

Survivorship Series: When Treatment is Over

An individual is considered a cancer survivor from the time of diagnosis throughout treatment and the remaining years of life.

There are an increasing number of lymphoma survivors each year. Current data show 88 percent of patients with Hodgkin lymphoma (HL) and 73 percent of patients with non-Hodgkin lymphoma (NHL) are still alive five years following their diagnosis. Better diagnostic tools and more effective treatments are associated with improved survival rates; however, the challenge now facing many survivors is how to achieve long-term quality of life after treatment has ended.

When treatment is over, it is common for survivors to continue experiencing side effects. In some cases, new side effects may even appear long after treatment has ended. This can make you feel like you are disease-free, but not free of the disease. Adopting a healthy lifestyle and coordinating a follow-up care plan with your healthcare team can help you navigate this new phase and facilitate a smooth the transition back into your daily routine. Below are some of the top concerns lymphoma survivors have when treatment is over and some ways survivors can pursue a healthier future.

Living with Treatment Side Effects

After your treatments have ended you may still experience side effects. Some side effects develop during treatment and last for months or longer (called “long-term side effects”) and others appear long after the treatment has ended (called “late side effects”). These effects may vary for each survivor and depend on the type of lymphoma you had, the treatment you received, and your age and overall health. While blood cancer survivors don’t always have serious long-term or late effects of treatment, it is important to know that some side effects may take time to go away and may even be permanent. Talk to your healthcare team about what these possible effects might be and ask for ways to prevent and/or relieve them.

Long-term and late treatment effect may include “chemo brain” or “brain fog” (decreased memory, concentration and inability to multitask), psychological effects (anxiety, depression and post-traumatic stress disorder) or a variety of physical effects, which are highly dependent on the treatment:

- Fertility issues
- Infections
- Thyroid problems
- Heart disease
- Lung damage
- Decreased bone density and osteoporosis (a condition that weakens bones, making them fragile and more likely to break)
- Eye and vision problems
- Nerve damage
- Dental and mouth problems
- Other cancers

Staying Healthy

A healthy diet and physical activity will help you feel more energized, rebuild your strength and manage treatment effects. These routines will also help you recover and keep a healthy weight, which reduces your risk of cancer in the future.

Nutrition

Getting the best nutrition your diet can give you is fundamental after treatment. The National Institutes of Health (NIH) and American Cancer Society (ACS)'s tips for healthy eating after cancer treatment include:

- Checking with your doctor/nutritionist to see if you have any food or diet needs or restrictions.
- Creating a balanced eating plan with the help of a dietitian.
- Eating colorful fruits and vegetables each day (at least 5-9 servings per day). Prioritize citrus fruits and dark-green (broccoli, bok choy, spinach, kale) and deep-yellow vegetables (carrots, pumpkins, sweet potatoes, winter squash).
- Eat plenty of high-fiber foods, like whole-grain breads, cereals and pasta.
- Buying a different fruit, vegetable, low-fat food, or whole-grain product each time you shop for groceries.
- Choose low-fat milk and dairy products.
- If consuming alcohol, limit the amount to no more than 1 drink per day for women, and 2 for men.

Studies have shown that eating more than 18 ounces of red meat per week can actually increase your risk of some types of cancer. You should consider the following:

- Limit intake of red meat (beef, pork, or lamb) to 3 portions (12-18 ounces) per week.
- Avoid processed meats and pickled foods.
- Prioritize other sources of animal protein like fish, poultry or lean meats, and think of them as side dishes.
- Choose vegetarian meals every now and then.

You can find answers to common questions regarding nutrition after cancer treatment on the NIH website (visit cancer.org).

Exercise

Staying physically active after treatment can help improve your quality of life. It is important that you start slow and adapt the exercise to what you can do. This may include simple activities like walking, housework or even dancing in your living room – the key is to incorporate physical activity back into your daily routine. As you feel better, you can gradually increase the frequency and intensity of the exercise. General guidance from the NIH and ACS include:

- Avoid inactivity and return to normal daily activities as soon as possible.
- Build up to at least 150 minutes of moderate or 75 minutes of vigorous intensity activity each week (see [Table 1](#)).
- Exercise several times a week for at least 10 minutes at a time.
- Include resistance training exercises at least 2 days per week.
- Do stretching exercises at least 2 days per week.

