

SURVIVORSHIP

Continuing Communication after Treatment and Beyond

Since you may not see your healthcare team as frequently as you did when you were in active treatment, it is important to communicate effectively during follow-up appointments.

Work with your healthcare team to create a written survivorship care plan. All cancer survivors should receive a survivorship care plan. If you do not have one, ask for one.

TIPS FOR COMMUNICATING WITH YOUR HEALTHCARE TEAM

- Ask who your designated contact for follow-up care will be. Will your care transfer to your primary care provider (PCP) or will you continue to see your hematologist/oncologist regularly? Which provider will cover which aspects of your care? You may have questions between appointments, so it's important to ask whom you should contact during this time.
- Ask for a referral to a survivorship clinic. These clinics specialize in providing services that help cancer patients manage issues related to surviving cancer.
- Keep a list of your questions in a designated notebook and take it with you to all appointments. If you feel like a question cannot wait until your next appointment or a concern causes you anxiety, reach out to your healthcare team.
- Use a calendar app on your mobile phone (or other method) to remember all of your follow-up appointments. You may schedule appointments months in advance, so they may be easy to forget.
- Ask how you can access your patient portal. Many hospitals and treatment centers now offer patient portals where you can view your upcoming appointments, message your providers, view and pay bills, and more.
- Tell your healthcare team about any new or worsening side effects.
- Inform your healthcare team about any new diagnoses, medications, surgeries, procedures or hospitalizations.
- Do not start or stop taking any medications, vitamins or supplements without consulting your doctor.
- Tell your healthcare team about your family plans, including pregnancy, breast feeding or plans to conceive.
- Let your healthcare team know about any changes to your health insurance or contact information.

PRIMARY HEALTHCARE PROFESSIONAL CONTACT FOR SURVIVORSHIP CARE

Name _____

Phone _____

Email _____



All of your questions are important. Do not feel embarrassed to ask them. You deserve to have your concerns addressed.

Survivorship Care Plan Checklist

Your survivorship care plan should include the following information:

- ☐ List all of your healthcare providers: PCP, hematologist-oncologist, radiation oncologist, etc.
- ☐ Diagnosis summary with specifics such as stage, sites of involvement, and molecular or genetic markers
- ☐ Treatment summary with specifics such as names of chemotherapy or biological agents used; radiation (type, dose, site); response to treatment; and side effects
- ☐ Maintenance treatment information with name of medication, dosage and duration
- ☐ Follow-up appointment schedule with coordinating provider and frequency
- ☐ Schedule for ongoing monitoring with recommended tests and frequency and which provider (for example, PCP or oncologist or other provider) will assist with each
- ☐ List of possible late- and long-term side effects
- ☐ Health and wellness lifestyle recommendations such as nutrition, exercise, other cancer and disease screenings, and referrals to specialists (as needed) to assist with these recommendations

To collect all the information you need throughout diagnosis, treatment, follow-up care and long-term management of a blood cancer, visit www.LLS.org/SurvivorshipWorkbook to view *Navigating Life During and After a Blood Cancer Diagnosis*. There is a version of the workbook for adults, young adults and children/adolescents.

Visit www.LLS.org/WhatToAsk for the full **Communicating With Your Healthcare Team** series and printable question guides.

QUESTIONS TO ASK YOUR HEALTHCARE TEAM

As you move into survivorship, be sure you have answers to the following questions:

- Will you provide me with a written survivorship care plan?
- Which members of my healthcare team will be responsible for which aspects of my follow-up and survivorship care?
- Does my survivorship care plan include maintenance therapy? If so, what is the proposed maintenance therapy, and how long will I receive it? (Not all patients will receive maintenance therapy.)
- What are the signs or symptoms that may indicate a relapse or recurrence?
- What are possible late- and long-term side effects of the treatment I received?
- What can I do to manage these side effects?
- What can I do to promote wellbeing during survivorship?

GET ONE-ON-ONE SUPPORT

The Leukemia & Lymphoma Society's **Information Specialists**, highly trained oncology social workers and nurses, can provide information and support and connect you to our **Clinical Trial Support Center** and **Registered Dietitians**.

- Call **800.955.4572** Mon.-Fri. 9 a.m. to 9 p.m. (ET)
- Visit www.LLS.org/PatientSupport

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.