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NAVIGATING LIFE DURING AND AFTER
A BLOOD CANCER DIAGNOSIS

ADULTS

Support for this publication provided by



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

To reach us call: **800.955.4572**

LLS also offers two other versions of this workbook:

A Workbook for Young Adults and

A Workbook for Parents, Children and Adolescents.

Visit www.LLS.org/SurvivorshipWorkbook for more.

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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.”

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.

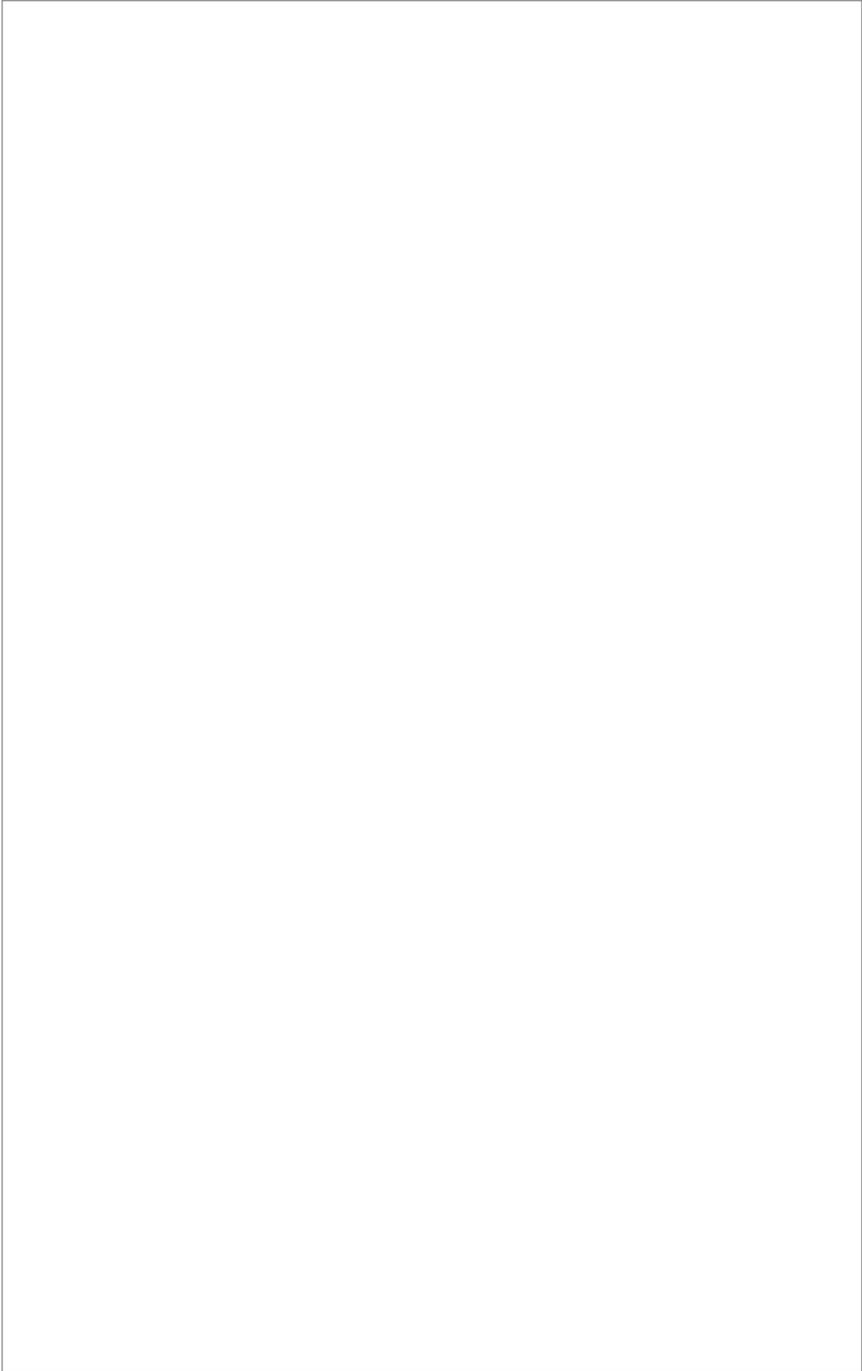
For patients with a blood cancer diagnosis, there may never be a clear-cut time when treatment ends, but the information, worksheets and questions in this workbook still apply.

The Leukemia & Lymphoma Society also offers two other versions of this workbook: *A Workbook for Young 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.

