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LYMPHOMA
SOCIETY®

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NAVIGATING LIFE DURING AND AFTER
A BLOOD CANCER DIAGNOSIS

**YOUNG
ADULTS**

Support for this publication
provided by



Navigating Life During and After a Blood Cancer Diagnosis: **A Workbook for Young Adults**

To reach us call: **800.955.4572**

LLS also offers two other versions of this workbook:

A Workbook for Adults and *A Workbook for Parents, Children and Adolescents*.

Visit www.LLS.org/SurvivorshipWorkbook for more information.

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This Workbook Belongs To

Name

Phone Number

Email Address

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

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.” People have different feelings and opinions about using the term “survivor.” After a cancer diagnosis, some people feel empowered by the word “survivor” to describe themselves. Others may not feel comfortable using the word until after their treatment ends. Others may prefer to use a different word. Your loved ones may not use the word “survivor” (or another word) in the same way as you do. If that’s the case, feel free to ask them to use the language you prefer. The different feelings people have about using the term “survivor” are all valid.

Welcome

Being diagnosed with cancer is like being sent on a journey that you did not want 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 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 to navigate new pathways and help you find your “new normal.”

Young Adults

As a young adult (YA) with cancer, you are not alone. According to The National Cancer Institute, about 89,000 young people ages 15 to 39 are diagnosed with cancer each year in the United States. As a YA cancer patient, you will likely face challenges specific to your age-group.



Visit www.LLS.org/YoungAdults for more resources and information.

How to Use this Workbook

Use this workbook to collect all the important information you need as you move through diagnosis and treatment into long-term management of a chronic blood cancer or finish treatment and begin post-treatment survivorship care. Make it personal. Part of the information you will need for long-term management of a blood cancer or survivorship will come from resources such as The Leukemia & Lymphoma Society (LLS) and your healthcare team. A good deal of important

information will also come from the time you take to reflect on your personal experience as a cancer survivor.

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

For some patients with a blood cancer diagnosis, there may never be a clear-cut time when treatment ends, but the information, worksheets and questions in this workbook still apply.

The Leukemia & Lymphoma Society also offers two other versions of this workbook: *A Workbook for Adults* and *A Workbook for Parents, Children and Adolescents*. 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.

Advocating for Your Care

Knowing how to navigate the healthcare system and advocate for your care is an important skill for young adult cancer survivors. To be successful:

- Learn about your cancer diagnosis and treatment options, including clinical trials.
 - Visit www.LLS.org/DiseaseInformation to find information about your cancer type.
 - Be aware that some young adult leukemia patients may benefit most from a pediatric treatment regimen.
- Ask if your cancer center has a young adult program.
- Don't be afraid to seek a second opinion, especially from a cancer center with a young adult program.
- Understand your health insurance plan and how to file an appeal if a claim is denied.
 - Visit www.LLS.org/booklets to view *Cancer and Your Finances* for information on insurance policies and how to file an appeal.
- Follow your treatment plan. Do not miss appointments. Be sure to take medications exactly as your doctor prescribes them.
- Ask how you can access your patient portal. Many hospitals and treatment centers now offer digital "patient portals" where you can view your medical record and upcoming appointments, message your providers, view and pay bills, and more online.
- Always ask questions. Do not be afraid to ask your doctor to slow down or explain things another way.
 - Visit www.LLS.org/WhatToAsk for lists of questions to ask members of your healthcare team.
- Do not withhold information about your medical history

or lifestyle from your healthcare team. If important or relevant information is withheld, you may not receive the best care.

- Tell your doctor about any new or worsening side effects or any other concerns you may have. You can download the free LLS Health Manager™ mobile app to help you manage your health by tracking side effects, medication, food and hydration, questions for your doctor, and more. Visit www.LLS.org/HealthManager for more information.
- Ask for a referral to supportive (palliative) care. Supportive care is appropriate for anyone who has a serious illness regardless of age, stage or prognosis. There are ways that can help you to manage side effects so you are more comfortable, both during and after cancer treatment.
- Ask for a referral to a mental health professional. Mental health is important to overall well-being.
- Talk to your healthcare team about any concerns you have that are related to work, school or finances. Resources may be available.
- Seek help from loved ones. Let your caregiver know when you do and do not need their help, and tell them what tasks they can help you with and how. Set boundaries early.
 - See *Defining Your Caregiver's Role* on page 64.
- Create an advance directive. Advance directives are your instructions about future medical care in the event that you are no longer able to speak for yourself. When a person becomes a legal adult, they can complete an advance directive that specifies the type of care they want to receive in case of a medical emergency.
 - See *Advance Care Planning and Estate Planning* on page 86.

Survivorship Care Plan



DIABETES
BLOOD TRANSFUSIONS
HEPATITIS
THYROID DISORDER

ALLERGIES
(SPECIFY)

FRACTURES
(SPECIFY)

OPERATIONS
(SPECIFY)

SYMPTOM WITHIN ONE YEAR:
INFECTIOUS DISEASE
HEAD INJURY
MAJOR SURGERY
TRAUMATIC OR OVERUSE INJURY

CONDITIONS MARKED "YES":

DATE COMPLETED:
SIGNATURE OF GUARDIAN OF ATHLETE UNDER 18 YEARS:

DATE(S) UPDATED:

CARE OF AUTHORIZED PERSONNEL ONLY

MEDICATIONS
PRESCRIBED:
NON-PRESCRIBED:

NOTE: MEDICAL DATA IS CONFIDENTIAL

Date:

Survivorship Care Plan

A survivorship care plan is a record of your cancer diagnosis, a treatment summary, including supportive (palliative) care, and a plan for follow-up care. Ask members of your healthcare team for a written survivorship care plan. If you received treatment as a child, you can request a copy of your medical records from your treatment center. You can use the information provided in that plan to fill out this section of the workbook and/or save a copy in the pocket of this section.



Visit www.LLS.org/booklets to view *Communicating with Your Healthcare Team: Survivorship* for a checklist of what your survivorship care plan can include and a list of questions to ask your healthcare team.

Record your diagnosis and all of your treatment information in the following pages. Knowing your exact diagnosis and treatment, including specific drugs and/or site of radiation, is very important information. It helps you and the members of your healthcare team 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 medical record and upcoming appointments, message your providers, view and pay bills, and more online. Ask how you can access your patient portal.

Diagnosis Information

Date of 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 and Diameter (if applicable)

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

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

Blood Cell Counts. Your healthcare team will order frequent blood tests to monitor your blood cell counts, both during and after treatment. Blood cancers and treatment for blood cancers can affect blood cell counts in a number of different ways.

