



Most people who have been diagnosed with chronic lymphocytic leukemia (CLL) or small lymphocytic lymphoma (SLL) have no symptoms initially and are usually advised that no treatment is necessary upon diagnosis. Since the disease is a chronic, slow-growing cancer, many have no symptoms and experience little to no change in their health for many years. So, actively monitoring the disease without starting treatment has been proven to be a safe standard of care. Worsening symptoms of the disease develop slowly over time, so it is more important to look at trends versus any one lab result or symptom. It is critical to be aware of the signs and symptoms that may indicate there is a need to begin treatment. The decision of when to start treatment can be complex and varies from person to person.

SHOULDN'T MY CANCER BE TREATED AS SOON AS POSSIBLE EVEN IF I DON'T HAVE SYMPTOMS?

The answer to this question is a resounding NO. It seems so counterintuitive and frustrating to be diagnosed with cancer and then be told that treatment is not yet needed. But CLL and SLL are very different from most other cancers in that they are very slow-growing. Many studies have shown that treating the disease before symptoms are present will not improve outcomes, and in the long run, starting treatment too early can even hurt rather than help. Also, some people need to be treated with many different types of treatments over their lifespan, and there are not an infinite number of treatments available. So, it is important to hold off until treatments are truly needed. The tricky part is not to wait until symptoms become too severe, but also not to intervene too soon. It is important to be aware of what symptoms to look for and then report any new or worsening symptoms to your healthcare team if they occur.

WHAT SYMPTOMS SHOULD I BE LOOKING FOR?

Most experts agree that treatment should begin when the disease begins to cause symptoms that interfere with daily life. Treatment will often be started when a person develops certain symptoms or when there are other signs that the cancer is worsening. These symptoms may include:

- **B Symptoms.** These are a group of specific signs and symptoms that may indicate the cancer is becoming more active in the body. Examples of B symptoms include:
 - » Unexplained weight loss of more than 10% of total body weight in the previous 6 months.
 - » Severe fatigue that makes it difficult to work or perform usual daily activities.

- » Fevers higher than 100.4°F lasting for at least 2 weeks without any other signs of infection.
- » Drenching night sweats (soaking the bed sheets) for more than a month without evidence of infection.

- **Low Blood Cell Counts.** Abnormally low blood cell count values can occur because of an overgrowth of the cancerous cells in the bone marrow that crowd out the number of healthy cells. Low blood cell counts to watch for include red blood cells (which are responsible for carrying oxygen to tissues and lead to tiredness or shortness of breath) or low platelet counts (which can cause an increased risk of bleeding, bruising, or red pinpoint spots under the skin called petechiae).
- **Enlarged Spleen.** The spleen is located on the upper left side of the abdomen. When it becomes enlarged it can cause a person to feel full or bloated. If it is pressing on the stomach, it can cause loss of appetite and a feeling of immediate fullness even after eating only a few bites. In some cases, it can cause abdominal pain.
- **Enlarged Lymph Nodes.** These lumps that are often first felt in the neck or throat area can be painless at first. But they can also grow to become very enlarged and painful, which can mean it is time to begin a new treatment.
- **Secondary Symptoms.** These are symptoms that tend to occur later in the course of the disease and may include:
 - » Repeat or prolonged infections that are caused by low levels of healthy white blood cells.
 - » Autoimmune cytopenias that can develop include Autoimmune Hemolytic Anemia (AIHA) or Immune Thrombocytopenic Purpura (ITP). Treating the underlying CLL or SLL will sometimes help control these conditions when they have not responded well to steroids or other standard therapy.



WHAT OTHER LABORATORY RESULTS INDICATE IT IS TIME FOR TREATMENT?

Lymphocytes are one of several types of white blood cells that are found in the bloodstream, and are called lymphocytes because they are found in lymph nodes. The absolute lymphocyte count (ALC) reflects the number of white blood cells that are lymphocytes. Treatment guidelines suggest that when the ALC increases by more than 50% within two months, or doubles in less than six months, and new or worsening symptoms are present, this is an indication to consider starting treatment. However, these suggested guidelines for a rising ALC only begin to apply when the ALC is over 30,000. This means when the ALC is less than 30,000 and the values increase by more than 50% within two months or double in less than six months, ALC results should not be cause for beginning treatment! **Please note that there is no absolute ALC level or value that demands treatment.** ALC Counts can exceed 500,000 or more. But if you otherwise feel good with no other symptoms, then continuing to monitor the disease without starting treatment is appropriate.

WHEN SHOULD I LET MY HEALTHCARE PROVIDER KNOW ABOUT MY SYMPTOMS?

While it is best to wait to begin treatment until symptoms are present, it is important not to wait until the symptoms are severe. When any new or worsening symptoms develop, inform your healthcare provider right away so that the symptoms you are experiencing can be closely monitored. Your healthcare provider will evaluate your condition to determine if the symptoms are caused by progression of the cancer or if symptoms are due to some other cause.

WHAT HAPPENS ONCE IT IS DETERMINED THAT TREATMENT IS NECESSARY?

When the decision is made to undergo medical treatment, your healthcare team will begin the process of planning and preparing you. Treatment is seldom considered urgent. It is important to consult with a CLL expert hematologist/oncologist who is part of your healthcare team (if you haven't already) when it is time to begin a new treatment. The process of preparing for treatment can sometimes take several weeks before the actual treatment begins. This process involves completing all necessary medical appointments and tests, making sure all immunizations are up to date before starting treatment, obtaining insurance authorization for the treatment, and addressing any other specific needs you may have. Before starting any new treatment, it will be necessary to repeat FISH and TP53 testing even if they were already done earlier in the disease.

WHAT CAN I EXPECT FROM TREATMENT?

People with CLL or SLL have a range of responses after treatment. The goal of available treatments can differ. Some will slow the growth of the cancerous cells, and some will rapidly kill cancerous cells resulting in remission (where there are no signs of the disease). However, the overall goal should be to help individuals feel better and drastically improve symptoms. Talk to your doctor about what results to expect from the treatment that is selected. The decision to start treatment should always be a shared medical decision between you and your healthcare provider and it should be personalized according to individual needs.

CLL SOCIETY MISSION

CLL Society is an inclusive, patient-centric, physician-curated nonprofit organization that addresses the unmet needs of the chronic lymphocytic leukemia and small lymphocytic lymphoma (CLL/SLL) community through patient education, advocacy, support, and research.