NOTES

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Survivorship Care Plan



DIABETES
BLOOD TRANSFUSIONS
HEPATITIS
THYROID DISORDER

ALLERGIES
(SPECIFY)

FRACTURES
(SPECIFY)

OPERATIONS
(SPECIFY)

PATIENT 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 medical care. Ask members of your healthcare team for a written survivorship care plan. You can use the information provided in the plan to fill out this section of the workbook and/or save a copy in the pocket of this section.



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 on 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

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 so that you can share them with your 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*.

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*.

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. **Supportive care is for anyone with 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 25).



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.



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

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. There is also a Diffuse Large B-Cell Lymphoma Survivorship Care Plan. 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.

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 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

Name	Hospital/Treatment Center
Phone	Email

Nurse Manager

Name	Hospital/Treatment Center
Phone	Email

My Healthcare Team (continued)

Transplant Coordinator

Name	Hospital/Treatment Center
Phone	Email

Social Worker

Name	Hospital/Treatment Center
Phone	Email

Financial Manager

Name	Hospital/Treatment Center
Phone	Email

Role:

Name	Hospital/Treatment Center
Phone	Email

Role:

Name	Hospital/Treatment Center
Phone	Email

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A scenic landscape at sunset. The sun is low on the horizon, casting a warm, golden glow over the scene. In the foreground, there are large, grey, layered rock formations. To the left, a large, green pine tree is partially visible. In the middle ground, a winding river flows through a valley, with a road following its curve. The hills are covered in dense green forest. The sky is a mix of blue and orange, with some light clouds.

Long-Term and Late Effects

Long-Term and Late Effects

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

Follow-up medical care to monitor survivors for possible long-term and/or late effects is important. 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 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 disease
- Thyroid problems
- Organ damage (lungs, kidneys)
- Bone issues, such as osteoporosis
- Fertility problems (See *Family Planning and Fertility* on page 70.)

- Secondary cancer
- Other conditions

Psychological Effects

Some people may experience long-term psychological effects after treatment, including:

- Depression or symptoms of depression
 - Depression as a mental health disorder includes ongoing sad moods and/or loss of interest in activities.
- Anxiety disorder
 - Anxiety disorder is different from the feelings of anxiety that are caused by 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)
 - 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 and/or frightening thoughts.

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. 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 45.

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 9-15.



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.



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 Survivorship Care for Healthy Living and Survivorship Care for Cancer-Related Late and Long-Term Effects.

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.

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 spaces 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:

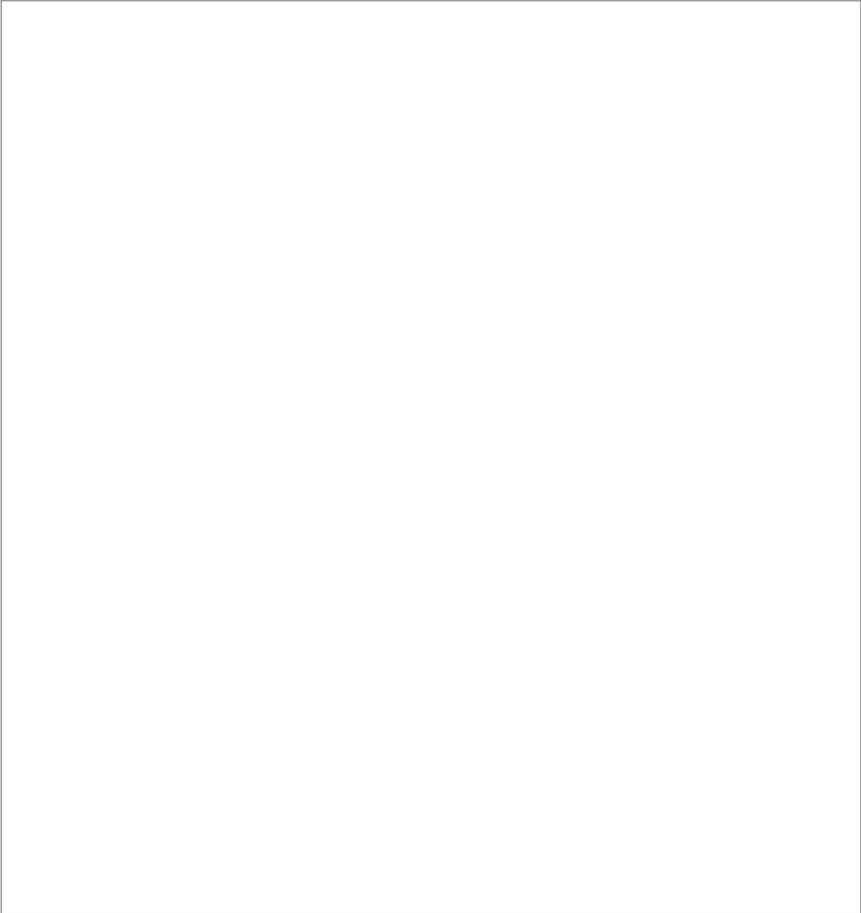
Example: Sometimes I do not have the energy to do all the things I need or want to do.

