

B-CLEAR

Blood Cancer Literacy Education
And Resources

Bringing Clarity to Blood Cancer

**Understanding Chronic Lymphocytic Leukemia (CLL):
A guide to diagnosis and treatment**



Not actual patients.

You've Been Diagnosed With CLL. Now What?

A diagnosis of Chronic Lymphocytic Leukemia can come as a surprise. But the more knowledge you have, the more confidently you can move forward. This brochure provides information you need to guide discussions with your healthcare team. Informed conversations will help you get the most out of your care.

The information in this brochure is provided by AstraZeneca for educational purposes only and should not take the place of talking with your doctor or healthcare professional.



Not an actual patient or healthcare provider.

Every patient's journey is different, but here is what yours may look like:



Step 1

Understand your diagnosis

- Know your main diagnosis and subtype
- Ask what types of tests are needed, including genetic tests
- Ask if and when you need to begin treatment



Step 2

Discuss treatments with your doctor

- Find out what treatments are available
- Consider how different treatments may impact your daily life
- Ask if a clinical trial is appropriate



Step 3

Actively participate in your treatment

- Understand how your treatment will fit into your daily routine
- Learn what you can do to get the most out of your care

Understanding a Diagnosis of CLL

Step 1
Understand your
diagnosis

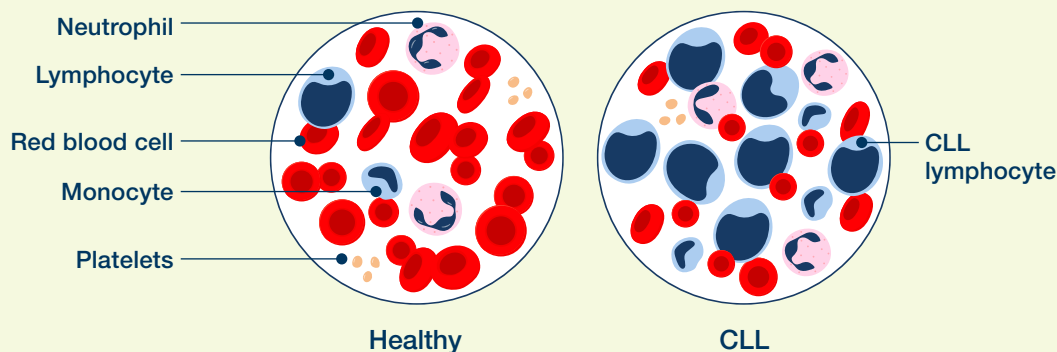
Step 2
Discuss treatments with
your doctor if necessary

Step 3
Actively participate in
your treatment

What is CLL?

CLL is a type of cancer that is found in the blood and bone marrow. CLL is caused by the rapid production of abnormal **lymphocytes**, a type of white blood cell.

CLL lymphocytes crowd the blood and bone marrow. Crowding leaves less room for healthy white blood cells, red blood cells, and platelets.



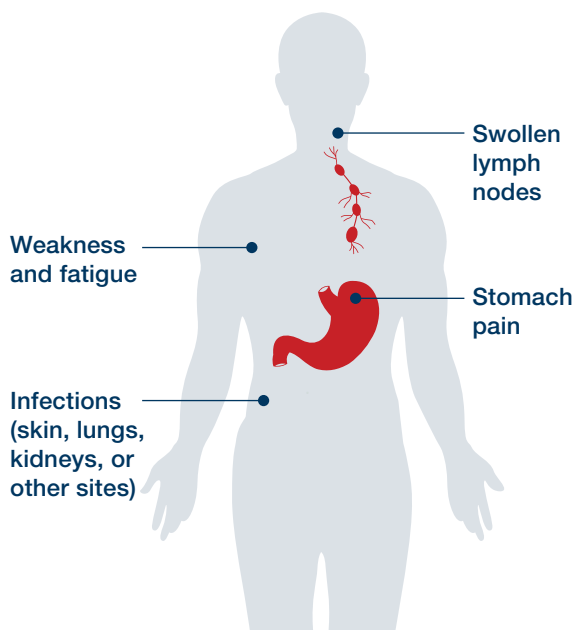
There are two different types of CLL

- **Slower growing (indolent):** May not require immediate treatment
- **Faster growing (aggressive):** May need to be treated quickly

You may have heard of **small lymphocytic lymphoma (SLL)**, which is another type of cancer. SLL cancer cells look the same as CLL cells, **but they are mostly found in the lymph nodes**. SLL is treated in the same way as CLL.

What are common symptoms* of CLL?

Generally, CLL symptoms develop over time. **As CLL gets worse, a person may experience:**



People with CLL may also experience these additional symptoms (known as “B symptoms”):

- ❗ **Fever**
- ❗ **Night sweats**
- ❗ **Weight loss (>10% of body weight over 6 months)**

*Symptoms are non-specific and could arise from other less serious conditions.

This information is intended for US consumers only.

Understanding a Diagnosis of CLL (cont'd)

Step 1

Understand your diagnosis

Step 2

Discuss treatments with your doctor if necessary

Step 3

Actively participate in your treatment



Questions you may have about your diagnosis:

- Do I need a second opinion?
- Do I need to begin treatment?
- Will CLL affect my daily life, and if so, how?
- Will CLL affect my ability to pursue hobbies and travel?
- Do I need any additional tests?
- Is my disease fast-growing (aggressive) or slow-growing (indolent)?
- If I need to begin treatment, what are the first steps?



