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NAVIGATING LIFE DURING AND AFTER
A BLOOD CANCER DIAGNOSIS

CHILDREN &
ADOLESCENTS

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Navigating Life During and After a Blood Cancer Diagnosis:

A Workbook for Parents, Children and Adolescents

To reach us call: **800.955.4572**

LLS also offers two other versions of this workbook:
A Workbook for Adults and *A Workbook for Young Adults*.
Visit www.LLS.org/SurvivorshipWorkbook for more.

Visit www.LLS.org/booklets to view, download or order
all free LLS publications.

This Workbook Belongs To

Patient's Name _____

Parent/Guardian's Name _____

Phone Number _____

Email Address _____

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INFORMATION FOR TEENS

If your child is a teenager, share the *Information for Teens* handout on page 80 of this workbook. This handout provides information on survivorship for your teenager.

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.

LLS provides information on other organizations and resources as a courtesy and in no way implies endorsement of the organizations listed. LLS reserves the right to include/exclude any organization at its own discretion.

Introduction

Survivorship noun (ser-VY-ver-ship)

“In cancer, survivorship focuses on the health and well-being of a person with cancer from the time of diagnosis until the end of life. This includes the physical, mental, emotional, social, and financial effects of cancer that begin at diagnosis and continue through treatment and beyond. The survivorship experience also includes issues related to follow-up care (including regular health and wellness checkups), late effects of treatment, cancer recurrence, second cancers, and quality of life. Family members, friends, and caregivers are also considered part of the survivorship experience.”

– The National Cancer Institute (NCI), www.cancer.gov

The Word “Survivor.” 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.

Welcome

Having a child diagnosed with cancer is like being sent on a journey that no parent wants to take. You are forced to go to places you did not want to go to, learn a language you never planned on learning, and do things you never wanted to do.

You and your child will have questions and concerns along the way. Navigating this foreign landscape and coping with the unpredictable demands of day-to-day life that come with the territory can be overwhelming. Remember you are not alone. The support of loved ones and organizations, such as The Leukemia & Lymphoma Society (LLS), can help you and your family to navigate new pathways and help you find your “new normal.”

Whether you are a parent, foster parent, adult sibling, grandparent or other legal guardian, this workbook is useful to anybody who is caring for a child with cancer.

How to Use the Workbook

Use this workbook to collect important information as your child moves through diagnosis and treatment into post-treatment survivorship care.

Take this workbook with you to your child’s appointments. Fill out the worksheets with help from members of your child’s healthcare team, as needed. When your child meets with new healthcare providers, share the information.

When your child becomes an adult or wishes to take a more active role in the management of their care, you can pass the workbook to them as it will contain information your child will need in adulthood.

The Leukemia & Lymphoma Society also offers two other versions of this work: *A Workbook for Adults* and *A Workbook for Young Adults*. Visit www.LLS.org/SurvivorshipWorkbook for more information.

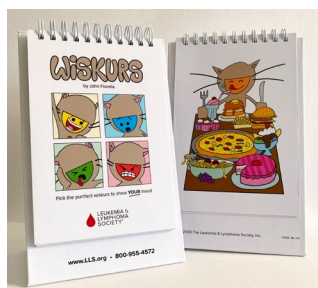
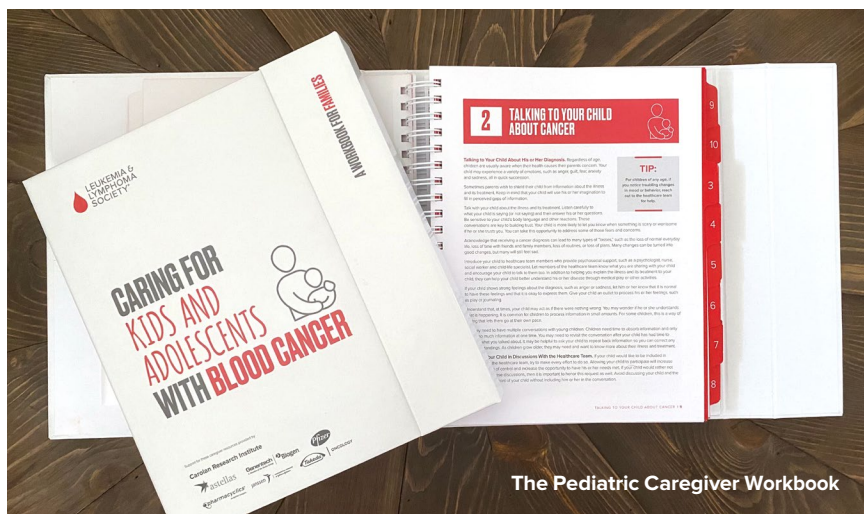
Visit www.LLS.org/booklets to view, download or order all free LLS publications mentioned in this workbook.

Feedback. Please visit www.LLS.org/PublicationFeedback.



Helping You and Your Child

The Leukemia & Lymphoma Society (LLS) has created a comprehensive set of materials for caregivers of pediatric patients.



Caregivers are encouraged to call with questions or to request pediatric resources including a dry erase/magnetic calendar, a Medi-Teddy, the *Wiskurs* emotions flipbook, and the Pediatric Caregiver Workbook.

For information about these materials and other resources, call one of our Information Specialists at **800.955.4572**. (Also available in Spanish)

Caring for Kids and Adolescents with Blood Cancer is available as a PDF on the LLS website at www.LLS.org/FamilyWorkbook.

Support for Parents and Caregivers

The Leukemia & Lymphoma Society (LLS) offers more resources for parents and caregivers.

- **Weekly Online Chat for Caregivers:** Our live, weekly online chat provides a friendly forum to share experiences and chat with other caregivers. Chats are moderated by an oncology social worker. Visit www.LLS.org/chat to learn more.
- **The *Patti Robinson Kaufmann First Connection Program*:** This is a telephone support program that links caregivers and patients with a trained peer volunteer who has experienced a similar situation. Visit www.LLS.org/FirstConnection to learn more.
- **LLS Community:** Chat with other caregivers and stay up-to-date on the latest diagnosis and treatment. Share personal experiences and get personalized support from trained LLS staff. Visit www.LLS.org/community to sign up.

To find more resources, visit www.LLS.org/booklets (filter by Children and Young Adults), visit www.LLS.org/caregiver or call an LLS Information Specialist at (800) 955-4572.

NOTES

Survivorship Care Plan



Survivorship Care Plan

A survivorship care plan is a record of your child's cancer diagnosis, a treatment summary, including supportive (palliative) care, and a plan for follow-up medical care. Ask members of the healthcare team for a printed survivorship care plan. You can use the information provided in the plan to fill out this section of the workbook and/or save a copy in the pocket of this section.

Record your child's diagnosis and all of the treatment information in the following pages. If you have printed medical records, you can paste copies in this section or keep copies in the pocket. Knowing your child's exact diagnosis and treatment, including specific drugs and/or site of radiation, is very important information. It helps you, your child, and the members of your child's healthcare team to develop a plan for follow-up care and the future.

Many hospitals and treatment centers now offer digital "patient portals" where you can view your child's medical record and upcoming appointments, message providers, view and pay bills, and more online. Ask how you can access your child's patient portal.

Diagnosis Information

Date of Diagnosis _____ Age at Diagnosis _____

Diagnosis _____

Subtype _____

Stage/Prognostic Information (at time of diagnosis)

Molecular or Genetic Markers/Mutations

(Include date of test as there can be changes throughout the course of treatment.)

Tumor Location (if applicable)

Date(s) of Relapse/Recurrence (if applicable)

End Date of Treatment

Additional Information

Diagnostic tests may also be used both during and after treatment to see how well treatment is working and to check for relapsed or refractory disease. You can record these tests here, as well.

Diagnostic Tests		
For example, imaging scans, bone marrow aspiration and/or biopsy, etc.		
Name of Procedure	Date	Findings/Results

You may also wish to keep track of lab reports. You can keep printed copies in the folder of this workbook. You may also be able to access your child’s lab reports online through a patient portal provided by the hospital or treatment center. Ask the healthcare team how to access your child’s reports.



Visit [**www.LLS.org/booklets**](http://www.LLS.org/booklets) to view *Understanding Lab and Imaging Tests*.

Chemotherapy or Other Drug Therapy

[illegible]

Visit www.LLS.org/drugs for information on specific drugs used in blood cancer treatment.

Radiation Therapy

Not all patients will receive radiation therapy.

Area of Body Treated	Dose	Dates Received or Duration of Treatment

Stem Cell Transplantation

Not all patients will receive a stem cell transplantation.

