

Getting the Facts

Lymphoma Survivorship

A survivor is a person with cancer from diagnosis to treatment and throughout the remaining years of life. There is an increasing number of lymphoma survivors each year. Current data from the National Cancer Institute show an overall five-year relative survival rate of 84 percent in patients with Hodgkin lymphoma (HL) and 68 percent in patients with non-Hodgkin lymphoma (NHL). 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, 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 preventing, detecting, and treating complications to improving 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

Typically, side effects from standard lymphoma treatment regimens, including chemotherapy, radiation, and steroids fall into two broad categories: long-term and late effects. Long-term side effects manifest during treatment and continue for months or several years after treatment and may include fatigue, menopausal symptoms, and cardiovascular problems. Late effects on health develop many years, even decades, after treatment completion and may include infertility, osteoporosis, and secondary cancers. Both the potential for developing late side effects and their level of severity depend on several factors, including when a patient was diagnosed and the type of treatment he or she received.

The late effects of radiation therapy can take decades to manifest and include the risk for secondary cancers such as breast, thyroid, and lung cancer as well as heart disease. Although advances in radiation therapy over the last three decades have led to reductions in the amount and field of radiation, the impact that these improvements may have in eliminating late effects in lymphoma survivors will 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, a decrease in cardiac function, atherosclerosis (plaque builds up on the inside of the arteries), 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, and maintaining regular follow-up medical care can reduce a survivor's risk factors for developing late health effects from treatment and help spot potential problems early.

Long-Term Follow-up Care

No standardized guidelines currently exist for how often lymphoma survivors should be monitored for cancer recurrence and late health effects from treatment; however, there are some general rules to help survivors stay healthy. Studies are currently underway to establish follow-up care recommendations.

Health Screenings

Based on the type of treatments a survivor received, the doctor 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 American Cancer Society and the Children's Oncology Group recommend that women who received radiation therapy to the chest area between the ages of ten and 30 should have clinical breast examinations every six months 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 first. Other health screenings the doctor may suggest to begin earlier include:

- Pap tests
- Colorectal screenings
- Prostate exams
- Bone density scans
- Thyroid function tests

After lymphoma treatment, having lipids, thyroid, liver, and kidneys checked on a regular basis is important. Some centers are also beginning to check vitamin D on a yearly basis, as well. Getting an annual flu vaccine and having regular cholesterol checks may also be beneficial. Because every one is different, survivors should talk with their doctor 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 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 treatment side effects. During these visits, the doctor will perform a physical examination and may prescribe a series of diagnostic tests such as computed tomography (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 effects.

Keeping Track of Your Care

Even when uniform guidelines are established for a cancer survivor's follow-up care, as an individual patient, the disease course may be very different from other patients. To ensure that long-term health needs are addressed, survivors should keep a detailed medical history of the lymphoma, including:

- Type (subtype) of lymphoma
- Date of diagnosis
- A list of the types of treatment received, including drug names and doses; and the location and doses of radiation therapy given
- Pathology reports
- Copies of any imaging studies, including X-rays, CT scans, and positron emission tomography (PET) scans

- Any treatment complications
- Types of side effects experienced
- A list of the possible late effects of the treatment
- The doctor's recommendations for frequency of follow-up visits
- Tips from the doctor on how to maintain optimal health

Fear of Recurrence

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, patients 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

Although research is needed that will show which types of interventions would be most effective for individual survivors, 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 are showing benefits in the management of lymphoma and are currently used to reduce disease symptoms and relieve treatment side effects. For example, acupuncture, meditation and massage are among the relaxation and symptom relieving techniques discussed in the Lymphoma Research Foundation's (LRF) Integrative Medical Care factsheet. Survivors should talk to their primary health 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 as well. For lymphoma patients without health insurance and who must self-pay for their care, the cost of treatment can be as high as \$200,000 or more the first year. 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 accommodation (for example, to allow time off for chemotherapy treatment). Also, survivors should be prepared to provide their employer with information from the doctor, 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); 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 health care 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. For details on COBRA benefits, visit www.dol.gov/dol/topic/health-plans/cobra.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 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. The American Cancer Society (www.cancer.org) also has information on its website about how to find a financial planner in your area. Suggested resources include:

- Certified Financial Planner Board of Standards (CFP Board): (800) 487-1497; www.cfp.net
- Financial Planning Association: (800) 322-4237; www.fpanet.org
- Society of Financial Service Professionals: (888) 243-2258; www.financialpro.org

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 (for example, basic fee, commission from the sale of financial products, fee plus commission)?

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Additional Resources

These websites provide information on a range of cancer survivorship issues.

- **Cancer Care** www.cancerca.org: This website provides important resources like counseling, support groups, patient education materials, and financial assistance guidance. You can listen-in live by telephone or online to The Connect Education Workshops. These 1-hour programs on various topics are presented by leading experts in cancer care.
- **Cancer.Net** www.cancer.net: This organization, sponsored by the American Society of Clinical Oncology (ASCO) offers a survivorship program that provides information about adjusting to life changes following cancer, including a free printable booklet *Cancer Survivorship: Next Steps for Patients and Their Families*.
- **Cancer Legal Resource Center** www.cancerlegalresourcecenter.org: A comprehensive website with information on a variety of legal issues, including health insurance coverage and employment discrimination.
- **Lance Armstrong Foundation** www.livestrong.org: The "Practical Effects of Cancer" section provides a list of assistance programs, employment, finances, health care planning, and insurance. You will also find information on the locations of seven National Cancer Institute-designated Comprehensive Cancer Centers that are members of the LIVESTRONG Survivorship Center of Excellence Network.
- **National Coalition for Cancer Survivorship** www.canceradvocacy.org: The oldest survivor-led cancer advocacy organization in the country, the NCCS provides a variety of patient education material and a Cancer Survivor Toolbox, a free, self-learning audio program that helps cancer survivors develop the skills they need to combat the challenges of their disease.
- **OncoLink** www.oncolink.org —Launched by the Abramson Cancer Center of the University of Pennsylvania, OncoLink, an award-winning cancer resource website, also launched LIVESTRONG Care Plan (www.livestrongcareplan.org), which allows survivors to develop their own individual care plan based on recommendations from the Institute of Medicine.
- **Patient Advocate Foundation** www.patientadvocate.org: This foundation provides patients with arbitration, mediation, and negotiation to settle issues with access to care, medical debt, and job retention related to their illness.

Solving the long-term health needs of cancer survivors may soon be addressed on the national level through a bill called the Comprehensive Cancer Care Improvement Act of 2012, which is currently making its way to Congress. The bill proposes to establish a system of integrated cancer care that would include better communication between patients and their health care providers regarding treatment options and follow-up care.