- Anemia (a low number of red blood cells)
 - o Red blood cells contain hemoglobin which carries oxygen around the body. Anemia can make you look pale, feel weak and tired, and become short of breath.
- Thrombocytopenia (a low number of platelets)
 - o Platelets help form blood clots to stop or slow bleeding. Thrombocytopenia can cause excessive bleeding and bruising.
- Neutropenia (a low number of neutrophils, a type of white blood cell)
 - o White blood cells help the body fight infection. A low number of neutrophils increases the risk of infection.

Keep track of your lab reports to share with all your medical providers. You can keep printed copies in the pocket of this section. You may also be able to access your lab reports online through a patient portal provided by your hospital or treatment center. Ask your healthcare team how to access your reports.



Visit www.LLS.org/booklets to view *Understanding Lab and Imaging Tests* and *Side Effect Management: Managing Low Blood Cell Counts*.

Chemotherapy or Other Drug Therapy

Drug Name	Cumulative Dosage and Method of Administration	Dates Received or Duration of Treatment



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 the medications you are currently taking for other health issues, including vitamins and supplements. If you use a pill box, 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 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.

Procedures

For example, port placement, blood transfusion, 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 both you and your family members. **Supportive care is appropriate for anyone who has a serious illness, regardless of age, stage or prognosis.** You may continue getting supportive care, even after you finish 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

You may be hospitalized for cancer treatment and/or to manage side effects of treatment. If you have had other significant hospitalizations, either related or unrelated to cancer, you may wish to record them here.

Date	Hospital Name	Reason

Maintenance/Ongoing Treatment

Not all patients will need ongoing or maintenance treatment for blood cancer.

Drug/Treatment Name	Duration	Possible Side Effects



Visit www.LLS.org/booklets to view *Oral Treatment Adherence Facts*. Call an LLS 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 current medications.

Other Personal 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
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 your long-term plans or goals for 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 you have a history of cancer, you will need lifelong follow-up medical care. Therefore, it is very important to maintain your health insurance. If possible, do not allow there to be gaps in your coverage. 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, record the appointment in the calendar on your mobile phone. Ask your provider's office to confirm your preferred method of communication for reminders. If you have tests scheduled, ask what you need to do to prepare, if anything, such as not eating before the test.

Upcoming Appointments

Provider/Reason	Location	Date	Time

Other Resources for Survivorship Care Plans

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 Survivorship (NCCS)

offers a Survivorship Checklist designed to be a simple straightforward tool that patients and caregivers can use as a guide for important information. Visit www.SurvivorshipChecklist.org 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.

The Children’s Oncology Group (COG) provides a downloadable *Summary of Cancer Treatment* template to fill out with the help of the members of the healthcare team. Visit www.survivorshipguidelines.org to download a template. See *Passport for Care*® with The Children’s Oncology Group on page 39 for more resources.

My Healthcare Team

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

My Healthcare Team

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
-------	-------

Pharmacist (Pharmacy)

Name	Hospital/Treatment Center
------	---------------------------

Phone	Email
-------	-------

Nurse Manager

Name	Hospital/Treatment Center
------	---------------------------

Phone	Email
-------	-------

Nurse Practitioner

Name	Hospital/Treatment Center
------	---------------------------

Phone	Email
-------	-------

My Healthcare Team (continued)

Transplant Coordinator

Name	Hospital/Treatment Center
Phone	Email

Supportive (Palliative) Care Team

Name	Hospital/Treatment Center
Phone	Email

Social Worker

Name	Hospital/Treatment Center
Phone	Email

Financial Manager

Name	Hospital/Treatment Center
Phone	Email

Emergency Room

Name	Hospital/Treatment Center
Phone	Email

Role:

Name	Hospital/Treatment Center
Phone	Email

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Long-Term and Late Effects

Long-Term and Late Effects

Treatments for 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. You should discuss the possible effects of treatment with your healthcare providers in order to plan treatment and follow-up care. The factors that determine the risk of long-term and/or late effects include:

- Type of treatment
 - For example, the specific drugs used or the part of the body treated with radiation
- Length of treatment
- Your age at the time of treatment
- Your 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 do not show up until years after treatment ends. Treatment-related cancer and heart disease are examples of late effects.

Keep a record of any cognitive, physical or emotional signs and/or symptoms that you experience and discuss them with your healthcare team. You can keep notes in a journal or notebook. You can also download the free LLS Health Manager™ mobile app to track side effects, medication, food and hydration, questions for your doctor, and more. Visit www.LLS.org/HealthManager to download.

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

Cancer treatments, such as chemotherapy and radiation to the brain, can cause changes with thinking, such as difficulty with concentration, memory and the ability to multi-task. These effects are sometimes referred to as “chemo brain” or “brain fog.” Many cancer patients experience cognitive effects to some degree. For most people, cognitive effects last only a short time and improve after treatment ends. Other people, however, may have long-term cognitive changes.



Visit www.LLS.org/booklets (filter by Side Effect Management) to view *Side-Effect Management: Memory and Concentration Problems in Adults*.

Physical Effects

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

- Fatigue
- Neuropathy (nerve damage)
- Heart issues
- Thyroid problems
- Organ damage (lungs, kidneys)
- Bone issues, such as osteoporosis
- Fertility problems

- Secondary cancer
- 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.

Options to preserve fertility depend on several factors. If patients need treatment immediately, there may not be time to complete the fertility preservation process.

- For males, sperm banking may be an option.
- For females, egg or embryo (egg fertilized with sperm) freezing may be an option.

Other more experimental options may also be available. Or, you may be able to take steps during treatment that will reduce the chance of infertility, such as using shields during radiation therapy or choosing different treatment options, if available.

Fertility Preservation Information			
Provide details of any fertility preservation procedures so that you can refer to 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. When you are ready to start a family, you can consider and discuss all options with your healthcare team.



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

Psychological effects after a cancer diagnosis are common. Diagnosing yourself or someone else may be tempting, but your best resource will be a trained mental health professional who will be able to make an accurate diagnosis and create an effective treatment plan for you. The following lists some symptoms of common mental health diagnoses. If you experience any of these, speak to a mental health professional.

- Depression or symptoms of depression
 - o Depression as a mental health disorder includes ongoing sad moods and/or loss of interest in activities. Often these symptoms are accompanied by other physical changes in sleep, fatigue and eating habits. Even if you do not meet the full criteria for depressive disorder, you may still benefit from therapy with a mental health professional.
- Anxiety disorders
 - o Anxiety disorders include multiple diagnoses such as generalized anxiety disorder, obsessive compulsive disorder (OCD), or panic disorder. Anxiety disorders are different from the common worries encountered in day-to-day life. Symptoms of anxiety disorder can include intrusive thoughts and make it difficult to pull yourself 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. Going to the hospital or being faced with foods that were eaten often during treatment are the sorts of things that may trigger these feelings.