Date of Transplantation	Type of Transplantation	Preparative Regimen



Visit www.LLS.org/booklets to view *Blood and Marrow Stem Cell Transplantation Guide*.

Other Medications

Write down all medications your child takes, including vitamins and supplements. If you use a pill box for your child’s medications, you may wish to add a description of the medication, such as size and color, to the medication column. You can also request a printout of your child’s medication list from the healthcare team to keep in the workbook.

Medication	Dosage and Method of Administration	Start Date	End Date

List all allergies to medications, foods and any other substances.



Visit **www.LLS.org/booklets** to view *Oral Treatment Adherence* Facts. Call an Information Specialist at (800) 955-4572 or visit **www.LLS.org/booklets** to download or order *A Medication Resource for Blood Cancer Patients* to help you manage your child's current medications.

Procedures

For example, port placement, blood transfusions, surgery, etc.

Name of Procedure	Date	Notes

Side Effects/Symptoms Experienced During Treatment			
Side Effect	Cause (specific drug or treatment, if known)	Start Date	End Date



Visit www.LLS.org/booklets (filter by Side Effect Management) for information on side effects.

Supportive (Palliative) Care		
Type	Reason	Start Date/End Date
<i>Example: Nutrition education</i>	<i>Nausea</i>	<i>November 2020 – January 2021</i>
<i>Example: Therapy</i>	<i>Anxiety</i>	<i>Ongoing</i>

Supportive (palliative) care is specialized medical care that focuses on providing relief from the side effects and emotional stress of a serious illness such as cancer. The goal is to improve quality of life for your child, you and your family. **Supportive care is for anyone with a serious illness, regardless of age, stage or prognosis.** Your child may continue getting supportive care, even after finishing treatment or between treatments to help with any long-term or late effects (see *Long-Term and Late Effects* on page 27).



Visit www.LLS.org/booklets to view *Palliative Care*.

Hospitalizations

Many childhood cancer patients are hospitalized for cancer treatment and/or to manage side effects of treatment. If your child experiences other significant hospitalizations, either related or unrelated to cancer, you may wish to record them here.

Date	Hospital Name	Reason

Other Medical History

- | | |
|---|---|
| <input type="checkbox"/> Anemia | <input type="checkbox"/> HIV/AIDS |
| <input type="checkbox"/> Arthritis | <input type="checkbox"/> Impaired Mobility |
| <input type="checkbox"/> Asthma | <input type="checkbox"/> Irritable Bowel Syndrome (IBS) |
| <input type="checkbox"/> Blood Clots | <input type="checkbox"/> Kidney Disease |
| <input type="checkbox"/> Cancer
(Type _____) | <input type="checkbox"/> Liver Disease |
| <input type="checkbox"/> Colitis | <input type="checkbox"/> Lung Disease |
| <input type="checkbox"/> Concussion | <input type="checkbox"/> Migraines |
| <input type="checkbox"/> Depression | <input type="checkbox"/> Sexually Transmitted Disease (STD) |
| <input type="checkbox"/> Diabetes | <input type="checkbox"/> Thyroid disease |
| <input type="checkbox"/> Heart Disease | <input type="checkbox"/> Urinary Tract Infection |
| <input type="checkbox"/> Hepatitis | <input type="checkbox"/> Other
_____ |
| <input type="checkbox"/> High Blood Pressure | <input type="checkbox"/> Other
_____ |
| <input type="checkbox"/> High Cholesterol Level | |

Family Medical History	
Disease	Relationship to Your Child
Asthma	
Blood Clots	
Cancer (Type _____)	
Depression	
Diabetes	
Heart Disease	
Hepatitis	
High Blood Pressure	
High Cholesterol Level	
Low Blood Pressure	
Kidney Disease	
Lung Disease	
Irritable Bowel Syndrome (IBS)	
Liver Disease	
Colitis	
HIV/AIDS	
Other	
Other	

Follow-Up Schedules		
Record the long-term plans or goals for your child's follow-up care.		
Office Visit		
Provider		How Often*
Tests/Screening		
Test	Provider	How Often

*Frequency may change over time, depending on your test results and health.

Health Insurance. Because your child has a history of cancer, they will need lifelong follow-up care. Therefore, it is very important that your child always maintains health insurance, even into adulthood. The Affordable Care Act (ACA) requires plans that cover dependent children to make the coverage available until the child reaches the age of 26. Both married and unmarried children qualify for this coverage.



Visit www.LLS.org/booklets to view *Cancer and Your Finances* for information on the types of health insurance and budgeting.

As soon as you schedule an appointment for you child, record the appointment in the calendar on your mobile phone. Ask the provider’s office to confirm your preferred method of communication for reminders. If there are tests scheduled, ask what needs to be done to prepare, if anything, such as not eating before the test.

Upcoming Appointments

Provider/Reason	Location	Date	Time

Other Resources for Survivorship Care Plans

The Children's Oncology Group (COG) provides a downloadable *Summary of Cancer Treatment* template to fill out with the healthcare team. Visit www.survivorshipguidelines.org to download a template. See *Passport for Care*® with The Children's Oncology Group on page 32 for more resources.

American Society of Clinical Oncology (ASCO®) provides a form for people to record important information about the given treatment, the need for future checkups and cancer tests, the potential for long-term and/or late effects of treatment and ideas to improve health. There is a general *ASCO Survivorship Care Plan* form that covers all cancers. Visit cancer.net and click "Survivorship." Then select "Follow-up Care After Cancer Treatment" to download (www.cancer.net/survivorship/follow-care-after-cancer-treatment/asco-cancer-treatment-and-survivorship-care-plans).

National Coalition for Cancer Survivors (NCCS) offers a *Survivorship Checklist* designed to be a simple straightforward tool patients and caregivers can use as a guide for important information. Go to www.canceradvocacy.org and click on "Resources" and select "Survivorship Checklist" (<https://canceradvocacy.org/resources/survivorship-checklist>) to start a checklist.

OncoLife Survivorship Care Plan is a free and easy-to-use program that provides cancer survivors with information regarding the health risks they face as a result of cancer therapies. Visit <https://oncolife.oncolink.org/> for more information.

My Child's Healthcare Team

Record the contact information for the members of your child's healthcare team. Your child's healthcare team may include many different doctors, nurses, and specialists. You may also want to collect business cards from all the members of the healthcare team and save them in a pocket of this workbook or on your phone.

My Healthcare Team	
Pediatrician/Primary Care Provider	
Name	Hospital/Treatment Center
Phone	Email
Hematologist-Oncologist	
Name	Hospital/Treatment Center
Phone	Email
Radiation Oncologist	
Name	Hospital/Treatment Center
Phone	Email
Nurse Practitioner	
Name	Hospital/Treatment Center
Phone	Email
Transplant Physician and/or Coordinator	
Name	Hospital/Treatment Center
Phone	Email
Surgeon	
Name	Hospital/Treatment Center
Phone	Email

My Healthcare Team (continued)

Pharmacist

Name	Hospital/Treatment Center
Phone	Email

Survivorship Oncologist

Name	Hospital/Treatment Center
Phone	Email

Survivorship Clinic Nurse

Name	Hospital/Treatment Center
Phone	Email

Social Worker

Name	Hospital/Treatment Center
Phone	Email

Child-Life Specialist

Name	Hospital/Treatment Center
Phone	Email

Role:

Name	Hospital/Treatment Center
Phone	Email

NOTES

A photograph of a young child with long, light-colored hair swinging on a swing set. The child is wearing a bright red t-shirt and dark pants. The swing is suspended by a chain from a metal frame. The background is a bright, hazy sky at sunset or sunrise, with the sun low on the horizon, creating a strong lens flare and a warm, golden glow. The child's hair is blowing in the wind, and a pink fabric is attached to the swing chain. In the top right corner, there is a red rectangular box containing white text.

Long-Term and Late Effects

Long-Term and Late Effects

Improved treatments for children with blood cancers have led to increased survival rates. However, some treatments may cause significant long-term and/or late effects.

Follow-up medical care to monitor survivors for possible long-term and/or late effects is important. Discuss the possible effects of your child's treatment with the members of the healthcare team in order to plan treatment and follow-up care. Factors that determine the risk of long-term and/or late effects include:

Keep a record of any cognitive (thinking), physical and/or emotional signs and/or symptoms that your child experiences and discuss them with the healthcare team.

- Type of treatment
 - For example, the specific drugs used or the part of the body treated with radiation
- Length of treatment
- Your child's age at the time of treatment
- Your child's sex
- Overall health

“Long-term effects” of cancer therapy are medical problems that last for months or years after treatment ends. Fertility (the ability to become pregnant or father a child) problems and treatment-related fatigue are examples of long-term effects.

