

Lymphoma Survivorship

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 86 percent of patients with Hodgkin lymphoma (HL) and 71 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. Public health initiatives are focused on addressing the numerous physical, psychological, social, spiritual, employment-related, and financial issues that cancer survivors face at diagnosis, during treatment, and for the remaining years of their lives. These initiatives are focused on raising awareness of, preventing, detecting, and treating complications; coordinating care between various healthcare providers; and providing suggestions and advice in managing employment and insurance challenges, all to improve the quality of life of survivors.

Here are some of the top concerns lymphoma survivors have and some ways survivors can pursue a healthier, more financially secure future.

Living With Treatment Side Effects

Some side effects from standard lymphoma treatment regimens, including chemotherapy, radiation, and steroids, can be long-term or even develop later in life. *Long-term side effects* manifest during treatment and continue after treatment ends; they may include fatigue, menopausal symptoms, cognitive problems, nerve damage, and heart problems. *Late side effects* develop after treatment completion—sometimes years or even decades later—and may include infertility, osteoporosis, cardiovascular disease, and secondary cancers. Many factors influence an individual's risk of developing late side effects and the potential severity of those side effects. These factors can include when a patient was diagnosed; patient characteristics such as age, overall health, the type of cancer and its location; and the type of treatment received.

The late side effects of radiation therapy can take decades to appear and include secondary cancers such as breast, thyroid, and lung cancer, as well as cardiovascular problems. Advances in radiation therapy have decreased the amount of radiation typically used and reduced the size of the areas commonly treated; however, the impact of these improvements on reducing the risk for late side effects may not be known for years.

Chemotherapy regimens such as CHOP (cyclophosphamide, doxorubicin, vincristine, prednisone), MOPP (mechlorethamine, vincristine, procarbazine, prednisone), and ABVD (doxorubicin,

bleomycin, vinblastine, dacarbazine) that include the alkylating agents cyclophosphamide, procarbazine, nitrogen mustard (mechlorethamine) or dacarbazine, as well as the anthracycline doxorubicin, are also linked to late health effects. These may include infertility, *gonadal dysfunction* (problems with testes producing healthy sperm or ovaries producing healthy eggs), reduced heart function, and secondary leukemia.

Newer antibody treatments such as nivolumab (Opdivo) or pembrolizumab (Keytruda) stimulate the immune system to fight against cancer cells; however, by stimulating the immune system, these drugs can also cause the immune system to attack healthy cells in some patients. Most of the immune-related side effects caused by these drugs are reversible and go away once the treatment is over. The most frequently reported immune-related side effects for nivolumab or pembrolizumab are diarrhea, *colitis* (inflammation of the colon), *hepatitis* (inflammation of the liver), *nephritis* (inflammation of the kidney), *hypophysitis* (inflammation of the pituitary gland), and thyroid dysfunction. *Pneumonitis* (inflammation of the lungs) is a rare but serious side effect observed in some patients treated with nivolumab and pembrolizumab.

Staying Healthy

Living a healthy lifestyle—including eating a diet rich in fruits and vegetables, exercising, not smoking, limiting alcohol consumption, avoiding prolonged sun exposure, and obtaining regular follow-up medical care—can reduce a survivor's risk of developing late health effects from treatment. For more information, please view the *Nutrition* fact sheet on the Lymphoma Research Foundation's (LRF's) website at www.lymphoma.org/publications.

Long-Term Follow-up Care

The National Comprehensive Cancer Network has established guidelines for cancer survivors. All survivors should have periodic checkups to assess the following: current disease status, ability to function in everyday tasks, medications, and chronic diseases such as high blood pressure or diabetes. During these checkups, patients are encouraged to share their prior cancer treatments. For lymphoma, a yearly health checkup and physical is recommended including checking blood cell counts and routine blood chemistries; depending on your specific diagnosis and treatment, additional tests may be recommended such as thyroid hormone levels. Surveillance imaging (such as computed tomography [CT] scans, positron emission tomography [PET] scans, or magnetic resonance imaging [MRI]) and vaccinations may also be recommended. As each survivor's situation and risk for late side effects and/or recurrence are different, each individual follow-up plan for monitoring will be different; however, there are some general rules to help survivors stay healthy.