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.



NOTES



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 of 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.
 - o Ask your doctor if it is safe for you to drink alcohol. 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.
- 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 re-apply every 2 hours.

- I keep up with my medical needs, such as 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 50.
- I connect with others (people I love, friends and/or members of a support group) regularly.
 - o Isolation is a risk factor for depression and anxiety disorder. See *Community Resources and Networking* on page 83.

LLS Community. The LLS Community 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.

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? Write your answer on the next page. (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 about healthy behaviors.

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 can deplete 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: Adapted from the Centers for Disease Control and Prevention's Recommended Adult Immunization Schedule for ages 19 years or older, 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 either 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.



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

- 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 Knowing this information can help you better understand your situation and minimize the fear of the unknown.
- 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 learn coping strategies to care for yourself. Ask your doctor for a referral or call your insurance provider.
- Make lifestyle changes to improve your overall health and well-being, such as making good food choices or starting an exercise program. See *Healthy Behavior Recommendations* on page 37.
 - 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 others who understand what you've been through can be helpful. See *Community Resources and Networking* on page 83.

Identifying and Coping with Emotional Triggers

Learn what triggers your emotions and find ways to cope.

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

Are there ways you can 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 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 consciously make the time and set self-care goals. 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 to do 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 _____
- Other _____

Any of these activities can be part of a self-care plan. Pick one or two of your favorite activities and make 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 37 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. However, try not to allow any negative feelings to get in the way of your happiness.



The following exercises can 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 37.
- 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 their 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.

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

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.

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.

Relationships and Family



Relationships and Family

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

Defining Your Caregiver's Role



What will your caregiver's role include? You may find it helpful to set some parameters and boundaries early. Try not to assume 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 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 either don't need or don't 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 74.

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.

Children and Grandchildren

Talking to the children in your life about your cancer diagnosis can be intimidating. You may worry about what to say or what not to say. You may even wish to protect your children or grandchildren 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. Giving your children or grandchildren honest information from the start will lead to feelings of trust, control and involvement. Teenagers and young adults may even wish to help with caregiving duties. Allow them to help, as age appropriate.



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

Your Significant Other

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 57.

Dating and New Relationships

If you feel well enough during treatment, you never have to stop dating. Due to side effects of treatment, 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 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 share their diagnosis

right away to clear the air and to see if the person will be supportive or not. Some people prefer to wait until they trust the person. Take some time to think about which is most comfortable for you.

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 *Family Planning and Fertility* on page 70.)

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.
 - Your doctor may even advise that you abstain from sex if your white blood cell or platelet counts are low.
- Speak to your healthcare team about sexual changes. There are treatments and therapies available to lessen 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).

- o 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.
- o Use condoms or another barrier method, to protect against sexually transmitted diseases (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*.

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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. After your diagnosis, you may have not been able to pursue career goals. Relationships with loved ones, 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 have for a family. (See *Long-Term and Late Effects* on page 25.) You may feel a sense of grief for your old life. This feeling is common among cancer survivors. Take the time you need to grieve, and then begin to look towards 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 is most important to you and order your priorities accordingly. Dedicate more time to your top priorities and allocate less time to others—especially the ones that don't support your goals.

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



In the list below, check 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 the 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

The resources in this list 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.

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 care. Therefore, it is very important to maintain health insurance. If at all possible, do not allow any gaps in your 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 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://tragecancer.org/>

(424) 258-4628

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

Health and Wellness

For more information, see *Healthy Behaviors Recommendations* section on page 37. Visit www.LLS.org/booklets to view *Healthy Behaviors*.

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 a 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 45.

Visit www.LLS.org/booklets to view *Managing Stress*.

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*.

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.

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**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 down 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:

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](http://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](http://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).

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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.