“Late effects” are medical problems that may appear after treatment ends, even years later. Treatment-related cancer and heart disease are examples of late effects.

Long-term and late effects for survivors of blood cancers may include:

- Cognitive effects (effects on thinking, learning and memory)

- Physical effects
- Psychological effects

Cognitive Effects

Learning difficulties can begin either during treatment or may become evident months or even years after treatment. Math, 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.

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, such as high-dose chemotherapy or radiation to the brain, increase the risk for cognitive effects including education issues. Talk to your child's healthcare team about any educational or learning issues that cause concern. See *School and Long-Term and Late Effects* on page 33 for more information.



Visit www.LLS.org/booklets (filter by Side Effect Management) to view *Side-Effect Management: Effects of Childhood Cancer Treatment on Learning*.

Physical Effects

Depending on the type and duration of treatment, age and overall health, childhood cancer patients may be at risk for:

- Fatigue
- Neuropathy (nerve damage)
- Heart disease
- Thyroid problems

- Organ damage (lungs, kidneys)
- Bone issues, such as osteoporosis
- Secondary cancer
- Early or delayed puberty
- Fertility problems
- Other conditions

Fertility Preservation

“Fertility” describes the ability to conceive a biological child. Some cancer treatments affect fertility in males and females. The risk of infertility is based on several factors including the type of treatment received, the duration or dosage of treatment and the patient’s age at the start of treatment. There are options to preserve fertility. Some of these options require that action be taken before treatment begins.

As much as possible, your child should be involved in the discussion about how cancer treatment may affect their ability to have children in the future. Members of the healthcare team and a child-life specialist can provide age-appropriate ways to explain and talk about these issues with your child.

Options to preserve fertility depend on several factors.

- If patients need treatment immediately, there may not be time to complete fertility preservation.
- If your child has reached puberty, and time allows, sperm banking or egg freezing may be an option.
- If a child has not reached puberty, and time allows, testicular or ovarian tissue freezing may be an option.
 - o For some types of cancer, the doctor may advise against tissue freezing because of a concern that transplanted tissue could carry cancer cells back into the body.

Fertility Preservation Information

Provide details of any fertility preservation procedures so that your child can reference them in the future.

Procedure	Date	Hospital or Clinic	Phone Number

Remember, there are many ways to build a family, whether through natural conception, using assisted reproductive technology, or adoption. Once your child is an adult and ready to start a family, they should consider and discuss all options.



To learn more about the process of fertility, visit www.LLS.org/YoungAdults or visit www.LLS.org/booklets to view *Fertility and Cancer*.

Psychological Effects

Some children may experience long-term psychological effects after treatment. Diagnosing your child may be tempting, but your best resource will be a trained mental health professional. The following lists some symptoms of common mental health diagnoses. If your child experiences any of these, speak to a mental health professional.

- Depression or symptoms of depression
 - Symptoms of depression include ongoing sad moods, loss of interest in activities and/or irritability. Physical signs and/or symptoms are often common, such as changes in sleep and/or eating habits and fatigue. Even children who do not meet the full criteria for depressive disorder may still benefit from therapy with a mental health professional.

- Anxiety disorders, such as generalized anxiety disorder, obsessive compulsive disorder (OCD) or panic disorder
 - o Anxiety disorders are different from the common worries encountered in day-to-day life. Symptoms of an anxiety disorder can include intrusive thoughts and make it difficult to pull away from a persistent anxious state of mind.
- Post-traumatic stress disorder (PTSD)
 - o Post-traumatic stress disorder can develop in some people who have experienced a shocking, scary or dangerous event (such as being diagnosed with cancer). Symptoms can include anxiety, nightmares, irritability, changes in mood, and frightening and/or intrusive thoughts. Some things may trigger these feelings, such as going to the hospital or foods that were eaten often during treatment.

Mental health is very important to your child's overall health and well-being. Ask the pediatrician or health insurance provider for a referral to a mental health professional. For more information, see *Mental Health* on page 45.



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



Visit www.LLS.org/HealthManager to download LLS Health Manager™. This free mobile app allows you to track your child's side effects, medication, food and hydration, and more.

Screening Recommendations

To help understand and manage your child's risk of long-term and late effects, talk to your child's healthcare team. You will need to know the possible side effects of your child's specific treatments. For each possible side effect, ask the healthcare

team for screening recommendations, including the specific type of test your child will need to screen for a particular side effect; when your child should start screening; how often your child should be screened; and which healthcare provider will be responsible for the screening.

Ask your child's healthcare team for a printout of screening recommendations and keep a copy in this workbook.

The Children's Oncology Group

The Children's Oncology Group (COG) 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 to download the guidelines and Health Links.

Passport for Care® with the Children's Oncology Group is a website where clinicians can enter details about the specific cancer treatments that a patient received to generate a summary of risks for late effects and recommendations for screening, as well as follow-up care to manage risks. This information can be shared with other care providers, including primary and specialty care providers. Ask members of the healthcare team for a printout of your child's survivorship summary.

Passport for Care® also offers a *Screening Recommendations Generator* that can be used by survivors or caregivers to receive information on the potential late effects associated with treatments, the recommended follow-up screenings, and more. Visit www.passportforcare.org for more information.

School and Long-Term and Late Effects

Going to school is a big part of feeling normal for children and adolescents, but going back to school after cancer treatment can also bring new challenges for your child and your family. It is important to identify the areas of learning where your child may struggle. Then you can work together with the healthcare team, teachers and school staff to provide support and resources to help your child be successful in school.

Neuropsychological Testing. Children who are at risk for cognitive effects (See *Cognitive Effects* on page 28) or who are having difficulty in school may benefit from neuropsychological testing done by a licensed pediatric neuropsychologist (an expert in the way the brain works) to check for possible learning challenges. Discuss the need for neuropsychological testing with members of your child’s healthcare team, who can refer you to a pediatric neuropsychologist.

School Psychological Assessment. Neuropsychological testing is often not covered by insurance and can be expensive. A school-based assessment may be an option (or may be a requirement of the school) to help determine your child’s educational needs. These assessments are usually performed to determine if your child is eligible for special education programs. Generally, school-based assessments are less effective than neuropsychological testing at linking cancer treatment with learning or behavior problems. Ask your child’s school administrators for more information.

Meeting Your Child’s Educational Needs. With the help of the healthcare team, inform teachers and school staff about your child’s educational needs before they return to school. Work together with the healthcare team, teachers and school staff to develop a program tailored to your child’s specific needs. The program may include:

- Special accommodations—accommodations can be made to meet a child’s educational needs, such as allowing for additional time to complete classwork or take exams. Children may qualify for special help under federal laws.
- Long-term planning—plans can be developed to help a child through school transitions from middle school to high school and into adult life.
- Cognitive behavioral therapy—certain cognitive therapies can help children develop strategies to address learning problems. For example, one strategy may be breaking down complex problems into smaller tasks.

Keep a copy of any educational plan created for your child in this workbook.

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)
- The Individuals with Disabilities Education Act (IDEA)
 - o Under IDEA, public school children with disabilities may receive an Individualized Education Plan (IEP) that outlines a formal plan to accommodate a child’s individual needs.

- The Rehabilitation Act of 1973 – Section 504
 - o The act requires all educational institutions receiving federal funding to provide accommodations (adaptations) for students with physical or mental impairment, or a record of impairment, that limits one or more major life activities.



Visit www.LLS.org/booklets to view *Learning & Living with Cancer: Advocating for Your Child's Educational Needs* for more information about the transition back to school and laws that help protect children.

Visit www.LLS.org/FamilyWorkbook to find additional information in the chapter *School* and to download the worksheet, *Information for School Staff*, to help communicate your child's educational needs to their teacher, school nurse and/or school administration.

NOTES

Healthy Behavior Recommendations



Healthy Behavior Recommendations

Developing healthy lifestyle habits are important for cancer survivors. Healthy lifestyle habits can help your child recover faster and decrease the risk of future disease, such as other cancers, heart disease and diabetes. Making changes so that your child (and family) can be healthier can also help you gain a sense of control throughout survivorship. Many things may be out of your control, but you can teach your child to take good care of themselves.

PearlPoint Nutrition Services®. LLS offers free one-on-one nutrition consultations to cancer patients, parents and caregivers by phone and email. Our registered dietitians have expertise in oncology nutrition. Visit www.LLS.org/consult to schedule a consultation.



Check all of the healthy behavior statements that are true for your child.