Health Screenings

Based on the type of treatments a survivor received, his/her physicians may recommend specific health screenings at an earlier age than currently recommended for the general population. For example, due to the increased risk of secondary breast cancer from radiation therapy, the Children's Oncology Group recommends that 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 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
- Colorectal cancer screenings
- Dental screenings
- Eye exams
- Lipid blood tests
- Skin cancer screenings
- Thyroid function tests

Getting an annual influenza vaccination and having regular cholesterol checks may also be beneficial. Because everyone is different, survivors should talk with their physicians about which screenings are most appropriate and when they should be started.

Establishing a Follow-Up Care Plan

After treatment completion, a hematologist/oncologist will set up a follow-up care schedule based on the type of lymphoma and other factors such as age and overall health status. Generally, survivors will have follow-up visits with a hematologist/oncologist every few months for two to three years following remission to ensure that the lymphoma has not returned and to monitor for the occurrence of long-term side effects and late side effects. During these visits, the physician will perform a physical examination and may prescribe a series of diagnostic tests such as blood tests and body imaging.

A hematologist/oncologist ideally will work in conjunction with the survivor's primary care physician from the time of diagnosis onward. To ensure that all health concerns, including both medical and psychosocial problems, are being addressed, survivors should maintain an ongoing relationship with the primary care physician during lymphoma treatment. Once a long-term *remission* (disappearance of signs and symptoms of lymphoma) is achieved, it is still critical for a hematologist/oncologist to work collaboratively with the primary care physician to monitor or manage any long-term side or late side effects. To help document a care plan, visit

www.lymphoma.org/publications to download LRF's *Lymphoma Care Plan*, which survivors should complete with their healthcare team.

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 CT and 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

Psychological Impact

Research shows that fear of cancer recurrence is a major concern for survivors; this fear can be associated with conditions such as depression and anxiety, which may linger for years or even begin only after treatment has been completed. While it is natural to experience occasional feelings of sadness or worry, survivors should seek professional help if they have symptoms of depression (e.g., difficulty sleeping, changes in appetite, or loss of interest in favorite activities) that last longer than two to three weeks.

Finding Relief

Mental health professionals can help cancer survivors develop coping skills to reduce depression and anxiety. They can also suggest strategies for managing stress levels, especially stress related to significant events such as the anniversary of a diagnosis or a follow-up visit.

Complementary therapies such as acupuncture, meditation, and massage can be beneficial in the management of lymphoma and are currently used to reduce disease symptoms and relieve treatment side effects. LRF's *Integrative Oncology* fact sheet has more information on these approaches. Survivors should talk to their healthcare providers to see what treatments could be best for them.

LRF is pleased to provide the *Lymphoma Care Plan* as a resource and guide to help survivors and their physicians discuss and document the cancer experience. Keeping your information in one location can help you feel more in control during and after treatment. For additional copies of the *Care Plan*, please visit www.lymphoma.org/publications or contact the LRF Helpline at (800) 500-9976 or helpline@lymphoma.org.

Securing Your Financial Future

Receiving a cancer diagnosis can be an overwhelming experience. It is perfectly understandable to be concerned about physical health and financial well-being. The specific cost of treatment can vary significantly depending on the type of treatment and what complications occur. Even for patients with health insurance, the out-of-pocket expenses for care can be staggering.

Concerns about losing health insurance, being discriminated against at work, or even losing a job because of a cancer diagnosis can compound the financial distress cancer survivors may experience. Here are some steps survivors can take to protect their financial well-being.

Knowing Your Legal Rights at the Workplace

Before telling anyone at the workplace—coworkers, an immediate supervisor, or someone in the human resources department—about their lymphoma, survivors should make sure they know their rights according to their employee manual regarding sick time, medical leave, short- and long-term disability benefits, and the company's policy on reasonable job accommodations (e.g., allowing time off for treatment). Also, survivors should be prepared to provide their employer with information from the physician, including the treatment plan and how it may affect their work schedule.