Your mental health is very important to your overall health and well-being. Ask your healthcare team or health insurance provider for a referral to a mental health professional. It is common to start taking medications that can improve your mental health. You can also visit www.helpstartshere.org and click "Find a Social Worker" for resources and information to help you search for local mental health professionals or to get online counseling. For more information, see *Mental Health* on page 52.

If you are 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.

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Possible Long-Term and Late Effects of My Cancer Treatment

To help you understand and manage your risk of long-term and late effects, fill in the Guidelines for Long-Term and Late Effects Screenings table following the instructions in the flow chart below.

Column 1 (Treatment)

What treatments did you receive, including specific drugs and dosages?

In the Treatment column, fill in all the treatments you received including specific drug names and/or site of radiation. This will be the same treatment information that you entered in the tables on pages 8-17.



Column 2 (Possible Side Effects)

What are the possible long-term and late effects of each treatment I received?

Go over the possible long-term and late effects of each treatment you received with members of your healthcare team and record them in the Possible Side Effects column.



Column 3 (Screening Recommendations)

What screenings are recommended to monitor for each of the possible long-term and late effects, including frequency of screening and which healthcare provider will be responsible?

For each possible side effect, ask your healthcare team for screening recommendations. Include the type of test you will need to screen for the side effect; when you should start screening; how often you should be screened; and which healthcare provider will be responsible for the screening.

Guidelines for Long-Term and Late Effects Screenings

Treatment	Possible Side Effects	Screening Recommendation (including tests, frequency and coordinating provider)
<i>Example: Radiation to the chest</i>	<i>Breast cancer</i>	<i>Yearly breast exam beginning at puberty until age 25, then every 6 months. Yearly mammogram and breast MRI, as an adjunct to mammography, beginning 8 years after radiation or at age 25 (whichever occurs last) with your primary care provider*</i>

*Source: Children’s Oncology Group (COG). *Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers*. Version 5.0-October 2018. Available at: <http://www.survivorshipguidelines.org/>.

Guidelines for Long-Term and Late Effects Screenings (continued)

Treatment	Possible Side Effects	Screening Recommendation (including tests, frequency and coordinating provider)

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National Comprehensive Cancer Network® (NCCN) Guidelines

Visit <https://www.nccn.org/patientguidelines> for Patient and Caregiver Resources provided by the National Comprehensive Cancer Network®, including *Adolescents and Young Adults with Cancer*, *Survivorship Care for Cancer-Related Late and Long-Term Effects*, and *Survivorship Care for Healthy Living*.

On the same website, you can also download the *NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®)* for Survivorship. You can create a free login at <https://www.nccn.org/store/Login/Register.aspx> to access this resource. This resource was created for healthcare professionals, but you can use it as a tool to help guide your discussions with members of your healthcare team.

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* (COG LTFU Guidelines). The information is reviewed and updated regularly by experts in survivorship care. The follow-up guidelines are written for healthcare professionals; therefore, it is best to review the guidelines with the help of the members of your 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 the members of healthcare team.

Visit www.survivorshipguidelines.org to download the guidelines and Health Links.

Passport for Care® with the Children’s Oncology Group (COG) 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 for 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 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.

Side Effect Management

Work with members of your healthcare team to manage any lingering or new side effects or symptoms you experience after treatment ends. Side effects such as fatigue, pain, neuropathy, or emotional side effects such as anxiety or depression can often be improved or managed with changes to your daily habits and/or with medication or therapy.

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



Visit www.LLS.org/booklets (filter by Side Effect Management) for a series of booklets that offer information on specific side effects.

Integrative Medicine and Complementary Therapies.

Complementary therapies are treatments used along with

standard treatments but are not considered standard medical care. Integrative medicine combines standard medicine (such as chemotherapy) with safe and effective complementary therapies. Some examples of complementary therapies include acupuncture, meditation, therapeutic massage, and yoga. Consult with your healthcare team before you try any complementary therapy to make sure it will not interfere with your treatment or medications. Ask your healthcare team if your cancer center has a complementary therapies program.



Visit www.LLS.org/booklets to view *Integrative Medicine and Complementary Therapies Facts*.

Medical Marijuana. Marijuana has been used in herbal remedies for centuries. The biologically active components in marijuana are called “cannabinoids.” The two best studied components are the chemicals delta-9-tetrahydrocannabinol (THC) and cannabidiol (CBD). Under federal law, marijuana cannot legally be prescribed, possessed, or sold. Under many state laws, the use of marijuana to treat some medical conditions is legal. Under some state laws, the use of recreational marijuana by adults is legal. (Even in these states, its use is still illegal for minors.)

In cancer care, medical marijuana is sometimes used to manage side effects, such as nausea, appetite loss, pain or anxiety, if other medications or treatments are unsuccessful. More research is needed to better understand the benefits and risks of marijuana and its cannabinoids.

Do not use marijuana or products made with cannabinoids without first talking to your healthcare team. Marijuana or related products (for example, CBD oils) could interfere with other medications. Marijuana products that are not obtained from licensed dispensaries carry additional risks as they may

contain unknown ingredients, including infectious agents. Talk honestly with members of the healthcare team about your use of marijuana or related products.

Educating Family Members and Friends About Long-Term and Late Effects

Once you finish cancer treatment, enter a watch-and-wait protocol, or become more comfortable managing the effects of living with a chronic blood cancer, your family and friends may assume that you will immediately feel the way you did before your cancer diagnosis. You may need to explain that even though you may seem okay you are still recovering or adjusting physically and/or emotionally.



Use the space below to plan what you will say to explain these feelings to family members and friends.

I am still experiencing:

Example: Fatigue

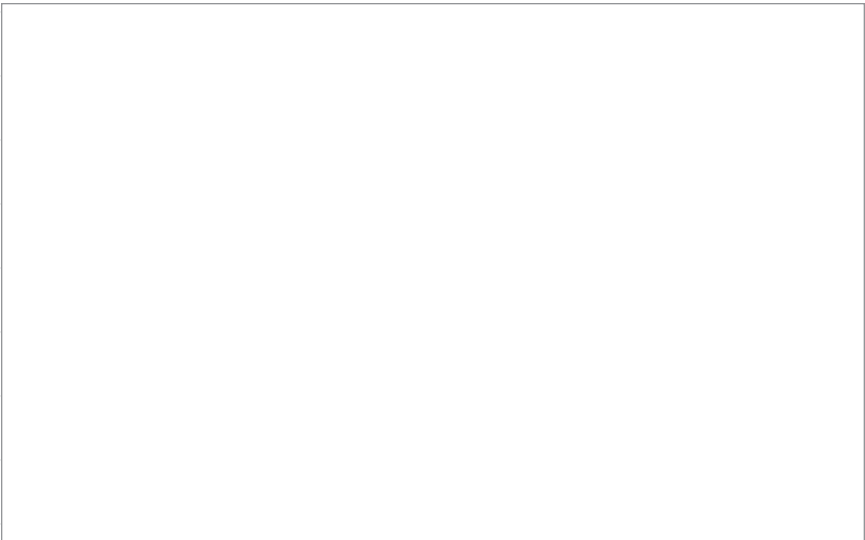
This affects me in the following ways:

Example: Sometimes I do not have the energy to do all the things I need or want to do.