- ☐ My child eats a well-balanced diet that includes a variety of fruits and vegetables, proteins, whole grains and healthy fats.
 - o Visit www.LLS.org/FamilyWorkbook and view the *Nutrition* chapter to find tips to help your child eat a healthy menu.
- ☐ My child drinks at least eight 8-oz glasses of water or liquids (not including caffeinated drinks or drinks with added sugars) each day.
- ☐ My child sleeps well each night and wakes up feeling rested.
 - o Children aged 1 to 2 years need 11 to 14 hours of sleep (including naps), children aged 3 to 5 years need 10 to 13 hours of sleep (including naps), children aged 6 to 12 years need 9 to 12 hours of sleep, and teens need 8 to 10 hours of sleep per day.

- ☐ My child exercises regularly.
- ☐ My child has daily opportunities for play and creativity.
- ☐ I have spoken to my child about the risks of smoking and tobacco use.
- ☐ I have spoken to my child about the risk of alcohol use.
- ☐ I have spoken to my child about safe sex, consent and the risk of unsafe sexual practices.
- ☐ My child avoids direct sun, when possible, and wears a broad-spectrum sunscreen with a sun protection factor (SPF) of 30 or higher and reapplies every 2 hours.
- ☐ I keep up with my child's medical needs, such as annual checkups with their pediatrician and getting regular dental cleanings.
- ☐ I keep my child's hematologist-oncologist informed about any changes in my child's well-being.
- ☐ I give my child all medications as prescribed by the healthcare team.
- ☐ I talk to my child's healthcare team about my child's mental health.
- ☐ My child connects with other children their age regularly.
 - o Isolation is a risk factor for depression and anxiety disorder.
 - o If it is not possible for your child to spend time with friends in person, arrange virtual video calls with peers.

Did you leave any of these statements unchecked? If so, you may need to consider making changes to your child's routine. Discuss healthy behaviors with your child's pediatrician. Ask for referrals to professionals for help with

specific issues (for example, a registered dietitian, a child-life specialist or a mental health professional).

What are some steps you can take to improve your child’s overall health and well-being? (Do not make changes to your child’s diet or exercise plan without first talking to the pediatrician.)



Visit www.LLS.org/booklets to view *Healthy Behaviors* and *Nutrition Handbook* for more information about healthy behaviors.

For more general information on parenting and health and wellness for children, visit www.healthychildren.org from the American Academy of Pediatrics.

Other Childhood Healthcare Needs

As part of a healthy lifestyle, in addition to screening for cancer relapse and the long-term and late effects of treatment, all children and teens need to see their pediatrician at least once a year to be screened for proper growth and development and for other diseases that may be unrelated to the cancer diagnosis. This is often called a “well-child” visit. Children under 3 years of age will see their pediatrician more often.

The specific screening recommendations for your child will depend on their age, sex and medical history. For more

information on childhood healthcare needs, visit the following resources:

- **Bright Futures/American Academy of Pediatrics (AAP) *Recommendations for Preventative Pediatric Health Care—Periodicity Schedule*.** For more well-child visit information, visit www.aap.org and search for “periodicity schedule” (https://downloads.aap.org/AAP/PDF/periodicity_schedule.pdf).
- **Centers for Disease Control and Prevention (CDC) *Developmental Milestones*.** Visit www.cdc.gov and search for “developmental milestones” (<https://www.cdc.gov/ncbddd/actearly/milestones/index.html>) for a list of developmental milestones, by age.

Immunizations

The Centers for Disease Control and Prevention (CDC) provides a recommended immunization schedule for children by age and medical indication. Your child may need to delay getting certain vaccines during cancer treatment. After treatment is completed, work with your child's healthcare team to create an appropriate catch-up schedule for your child. Some vaccines may need to be repeated or your child may need an additional booster of previously received vaccines.

Immunization Record

Vaccine	Date(s) Given	Comments/ Reactions
Hepatitis B (HepB)		
Rotavirus (RV)		
Diphtheria, tetanus, & acellular pertussis (DTap: <7 yrs)		
<i>Haemophilus influenza</i> type b (Hib)		
Pneumococcal conjugate (PCV13)		
Inactivated poliovirus (IPV)		
Measles, mumps, rubella (MMR) ¹		
Chicken pox/ varicella (VAR) ¹		
Hepatitis A (HepA)		
Tetanus, diphtheria, & acellular pertussis (Tdap: ≥ 7 yrs)		
Human papillomavirus (HPV)		
Meningococcal		
Meningococcal B (MenB)		
Pneumococcal polysaccharide (PPSV23)		
Flu (influenza) ²		
COVID-19 (SARS-CoV-2) ³		

Visit www.cdc.gov/vaccines/schedules/easy-to-read/child-easyread.html to view the CDC's recommended vaccination schedule, by age.

¹ **Live Vaccines.** Vaccines that contain a live virus are dangerous for immunosuppressed patients. Live vaccines include MMR, varicella (chicken pox) and flu nasal spray. If anyone in the home or who spends time with your child will be receiving a live virus, such as the shingles vaccine, tell your child's healthcare team. Ask what precautions to take.

Siblings. Siblings should continue to receive their regularly scheduled vaccinations. If a sibling will be receiving a vaccine with a live virus, ask the healthcare team if you need to take any precautions.

² **Flu Shot.** An annual flu shot is recommended for all children older than 6 months, even children receiving cancer treatment. Your child should receive the flu shot, which is made from the dead virus. They must **not** get the nasal spray vaccine because the spray contains the live flu virus. The live virus can be dangerous for immunosuppressed patients.

Everyone in your home or who spends time with your child should also receive the flu shot, not the nasal spray vaccine.

³ **COVID-19.** Discuss the COVID-19 (coronavirus disease) vaccine with your child's healthcare team. Research on the safety and efficacy of the vaccine in children is ongoing.

Source: Adapted from the Centers for Disease Control and Prevention's *Recommended Child and Adolescent Immunization Schedule for ages 18 years or younger, United States, 2021*.



**Mental
Health**

Mental Health

Mental health, like physical health, is important to your child's overall well-being. Even years after diagnosis or treatment, some children continue to struggle with feelings of sadness, anxiety, grief or guilt.

Some of the specific emotions that childhood cancer survivors may struggle with include:

- “Survivor’s guilt,” especially if a close friend or family member passed away from cancer
- Fear that their cancer may come back or get worse. This fear may become worse around the anniversary of their diagnosis.
- Anxiety about checkups and screenings that either surfaces or become worse, called “scanxiety”
- Sense of loss or grief for their life before the cancer diagnosis, especially in older children and teens

Having these feelings is normal; however, negative feelings shouldn't be interfering with your child's daily life, growth and development.

Childhood Depression, Anxiety and Other Mental Health Issues

Signs of mental health issues in children may include:

- Loss of pleasure in favorite activities
- Stomachaches or headaches that don't seem to have another cause
- Eating more or less than usual

MENTAL HEALTH FOR PARENTS

While caring for your child is likely your top priority, your own mental health is very important too. Ask your primary care provider for a referral to a mental health professional. Visit www.LLS.org/FamilyWorkbook to download the *Caring for Yourself* chapter for more information.

Even if your child does not have signs and/or symptoms of clinical depression or anxiety, they can still benefit from talking to a mental health professional. A therapist can provide your child with tools for identifying their emotions and teach ways to cope with them.

- Decreased energy
- Trouble sleeping and/or nightmares
- Angry outbursts
- Poor grades or social difficulties in school
- Destructive or risky behaviors, including self-harm

Talk to members of your child's healthcare team about mental health concerns. Your child may benefit from the support of a medical health professional, such as a therapist or counselor, or, in some cases, medication to help with depression and anxiety.

Visit <https://www.cdc.gov/childrensmentalhealth/> for more information.

If your child is having trouble coping, call the National Suicide Prevention Lifeline at **(800) 273-TALK ([800] 273-8255)** to talk to a community crisis center representative. The Lifeline is free, confidential and always available. If your child is a teenager, you may also want to share this resource with them so that they can call on their own if they are ever in need of someone to talk to.

Checking in with Your Child About Mental Health

Check-ins with your child do not always need to be planned. You can talk to your child over meals or during car rides. If you suspect something is wrong or bothering your child, however, you may want to plan a time to speak to your child in a place where you are both comfortable and won't be interrupted. Some questions you may wish to ask include:

- How do you feel?
- When was the last time you felt happy/sad/scared/excited?
- Do you sleep well? Do you have dreams? If so, what type of dreams?

- Is there anything you are looking forward to?
- How is school? What subjects do you enjoy?
- Do you have friends at school? Does anyone bother you at school?
- What do you like to do with your friends for fun?
- If you are sad or scared, is there someone you can talk to (such as a parent, teacher, guidance counselor or other trusted adult)?