Before meeting with a supervisor or human resources manager, survivors should prepare a list of questions to ask, including:

- What is the company's policy on medical leave?
- How can my workload be adjusted to accommodate the time off I may need for treatment?
- How much of the cost of my treatment is covered by my health insurance, and how much will I be responsible for paying?
- Will the cost of my health insurance premiums increase?
- Will I be eligible for the company's short- or long-term disability benefits?

Protecting Yourself Against Workplace Discrimination

Survivors should become familiar with the laws and agencies that protect against workplace discrimination and allow for medical leave, such as the Americans With Disabilities Act (www.ada.gov); the Family and Medical Leave Act (www.dol.gov/whd/fmla); and the Equal Employment Opportunity Commission (www.eeoc.gov).

There are also laws in place, such as the Consolidated Omnibus Budget Reconciliation Act (COBRA) and the Health Insurance Portability and Accountability Act (HIPAA), to protect survivors from losing their healthcare coverage if they change or lose their job. Visit www.dol.gov/dol/topic/health-plans/cobra.htm for details on COBRA benefits.

To learn more about HIPAA provisions, visit the U.S. Department of Labor website at www.dol.gov/dol/topic/health-plans/portability.htm.

Protecting Your Financial Assets

Meeting with a finance professional to help assess all monetary concerns, including medical bills, income, taxes, insurance, investments, and employee benefits can help relieve financial anxiety and provide the information survivors need to protect their assets. Because financial issues can be ongoing after treatment has ended, having someone experienced in handling financial concerns related to a cancer diagnosis can be especially beneficial in developing a plan that works for a survivor's individual and specific needs.

Survivors may want to speak with family members, friends, or other professionals they work with, such as lawyers or accountants, for referrals to financial planners. Other suggested resources for finding a financial planner include:

- Certified Financial Planner Board of Standards (CFP Board): (800) 487-1497; www.cfp.net
- Financial Planning Association: (800) 322-4237; www.onefpa.org
- Society of Financial Service Professionals: (800) 392-6900; <http://national.societyoffsp.org>

Questions to Ask a Financial Planner

Before meeting with a financial planner, write down questions regarding your concerns and goals. Some specific questions to consider asking the financial planner include:

- Have you ever worked with a client who has cancer?
- How would your financial advice for me be different from a typical client?
- What are some of the financial issues you see regarding my specific situation?
- Are you familiar with all aspects of medical coverage, disability benefits, life insurance, and *viatical settlements* (a provision in a life insurance policy that allows an insured person with a life-threatening illness to redeem the policy for an amount close to its face value)?
- Are you familiar with the employee rights of a cancer patient?
- How are your fees determined (e.g., flat fee, hourly fee, commission from the sale of financial products, fee plus commission)?

Resources

LRF offers a wide range of resources that address treatment options, the latest research advances, and ways to cope with all aspects of lymphoma and chronic lymphocytic leukemia/small lymphocytic lymphoma (CLL/SLL) including our award-winning mobile app. LRF also provides many educational activities, from in-person meetings to teleconferences and webcasts for people with lymphoma and CLL/SLL, 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.

Patient Education

LRF offers a wide range of opportunities to learn about lymphoma.

Ask the Doctor About Lymphoma is a national series of two-hour, topic-specific, community-based programs that combine a presentation by a medical doctor with an extensive question-and-answer session.

Lymphoma Workshops are regional, full-day educational programs that provide the latest information about lymphoma, current treatment options, and patient support issues.

The North American Educational Forum on Lymphoma is held annually and provides critical information on treatment options, patient support issues, and the latest in lymphoma research.

Webcasts are available on specific types of lymphoma, treatment options, and support topics.

Teleconferences are hour-long, interactive telephone programs that provide an opportunity to learn more about lymphoma, treatments, and promising research from leading lymphoma experts.

Patient Services and Support

The LRF Helpline staff members are available to answer your general questions about a lymphoma or CLL/SLL 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.

Patient Publications

LRF offers a series of print and digital patient education publications. LRF offers comprehensive guides on NHL, HL, CLL/SLL, and the transplantation process in lymphoma, along with a variety of disease- and topic-specific fact sheets. Contact the LRF Helpline at (800) 500-9976 or visit our website at www.lymphoma.org/publications.

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 disease 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 www.FocusOnLymphoma.org.

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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