A large, empty rectangular box with a thin black border, intended for the user to write their response to the question above.

You can help me by:

Example: Picking up my grocery order for me and understanding when I may not feel up for family game night.

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NOTES

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Healthy Behavior Recommendations



Healthy Behavior Recommendations

Developing healthy lifestyle habits are important for cancer survivors. Healthy lifestyle habits can help you recover faster and decrease the risk of disease, such as other cancers, heart disease and diabetes. Making changes so that you 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 still take good care of yourself.



Check all the healthy behavior statements that are true for you.

- I eat a well-balanced diet that includes a variety of fruits and vegetables, proteins, whole grains and healthy fats.
- I drink at least eight 8-oz glasses of water or liquids (not including caffeinated drinks, such as coffee, or drinks with added sugars) each day.
- I sleep well each night and wake up feeling rested.
 - o Most adults need at least 7 to 8 hours of rest each night.
- I exercise regularly.
- I do not smoke or use tobacco.
- I drink alcohol not at all or only in moderation. If I am not of legal drinking age, I do not consume alcohol.
 - o Limit consumption to no more than one drink per day for women and two drinks per day for men. One drink is defined as 12 ounces of beer, 5 ounces of wine, or 1.5 ounces of liquor.
 - o If you are taking any medications, ask your doctor if it is okay for you to drink alcohol. It is not safe to drink alcohol with some medications.

- I protect myself from sun damage.
 - o Avoid direct sun, when possible, and wear broad-spectrum sunscreen with a sun protection factor (SPF) of 30 or higher and reapply every 2 hours.
- I keep up with my medical needs, such as getting annual checkups with my primary care provider and getting regular dental cleanings.
- I keep my hematologist-oncologist informed about any changes in my well-being.
- I take all medications as prescribed.
- I talk to my healthcare team about my mental health.
- I practice self-care and do things to manage stress.
 - o See *Creating a Self-Care Plan* on page 57.
- I connect with others (people I love, friends, family members and/or members of a support group) regularly.
 - o Isolation is a risk factor for depression and anxiety disorder. Many young adult cancer patients struggle with feeling isolated. See *Community Resources and Networking* on page 94 for ways to connect with others.

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 members. 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. There are chats that focus on a specific diagnosis and there is also a "young adult" chat. Please visit www.LLS.org/chat for more information.

Did you leave any of these statements unchecked? If so, you may need to consider working on those aspects of your lifestyle. Discuss healthy behaviors with your primary care provider.

Ask for referrals to professionals for help with specific issues (for example, a registered dietitian, physical therapist or a mental health professional).

What are some steps you would like to take to improve your overall health and well-being? (Do not make changes to your diet or exercise plan without first talking to your healthcare provider.)



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

Other Disease Screenings

As part of a healthy lifestyle, in addition to screening for cancer relapse and the long-term and late effects of treatment, you will need to be screened for other diseases that may be unrelated to your cancer diagnosis. Everyone needs to be checked for diseases, such as diabetes, heart disease and other cancers. The specific screening recommendations for you will depend on your age, sex and medical history. Most diseases are easier to treat or manage if discovered early. Many disease screening tests can be part of your annual wellness exam. Your primary care provider can help coordinate any tests you will need.

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

Talk to your primary care provider about the disease screenings you need and how often you need them. The Affordable Care Act (ACA) requires most insurance plans to cover preventative services at no cost.



Visit www.health.gov/myhealthfinder to use MyHealthfinder to get disease screening and vaccine recommendations based on your 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 these recommendations with your primary care provider.

Other Disease Screening Recommendations	
Disease	Screening Recommendation

Immunizations

Immunizations help the body build resistance to a specific disease. Ask your primary care provider which immunizations you need. You likely received many immunizations as a child. However, other immunizations are given annually or need periodic boosters of vaccines to remain effective. You may also need new immunizations, depending on your medical history. Some cancer treatments, such as stem cell transplantation, can deplete or remove the protection that a previous immunization provided.

Immunization Record

Vaccine	Date(s) Given	Comments/ Reactions
Flu (influenza)		
Tdap or Td (tetanus, diphtheria, pertussis)		
Shingles (recombinant zoster vaccine [RZV])		
Pneumococcal conjugate—PCV13		
Pneumococcal polysaccharide—PPSV23		
Meningococcal A, C, W, Y—MenACWY		
Meningococcal—MenB		
MMR (measles, mumps, rubella)*		
HPV (human papillomavirus)		
Chicken pox/ varicella (VAR)*		
HepA (Hepatitis A)		
HepB (Hepatitis B)		
Hib (<i>haemophilus influenzae</i> type b)		
COVID-19 (SARS-CoV-2)		

*Vaccines noted with an asterisk are not recommended for patients who have a weakened immune system. If the patient received these vaccines before the cancer diagnosis, there is no harm done.

People undergoing cancer treatment should receive the flu shot that is made with the dead virus. Patients must **not** get the nasal spray vaccine because it contains the live virus and can be dangerous for immunosuppressed patients.

People who are receiving cancer treatment and require the shingles (zoster) vaccine should receive the recombinant zoster vaccine (RZV, Shingrix), not the zoster vaccine live.

If you plan to travel outside of the United States, check the recommended vaccines for that location. You may need additional immunizations. **Always clear travel with your healthcare team.**

Discuss the COVID-19 vaccine with your healthcare team. Ask about the latest recommendations and availability in your area.

Source: Centers for Disease Control and Prevention's *Recommended Adult Immunization Schedule by Medical Condition and Other Indications, United States, 2021.*

Mental Health



Mental Health

Mental health, like physical health, is important to your overall well-being. Even years after diagnosis or treatment, some people continue to struggle with feelings of sadness, anxiety, grief or guilt. Some people experience “survivor’s guilt” especially if a close friend or family member passed away from cancer. Others fear that their cancer may come back or get worse. Some feel a sense of loss or grief for their life before the cancer diagnosis. Having these feelings is normal; however, negative feelings shouldn’t be interfering with your daily life.

Talk to members of your healthcare team about your mental health concerns. You 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.

Fear of Relapse

Many people who have been diagnosed with cancer fear their cancer coming back or getting worse. For some, these fears surface or become worse around the anniversary of their diagnosis or transplant date. For others, these fears surface or become worse around checkups and screenings. Some cancer survivors call this “scanxiety.” These fears are normal, and there are things you can do to manage them.

