



Most people with chronic lymphocytic leukemia (CLL) at the time of diagnosis have no obvious symptoms and are often diagnosed based on the results of a routine blood test. However, symptoms can be present at diagnosis or can develop over time and should never be ignored. It is important to discuss any new or unusual symptoms with your healthcare provider so that they can determine the underlying cause. Symptoms can be completely unrelated to the cancer, they can be caused by certain medications and other health conditions, or they can be a sign that the cancer is progressing and it may be time to start treatment.

WHAT ARE SOME COMMON SYMPTOMS ASSOCIATED WITH HAVING CLL?

- **Persistent fatigue.** This may result from high levels of enzymes (called cytokines) released by white blood cells in response to inflammation caused by the cancer. Other factors that may contribute to fatigue include medications, anemia, other chronic diseases, nutritional deficiencies, chronic pain, and sleep disorders among others.
- **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.
- **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.
- **Increased sensitivity to insect bites.** Increased swelling, itchiness, and redness in response to insect bites (particularly mosquitoes) is a relatively common complaint and may be related to the immune dysregulation that accompanies the disease.
- **Joint, muscle, or bone aches and pains.** It is thought that bone pain can happen if too many cancer cells in the bone marrow put pressure on nerves, and joint pain can occur if too many cancer cells collect in the joints. But as people age, they tend to have more joint aches and pains in general. So, this is a particularly difficult symptom to pinpoint the cause.
- **Anxiety and depression.** It is not uncommon for anxiety and depression to be triggered by a cancer diagnosis. The diagnosis causes uncertainty associated with having a chronic serious illness, it is frightening to learn that you have cancer, and it can be scary and confusing not to start treatment right away.

WHAT SYMPTOMS CAN INDICATE THE CANCER IS PROGRESSING?

When CLL progresses, it often causes something called “B symptoms” to occur. Because B symptoms overlap with those of common illnesses like a cold or the flu, they can be difficult to identify. The presence of B symptoms may indicate the cancer is becoming more active and it may be time to begin treatment, so it is important to monitor for them. Oftentimes, treating the disease can make B symptoms go away.

Examples of B symptoms include:

- Unexplained weight loss that is 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.

Some symptoms tend to occur later in the course of the disease and are sometimes referred to as secondary symptoms. These may include:

- Repeat infections that are caused by low levels of healthy white blood cells.
- Red, flat, pinpoint spots under the skin called petechiae.
- Easy bleeding or excessive bruising that occurs when the cancerous CLL cells in the bone marrow crowd out the number of cells that are needed to help with blood clotting (called platelets).
- Shortness of breath or light-headedness that occurs when the cancerous CLL cells reduce the number of cells that are needed to carry oxygen to tissues (called red blood cells).



ARE THERE ANY SELF-CARE STRATEGIES THAT HELP TO IMPROVE SYMPTOMS?

Self-Care Strategies for Fatigue

- Exercise, including light activities and movement like stretching and walking, has been shown to boost energy levels and improve cancer-related fatigue.
- Eat a healthy, balanced diet that includes plenty of grains, fruits, vegetables, healthy fats, and protein.
- Stay well hydrated by drinking at least 64 ounces of water per day and limit caffeinated beverages.
- Conserve your energy. Plan your day to include rest in between activities.
- Practice good sleep habits and try to get 7-8 hours of uninterrupted sleep each night.
- Be willing to accept help. Prioritize the activities that are most important to you, and let others help with tasks like grocery shopping, meal preparation, and other household chores.
- Use relaxation techniques that decrease stress and improve relaxation, such as massage therapy, yoga, and meditation.

Self-Care Strategies for Painful Lymph Nodes

- A warm compress, rest, or over-the-counter pain medicine may provide temporary pain relief. Discuss the use of over-the-counter pain relievers with your healthcare provider.

Self-Care Strategies for Fullness or Discomfort with Eating

- Eat small frequent meals to help ensure enough calories are being taken in throughout the day.

Self-Care Strategies for Increased Sensitivity to Insect Bites

- Avoid scratching the area as much as possible.
- Apply an over-the-counter topical anti-itch cream, or apply a paste made of baking soda and water to the affected area. Reapply the cream or paste three times a day until the itching is gone.
- Apply an ice cube to the affected area for 30 seconds.
- Discuss the use of an over-the-counter antihistamine, such as loratadine (Claritin), with your healthcare provider.

Self-Care Strategies to Help Cope with Stress, Anxiety, or Depression

- Consider joining one of CLL Society's online support groups that are led by trained facilitators.
- Regular light physical activity has been shown to help relieve stress and improve mood. Check with your healthcare provider first before engaging in any new physical activity or exercise program.
- Some people and their families also find that counseling can help them cope with the strong emotions that often accompanies a cancer diagnosis.
- Utilize techniques that decrease stress and improve relaxation, such as massage therapy, yoga, and meditation.
- Practice good sleep habits as much as possible since not getting enough sleep can worsen anxiety and depression.

In most cases, there may be steps that can be taken to improve symptoms. However, it is always important to discuss any new or worsening symptoms with your healthcare team. They may need to determine if further testing is needed or if any changes to your medication regimen are necessary. New or worsening symptoms can be reason enough to begin treatment for the first time or to start a new treatment for the cancer.

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.