The goal is to be as active as possible, which is different for each person. Your healthcare team can help you determine which exercise program is the right one for you. They may advise you to avoid gyms if you are at increased risk of infection, or suggest limiting your use of weights if you have low bone density or osteoporosis. Make sure to let them know if you are taking any other medications, as they may affect your physical endurance. Remember that the key to staying active is to make your exercise routine easy and fun.

You can find answers to common questions regarding exercise after cancer treatment on the NIH website (visit cancer.org). The American College of Sports Medicine also provides specialized information on this topic (visit exerciseismedicine.org).

Table 1

Exercise Intensity	Description	Examples
Moderate	Activity at a pace where you can talk but cannot sing	<ul style="list-style-type: none"> • Brisk walking (4 mph) • Light biking (10-12 mph) • Water exercise • Dancing
Vigorous	Activity at a pace where you may have trouble talking or be out of breath	<ul style="list-style-type: none"> • Jogging (6 mph) • Tennis • Fast cycling (14-16 mph)

Long Term Follow-Up Care Plan

All lymphoma survivors should have a long term follow up plan (also called a “survivorship care plan”) after treatment ends. This plan is arranged by your healthcare team and includes a summary of the treatments you received, recommendations for follow-up care based on your medical history, and schedules for medical exams to check if the lymphoma has come back (recurrence). This allows your healthcare team to monitor your overall health and look out for long-term effects or other problems that may occur at any point after treatment. Your doctor will let you know how often you need to return for checkup appointments and which physical exams and blood tests are necessary. These checkups usually include a review of your medical history, physical exam and bloodwork, as well as specific exams or screenings recommended by your doctor (see [Health Screenings to Consider](#) on next page).

A follow-up care plan may also provide information to help you meet any emotional, social, legal, and/or financial needs. Your health care team can help you decide which doctor to see for your follow-up care plan (the same doctor who treated your lymphoma, a health care provider specialized in caring for cancer survivors, or your primary care provider [PCP]). Some clinics specialized in follow-up cancer plans offer comprehensive support to cancer survivors (called “survivorship clinics”). You can visit oncolink.org/clinics/search to check for survivorship clinics in your area.

Health Screenings To Consider

As a survivor, there are specific health screenings and exams that you may do at an earlier age than the general population. These will be adapted to the type of lymphoma you had and the treatment you received. For instance, due to the increased risk of secondary breast cancer from radiation therapy, women who received radiation therapy to the chest area during childhood, adolescence, or young adulthood should have clinical breast examinations yearly until age 25, then every six months thereafter. In addition, these women should receive yearly mammograms and breast magnetic resonance imaging (MRI) beginning at age 25 or eight years after completion of the radiation therapy, whichever comes last.

Other health screenings the physician may suggest include:

- Bone density scans
- Cardiovascular monitoring
- Chest or whole body imaging
- Screening for other cancers (e.g. colorectal or skin)
- Dental screenings
- Eye exams
- Lipid blood tests
- Thyroid function tests

Because everyone is different, survivors should talk with their physicians about which screenings are most appropriate and when they should be started.

Transitioning Care to Your Primary Care Provider (PCP) and Establishing an Oncology Follow-Up Care Plan

The healthcare team who treated you for lymphoma has important information about your treatment, which is essential to establishing a follow-up care plan suited to your needs. This team should give you a written document with information about your diagnosis and treatment (called a “treatment summary”). Keep this document and your medical records in a safe place where they can be easily found (like a binder or folder that you always keep in the same place). If the healthcare team who treated you kept electronic medical records, ask how you can access them. It is very important to have this information organized so that you can share it with the doctor that will establish your follow-up care plan, especially with your PCP. Once a long-term remission (disappearance of your lymphoma) is achieved, it is still critical for a hematologist/oncologist to work collaboratively with the PCP to monitor for or manage any long-term side effects or late side effects. If you see different doctors in your follow-up care, ask them to share clinic notes with each other so everyone can be informed. Always tell any new doctors you see about your history of lymphoma and the treatment you received, as this can affect decisions about your care in the future. To help document a care plan, click [here](#) to download Lymphoma Care Plan, which survivors should complete with their healthcare team.

According to the NIH, questions to ask your provider about your follow-up care plan include:

- How long will it take for me to get better and feel more like myself?
- Which doctor(s) should I see for my follow-up care? How often?
- What symptoms should I watch out for?
- What tests do I need after treatment is over? How often will I have them?
- What are long-term health issues I might expect as a result of my cancer treatment?
- What is the chance that my cancer will return?
- What records do I need to keep about my treatment?
- What can I do to take care of myself and be as healthy as possible?
- Can you suggest a support group that might help me?

