

## Lymphoma Survivorship

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**T**he good news for people diagnosed with cancer continues to be the increasing numbers of survivors each year. According to the latest statistics from the National Cancer Institute, which defines survivorship from the time of diagnosis to the end of life, there are nearly 12 million cancer survivors in the United States, a 14 percent increase over 2007. While the combination of early detection, better diagnostic tools and more effective treatments is credited with the rise in survival rates, the challenge now facing many survivors is how to achieve long-term quality of life after treatment has ended. According to the National Action Plan for Cancer Survivorship, one-third of survivors say they suffer from ongoing physical, psychological or financial consequences of their cancer diagnosis and treatment.

Here are some of the top concerns lymphoma survivors have and what can be done to ensure 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 and may include fatigue, menopausal symptoms and cardiovascular problems. Late effects on health develop many years—and even decades—after treatment has ended 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 and heart disease. Although advances in radiation therapy over the last three decades have led to reductions in both the amount of radiation given to treat lymphoma—from 45 gray to approximately 30 gray—and the field of radiation—from extended field to involved field in which only the cancerous nodes are treated—whether they will result in eliminating late toxic effects in lymphoma survivors will not be known for years.

Chemotherapy regimens such as CHOP, MOPP and ABVD that include the alkylating agents cytoxan, procarbazine, nitrogen mustard and dacarbazine and the anthracycline adriamycin found in CHOP and ABVD are also linked to late health effects, including infertility, gonadal dysfunction, a decrease in cardiac function, atherosclerosis in which 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 your risk factors for developing late health effects from treatment and spot potential problems early.

## Long-Term Follow-up Care

Although no standardized guidelines currently exist for how often lymphoma survivors should be monitored for cancer recurrence and late health effects from treatment—studies are underway to establish a follow-up care protocol that includes the types of routine health screenings that should be done and their frequency—there are some general rules to help you stay healthy.

### Health Screenings

Based on the type of treatments you have had to combat your lymphoma, your doctor may recommend that certain health screenings be started at an earlier age than what is 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 recommends that women who received radiation therapy to the chest area between the ages of 10 and 30 should have clinical breast examinations every six months and yearly mammograms and MRI screenings beginning at age 25 or eight years after the completion of the radiation therapy, whichever comes first. Other health screenings your doctor may suggest you begin earlier include:

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

After lymphoma treatment, having your 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. Talk to your doctor about which screenings are most appropriate for you and when they should be started.

### Establishing Your Follow-Up Care Plan

Upon completion of your treatment, your oncologist will set up a follow-up care schedule with you based on your specific type of lymphoma and other factors such as age and your general health. Usually you will have to see your oncologist every few months for two to three years following remission to ensure that your lymphoma has not returned and to detect long-term and late treatment side effects. During these visits, your doctor will perform a physical examination and may prescribe a series of diagnostic tests such as CT scans, chest X-rays and blood tests.

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

### Keeping Track of Your Care

Until uniform guidelines are put in place for cancer survivor follow-up care, you can ensure that your long-term health needs will be met by keeping a detailed medical history of your lymphoma, including:

- Type of lymphoma
- Date of diagnosis
- A list of the types of treatment you received, including drug names and doses; and the location and doses of radiation therapy given
- Pathology reports
- Copies of imaging studies, including X-rays, CT scans, PET scans, etc.
- Any treatment complications
- Types of side effects you experienced
- A list of the possible late effects of your treatment
- Your doctor's recommendations for frequency of follow-up visits
- Tips from your 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 such maladies as depression and anxiety, which can linger on-and-off for years. While it is natural to experience occasional feelings of sadness, if you are having bouts of depression that last longer than two to three weeks, you cannot sleep or have changes in appetite, it is time to seek professional help.

### Finding Relief

Although research needs to be done to determine which types of intervention 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 as significant dates like anniversaries of their lymphoma diagnosis or follow-up visits approach. Medication may also be appropriate under certain circumstances. Talk to your primary health provider or a mental health professional to see what treatment is best for you.

