

Patient Education

Chronic Lymphocytic Leukemia/ Small Lymphocytic Lymphoma

What is Chronic Lymphocytic Leukemia/ Small Lymphocytic Lymphoma?

Chronic lymphocytic leukemia (CLL) and small lymphocytic lymphoma (SLL) are cancers that affect the same lymphocytes, a type of white blood cell. CLL and SLL are essentially the same disease, with the only difference being the location where the cancer primarily occurs:

- When most of the cancer cells are located in the bloodstream and the bone marrow, the disease is referred to as CLL, although the lymph nodes and spleen are often involved.
- When the cancer cells are located mostly in the lymph nodes, the disease is called SLL.

How is CLL/SLL Diagnosed?

Many patients with CLL/SLL do not have any obvious symptoms of the disease. Their doctors might detect the disease during a routine blood test and/or a physical examination. For others, the disease is detected when symptoms occur and the patient goes to the doctor because he or she is worried, uncomfortable, or does not feel well.

If symptoms occur, they may be different for each patient due to the location of the tumor in the body. The symptoms of CLL/SLL include a tender, swollen abdomen and feeling full even after eating only a small amount. Other symptoms of CLL/SLL can include fatigue, shortness of breath, anemia, bruising easily, night sweats, weight loss, and frequent infections. However, many patients with CLL/SLL will live for years without symptoms.

Treatment Options

Treatment is based on the severity of associated symptoms as well as the rate of cancer growth. If patients show no or very few symptoms, doctors may decide not to treat the disease right away, an approach referred to as “watch and wait” or “watchful waiting.” Studies have shown that patients suitable for a “watch and wait” approach have outcomes similar to those treated early in the course of their disease. However, patients with high-risk disease may need to start treatment right away.

There are many first-line treatment options for CLL/SLL. The choice of treatment will depend on the stage of the disease, whether or not the patient is experiencing symptoms, the age and overall health of the patient, and the benefits versus side effects of treatment.

It is not yet clear if stem cell transplantation is helpful for patients with CLL/SLL. Stem cell transplants are usually done as part of a clinical trial in patients with high-risk or relapsed (returns after treatment) or refractory (does not respond to treatment) disease. Typically, stem cells from a donor are used.

Common drugs or combinations of drugs used as initial treatments for CLL/SLL include:

- BR (bendamustine and rituximab)
- CO (chlorambucil and obinutuzumab)
- FCR (fludarabine, cyclophosphamide, and rituximab)
- FR (fludarabine and rituximab)
- Ibrutinib (for patients with 17p deletions)
- Ofatumumab and chlorambucil
- PCR (pentostatin, cyclophosphamide, and rituximab)

For patients who become refractory or relapse, secondary therapies may be successful in providing another remission. Some common single-agent and combination therapies used in the relapsed/refractory setting include:

- Alemtuzumab
- Bendamustine
- Idelalisib
- Chlorambucil
- Ofatumumab
- Fludarabine
- Rituximab
- Ibrutinib
- Lenalidomide with or without rituximab
- R-CHOP (rituximab, cyclophosphamide, doxorubicin, vincristine, and prednisone)

Treatments Under Investigation

Many treatments are currently being tested in clinical trials for both newly diagnosed and relapsed/refractory CLL/SLL patients.

- Chemoimmunotherapy agents are being explored as induction therapy in newly diagnosed patients.
- Researchers are also investigating ways to improve stem cell transplantation in patients with CLL/SLL.
- Genetically engineered immune cells, or T cells, designed to recognize and kill CLL cells are another area of research for treating CLL. It is critical to remember that today’s scientific research is continuously evolving.

Treatment options may change as new therapies are discovered and current therapies are improved. Therefore, it is important that patients check with their physician for any treatment updates that may have recently emerged.

Clinical trials are crucial in identifying effective drugs and determining optimal doses for patients with lymphoma. Patients interested in participating in a clinical trial should talk with their physician.

Follow-Up

Because CLL/SLL is generally characterized by multiple disease relapses after responses to a variety of treatments, patients in remission 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 and CAT scans) may be required at various times during remission to evaluate the need for additional treatment.

Some treatments can cause long-term effects or late effects, which can vary based on duration and frequency of treatments, age, gender, and the overall health of each patient at the time of treatment. A physician will 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.

Lymphoma Research Foundation Patient Resources

The Lymphoma Research Foundation (LRF) offers patients with lymphoma and CLL a wide range of resources that provide a comprehensive overview as well as address treatment options, the latest research advances, and ways to cope with all aspects of lymphoma

LRF also provides many educational activities, from in-person meetings to teleconferences and webcasts, as well as an *Understanding Chronic Lymphocytic Leukemia and Small Lymphocytic Lymphoma* booklet, e-Updates that provide the latest disease-specific news and treatment options, and an award-winning mobile app (*Focus on Lymphoma*) that provides tools to help manage the disease.

For more information about any of these resources, visit the Lymphoma Research Foundation’s websites at www.lymphoma.org or www.FocusOnCLL.org or contact the LRF Helpline at 800-500-9976 or helpline@lymphoma.org.

This “Patient Education” tear sheet was produced in collaboration with the Lymphoma Research Foundation (LRF) (www.lymphoma.org).