Connect with Other Young Adult Survivors

Join other young adult blood cancer survivors on LLS’s live, weekly online chat. Visit www.LLS.org/chat to learn more. You can also visit Stupid Cancer at www.stupidcancer.org, Cactus Cancer Society (formerly Lacuna Loft) at www.cactuscancer.org, and Elephants and Tea at www.elephantsandtea.com to learn more about programs and resources to help young adult cancer survivors connect with each other and build community. Call an LLS Information Specialist at (800) 955-4572 for more information.



Check off the action items in the list below that you think may help alleviate your fear of relapse or disease progression. You do not need to do all of them. Find what works best for you.

- Get answers to your questions. Talk to your oncologist about your risk for relapse or disease progression and the signs and/or symptoms that may indicate a relapse or disease progression.
 - o This information can help you better understand your situation and minimize the fear of the unknown.
- Share the thoughts and feelings that are upsetting you. Talk to a mental health professional.
 - o A mental health professional can help you to fine-tune your awareness of your emotions so that you feel more in control. They can also help you to learn coping strategies to care for yourself. Ask your doctor for a referral or call your insurance provider.
- Pay attention to the lifestyle changes that improve your overall health and well-being, such as making good food choices or starting an exercise program. See *Healthy Behavior Recommendations* on page 44.
 - o Talk to your doctor before changing your diet or starting an exercise program.
- Find a hobby to occupy your mind.
 - o Try knitting, cooking, playing video games, painting, hiking or any other activity that appeals to you.
- Journal.
 - o Keeping a journal, or “journaling,” provides an outlet to express yourself. It can help you to identify (name) and cope with your emotions.
 - o 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.

- Connect with other cancer survivors.
 - o Cancer support groups and peer-to-peer programs are not just for patients receiving treatment. There are programs for people who are years out of treatment, as well as for those living with a chronic diagnosis. Talking to other people who understand what you've been through can be helpful. See *Community Resources and Networking* on page 94.

Identifying and Coping with Emotional Triggers

Know what triggers your emotions and what helps you feel more grounded and calmer.

Do movies or TV shows that address cancer upset you? Don't watch them. Does the sight of the sweatshirt you wore on treatment days bother you? Throw it out or donate it to a clothing bank. Do you get especially anxious around scan days? Ask a friend to video chat with you. Do you feel calmer after a good walk? Do you feel more energized after connecting with a group of friends? Is your perspective different after a good night's sleep?

Identify the objects, activities, specific foods, or situations that trigger negative feelings so you may feel more confident about your ability to care for yourself.



To begin to understand what helps you feel less stressed, answer the questions below.

What triggers your fear of relapse?

Example: Anniversary date of diagnosis

Think of ways to avoid these triggers. Or, are there things you can do in advance to manage your response?

Example: Plan a special outing or video chat on the anniversary of my diagnosis.



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

Stay Calm Strategy

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

Try the following strategies:

- Do a deep breathing exercise.
- Repeat a meaningful mantra, affirmation or prayer.
- Close your eyes and sit in silence.
- Count to 10 slowly.
- List the items you see in your surroundings.
- Stand up and stretch.
- Take a walk.
- Call a close friend or family member.

Visit www.healthline.com/health/grounding-techniques for more ideas for coping with difficult and/or emotional times.

When I feel overwhelmed, I will

When I feel sad, anxious or scared, I will reach out to someone I trust (such as a significant other, family member, or friend). When I feel overwhelmed, I will reach out to

Creating a Self-Care Plan

Self-care is

- Taking action to maintain or improve your own mental, emotional and physical health, especially during times of stress
- Responding to your distress with compassion and care
- Intentionally doing things you enjoy and things that improve your mood and lower your stress levels

Self-care helps you improve your relationship with yourself.

How to Create a Self-Care Plan



Self-care comes in many different forms. It's easy to say you want to take more time for yourself, but it can be hard to actually find the time. You will have to set goals and consciously make the time for self-care. Complete the following activities to create a self-care plan:

Mental and Emotional Self-Care

Taking care of your mental and emotional health is just as important as caring for your physical health. It's important to take time for yourself each day and spend it doing activities that you enjoy. Make a conscious effort to care for your own mental and emotional health.

What activities do you enjoy? Check all that apply.

- Listening to music, playing an instrument or singing
- Reading or listening to audiobooks
- Exercising or participating in group exercise classes
- Playing sports or organized games with friends
- Hiking, fishing or participating in other outdoor spots
- Meditating or practicing yoga
- Painting, drawing or other artistic pursuits
- Journaling or creative writing
- Attending religious or spiritual services
- Spending time with family members or friends
- Practicing personal care, such as taking long baths, having manicures or using face masks
- Cooking or baking
- Watching TV or movies
- Playing video or computer games
- Yard work or gardening
- Other _____

Any of these activities can be part of a self-care plan. Pick one or two of your favorite activities and make taking the time for them a priority in your day-to-day life.

I will set aside time to _____
once a day.

Examples: spend time outside, read a devotional passage, meditate and stretch, write in my journal

I will set aside time to _____
once a week.

Examples: talk to friends, attend a religious or spiritual service, go to an art class

Change the activity and frequency to accommodate your lifestyle and needs, but do make sure you are making time for yourself.

Physical Self-Care

Taking care of your physical well-being is also an important part of self-care. See *Healthy Behavior Recommendations* on page 44 for more information.

Body Image and Self-Esteem

Almost every person struggles with body image and self-esteem at some point, but 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. Many cancer survivors struggle with these side effects. Other cancer survivors don't experience them so people around them may assume that they aren't "really sick." There is no one way a cancer survivor should look. It's normal to feel differently about your body after a cancer diagnosis, whether or not there are visible changes. It takes time to get to know your body after cancer and having patience with the process can be hard.



The following exercises may help you begin to understand yourself in new ways.

Write down some important things your body can do.

Example: My arms can hug the people I love. My hands can cook a good meal.

Write down some things you like about yourself.

Examples: my sense of humor, my smile.

Here are some other things you can do to feel more comfortable in your own skin.

- Wear clothes that are comfortable. Don't worry about the number on the tag. Wear the size that feels the best on your body.

- Avoid looking at images online and in magazines that make you feel badly about your body or appearance.
- Treat your body well by adopting healthy habits. See *Healthy Behavior Recommendations* on page 44.
- Move your body. Go for a walk, do chair exercises or some other form of gentle movement.
- Watch for negative self-talk (thinking or saying negative things about yourself). We are often our own harshest critics. Next time you have a negative thought about yourself, ask yourself, “Would I say or think this sort of thing about someone I love?” Talk to yourself in the same way you would talk to someone you love.
- If some of your family members or friends talk about appearance or body size around you, ask them not to. Almost everyone is self-conscious about his or her appearance and talking about it frequently only adds to those feelings. There are much more interesting things to talk about!
- Remember, you don’t have to love everything about your body, but you do need to respect and care for it.
- Ask members of your healthcare team for a referral to a therapist or counselor who can help you work on your self-esteem.