### Securing Your Financial Future

Receiving a cancer diagnosis is not just a threat to your physical health, it can put your 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. According to a recent report published by the nonprofit organization Patient Advocate Foundation, over 70 percent of the more than 44,800 cancer patients it served in 2007 said that rising medical debt was their main concern.

Losing health insurance due to a pre-existing medical condition and worries about being discriminated at work or even losing a job because of a cancer diagnosis only adds to the financial distress some cancer survivors experience. Here are some steps you can take to protect your financial well-being.

### Knowing Your Legal Rights at the Workplace

Before telling anyone at your workplace—co-workers, your immediate supervisor or someone in the human resources department—about your lymphoma, make sure you know what your rights are by reading your employee manual regarding sick time, medical leave, short- and long-term disability benefits and your company's policy on reasonable job accommodation, for example, to allow time off for chemotherapy treatment. Also, be prepared to provide your employer with information from your doctor, including your treatment plan and how it may affect your work schedule.

Before meeting with your supervisor or human resources manager, 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

Familiarize yourself with the laws and agencies that protect against workplace discrimination and allow for medical leave such as the Americans With Disabilities Act ([Ada.gov](http://ada.gov)); the Family and Medical Leave Act ([Dol.gov/esa/whd/fmla](http://Dol.gov/esa/whd/fmla)); and the Equal Employment Opportunity Commission ([Eeoc.gov](http://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 you from losing your health care coverage if you change or lose your job. To learn more about HIPAA provisions, visit the U.S. Department of Labor website at [Dol.gov/dol/topic/health-plans/portability.htm](http://Dol.gov/dol/topic/health-plans/portability.htm). For details on COBRA benefits, visit [Dol.gov/dol/topic/health-plans/cobra.htm](http://Dol.gov/dol/topic/health-plans/cobra.htm).

### Protecting Your Money

Meeting with a professional to help you assess all your money concerns, including medical bills, income, taxes, insurance, investments and employee benefits can relieve some of your financial anxiety and provide you with the information you need to protect your assets. Because financial issues can be ongoing after treatment has ended, for example, if you were forced into early retirement due to treatment or you lost your health insurance coverage and have to pay out-of-pocket for care, having someone experienced in handling the financial problems related to a cancer diagnosis can be especially beneficial in developing a plan that works for your 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 ([cancer.org](http://cancer.org)) also has information on its website about how to find a financial planner in your area. Here are some suggestions to get you started:

- Certified Financial Planner Board of Standards (CFP Board); (888) 237-6275; [cfp.net](http://cfp.net)
- Financial Planning Association; (800) 647-6340; [fpanet.org](http://fpanet.org)
- Society of Financial Service Professionals; (888) 243-2258; [financialpro.org](http://financialpro.org)

# Contact Us

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The Lymphoma Research Foundation offers a comprehensive slate of patient education and support programs including

- *Lymphoma Helpline & Clinical Trials Information Service*
- *Lymphoma Support Network*
- Publications and newsletters
- Informational teleconferences and webcasts
- In-person conferences
- National Chapter Network

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## Questions to Ask a Financial Planner

Before meeting with a financial planner, write down some 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?
- 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?

## Additional Resources

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

- **Cancer Legal Resource Center** (Cancerlegalresourcecenter.org)—A comprehensive website with information on a variety of legal issues, including health insurance coverage and employment discrimination.
- **Lance Armstrong Foundation** (Livestrong.org)—Type in “Practical Effects of Cancer” in the search bar and you’ll be taken to a list of resources on assistance programs, employment, finances, health care planning and insurance. Here you’ll also find information on the locations of eight Survivorship Centers of Excellence nationwide.
- **National Coalition for Cancer Survivorship** (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** (Oncolink.org)—Launched by the University of Pennsylvania School of Medicine, OncoLink, an award-winning cancer resource website, recently added a new feature called OncoLife, which allows survivors to develop their own individual care plan based on recommendations from the Institute of Medicine.
- **Patient Advocate Foundation** (Patientadvocate.org)—This website offers practical help with a variety of concerns, including patient assistance programs for health care and provides information on employment issues and Medicare benefits, among other features.

## How to Get Involved

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, 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.