Older children and teens may wish to speak to members of their healthcare team privately about mental health. Allow them to do so.



Younger children may not yet have the emotional or language skills to tell you how they are feeling. LLS offers *Wiskurs*, a free illustrated flipbook that lets children find a picture that best represents their current mood. This fun form of expression can help you better understand your child's emotional well-being. Call an LLS Information Specialist at (800) 955-4572 to order.

Stay Calm Strategy

There will be times that are difficult and emotional. It's unavoidable. Help your child prepare for these moments by having a strategy in place to help themselves calm down if they feel anxious or overwhelmed. Having a plan in place, in advance, will help your child better manage unexpected intense emotions.

Encourage your child to use the following strategies:

- Take deep breaths.
- Repeat a meaningful saying or mantra.

- Close their eyes and sit in silence.
- Count to 10 slowly or repeat their ABCs.
- List the items they see in their surroundings.
- Stand up and stretch.
- Talk to a parent or other trusted adult.

Visit www.healthline.com/health/grounding-techniques for more ideas to help your child to cope with difficult and/or emotional times.



Help your child record their answers to the following questions.

When I feel overwhelmed, I will

When I feel sad, anxious or scared, I will reach out to someone I trust. When I feel overwhelmed, I will reach out to



Visit www.LLS.org/FamilyWorkbook to view the *Talking to Your Child About Cancer* and *Coping with a Childhood Cancer Diagnosis* chapters. These chapters also include support for parents and siblings.

Visit www.LLS.org/booklets to view *Managing Stress: How stress affects you and ways to cope* to learn more.

A close-up photograph of a person's hands being washed under a stream of water from a modern, curved chrome faucet. The water is clear and splashing. The person's hands are positioned under the water, and their fingers are slightly spread. The background is softly blurred, showing a green leafy plant in a wicker basket on the left and a striped shirt sleeve on the right. A red rectangular box with white text is overlaid in the upper right corner.

Teaching Your Child About Self-Care

Teaching Your Child About Self-Care

Self-care is

- Taking action to maintain or improve mental, emotional and physical health, especially during times of stress
- Intentionally doing enjoyable things to improve mood and lower stress levels

SELF-CARE FOR PARENTS

To create a self-care plan for yourself, visit www.LLS.org/FamilyWorkbook to download the *Caring for Yourself* chapter and the *Creating a Self-Care Plan* worksheet.

Everyone should incorporate self-care into their daily lives. You can teach your child about self-care and encourage them to take time for themselves to improve their own well-being. These are invaluable skills that will serve your child well throughout their life.

Self-Care at Every Age

Tips and ideas to help your child learn self-care

Baby/Toddlers (0 to 3 Years)

- When your child is a baby or toddler, you will be responsible for most aspects of self-care. Helping your child with hand washing, teeth brushing, regular bathing and cleaning their face after eating is a way to show that you care and to begin to teach your child the importance of self-care and good hygiene.
- Teach your toddler to wash their hands with warm water and soap for 20 seconds by singing their ABCs.
 - o Hand washing is very important, especially if your child is immunosuppressed from cancer treatment. Hand washing helps prevent infections and illness.
- Allow toddlers to assist with their own self-care, as able, with your assistance. This may include:
 - o Getting dressed and/or choosing clothes
 - o Wiping up spills

- o Putting toys away
- o Using a napkin or wet wipe to clean hands and face
- Self-care for infants and toddlers may include:
 - o Supervised short time periods for infants to lay on their belly to help build muscles and mobility, often called “tummy time”
 - o Holding your child
 - o Listening to music
 - o Reading to your child
 - o Playing with safe, age-appropriate toys that allow your child to learn and explore, such as soft or textured toys (stuffed animals), toys that make noise (rattles), toys to build or create (blocks, non-toxic crayons or markers), things to pretend with (dolls, cars)
 - o Check the tag or box of toys for safe age ranges. Watch out for toys with small parts that could be a choking hazard. If your child is immunosuppressed from cancer treatment, choose toys that are easy to clean and sanitize as children often put toys in their mouths. Visit <https://www.naeyc.org/resources/topics/play/toys> for more information.

Preschool/Kindergarten (4 to 6 Years)

- Provide your child with plenty of time to play. Children learn, explore and process their emotions through play. Play can also be a source of exercise and a way for your child to socialize with other children.
- Teach your child good hygiene habits such as washing hands and brushing teeth. Supervise as necessary.
 - o Teach your child to wash their hands with warm water and soap for 20 seconds by counting to 20 slowly or by singing their ABCs. Hand washing is very important, especially if your child is immunosuppressed from cancer treatment. Hand washing helps prevent infections and illness.
- Allow your child to help pick out clothes and outfits.
- Help your child to memorize important phone numbers for emergency situations.

- Self-care for children in this age group may include:
 - o Holding a comfort item, such as a stuffed animal or blanket
 - o Playing alone and with other children their age
 - o Listening to music, dancing, coloring, or other forms of creative expression
 - o Movement
 - o Spending time outdoors
 - o Learning to ask for help when upset

Elementary/Middle School (7 to 12 Years)

- Provide your child with plenty of time to play. Children learn, explore and process their emotions through play. Play can also be a source of exercise and a way for your child to socialize with other children.
- Allow your child to pick out their own clothes and outfits.
- Encourage good hygiene, including washing well and wearing deodorant as your child enters puberty. Hand washing helps prevent infections and illness which is especially important for children in cancer treatment.
- Prepare your child for the changes they may experience as they enter puberty such as additional body hair or the beginning of the menstrual cycle (period). Members of the healthcare team can help with this discussion.
 - o Childhood cancer treatment can cause delays or changes to the onset of puberty. Talk to your child's healthcare team if you or your child have any concerns.
- Self-care for children in this age-group may include:
 - o Holding a comfort item such as a stuffed animal or blanket
 - o Playing alone and with other children their age
 - o Journaling
 - o Music, art or other form of creative expression
 - o Exercise, movement and/or spending time outdoors
 - o Identifying and using a "Stay Calm Strategy" (See *Stay Calm Strategy* on page 48.)

High Schoolers/Teenagers (13 to 18 Years)

- Respect your teen's privacy and allow them opportunities to do things alone when it is safe and appropriate to do so.
- Encourage your teen to adopt healthy behaviors to care for their physical and emotional well-being. (See *Healthy Behavior Recommendations* on page 37.)
- When teenagers are struggling to find independence, a cancer diagnosis may feel like a setback and lead to feelings of frustration and anger. They may try to test boundaries or engage in risky behaviors such as drinking, drug use or sex.
- Educate your teen about safe sex and consent, even if you think they are not sexually active. Provide comprehensive sexual education related to sexual behaviors, risk of pregnancy and sexually transmitted diseases (STDs). You can ask the healthcare team for help with this discussion. During cancer treatment there may be additional risks associated with sexual activities. Teens who are sexually active must:
 - o Use some form of birth control.
 - o Use condoms or another barrier method, to protect against STDs. Oral contraception (birth control pills) and implants (for example, an intrauterine device [IUD]) do not protect against STDs.
 - o Visit www.cdc.gov/sexualhealth for more information.
- Talk to your teen about tobacco, drug and alcohol use, even if you believe they do not use them. These substances can increase the risk of disease and may not be safe to use during cancer treatment or while taking certain medications.
 - o If your child does smoke, visit <https://smokefree.gov> for resources to help them quit.
- Allow your teenager to speak to members of the healthcare team privately about sensitive matters such as mental health, sex, tobacco, drug, alcohol use or any other issues.
- Teenagers may struggle with body image and self-esteem. (See *Body Image and Self Esteem* on page 55.)
- Self-care for a teenager may include:
 - o Journaling

- o Music, art or other form of creative expression
 - o Hobbies such as reading, video games or baking
 - o Spending time with friends and family
 - o Attending a peer support group
 - o Exercising or playing sports
 - o Hiking or spending times outdoors
 - o Practicing personal care, such as taking long baths, painting nails or using face masks
 - o Learning to take all medications as prescribed (with adult supervision)
 - o Identifying and using a “Stay Calm Strategy” (See *Stay Calm Strategy* on page 48.)
 - o Creating an intentional self-care plan (Visit www.LLS.org/FamilyWorkbook to download the *Creating a Self-Care Plan* worksheet.)
- Share the *Information for Teens* handout in the pocket on the back cover of this workbook with your teenager. This handout provides information about survivorship for your teenager to read. Encourage your teenager to come to you and/or members of their healthcare team with any questions or concerns.



