

Understanding Survivorship: Psychological Impact on Survivors

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.

While each experience is different, it is common for survivors to struggle with negative feelings and the fear that the disease may come back. This can make it challenging to return to the routine they had before the lymphoma diagnosis. Below are some of the top concerns regarding the psychological impact on lymphoma survivors and options for support networks to help survivors navigate through this new stage.



EMOTIONAL EFFECTS AND FEAR OF RECURRENCE

Survivors often report that they entered a very different world once treatment ended. While it may be a time to rejoice and recover from the experience, this “new normal” period often comes with mixed emotions. You may have a hard time trying to return to your routine as it was before you were diagnosed with lymphoma. For instance, some things you once did easily may now be challenging, or you may not have the same energy. It is also very common for survivors to feel anxious about the future and find it particularly hard not knowing what happens next. These feelings stem out of the fear that the lymphoma will return (also known as *fear of recurrence*) and can be triggered by simple things like birthdays, a visit to a doctor’s office or an unexpected symptom. While feelings of sadness and worry are normal and may even decrease over time, this can have a negative impact on your daily life. Even though you cannot necessarily control whether or not your lymphoma returns, you can be proactive and take the following steps to cope with fear of recurrence:

- Be informed about the signs of recurrence for your type of lymphoma.
- Keep track of any questions and symptoms you have and discuss them with your healthcare team.
- Stay up-to-date with your medical appointments and follow your doctor’s recommendations.
- Verbalize your concerns to a friend, family member or a survivor’s support group.
- Be patient and allow yourself time to process your feelings.
- Take control of what you can and make a follow-up care plan (see *When Treatment is Over*).

Fear of recurrence can be associated with conditions such as depression and anxiety, which may linger for years or even begin only after treatment has been completed. This can manifest in different ways, like trouble sleeping, changes in appetite, lack of interest in activities you previously enjoyed and inability to handle daily chores. You may want to seek help from a trained counselor or a mental health professional if these symptoms last longer than two to three weeks. Mental health professionals can help you develop skills to reduce stress levels and cope with anxiety and depression. Complementary therapies such as acupuncture, meditation, and massage can also be beneficial in the management of the emotional effects of treatment.



TAKING CARE OF YOURSELF

As a cancer survivor, it is important that you practice self-care regularly to reset your physical and emotional well-being. Adopting routines of self-care will help you recharge your batteries and stay healthy. Talk with your healthcare team about developing a wellness plan to help you stay physically and emotionally healthy and improve your mood. Consider the following suggestions:

- **Watch your health.** Stay up-to-date with your own medical appointments and take any medications as prescribed.
- **Exercise.** Stay active with short periods of daily exercise (30 minutes of power walking, jogging or biking). If not possible, take the stairs instead of the elevator or park farther away than usual.
- **Eat well.** Include fruits and vegetables in your meals and maintain a balanced diet.
- **Cut down on risk factors.** Quit smoking and reduce alcohol intake.

- **Sleep.** Try to get 7 hours of sleep per night, or take naps when needed.
- **Rest.** Meditation, deep breathing and stretching can help you relax and reduce stress.
- **Write it down.** Keeping a journal with thoughts and feelings may help you to let go of worries and fears.

FINDING SUPPORT

Identify at least one person with whom you feel you can be honest about your feelings. You can open up to friends and family or join a support group for cancer survivors.

The Lymphoma Research Foundation (LRF)'s one-to-one peer support programs - *Lymphoma Support Network* - 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. For more information about this program, please contact the LRF Helpline or visit lymphoma.org/resources/supportservices/lsn.

You can find assistance online with support-oriented patient organizations such as Cancer Care (call **800-813-HOPE** (4673) or visit cancercaresupportgroups.org) and the Cancer Support Community (call **(888) 793-9355** or visit cancersupportcommunity.org). For some individuals, faith and spirituality is the best route to find comfort. Some members of your place of worship may help you cope with your concerns, such as feeling alone, fear of death, searching for meaning, and doubts about faith. As mentioned earlier, speaking with a mental health professional can also be very helpful.

There are many options available, and it is important that you choose the one that is right for you. Having a reliable support network can provide a means to work through your negative emotions and help you cope with physical effects of treatment or deal with aspects of daily life (like family, school or work responsibilities). Follow-up care can also include home care, occupational or vocational therapy, pain management or physical therapy.

LRF'S HELPLINE

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.

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.

Medical Reviewer:

MD Linda A. Jacobs, PhD, CRNP
Abramson Cancer Center, University of Pennsylvania

Contact LRF:

Helpline: (800) 500-9976
Email: helpline@lymphoma.org
www.lymphoma.org

Supported through grants from:    

Understanding Lymphoma fact sheet series is published by the Lymphoma Research Foundation (LRF) for the purpose of informing and educating readers. Facts and statistics were obtained using published information, including data from the Surveillance, Epidemiology, and End Results (SEER) Program. Because each person's body and response to treatment is different, no individual should self-diagnose or embark upon any course of medical treatment without first consulting with his or her physician. The medical reviewer, the medical reviewer's institution, and LRF are not responsible for the medical care or treatment of any individual.

© 2022 Lymphoma Research Foundation

Last updated 2022

Stay Connected through our social media:    