

Understanding Survivorship: 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](https://www.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.

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)

Mph, miles per hour.

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](https://www.cancer.org)). The American College of Sports Medicine also provides specialized information on this topic (visit [exerciseismedicine.org](https://www.exerciseismedicine.org)).



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](https://www.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 LRF’s *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 cancercares.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.

LRF'S HELPLINE AND LYMPHOMA SUPPORT NETWORK

A lymphoma diagnosis often triggers a range of feelings and concerns. In addition, cancer treatment can cause physical discomfort. The LRF Helpline staff members are available to answer your general questions about a lymphoma diagnosis 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. A part of the Helpline is LRF's one-to-one peer support programs, *Lymphoma Support Network*. This program connects patients and caregivers with volunteers who have experience with lymphomas, similar treatments, or challenges, for mutual emotional support and encouragement. You may find this useful whether you or a loved one is newly diagnosed, in treatment, or in remission.

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MOBILE APP

Focus On Lymphoma is the first mobile application (app) that provides patients and caregivers comprehensive content based on their lymphoma subtype and tools to help manage their lymphoma such as, keep track of medications and blood work, track symptoms, and document treatment side effects. The *Focus On Lymphoma* mobile app is available for download for iOS and Android devices in the Apple App Store and Google Play. For additional information on the mobile app, visit **FocusOnLymphoma.org**. To learn more about any of these resources, visit our website at **lymphoma.org**, or contact the LRF Helpline at **800-500-9976** or **helpline@lymphoma.org**.

Resources

LRF offers a wide range of free resources that address treatment options, the latest research advances, and ways to cope with all aspects of lymphoma and CLL/SLL including our award-winning mobile app. LRF also provides many educational activities, including our in-person meetings, podcasts, webinars for people with lymphoma, as well as patient guides and e-Updates that provide the latest disease-specific news and treatment options. To learn more about any of these resources, visit our website at **www.lymphoma.org**, or contact the LRF Helpline at **(800) 500-9976** or **helpline@lymphoma.org**.

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