

Understanding Lymphoma and Active Surveillance

Types of lymphoma that grow slowly are referred to as *indolent* or *low-grade* lymphomas. Indolent lymphomas are often managed like a chronic disease, requiring long-term treatment and monitoring.

Periods of remission followed by reoccurrence (*relapse*) are common. For patients with an indolent lymphoma who are not experiencing symptoms and who have a low tumor burden (i.e., small-sized tumors), it is often recommended that treatment be reserved for when symptoms appear. This approach is called “*watchful waiting*,” “*watch and wait*,” or “*active surveillance*.” Active surveillance is not recommended for patients with fast-growing, aggressive lymphomas. Treatment for these patients is usually initiated as soon as possible after diagnosis.

With active surveillance, patients do not initially receive anti-lymphoma treatment. The lymphoma is not being ignored; rather, an active observation strategy is being used to follow it closely. With this strategy, patients’ overall health and disease are monitored through regular checkup visits. In addition, follow-up evaluation procedures, such as laboratory and imaging tests, are performed often to determine if the lymphoma is progressing and how urgently treatment is needed.

Health care providers recommend active surveillance for selected patients with indolent lymphomas. This approach may be started after initial diagnosis or following relapse, depending on individual circumstances. Active treatment is started if the patient begins to develop lymphoma-related symptoms or if there are signs that the disease is progressing based on testing during follow-up visits.

The appearance of the following common symptoms of lymphoma might mean that treatment should be started:

- Recurrent or persistent fevers
- Drenching night sweats
- Unexplained weight loss
- Increasing tiredness or fatigue

Various other symptoms, such as pain, shortness of breath or increased abdominal girth can indicate a need to start treatment as well. As long as the patient feels generally well, and clinical and imaging assessments suggest that the disease has not progressed and no major organs are in danger of being compromised, treatment can be delayed. There is currently no evidence that early intervention in indolent lymphomas prolongs a patient’s survival, and there are advantages to active surveillance over active treatment for a disease that is not progressing. For example, patients do not experience the many possible side effects associated with anti-cancer treatments that can negatively impact quality

of life. Treatments are also associated with expenses and inconvenience. In addition, rapid progress is being made in developing new and more effective therapies for indolent lymphomas, which might be available when the patient eventually requires treatment.

Active surveillance can be difficult for patients emotionally. Patients should discuss with their physicians any concerns they may have regarding the active surveillance approach. The following are common questions patients might ask their doctors:

- What if I am uncomfortable with active surveillance and would rather receive treatment?
- Will the disease be harder to treat later?
- How often will I have checkups?
- Between checkups, what symptoms and other problems should I report?
- How will you know when it is time for treatment?
- How will you decide which anti-cancer treatment I should start?



CLINICAL TRIALS

Clinical trials are crucial in identifying effective drugs and determining optimal doses for lymphoma patients. Patients interested in participating in a clinical trial should view the *Understanding Clinical Trials* factsheet on LRF’s website (visit lymphoma.org/publications), talk to their physician or contact LRF’s Helpline for an individualized clinical trial search by calling (800) 500-9976 or emailing helpline@lymphoma.org.

FOLLOW-UP

Patients with lymphoma should have regular visits with a physician who is familiar with their medical history and the treatments they have received. Medical tests (such as blood tests, computed tomography [CT] scans, and positron emission tomography [PET] scans), may be required at various times to evaluate the need for treatment.

Some treatments can cause long-term effects or late effects, which can vary based on duration and frequency of treatments, age, gender, and overall health of each patient at the time of treatment. Doctors will also check for these effects during follow-up care.

Patients and their caregivers are encouraged to keep copies of all medical records and test results as well as information on the types, amounts, and duration of all treatments received.

This documentation will be important for keeping track of any effects resulting from treatment or potential disease recurrences.

LRF'S HELPLINE AND LYMPHOMA SUPPORT NETWORK

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. A part of the Helpline is LRF's one-to-one peer support program, Lymphoma Support Network. This program 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.

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LRF FOCUS ON LYMPHOMA MOBILE APP

Focus on Lymphoma is the first app to provide patients and their caregivers with tailored content based on lymphoma subtype, and actionable tools to better manage diagnosis and treatment. Comprehensive lymphoma management, conveniently in one secure and easy-to-navigate app, no matter where you are on the care continuum. Get the right information, first, with resources from the entire Lymphoma Research Foundation content library, use unique tracking and reminder tools, and connect with a community of specialists and patients. To learn more this resource, visit our website at lymphoma.org/mobileapp, or contact the LRF Helpline at 800-500-9976 or helpline@lymphoma.org.

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 CLL/SLL including our award-winning mobile app. LRF also provides many educational activities, including our in-person meetings, 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 Helpline at (800) 500-9976 or helpline@lymphoma.org.

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