find a support group for parents of childhood cancer survivors.
- Recognize that your fears and anxieties are a normal part of the healing process. However, if you feel that dealing with them is too much of a struggle, you may want to speak to a mental health professional.

Although you may feel a need to protect your child, try not to let this feeling stop you from allowing your child to grow, explore, learn, socialize with peers, and gain independence, as age appropriate.

**Survivorship Care Plan.** Generally, “survivorship” refers to the health and well-being of a person after cancer treatment. Your child’s oncologist will help create a survivorship care plan for your child to guide follow-up care. Share the survivorship care plan with any healthcare providers your child sees. Once your child moves into adult healthcare, make sure they have a copy of the survivorship care plan and a complete medical history to share with their future healthcare providers. The survivorship care plan should include the following information:

- List of all your child’s healthcare providers: pediatrician, hematologist-oncologist, radiation oncologist, etc.
- Diagnosis summary with specifics such as stage, sites of involvement, and molecular or genetic markers
- Treatment summary with specifics such as names of chemotherapy or other drugs received, radiation dosage and site, response to treatment and side effects
- Follow-up appointment schedule including the name of the coordinating provider and frequency
- Schedule for ongoing monitoring with recommended tests and frequency
- List of possible long-term and late effects
- Health and wellness lifestyle recommendations, such as nutrition, exercise, other cancer and disease screenings, and referrals to specialists (as needed) to assist with these recommendations



The Children's Oncology Group provides a downloadable Summary of Cancer Treatment template to fill out with the healthcare team. Visit [www.survivorshipguidelines.org](http://www.survivorshipguidelines.org) to download a template.

The Passport for Care® Survivor website offers free access to resources, education, and tools for survivorship for childhood cancer survivors. Visit <https://cancersurvivor.passportforcare.org/> to learn more.

For more general information on parenting and health and wellness for children, visit [www.healthychildren.org](http://www.healthychildren.org) from the American Academy of Pediatrics.

For healthy lifestyle recommendations, visit [www.LLS.org/booklets](http://www.LLS.org/booklets) to view **Healthy Behaviors**.

**Survivorship Workbook.** Use the free LLS Survivorship Workbook to collect all the important information you need as your child moves through diagnosis and treatment into post-treatment follow-up care.

In the workbook, you will find:

- Survivorship care plan worksheets
- Long-term and late effects information
- Healthy behavior recommendations
- Mental health exercises and information
- Resources for planning for the future

There are three versions of the workbook:

- A Workbook for Adults
- A Workbook for Young Adults
- A Workbook for Children and Adolescents

Visit [www.LLS.org/SurvivorshipWorkbook](http://www.LLS.org/SurvivorshipWorkbook) to learn more.

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**Survivorship Clinics.** Childhood cancer survivors have special lifelong healthcare needs. Many hospitals and treatment centers offer survivorship clinics that specialize in long-term, follow-up care for cancer survivors. Childhood cancer survivors often begin visiting a survivorship clinic 2 years after finishing treatment. However, the timeline can differ, based on your child's unique needs and medical history. Additionally, coordination between members of your child's cancer survivorship healthcare team and primary care pediatrician is essential.

Even if your child is feeling well, they should visit the survivorship clinic and their primary care pediatrician at least once a year for a complete physical examination and any additional tests. Regular visits allow the doctor to:

- Assess the full effects of therapy
- Identify and manage long-term and late effects of treatment (see **Long-term and Late Effects** on page 6)
- Detect and treat disease recurrence

In preparation for your child's visits, keep a record of the physical or emotional symptoms that your child experiences so that you can discuss them with members of the healthcare team.

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For a comprehensive list of survivorship care or long-term follow-up clinics for childhood cancer survivors, visit The National Children's Cancer Society at <https://thenccs.org/long-term-clinics/> for a list by state.

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If it is not possible for your child to visit a survivorship clinic for long-term follow-up care, it is very important to find a pediatrician who understands your child's previous cancer treatments and their associated risks. The pediatrician should also know the signs and/or symptoms of late effects and be able to track your child's health to make certain that the cancer is still in remission and has not relapsed.

**Long-term and Late Effects.** "Long-term effects" of cancer therapy are medical problems that persist for months or years after treatment ends. Examples of long-term effects are infertility, growth problems and treatment-related fatigue.

"Late effects" are medical problems that do not develop or become apparent until years after treatment ends. Examples of late effects include the development of a treatment-related cancer or heart disease. The long-term and late effects for survivors of childhood leukemia or lymphoma that may occur include effects on:

- Learning (cognitive effects)
- Physical development
- Psychological development

Factors that influence a child's risk for developing long-term or late effects include:

- Type and duration of treatment
- Sex
- Age at time of treatment
- Overall health

The range and severity of potential long-term and late effects vary. Some children will have no significant long-term or late effects or very mild effects, and others may have serious complications. Some late effects become evident with the onset of puberty, growth and the normal aging process. Early intervention and healthy lifestyle practices (not smoking, good nutrition and exercise, regular screening and follow-up care) may have a positive effect on the occurrence and/or severity of effects.

It is important for parents to discuss possible late effects with members of their child's healthcare team so that the proper planning, evaluation and follow-up care can take place.

**Types of Long-term and Late Effects.** The types of long-term and late effects include cognitive, physical and psychological effects.

**Cognitive (Mental or Learning) Effects.** Learning difficulties can begin either during treatment or may become evident months or even years after treatment. Mathematics, spatial relationships, problem solving, attention span, reading and spelling, processing of information, planning and organizing, and concentration skills are all areas of learning that may be affected. Problems with fine motor coordination, which might cause poor handwriting, can also develop.