Look Good Feel Better is a program that teaches beauty techniques to people with cancer to help them manage the appearance-related side effects of cancer treatment. The program includes lessons on skin and nail care, cosmetics, wigs and turbans, accessories and styling. Visit www.lookgoodfeelbetter.org for more information.

You can also ask your healthcare team about local programs for hats, wigs, or other services. Or, call an LLS Information Specialist at (800) 955-4572.

Managing Depression

It is normal to feel sad, depressed, or anxious even many years after a cancer diagnosis. However, if these feelings start interfering with your daily activities, talk to your doctor and seek counseling from a mental health professional.

Even if you do not have symptoms of clinical depression or anxiety, you can still benefit from talking to a mental health professional. They will provide you with tools for identifying your emotions and help you to learn ways to cope with them.

Symptoms of clinical depression include:

- Ongoing sadness or feelings of hopelessness
- Loss of interest or pleasure in most activities
- Major weight loss or weight gain
- Agitation or restlessness
- Fatigue or no energy
- Trouble sleeping
- Trouble focusing, remembering, or making decisions
- Feeling worthless, guilty, or helpless
- Thoughts of death or suicide

Don't be afraid to seek help. For a referral to a mental health professional, reach out to your doctor or call your insurance provider for recommendations. You can also visit www.helpstartshere.org and click "Find a Social Worker" for resources and information to help you search for local mental health professionals or to get online counseling.

If you are 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.

A photograph showing the backs of two people sitting on a light-colored couch. The person on the left has dark, curly hair and is wearing a grey long-sleeved shirt. The person on the right has lighter, curly hair and is wearing a white long-sleeved shirt. They are embracing each other from behind. The background is a bright, out-of-focus window with white curtains. A red rectangular box is overlaid in the top right corner, containing white text.

Your Family and Support System

Your Family and Support System

During your cancer treatment, one or more of the people in your life will be likely to step into the caregiver role. This person may be your significant other, a parent, another relative or a close friend. Your caregiver may go with you to appointments or perhaps stay with you during treatments, assist with daily chores and errands, help prepare food, offer emotional support, and help with other tasks as needed.

Tasks, easily accomplished before cancer, may not be as doable now. Or, you may not have the energy or strength to complete tasks as your body recovers. See *Educating Family Members and Friends About Long-Term and Late Effects* on page 41.

As a young adult, the loss of independence that may come with cancer treatment can be very frustrating. You may have only recently left your family home or begun to build your own life. If your parents become your primary caregivers, this sense of frustration can be especially strong. If your spouse is your primary caregiver, your spouse may need to help more with daily chores or childcare. These changes may be difficult for you both, as you likely view your relationship as an equal partnership.

Remember, your caregiver cares about you. If you feel yourself becoming frustrated with your caregiver, try not to lash out in anger. Instead try to talk with your caregiver openly about your feelings.

Defining Your Caregiver's Role



What will your caregiver's role include? You may find it helpful to set some parameters and boundaries early on. Try not to assume that your caregiver will know what you need or want from them. Here are some questions you can work through together.

Do you wish to share **all** your medical information with your caregiver?

- Yes
- No
- Other

If you answer “Yes” to this question, you will need to sign paperwork at the treatment center to give the healthcare team permission to communicate with your caregiver.

Who will be the main contact person for the healthcare team, you or your caregiver?

Who will schedule appointments?

What do you need or want help with? Check all that apply.

- Going to appointments
- Booking appointments
- Talking to members of the healthcare team
- Remembering to take medication
- Grocery shopping
- Cooking
- Household chores
- Pet care
- Childcare

- Managing health insurance
- Managing finances
- Hygiene and personal care (bathing, dressing, etc.)
- Updating friends and loved ones
- Other _____
- Other _____

Are there tasks you don't either need or want help with?

Are you okay with your caregiver sharing updates about your treatment or well-being with other family members and friends? And, if so, in what format—phone, email, caregiver app or webpage, social media?

Many people share their lives on social media, but even if you have a private profile, social media may not be as private as you think. It is important to consider all the implications of sharing a cancer diagnosis on social media. Take time to think them over. Would it upset you if a potential employer, a date or a casual acquaintance learned about the diagnosis from an internet search?

Do you have an advance directive? Where can your caregiver find copies of these documents? Do any of them need to be updated? See *Advance Care Planning and Estate Planning* on page 86.

Support for Your Caregiver

After your cancer diagnosis, your loved ones may have had difficulty coping, especially the person(s) who became your primary caregiver(s). The Leukemia & Lymphoma Society (LLS) offers resources for caregivers. Share these resources with your loved ones.

- **The Caregiver Workbook:** This is a guide your loved ones can use when they are your caregivers. Visit www.LLS.org/CaregiverWorkbook to learn more or call an LLS Information Specialist at (800) 955-4572 to request a copy.
- **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 your caregiver with a trained peer volunteer who has experienced a similar situation. Anyone with a blood cancer diagnosis, as well as their caregiver, is eligible to receive a call. 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/caregiver or call an LLS Information Specialist at (800) 955-4572.

Parenting

Most parents struggle to fit everything into their family's schedule, even without the demands of cancer and cancer treatment. It's important to accept that you may not have the time nor the energy to do everything. Be realistic about what you can and cannot do. Here are some tips to help you juggle parenting and cancer treatment.

- **Work with your co-parent.** If you have a co-parent, discuss how parenting responsibilities may need to shift during your treatment. Recognize that added responsibilities may lead to feelings of frustration. It helps to talk openly about each other's limitations and brainstorm possible solutions. If you do not have a co-parent, reach out to close friends and family members for ongoing help.
- **Talk to your children about your diagnosis.** You may worry about what to say or what not to say. You may even wish to protect children by not telling them about the cancer diagnosis. However, children are very perceptive. Even young children may be able to tell that something is wrong. Children will use their imagination and fill in the gaps of information. Explain to younger children that they cannot "catch" cancer and no one did anything wrong to cause the cancer. Giving your children honest information from the start will lead to feelings of trust, control and involvement.



Visit www.LLS.org/parenting to view Age-Appropriate Discussion Guidelines.

- **Maintain a normal schedule for your child.** Children crave structure in their environment. Ask family members and

friends for help. If your child's schedule needs to change, let your child know in advance.

- **Ask for help and accept help when offered.** Friends and loved ones will likely want to help you, but they may not know how. Make a list of specific tasks you know you'll need help with. These tasks may include picking up your children from activities, walking the dog, grocery shopping, or making meals. When someone offers to help, choose a task from your list that is a good fit for that person. For example, allow a classmate's parent to drive your child to school each day.