Visit www.LLS.org/FamilyWorkbook to view the *Caring for Your Child During Treatment* chapter for information on hygiene and personal care.

Body Image and Self-Esteem

Almost every person struggles with body image and self-esteem at some point, but childhood cancer survivors may face unique challenges. Cancer treatment can cause changes to the body such as hair loss, weight loss or weight gain, and skin changes. Your child may especially struggle with body image around puberty. Comments or even bullying

from classmates due to changes in appearance could possibly make this worse. Visit www.stopbullying.gov for bullying prevention resources.



Work through the following prompts with your child to help encourage positive thinking.

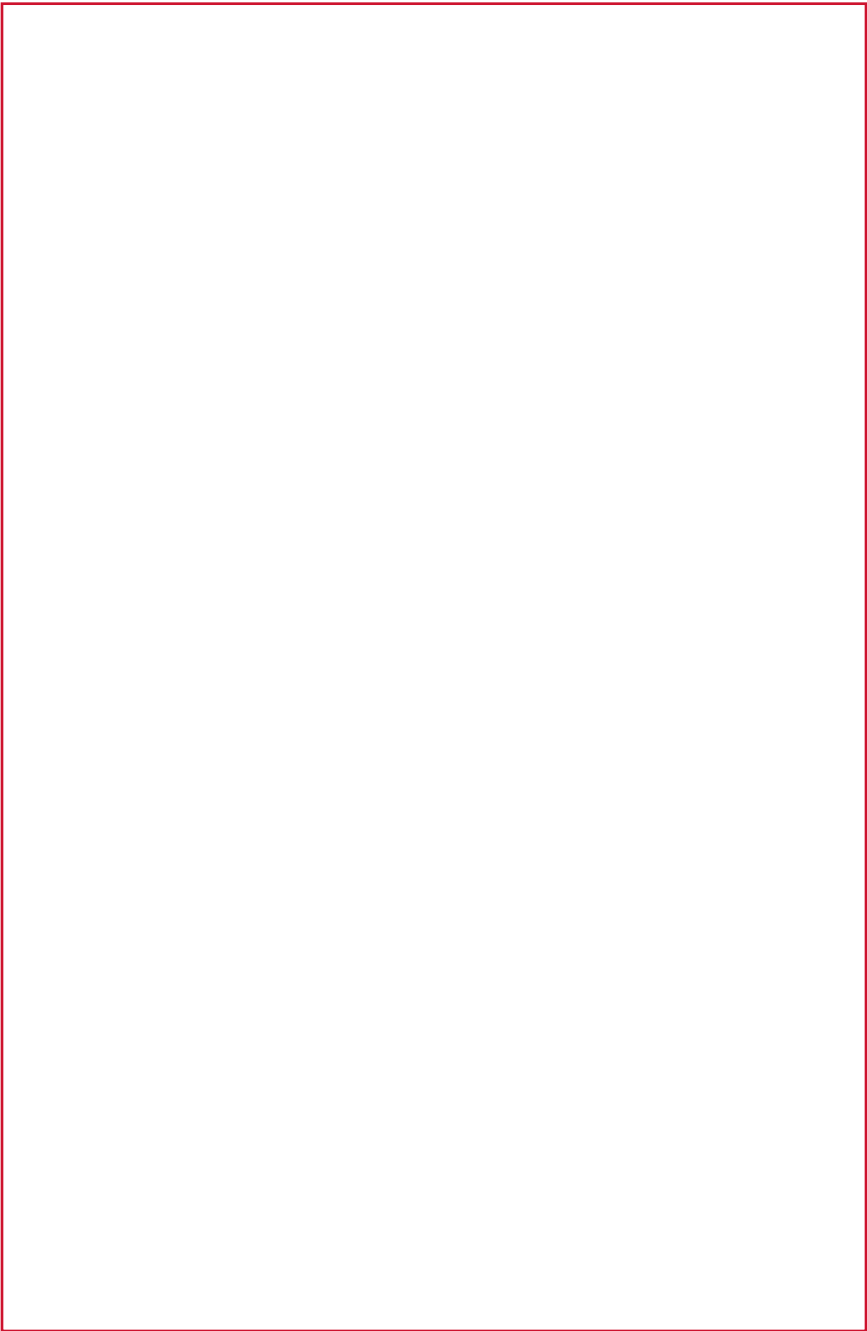
Write down some important things your body can do.

Example: My arms can hug my mom and dad. My hands can build a block tower. My feet can dance to music.

Write down some things you like about yourself.

Examples: my sense of humor, my smile

Ask your child to draw a picture of themselves in the space below.
When they finish the drawing, ask them to describe it to you.



Here are some other things you can do to help your child feel more comfortable:

- Provide clothes that are comfortable. Don't worry about the number on the tag. Your child can wear the size or style that feels the best on their body.
- Monitor the media your child consumes. Encourage your child to avoid looking at images online and in magazines that make them feel badly about their body or appearance.
- Teach your child to treat their body well by adopting healthy habits. See *Healthy Behavior Recommendations* on page 37.
- Encourage your child to move their body with daily exercise and/or play. Ask the healthcare team for an exercise program.
 - o As a side effect of treatment, your child may have mobility or balance issues. Ask for a referral to a physical therapist to help with these issues and to discuss appropriate forms of physical activity.
- Watch for negative self-talk (thinking or saying negative things about oneself). Children are often their own harshest critics. The next time you hear your child say something negative about themselves, ask "Would you say or think that sort of thing about your friend?" Help your child to learn to treat and think of themselves in the same way they would talk to or about someone they love.
- Try not to talk about appearance or body size around your child. Try not to criticize yourself or others in front of your child. If other people your child spends time with talk about appearance or body size around your child, ask them not to. Almost everyone is self-conscious about their appearance, and talking about it frequently only adds to those feelings. There are much more interesting things to talk about!
- Teach your child that you don't have to love everything about your body, but you do need to respect and care for it.

- Ask members of your child's healthcare team for a referral to a therapist or counselor who can help your child work on self-esteem.

When children reach their preteen or teenage years, they often become more aware of their bodies. They may feel pressure to look a certain way or be a certain size. To achieve this, they may even try trendy diets, pills or supplements, or other dangerous weight-loss techniques. Visit the National Eating Disorders Association website at www.nationaleatingdisorders.org/warning-signs-and-symptoms to learn the warning signs and symptoms for an eating disorder. If you suspect your child is struggling with an eating disorder, talk to your child's pediatrician. Ask for a referral to a registered dietitian and/or therapist who specializes in eating disorders.

Ask Your Child to Take the Pledge

Read the pledge on the next page to your child or allow your child to read alone. Talk through any questions or thoughts that come up. If your child wants to add any additional goals to the pledge, add them in the blank spaces at the end of the list.

I, _____,

(child's name)

promise to myself that I will:

- Be kind to myself
- Be kind to my friends, family and loved ones
- Make my health a priority
- Respect and care for my body and mind
- Ask for help when I need it
- Take steps to achieve my goals as I am able
- Celebrate small wins
- Learn from setbacks but not dwell on them
- Say No to things that do not support my goals or well-being

• _____

• _____

• _____

Signature _____

Date _____



A close-up photograph of a person's hands writing in a notebook. The person is wearing a blue long-sleeved shirt with white polka dots. Their right hand holds a white pen, and their left hand rests on the notebook. The notebook is open, showing two pages of text. In the background, a laptop is visible on a wooden desk. A red rectangular box is overlaid in the top right corner, containing the text "Planning for Adulthood" in white.

Planning for Adulthood

Planning for Adulthood

When your child was first diagnosed, you may have found it difficult to think about the future. Many aspects of life may have felt uncertain. However, most childhood cancer survivors can expect to lead full and productive lives. As your child nears the end of cancer treatment, you and your child may be ready to think about the future again.

Your child's transition to adult life could include college; vocational or technical school; internships; apprenticeships; employment and independent living. Your child may move out of your home or even to a new city. They will need new skills such as money management and advocating for their own healthcare. Check out the following resources that can help you and your child achieve these future goals.

Support for the Future

The information and resources in this list are organized by subjects that may be part of your child's future plans. Some of these resources are from The Leukemia & Lymphoma Society (LLS) and some are from different organizations that specialize in specific issues.

College

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

Your child may want to keep in mind the following questions when researching different colleges:

- 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 that is provided by the center or clinic close to the school?
- What financial aid or scholarships are available?
 - o To help childhood cancer survivors offset the cost of education, scholarships and grants are sometimes available. Visit www.LLS.org/scholarships to view a list of potential scholarships.
- Would a community or technical college offer similar programs?