Childhood leukemia and lymphoma patients may receive therapy that affects the central nervous system (CNS). The CNS includes the brain and spinal cord. Therapies that affect the CNS increase the risk for cognitive effects including educational issues. Examples of these therapies include:

- Methotrexate or cytarabine—if given in high doses intravenously (IV) or injected into the spinal fluid (intrathecal [IT])
- Total body irradiation (TBI), prior to a stem cell transplantation

Receiving cancer treatment at a younger age also increases the risk. Significant cognitive effects are more often associated with treatment plans that include radiation to the brain or brain surgery, neither of which are routinely used to treat childhood leukemia or lymphoma. Visit [www.LLS.org/drugs](http://www.LLS.org/drugs) for more information on the drugs mentioned on this page.

Talk to your child's healthcare team about any educational or learning issues that cause concern. A pediatric psychologist can perform neuropsychological testing to evaluate your child for any signs of these potential late effects.

**Physical Effects.** Depending on the specific type of treatment they have received, children treated for leukemia or lymphoma may be at risk for growth delays, bone health issues, heart, thyroid gland or other organ damage, obesity, fatigue and secondary cancers.

Cancer treatment may also affect fertility, the ability to conceive a biological child. The risk of fertility issues depends on the specific treatment.

Children who receive radiation therapy to the neck and chest or total body irradiation (TBI) before a stem cell transplant have an increased risk for breast cancer later in life. Current recommendations for female patients include monthly breast self-examinations; an annual clinical breast examination until the age of 25 years and then every 6 months; yearly mammogram starting at the age of 25 years or 8 years after radiation therapy, whichever happens later. Men should have careful lifelong followup.

**Psychological Effects.** Most childhood survivors of cancer are psychologically healthy. However, some studies indicate that a small number of childhood leukemia or lymphoma survivors were more likely than healthy peers to report changes in mood, feelings or behavior, including depression or posttraumatic stress disorder (PTSD). Talk to your child's healthcare team if you notice any changes in your child's mood or behavior, especially if these changes begin to interfere with your child's daily life.

**Monitoring for Long-term and Late Effects.** Depending on the treatment your child received, they may need additional, ongoing tests to monitor for late effects. Baseline labs and other testing are often done at entry into survivorship care and then as recommended based on results, your child's prior treatment, and their current health. Talk to the members of your child's healthcare team to determine the best screening schedule for your child or if you have any questions or concerns.



The Children's Oncology Group provides recommendations for monitoring late effects in the resource *Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent and Young Adult Cancers*. The information is reviewed and updated regularly by experts in survivorship care. The guidelines are written for healthcare professionals; therefore, it is best to review the guidelines with the help of your child's healthcare team. The "Health Links" documents provided with the guidelines are written for patients and their families. As you read through these resources, write down any questions you want to address with members of your child's healthcare team.

Visit [www.survivorshipguidelines.org](http://www.survivorshipguidelines.org) to download the guidelines and Health Links.

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**Research.** Research to better understand and treat long-term and late effects associated with certain cancer therapies is ongoing. Researchers are studying ways to lessen or minimize the negative impact of existing therapies. They are also searching for new ways to predict if a patient is at increased risk for specific late effects so that doctors can plan treatment and follow-up care accordingly.

**Parents Transitioning to Survivorship.** Once your child enters survivorship care, depending on your child's age, your child may no longer need the same level of care from you. As a parent, you will always support and care for your child in some capacity. However, as your child grows into a young adult, your hands-on parenting time will likely become less and less. Take advantage of the free time your child's growing independence grants you. The following ideas may give you a place to start:

- Go back to work. If you had to take a leave or if you left your job entirely to care for your child, try going back to work. Reach out to your past employer or seek a new job. Working and having a regular schedule will help you to adjust to the new normal.

- Reach out to friends and family members. Your social life may have been put on hold while you were caring for your child during their treatment. Rekindle these relationships.
- Try volunteering. If you find yourself with free time on your hands, volunteer with a local organization. What cause do you care about—animals, education, hunger, the environment?
- Take care of yourself. Now, you have more time, and you can focus much more on yourself. Improve the food choices you make. Stop smoking. Be more active. Do something you love—travel, write or pursue any other hobby you enjoy.

**Transitioning to Adulthood.** Your child's need for follow-up care will continue even after your child becomes an adult. Educate your young adult on the importance of follow-up care.

Keep in mind that the day your child becomes a legal adult, members of the healthcare team will start asking your child to make medical decisions and sign consent forms. Your young adult will need to give providers permission in order for healthcare professionals to communicate with you about your child's medical information.

Your young adult will have to decide who will be the primary decision maker for their continued medical care. Some young adults may feel more comfortable leaving their parents in charge of their care. Other young adults may wish to take a more active role. You may need to step back and allow them to make decisions. Either way, be respectful of your young adult's wishes. Remind your young adult to tell members of the healthcare team who will be the main contact person.

If your young adult moves away for college or work, they will need to find new healthcare providers to continue follow-up care. Your young adult can ask members of the healthcare team for a referral to a survivorship program in their new city. If there is not a survivorship program nearby, help your young adult to find a good primary care provider who can provide the necessary follow-up care. Your young adult can also ask the insurance provider for a list of in-network providers. Any new providers will need to know your young adult's detailed medical history and survivorship care plan. You and your young adult should work with members of the healthcare team that treated the cancer to coordinate care and transfer medical records to new providers.

For childhood cancer survivors, maintaining health insurance is very important. Young adults can remain on a parent's health insurance plan until they turn 26 years old. Then, they will need to find their own health insurance plan. Young adults also need to learn how to create and follow a budget and to manage their finances.



Visit Got Transition at [www.gottransition.org](http://www.gottransition.org) for a list of available healthcare resources and more information for you and your young adult about the process of transitioning from pediatric healthcare to adult healthcare.

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