Task	Helper	Notes
<i>Example: Drive children to school in the mornings</i>	<i>Jennifer</i>	<i>Jennifer isn't available Fridays</i>

- **Keep in mind your child's mental health.** If your child begins to demonstrate unusual behavior, such as angry outbursts, nightmares, or poor grades in school, talk to your child's pediatrician. You can also ask for a referral to a family counselor.

A close-up photograph of two hands clasped together, set against a bright, golden sunset background. The hands are positioned in the lower half of the frame, with the fingers interlaced. The lighting is warm and soft, creating a romantic and intimate atmosphere. A red rectangular box is overlaid in the upper right corner, containing white text.

Dating, Relationships, Intimacy and Sex

Dating, Relationships, Intimacy and Sex

Dating

Dating can be intimidating no matter what your situation. Remember, every date probably did not go perfectly before your diagnosis. You may have bad dates after your diagnosis as well. You may also meet incredible new people.

If you feel well enough during treatment, you don't have to stop dating. If the side effects of treatment are too much, you may not feel up for it. You may want to take time for yourself to heal. It is your choice. Do not feel pressured to date if you are not interested or not feeling up to it. However, do not let cancer stop you from dating if you feel like you are ready to meet new people.

Telling a Date About Your Diagnosis

When and how you tell someone about your cancer diagnosis is your choice. Some people prefer to tell a date about their diagnosis right away to clear the air, so they will be able to see whether or not the person will be supportive. Other people prefer to wait until they get to know a person, feel comfortable in the relationship and sense that they can trust them. Take some time. Think about which approach is most comfortable for you. There is no perfect time to tell someone about a cancer diagnosis.

If your date reacts negatively, it is not your fault. People have different histories with cancer. In some cases, you may be able to teach this person what it means to be living with a cancer diagnosis. In other cases, you may have to move on.



Answer the questions below to think through disclosing your diagnosis.

When would you prefer to tell a potential date or partner about your diagnosis, and why?

What do you want to say? Write down the information that you are planning to share. Be prepared for questions and think of possible ways to answer in advance.

When you tell a date or partner about your diagnosis, what response are you hoping for? For example, would you want your partner to provide emotional support and/or attend appointments with you?

Your Significant Other

If you are in an established relationship, even a new one, your diagnosis may reveal both positive and negative aspects of your relationship and your partner. Coping with a cancer diagnosis can be difficult for everyone affected by it.

People react to cancer differently. Your partner may be supportive and end up being your best caregiver. Your partner may have a difficult time coping. Either way, your relationship will probably change. If you hit a rough patch, it may be beneficial for you and your partner to attend couples counseling. Look to your healthcare team, support group, or place of worship for resources and recommendations. If your partner will be your primary caregiver, set expectations in advance. See *Defining Your Caregiver's Role* on page 64.

Cancer treatment often brings up fertility issues. You will need to consider plans about parenthood. If you have a life partner, discussing these issues is important because you may want to make these decisions together. See *Fertility Preservation* on page 30.

Sex and Intimacy

Cancer treatment may affect your sexuality and the way you feel about your body. Potential sexual side effects of cancer treatment include:

- Erectile dysfunction
- Vaginal dryness
- Pain during intercourse
- Lack of desire
- Difficulty reaching climax
- Fertility problems (See *Fertility Preservation* on page 30.)

You may be self-conscious about physical changes to your body such as hair loss, weight changes, swelling, scars or the presence of a central line or port. Fatigue, nausea, pain or other side effects may interfere with your desire for sex.

Here are some of the most important things to keep in mind:

- Ask your doctor if it is safe for you to have sex.
 - For example, your doctor may advise that you abstain from sex if your white blood cell or platelet counts are low. During treatment, your doctor may recommend abstaining from sex for 48 hours after chemotherapy because the drugs can be in bodily fluids.
- Speak to your healthcare team about sexual changes. There are treatments and therapies available to alleviate sexual side effects.
- Ask for a referral to a sex therapist.
- Be open with your partner about any changes, especially if something hurts or is uncomfortable.
- Always use protection to prevent pregnancy and sexually transmitted diseases (STDs).
 - Pregnancy during cancer treatment is usually not safe for either the pregnant person or the child. If you suspect you are pregnant, talk to your healthcare team.
 - 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.

The decision to have sex or be intimate with someone is completely your decision. It may not be safe, comfortable, or enjoyable for you to have sex during cancer treatment. If this is the case, rethink intimacy and find new ways for you and your partner to be intimate such as writing love notes, massages or light touching, or simply spending time alone together.



Visit www.LLS.org/sexuality or www.LLS.org/booklets to view *Sexuality and Intimacy Facts*.

NOTES

NOTES

A large, empty rectangular box with a thin black border, occupying most of the page below the 'NOTES' header. It is intended for the user to write their notes.

A close-up photograph of a person's hands typing on a silver laptop keyboard. The person is wearing a watch on their left wrist. In the background, an open notebook is visible on a wooden desk, and another person's hand is seen holding a pen, suggesting a collaborative or professional setting. The lighting is warm and focused on the hands and keyboard.

Planning for the Future

Planning for the Future

When you were first diagnosed, you may have found it difficult to think about the future. Many aspects of your life may have felt uncertain. Now that you've completed cancer treatment or become more comfortable with long-term management of a chronic illness, you may be ready to start thinking about the future again.

You may also need to come to terms with a future that looks different now than the future you envisioned before you were diagnosed with cancer. It can be difficult to accept the impact of your cancer diagnosis on your future goals and aspirations. You may not have been able to pursue career goals after your diagnosis. Relationships with loved ones, family members, friends, and colleagues may have changed too. You are likely to encounter problems you hadn't anticipated. For example, you may be facing fertility issues that affect the plans you had for a family. (See *Long-Term and Late Effects* on page 27.) You may feel a sense of grief for your old life. This is a common feeling among cancer survivors. Take the time you need to grieve, and then begin to look toward the future. You may still be able to accomplish many of the goals you had before your diagnosis or, now, you may have set new goals for yourself.

Setting Priorities

When you are planning for the future, take some time to consider your priorities. What are your goals for the future? Are there specific things you want to achieve or activities you would like to enjoy more? Think about what matters most to you and order your priorities accordingly. Dedicate more time to your top priorities and allocate less time to others—especially if they don't support your goals.

Setting priorities or goals helps you to focus your time and energy on the things that matter most. However, don't let

setting priorities become an additional source of stress or anxiety. You can revisit your goals and priorities and change them at any time.

Use the following exercise to help you think through your priorities.



In the list below, circle your top 10 priorities or goals for the future. Use the blank spaces to add things that are not included in the list, but that you place in your top ten.

