

## Lymphoma Survivorship

An individual is considered a survivor from the time of a cancer diagnosis throughout treatment and the remaining years of life. There are an increasing number of lymphoma survivors each year. Current data show 85 percent of patients with Hodgkin lymphoma (HL) and 69 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 increasing 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, and financial issues that survivors are faced with 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

Side effects from standard lymphoma treatment regimens, including chemotherapy, radiation, and steroids, can include both long-term and late effects. Long-term side effects manifest during treatment and continue after treatment and may include fatigue, menopausal symptoms, cognitive problems, and heart problems. Late effects on health develop after treatment completion, sometimes years, or even decades, later and may include infertility, osteoporosis, and secondary cancers. Many factors influence both an individual's risk of developing late effects and the potential intensity of those side effects. These factors can include when a patient was diagnosed, individual patient characteristics such as age, the specific type of cancer and its location, and the type of treatment he or she received.

The late effects of radiation therapy can take decades to appear and include the risk for secondary cancers such as breast, thyroid, and lung cancer as well as heart problems. Although advances in radiation therapy have allowed for less radiation to be used in treatment and smaller areas to be treated, the impact of these improvements on late effects may not be known for years.

Chemotherapy regimens such as CHOP, MOPP, and ABVD that include the alkylating agents cyclophosphamide, procarbazine, nitrogen mustard, and dacarbazine and the anthracycline doxorubicin found in CHOP and ABVD are also linked to late health effects, including infertility, gonadal dysfunction (problems with testes producing healthy sperm or ovaries producing healthy eggs), a decrease in heart function, coronary artery disease, and secondary leukemia.

### Staying Healthy

Living a healthy lifestyle that includes eating a diet high in fruits and vegetables, exercising, quitting smoking, reducing alcohol consumption, limiting sun exposure, and maintaining regular follow-up medical care can reduce a survivor's risk of developing late health effects from treatment.

### 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 and how these treatments were given. For HL, a yearly health check and physical is recommended including checking blood cell counts, erythrocyte (red blood cell) sedimentation rate, blood chemistry, and thyroid hormone levels. Chest and abdominal computed tomography (CT) scans, and vaccinations may also be recommended. As each survivor's situation and risk for late effects and/or recurrence is 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, the physician 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,

and yearly mammograms and magnetic resonance imaging (MRI) screenings beginning at age 25 or eight years after the completion of the radiation therapy, whichever comes last. Other health screenings the physician may suggest include:

- Bone density scans
- Cardiovascular monitoring
- Chest imaging
- Colorectal screenings
- Dental screenings
- Eye exams
- Lipid blood test
- Pap tests
- Prostate exams
- Skin cancer screenings
- Thyroid function tests

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

### *Establishing A Follow-Up Care Plan*

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

The hematologist/oncologist should ideally work in conjunction with the survivor's primary care physician from the time of diagnosis onward. To ensure that all health concerns, including psychological issues such as depression, are being met, survivors should maintain an ongoing relationship with the primary care physician during lymphoma treatment. Once a long-term remission is achieved, it is still critical for the hematologist/oncologist to work collaboratively

with the primary care physician to monitor or manage any long-term or late-term effects.

### *Keeping Track of Your Care*

To ensure that long-term health needs are addressed, survivors should keep a detailed medical history of their lymphoma diagnosis, including:

- Type (subtype) of lymphoma
- Date of diagnosis
- Pathology reports
- Copies of any imaging studies, including X-rays, CT scans, and positron emission tomography (PET) scans
- A list of the types and dates of treatment received (including drug names and doses), the location and doses of radiation therapy given, and the identification numbers and titles for 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 demonstrates that fear of cancer recurrence is a main concern for survivors, often associated with conditions like depression and anxiety which can linger on-and-off for years. While it is natural to experience occasional feelings of sadness, survivors who are having bouts of depression that last longer than two to three weeks, cannot sleep, or experience changes in appetite, should seek professional help.

### *Finding Relief*

Seeing a mental health professional may be beneficial in helping cancer survivors develop coping skills to reduce their stress levels, especially stress related to significant dates, such as an anniversary of the lymphoma diagnosis or a follow-up visit.

Complementary therapies such as acupuncture, meditation, and massage, are showing benefits in the management of lymphoma and are currently used to reduce disease symptoms and relieve treatment side effects. The Lymphoma Research Foundation's (LRF's) *Integrative Oncology* fact sheet has more information on these approaches. Survivors should talk to their primary care provider or a mental health professional to see what treatments could be best for them.

## Securing Your Financial Future

Receiving a cancer diagnosis is not just a threat to physical health; it can also put a survivor's financial well-being in jeopardy. 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.

Losing health insurance and worries about being discriminated against at work or even losing a job because of a cancer diagnosis only adds to the financial distress some 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—co-workers, their 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., to allow 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 to cover?
- Will my health insurance premiums go up?
- 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](http://www.ada.gov)); the Family and Medical Leave Act ([www.dol.gov/whd/fmla](http://www.dol.gov/whd/fmla)); and the Equal Employment Opportunity Commission ([www.eeoc.gov](http://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. To learn more about HIPAA provisions, visit the U.S. Department of Labor website at [www.dol.gov/dol/topic/health-plans/portability.htm](http://www.dol.gov/dol/topic/health-plans/portability.htm). Visit [www.dol.gov/dol/topic/health-plans/cobra.htm](http://www.dol.gov/dol/topic/health-plans/cobra.htm) for details on COBRA benefits.

### *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 relieve some of the 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 the financial problems related to a cancer diagnosis can be especially beneficial in developing a plan that works for a survivor's specific needs.

Ask family members, friends, or other professionals you work with, such as a lawyer or accountant, for referrals of financial planners. Suggested resources to find a financial planner in your area include:

- Certified Financial Planner Board of Standards (CFP Board): (800) 487-1497; [www.cfp.net](http://www.cfp.net)
- Financial Planning Association: (800) 322-4237; [www.onefpa.org](http://www.onefpa.org)
- Society of Financial Service Professionals: (610) 526-2500; [www.financialpro.org](http://www.financialpro.org)

#### National Headquarters

115 Broadway, Suite 1301  
New York, NY 10006  
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(212) 349-2886 fax

Helpline: (800) 500-9976  
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Website: [www.lymphoma.org](http://www.lymphoma.org)

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#### Questions to Ask a Financial Planner

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

- Have you ever worked with a client who has cancer?
- How would your planning 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., basic 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, including our award-winning mobile app. LRF also provides many educational activities, from in-person meetings to teleconferences and webcasts, as well as disease-specific websites, videos, and eNewsletters for current lymphoma information and treatment options. To learn more about any of these resources, visit our website at [www.lymphoma.org](http://www.lymphoma.org), or contact the LRF Helpline at (800) 500-9976 or [helpline@lymphoma.org](mailto:helpline@lymphoma.org).

In March of 2010 the Patient Protection and Affordable Care Act became law. This law affects both cost and access to cancer care. It includes some provisions that can directly impact cancer patients such as coverage for patients with pre-existing conditions such as cancer, and patients who develop cancer, or relapse, removal of lifetime coverage limits and annual dollar limits, and coverage for proven preventative services.