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

Career

As a person who has a history of cancer, your child can best protect themselves from employment discrimination by learning how to advocate for their rights in the workplace. Your child can visit www.LLS.org/EmploymentRights to learn more about employment discrimination laws and how to enforce their legal rights. At this link, your child can also find tips for the job application process.

If your child plans to enter the workforce after graduating from high school, they can ask their guidance counselor for help and information about resources available to them. If your child attends

college, most colleges and universities provide Career Services for students and alumni to assist with job search preparation and professional development. Career Services may provide a tool to search for employment opportunities and help with tasks such as creating a résumé and practicing for interviews.

Cancer and Careers

<https://www.cancerandcareers.org/>

Cancer and Careers empowers and educates people with cancer to thrive in their workplace, by providing expert advice, interactive tools and educational events. The organization also offers a résumé review service (https://www.cancerandcareers.org/resume_reviews/new) and a comprehensive database of helpful resources.

Finances

Teach your child about personal finances such as budgeting and saving. As your child enters adulthood and begins a career, they will need to know how to manage their finances responsibly.

For childhood cancer survivors, maintaining health insurance is very important. Young adults can remain on a parent's or legal guardian's health insurance plan until they turn 26 years old. After that, 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.

For information on budgeting and the different types of health insurance, visit www.LLS.org/booklets to view *Cancer and Your Finances*. The booklet also includes worksheets to help navigate health insurance and create a personal budget.

Triage Cancer

<https://tragecancer.org/>

(424) 258-4628

Triage Cancer is a national, nonprofit organization that provides education on the practical and legal issues that may

impact individuals who have been diagnosed with cancer and their caregivers, through free events, materials and resources.

Mental Health and Self-Care

For more information, see *Mental Health* on page 45. Visit www.LLS.org/booklets to view *Managing Stress: How stress affects you and ways to cope*.

National Institute of Mental Health Information Resource Center

<https://www.nimh.nih.gov>

(866) 615-6464

The National Institute of Mental Health (NIMH) is part of the National Health Institute (NIH). This federal agency provides information on mental illness and treatment.

More Resources. You can also reach out to The Leukemia & Lymphoma Society's Information Specialists at (800) 955-4572 or visit www.LLS.org/ResourceDirectory to find more organizations that can help.

Transitioning to Adult Healthcare

As your child transitions to adult healthcare, you can give them this completed workbook so they have a detailed record of their cancer treatment and information about possible long-term and late effects. Your child can share this information with all new healthcare providers.

Teaching Your Child to Navigate the Healthcare System

It is important for everyone (parents and children, as age appropriate) to learn how to navigate the healthcare system and advocate for care. To be successful, a person needs to be able to:

- Talk to healthcare professionals and ask questions

- Request written information about a diagnosis, treatment, or medication
- Know family and personal medical history
- Alert the healthcare team to any new or worsening signs and/or symptoms
- Schedule appointments
- Take an insurance card and a list of all current medications to appointments
- Make appointments with new providers
- Seek a second opinion or ask for a referral to a specialist, when needed
- Know how to access medical records
- Maintain recommended follow-up and disease-screening schedules
- Stay up-to-date on recommended vaccinations
- Make sure that medications are taken as prescribed
- Check with members of the healthcare team before taking any new medications (including over-the-counter medications, vitamins and supplements)
- Be honest with the healthcare team about lifestyle, including drug and alcohol use and sexual activity
- Understand health insurance coverage and medical costs
- File a claim with insurance providers and appeal an unapproved claim

Every child, depending on their age, can learn many of these skills. Allow your child to learn by participating in their own care, as age appropriate. For example, encourage them to ask members of the healthcare team questions. Some children may wish to administer their own medications. You can allow them to do so, with your supervision. By learning and practicing, your child will develop the necessary skills and awareness to advocate for their own care in the future.

When Your Child Becomes a Legal Adult

Your child's need for follow-up care will continue even after they become 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 them 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 their medical information.

Changing Healthcare Providers

If your young adult moves away from home 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 provider who can provide the necessary follow-up care.

Give this completed workbook to your young adult so they have a record of their cancer diagnosis, treatment and long-term and late effects screening recommendations.

Any new providers will need to know your young adult's detailed medical history. 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.

Visit Got Transition® at www.gottransition.org for a list of available healthcare resources and more information about the process of transitioning from pediatric healthcare to adult healthcare.

Advance Care Planning

All adults, even young adults, can participate in advance care planning. Advance care planning includes reflecting on the persons' wishes and preference for medical care, discussing their end-of-life wishes with people they love and trust and completing the appropriate legal documents. Visit www.LLS.org/booklets to view *Advance Care Planning*.

Other Adult Healthcare Needs

As a natural part of aging, your child may also need to begin screening for other diseases and conditions that are unrelated to the cancer diagnosis or treatment. Most diseases are easier to treat or manage if discovered early. Many disease screening tests can be part of an annual wellness exam. A primary care provider can help coordinate any tests.

Diseases commonly screened for include:

- Some types of cancer, including colorectal, breast, cervical, prostate
- High blood pressure and high cholesterol levels (risk factors for heart disease)
- Diabetes
- Osteoporosis (weak bones)
- STDs (sexually transmitted diseases)
- Mental health conditions, such as depression

The Affordable Care Act (ACA) requires most insurance plans to cover preventative services at no cost.



Visit **www.health.gov/myhealthfinder**. Use the MyHealthfinder to get disease screening and vaccine recommendations, based on age and sex. The MyHealthfinder recommendations come from the United States Preventive Services Task Force (USPSTF), the Centers for Disease Control and Prevention (CDC) Advisory Committee on Immunization Practices (ACIP), and the Health Resources and Services Administration (HRSA). Discuss results with your child's primary care provider.

NOTES

Questions to Ask Members of the Healthcare Team and Resources



Questions to Ask Members of the Healthcare Team

If either you or your child has questions, ask the members of the healthcare team for answers. Write the questions down in the fold out.. At the appointments, you can fill in the answers. For suggested questions, visit www.LLS.org/WhatToAsk for printable question guides.



LLS Health Manager™ App. With LLS Health Manager,™ you can now use your phone to manage your child's daily health by tracking side effects, medication, food and hydration, questions for the doctor, grocery lists and more. You can also set up reminders to take medications and to eat/drink throughout the day. Visit www.LLS.org/HealthManager to download for free.

Always tell members of your child's healthcare team about any new or worsening signs and symptoms. All of your and your child's concerns are important. Do not feel embarrassed to ask healthcare providers to answer your questions. You and your child deserve to have your concerns addressed. Visit www.LLS.org/booklets to view *Communicating with Your Healthcare Team: Survivorship*.

Question:

Date: _____

Answer:

Question:

Date: _____

Answer:

Question:

Date: _____

Answer:

Question:

Date: _____

Answer:

Question:

Date: _____

Answer:

Question:

Date: _____

Answer:

Question:

Date: _____

Answer:

Question:

Date: _____

Answer:

Question:

Date: _____

Answer:

Resources and Information

LLS offers free information and services to patients, caregivers and families affected by blood cancers. This section of the book lists various resources that can be helpful to you. Use this information to learn more, to ask questions and to make the most of your child's healthcare team members' knowledge and skills.

For Help and Information

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

- Call: (800) 955-4572 (Monday through Friday, 9 am to 9 pm ET)
- Email or live chat: www.LLS.org/InformationSpecialists

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

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

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

Financial Assistance. LLS offers financial support including insurance premium and medication co-pay assistance as well as travel and other needs to eligible individuals with blood cancer. For more information, please:

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

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

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

Free Mobile Apps.

- LLS Coloring For Kids™ - Allows children (and adults) to express their creativity and offers activities to help them learn about blood cancer and its treatment. Visit www.LLS.org/ColoringApp to download for free.
- LLS Health Manager™ - Helps you track side effects, medication, food and hydration, questions for your doctor, and more. Visit www.LLS.org/HealthManager to download for free.

School Reentry. *The Trish Greene Back to School Program for Children With Cancer* is a program designed to increase communication among healthcare professionals, school personnel, parents and patients to assure children with cancer a smooth transition back to school. Visit www.LLS.org/BackToSchool for more information.

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

Community Resources and Networking

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

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

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

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

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

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

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

Additional Help for Specific Populations

Language Services. Let members of your healthcare team know if you need translation or interpreting services because English is not your native language, or if you need other assistance, such as the service of a sign language interpreter. Often these services are free.

Information for Veterans. Veterans who were exposed to Agent Orange while serving in Vietnam may be able to get help from the United States Department of Veterans Affairs. Please visit www.publichealth.va.gov/exposures/agentorange or call the Department of Veterans Affairs at (877) 222-8387 for more information.