Spending time with family members and friends

Your relationship with your partner or spouse

Meeting new people

Traveling

Education

Learning new skills

Career building

Planning for retirement

Creating things

Spending time outdoors

Financial independence

Building healthy lifestyle habits

Exercising or moving more

Trying new things

Improving mental health

Spiritual or religious pursuits

Volunteering in your community

Creating a comfortable living space

Practicing self-care

Getting out of your comfort zone

Saying “Yes” to new experiences

Saying “No” to things you do not enjoy

Giving back

Caring for pets

Gardening

Reading

Listening to music

Writing

Estate planning

Next, out of those 10 priorities, rank your top five priorities in order of importance— with 1 being the most important.

1. _____
2. _____
3. _____
4. _____
5. _____

Are there specific actions you can take that can help you to achieve your goals? Or, can you manage your time in such a way that you can spend more time on your priorities?

What are some things you can do on a daily, weekly, and/or monthly basis that will support your top five priorities or goals?

Take the Pledge

I pledge to myself that I will:

- Be kind to myself
- Make my health a priority
- Respect and care for my body and mind
- Seek help and support when needed and accept help when offered
- Take steps to achieve my goals as I am able
- Adjust my goals as my priorities change
- Celebrate small wins
- Learn from setbacks but not dwell on them
- Say “No” to things that do not support my goals or well-being
- Not let the fear of the unknown hold me back from leading a happy life

Signature _____

Date _____

Supporting Your Future Plans

These resources are organized by subjects that may be part of your future plans. Some of the following resources are from The Leukemia & Lymphoma Society (LLS) and some are from different organizations that specialize in specific issues.

Career

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

When returning to work after a cancer diagnosis, be patient with yourself. If you are looking for a new job, it may take time to find one that is a good fit. If you are returning to an existing job, you may find it takes some time to get back up to speed and to work at your pre-diagnosis capacity.

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.

Education

While going through cancer treatment, you may have taken a medical leave from a college, university or vocational program. Or, you may be interested in applying to a new college, graduate school or vocational program. Here are some things

to keep in mind:

- Online classes may be a good option for you if you are still recovering from cancer treatment or managing side effects such as fatigue.
- You may be eligible for accommodations under The Americans with Disabilities Act (ADA). However, cancer is not always considered a disability. The ADA may include accommodations such as due date extensions or additional time for taking exams. Talk to your school or program’s administration for more information.
- You may be eligible for scholarships. To help 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.

Family Planning and Fertility

“Fertility” describes the ability to conceive a biological child. Some cancers and some cancer treatments affect fertility in males and females. The risk of infertility caused by cancer and its treatment is based on several factors, including the type of cancer; the type, duration, and doses of treatment; and the patient’s age at the start of treatment. Addressing fertility and sexual health is an essential part of cancer treatment and follow-up care.

There are many ways to build a family, whether through natural conception, using assisted reproductive technology, or adoption. Patients who want children should consider and discuss all options. Visit www.LLS.org/booklets to view *Fertility and Cancer*.

Finances

As a person with a history of cancer, you will need lifelong follow-up medical care. Therefore, it is very important for you

to maintain your health insurance. If at all possible, do not allow there to be gaps in your coverage. 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.

Even if you have health insurance, cancer can still take a toll on your finances. You may have new expenses such as co-pays or the costs of travel for treatment. You may also have less income if you needed to take time off work.

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

The Leukemia & Lymphoma Society (LLS) offers financial assistance programs to help with insurance premiums, treatment-related co-pays, travel and other expenses for eligible patients. Other organizations also offer financial assistance programs. Call an LLS Information Specialist at (800) 955-4572 for more information and referrals.

Triage Cancer

<https://triagecancer.org/>

(424) 258-4628

Triage Cancer is a national, nonprofit organization that provides education on the practical and legal issues that may impact individuals diagnosed with cancer and their caregivers, through free events, materials and resources.

Health and Wellness

See *Healthy Behaviors Recommendations* section on page 44 and visit www.LLS.org/booklets to view the LLS booklet *Healthy Behaviors* for more information.

The Academy of Nutrition and Dietetics

www.eatright.org

(800) 877-1600

The Academy of Nutrition and Dietetics (AND) is the world's largest organization of food and nutrition professionals. The eatright.org website provides educational nutrition information and a locator to find a registered dietitian by zip code and expertise.

American Institute for Cancer Research

www.aicr.org

(800) 843-8114

The American Institute for Cancer Research (AICR) focuses its research on the link between diet and cancer and translates the results into practical information for the public and provides funding for research at leading universities, hospitals and research centers throughout the United States and abroad. The AICR website offers nutrition information, recipes, interactive web tools and more.

MyPlate

www.myplate.gov

The United States Department of Agriculture (USDA) provides this website, based on the *Dietary Guidelines for Americans 2020-2025*, which includes nutrition information, recipes and the option to get personalized resources.

Health.gov

www.health.gov

Health.gov is coordinated by the Office of Disease Prevention and Health Promotion, Office of the Assistant Secretary for Health, Office of the Secretary, United States Department of Health and Human Services. The website provides information on food and nutrition, exercise and initiatives to improve health care quality. Visit www.health.gov/myhealthfinder to use MyHealthfinder to get disease screening and vaccine recommendations based on your age and sex to discuss with your doctor.

Smokefree

www.smokefree.gov

(800) QUIT-NOW ([800] 784-8669)

Smokefree provides resources and information about smoking cessation. All states have “quitlines” with counselors who are trained specifically to help smokers quit. Call the number above to connect directly to your state’s quitline.

Mental Health and Self-Care

For more information, see *Mental Health* on page 52.

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.

Advance Care Planning and Estate Planning

All adults can participate in advance care planning. Advance care planning includes reflecting on your wishes and preference for medical care, discussing your end-of-life wishes with people you love and trust, and completing the appropriate legal documents. Visit www.LLS.org/booklets to view *Advance Care Planning: Making decisions for your future* for more information.

Estate planning deals with the financial and practical matters that come up at the end of life. It addresses such questions as

- What will happen to your property?
- What will your funeral be like?

Visit Triage Cancer at <https://triagecancer.org/estateplanning> to learn more.

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.

NOTES





**Questions to Ask Members
of My Healthcare Team
and
Resources**

Questions to Ask Members of My Healthcare Team

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



LLS Health Manager™ App. This free mobile app helps you manage your health by tracking side effects, medication, food and hydration, questions for your doctor, and more. Export the information you've tracked in a calendar format and share it with your doctor. You can also set up reminders to take medications, hydrate, and eat. Visit www.LLS.org/HealthManager to download for free.

Always tell members of your healthcare team about any new or worsening symptoms. All of your concerns are important. Do not feel embarrassed to ask healthcare providers to answer your questions. You 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:

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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 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. 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.

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.

Acknowledgements

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

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A special thank you to the blood cancer survivors who shared their experiences to help create this resource.



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)



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

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

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.