You can consult the guidelines from the National Comprehensive Cancer Network (NCCN) (visit nccn.org/guidelines) for helpful information on what to discuss with your doctor. If you don't have insurance, Medicare or Medicaid, there still may be resources in your community to help you establish a follow-up care plan. Talk to your healthcare team, social worker or local hospital about your options. Below is a list of organizations that may be able to provide financial assistance:

- Cancer Legal Resource Center: call (866) THE-CLRC (843-2572) or visit thedrlc.org/cancer
- Medicine Assistance Tool: call 571-350-8643 or visit medicineassistancetool.org
- CancerCare: call 800-813-HOPE (4673) or visit cancercare.org
- Patient Advocate Foundation: call 800-532-5274 or visit patientadvocate.org
- Social Security Administration: call 800-772-1213 or visit ssa.gov

Keeping Track of Your Care

To ensure that long-term health needs are addressed, survivors should keep detailed records of their lymphoma diagnosis and treatment, including:

- Type (subtype) of lymphoma
- Date of diagnosis
- Pathology reports
- Copies of any imaging studies, including computed tomography (CT) and positron emission tomography (PET) scans
- Types and dates of treatment received (including drug names and doses) and the location and doses of radiation therapy given
- Identification numbers and names of any clinical trials in which the survivor participated
- Any treatment complications
- Types of side effects experienced
- Supportive care received
- A list of the possible late effects of the treatment
- Contact information for all physicians involved in treatment and follow-up care
- The physician's recommendations for frequency of follow-up visits and guidance on maintaining a healthy lifestyle

Staying involved in your follow up care can be a good way for you to regain a sense of control after treatment is over. You can be an active partner throughout the process and keep track of your follow up care. For each follow-up visit:

- Write down the date and what was discussed.
- Ask which exams are needed, what to expect and what the results mean.
- Keep copies of lab reports in the same folder or binder organized by date.
- Track upcoming appointments and exams in your agenda.

Lymphoma Care Plan

Keeping your information in one location can help you feel more organized and in control. This also makes it easier to find information pertaining to your care and saves valuable time. The Foundation's Lymphoma Care Plan document organizes information on your health care team, treatment regimen, and follow-up care. You can also keep track of health screenings and any symptoms you experience to discuss with your health care provider during future appointments. The Lymphoma Care Plan document can be accessed by visiting lymphoma.org/publications.

Patient Education Programs

The Foundation also offers a variety of educational activities, including live meetings and webinars for individuals looking to learn directly from lymphoma experts. These programs provide the lymphoma community with important information about the diagnosis and treatment of lymphoma, as well as information about clinical trials, research advances and how to manage/cope with the disease. These programs are designed to meet the needs of a lymphoma patient from the point of diagnosis through long-term survivorship. To view our schedule of upcoming programs, please visit lymphoma.org/programs.

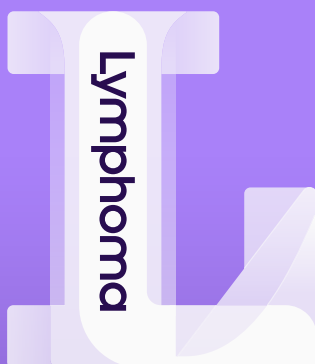
Helpline

The Foundation's Helpline staff are available to answer your general questions about lymphoma and treatment information, as well as provide individual support and referrals to you and your loved ones. Callers may request the services of a language interpreter. The Foundation also offers a one-to-one peer support program called the Lymphoma Support Network and clinical trials information through our Clinical Trials Information Service. For more information about any of these resources, visit our website at lymphoma.org, or contact the Helpline at (800) 500-9976 or helpline@lymphoma.org.

Para información en Español, por favor visite lymphoma.org/es. (For Information in Spanish please visit lymphoma.org/es).

Focus on Lymphoma Mobile App

Focus on Lymphoma is the first app to provide patients and their care partners with tailored content based on lymphoma subtype, and actionable tools to better manage diagnosis and treatment. Comprehensive lymphoma management, conveniently in one secure and easy-to-navigate app, no matter where you are on the care continuum. Get the right information, first, with resources from the entire Lymphoma Research Foundation content library, use unique tracking and reminder tools, and connect with a community of specialists and patients. To learn more about this resource, visit our website at lymphoma.org/mobileapp, or contact the Foundation's Helpline at (800) 500-9976 or helpline@lymphoma.org.



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