Information for Firefighters. Firefighters are at an increased risk of developing cancer. There are steps that firefighters can take to reduce the risk. Please visit www.LLS.org/FireFighters for resources and information.

World Trade Center (WTC) Survivors. People involved in the aftermath of the 9/11 attacks and subsequently diagnosed with a blood cancer may be eligible for help from the World Trade Center (WTC) Health Program. People eligible for help include

- Responders
- Workers and volunteers who helped with rescue, recovery and cleanup at the WTC-related sites in New York City (NYC)
- Survivors who were in the NYC disaster area, lived, worked or were in school in the area
- Responders to the Pentagon and the Shanksville, PA, crashes

For more information, please

- Call: WTC Health Program at (888) 982-4748
- Visit: www.cdc.gov/wtc/faq.html

People Suffering from Depression. Treating depression has benefits for cancer patients. Contact your doctor if your mood does not improve over time—for example, if you feel depressed every day for a 2-week period.

For more information, please:

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

INFORMATION FOR TEENS

Message to parents and guardians: read through this information and share this section with your teenager. Fill out the Emergency Plan information with them. You can either go over the rest of the information with your teenager or allow them to read it alone. Encourage them to come to you and/or their healthcare team with any questions or concerns.

Emergency Plan

If you experience an emergency, either when you are alone or without adult supervision, you need to know what to do. Save this information on your phone or keep a printed copy with you, such as in your backpack or purse.

What signs or symptoms require a trip to the emergency room? List them below:

☐☐☐☐

Who should I call during an emergency?

Parent or guardian

Hospital or treatment center

Emergency contact

☐☐

WHEN IN DOUBT, CALL 911 IN AN EMERGENCY.

If you are hanging out with friends, make sure your friends know to call your parents and/or 911 in an emergency if you are unable to do so yourself.

Your Healthcare Team

- Communicate with the members of your healthcare team.
 - Your parent or guardian may take the lead at appointments, but don't be afraid to speak up and ask questions.
- Be open and honest with your healthcare team about how you are feeling.
 - Don't keep information from your healthcare team or be afraid to ask questions, even about sensitive subjects such as your mental health, tobacco, vaping, drug and alcohol use, and sex.
 - If there is something you would like to discuss with a member of your healthcare team without your parent present, ask to speak privately.
- If you struggle to communicate with your parent or guardian, ask a member of your healthcare team, such as a social worker, to help you.

Treatment

- Learn about your diagnosis and treatment.
 - Ask your parent or guardian or members of your healthcare team to help you find reliable information.
- Be careful searching for information about cancer online. Not everything you find online is true or applies to your diagnosis or health.
 - If you read something that upsets you, talk to the members of your healthcare team.
- Daily medications and hospital visits can be upsetting, frustrating or even boring, but it is important to follow your treatment plan exactly how your doctor prescribes.
 - Missing medications or doing activities your healthcare team told you to avoid can be dangerous. Your medications may not work as well or you may have more side effects or complications.

Side Effects

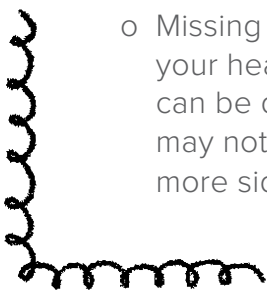
- You may have side effects from treatment such as fatigue, nausea and vomiting, hair loss, mouth sores, or others.
 - Ask your healthcare team what to expect and how to make side effects better.
 - Tell your healthcare team about any new or worsening side effects you have.
- Your immune system fights illness and infections. Cancer and cancer treatment can weaken your immune system, so it may be easier for you to get sick. Your healthcare team may suggest that you take steps to protect yourself, such as washing your hands more and avoiding people who are sick and some activities.
 - Ask your healthcare team what you can do to prevent illness and infection.



Ask your parent or guardian to visit www.LLS.org/booklets to view *Side Effect Management: Reducing Your Risk of Infection*.

Fertility

- Cancer treatment can also affect your fertility.
 - Fertility is the ability to have a biological child. If your cancer treatment may affect your fertility, you may have the option to take steps to preserve your fertility through a process called egg freezing or sperm "banking." This usually needs to be done before treatment that can affect fertility begins. Talk to your healthcare team about what this means for your fertility.
 - If you are getting your period, cancer treatment can interrupt or stop your cycle. Even if your period stops, you still may be able to become pregnant. Ask your healthcare team what to expect and let them know about any changes you experience.





Ask your parent or guardian to visit www.LLS.org/booklets to view *Fertility and Cancer* for more information.



Go over *Healthy Behavior Recommendations* on page 37 with your parent or guardian.

Mental Health and Self-Care



Mental health, like physical health, is important to your overall well-being. You may experience feelings of sadness, anxiety, grief or guilt. These feelings are normal. Most cancer patients, even adults, have them at some point. Talk to someone you trust about how you are feeling. If these feelings begin to be scary or overwhelming, talk to your healthcare team and your parent or guardian for help.

Ask to talk to a therapist or social worker. A therapist or social worker can provide you with tools to identify and cope with your emotions in a healthy way. Therapy can be beneficial for everyone, not just those with symptoms of depression or anxiety.

Self-care can help improve your mental health. Self-care can include

- Journaling
- Music, drawing or painting
- Hobbies such as reading, video games or baking
- Spending time with friends and family
- Walking or spending time outdoors
- Hygiene and personal care such as bathing and brushing your teeth
- Eating a variety of nutritious foods
- Asking a trusted adult for help when you are sad, scared or overwhelmed



Ask your parent or guardian to visit www.LLS.org/booklets to order *Write It Out*, a journal for blood cancer patients with prompts, tips, coloring pages and many blank pages.

If you are having trouble coping and do not know who you can turn to for support, call the National Suicide Prevention Lifeline at (800) 273-TALK ([800] 273-8255) to talk to a community crisis center representative. The Lifeline is free, confidential and always available.

Friends



- During treatment, you may find that some of your friends are your biggest supporters. Even if you may not be able to spend as much time with them while you are in treatment, you can stay in touch with them through video calls and messaging.
- Other friends may not know how to cope with your diagnosis. Although this may hurt, try not to take it personally. Not everyone knows how to handle a cancer diagnosis. Focus on the friends who do stick around.
- Connect with other teens with a cancer diagnosis. Talking to someone who understands what you are going through can be very helpful.
 - Ask your healthcare team about local and online support groups.
- Be careful about what you post on social media. Ask your parent or guardian for permission to have a social media account. When posting on social media, remember that even a private profile may not be as private as you think. Would you be upset if a new friend, a date, or employer learned about your diagnosis from an internet search? Take time to think it over before you share personal information online.



Body Image

Cancer treatment can cause changes to your body such as hair loss, weight loss or gain, and skin changes. You may also not feel your best or feel more tired than usual. Puberty can also change the way your body looks and feels. Be gentle with yourself. Your appearance does not determine your worth. You do not have to love everything about your body, but you do need to respect and care for it.



Read and work through *Body Image and Self-Esteem* on page 55 with your parent or guardian.

School



You may not be able to attend school during treatment, but you can still continue your education. You may work with a teacher at the treatment center or be able to participate in classes virtually. When you can attend school in person again, work with your parent or guardian, healthcare team, and teacher or guidance counselor to help you return to school. Let them know about any concerns or questions you have. There are resources to help you.



Ask your parent or guardian to visit www.LLS.org/booklets to view *Learning & Living with Cancer: Advocating for your child's educational needs*.

Future Plans



- You may already be thinking about your plans for after high school. Your plans may include college, vocational or technical school, internships, employment or independent living.
 - Discuss your goals and dreams with your parent or guardian, healthcare team, and guidance counselor to see what you can do to stay on track.
 - There may be resources to help you such as scholarships for cancer survivors.
- The day you become a legal adult, your healthcare team will begin to ask you to make medical decisions and sign consent forms.
 - If you still want to have your parent or guardian make decisions for you, you can sign paperwork to allow your healthcare team to continue to communicate with your parent or guardian about your medical needs.



Go over *Support for the Future* on page 62 and *Transitioning to Adult Healthcare* on page 65 with your parent or guardian.

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## Acknowledgements

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

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NOTES



# Get support. Reach out to our **INFORMATION SPECIALISTS**

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

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

Contact us at

**800-955-4572** or  
**[www.LLS.org/  
InformationSpecialists](http://www.LLS.org/InformationSpecialists)**

(Language interpreters can be requested)



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

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



Discover what thousands already have at  
[\*\*www.LLS.org/Community\*\*](http://www.LLS.org/Community)

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

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



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

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

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