Your doctor may use some of these terms at diagnosis:

Aggressive: A tumor or disease that spreads, grows, or forms quickly.

Anemia: A condition in which the number of red blood cells is below normal.

B cell: A type of white blood cell, also called a B lymphocyte. B cells are part of the immune system and develop from stem cells in the bone marrow.

Bone marrow: Soft tissue at the center of most bones where blood cells are made.

Chronic Lymphocytic Leukemia (CLL): A cancer in which too many white blood cells are found mostly in the blood and bone marrow.

Indolent: A term used to describe a slow-growing type of cancer.

Lymph node: A small structure that is part of the immune system. Lymph nodes contain immune cells that help the body fight infections and disease.

Lymphocyte: A type of immune cell that is made in the bone marrow and is found in the blood and in lymph tissue. B cells and T cells are the two types of lymphocytes that can develop into lymphomas.

Lymphoma: Cancer that affects the lymphatic system. The two main types of lymphoma are Hodgkin lymphoma and non-Hodgkin lymphoma.

Monocytes and neutrophils: Types of white blood cells that are important parts of the immune system and help the body fight infection.

Platelet: A part of the cell that helps to stop bleeding. Platelets are also called thrombocytes.

Red blood cells: Cells that carry oxygen to other cells in your body.

Small lymphocytic lymphoma (SLL): An indolent (slow-growing) type of lymphoma in which too many immature lymphocytes (white blood cells) are found mostly in the lymph nodes. SLL is a type of non-Hodgkin lymphoma.

T cell: A type of white blood cell that is part of the immune system. It develops from stem cells in the bone marrow. T cells help protect the body from infection and may help fight cancer.

White blood cell: A type of blood cell that helps the body fight infection and other diseases.

[Click here for additional terms >](#)

Understanding a Diagnosis of CLL (cont'd)

Step 1

Understand your diagnosis

Step 2

Discuss treatments with your doctor if necessary

Step 3

Actively participate in your treatment



Your doctor may use some of these terms when discussing testing:

Biomarker: A molecule found in blood, other body fluids, or tissues that may be used as a sign of a normal or abnormal bodily process, or of a disease. Biomarker testing may be used to help plan treatment, find out how well treatment is working, or predict whether cancer will come back or spread to other parts of the body.

Biopsy: A procedure where a piece of tissue or a sample of cells is removed from the body so it can be tested in a laboratory.

Complete blood count (CBC): A measure of the number of red blood cells, white blood cells, and platelets in the blood. A CBC is used to help diagnose and monitor many conditions. Also called blood cell count or full blood count.

Fluorescence in situ hybridization (FISH): A test performed on your blood or bone marrow cells to detect chromosome changes in blood cancer cells.

Genetic tumor marker: A genetic change in tissue, blood, bone marrow, or other body fluids that can help determine treatment selections.

Karyotyping: A test that pairs and orders the chromosomes in blood or bone marrow. It is performed on the tissue that is obtained from a biopsy or blood sample.

Metabolic panel: Blood tests that measure liver and kidney function, electrolytes, acid/base balance, and the levels of blood sugar and blood proteins. They can help people and their doctors choose between different treatments. Blood tests may be repeated several times during the course of treatment to ensure no complications of treatment are developing.

Next-generation sequencing (NGS): A test that examines genetic sequences in DNA. NGS can look for alterations in multiple genes all at once.

[Click here for additional terms >](#)

Understanding Treatment Options

Step 1

Understand your diagnosis

Step 2

Discuss treatments with your doctor if necessary

Step 3

Actively participate in your treatment

There are many approaches to managing your CLL. Based on your symptoms and medical condition, your doctor may initially recommend an approach called **“watch-and-wait.”** This means your doctor will monitor your disease without starting treatment. These questions can help you explore your options with your doctor.



Questions you may have when discussing treatment options:

- Would a **watch-and-wait** approach be appropriate for me?
- When should treatment begin? What are reasons to start treatment?
- What types of treatments are available to me?
- Why are you recommending this treatment?
- What are the goals of this treatment?
- How was this treatment studied and what were the clinical study results?
- How will you monitor my progress on treatment?
- What side effects might I experience with this treatment?
- What is a clinical trial and could it be right for me?
- What happens if the treatment does not work?
- Will I take one type of medication on its own or multiple treatments together? What are the pros and cons of each approach?

Testing should be repeated throughout your journey with CLL. This is to evaluate your progress on treatment. These tests might include an updated medical history, physical exam, bloodwork, and sometimes imaging.



Here are some terms that may be used when discussing treatment options:

Chemotherapy: A treatment that uses certain drugs to stop cancer cells from multiplying, either by killing the cells or stopping them from dividing.

Clinical trial: Also known as a clinical study, this is a type of research study that tests the risks and benefits of new medical approaches in people.

Immunotherapy: Therapy that uses the immune system to help the body fight cancer.

Oral anticancer therapy: Treatment given by mouth to help kill specific cancer cells or stop them from dividing.

Radiation therapy: Use of high-energy radiation to kill cancer cells and shrink tumors.

Targeted cancer therapy: A type of treatment that targets specific proteins—like BTK, PI3K, or BCL2—that control how cancer cells grow, divide, and spread.

Watch-and-wait: An approach in which a condition is monitored without treatment until symptoms appear or change.

[Click here for additional terms >](#)

Your Treatment Team

Step 1

Understand your diagnosis

Step 2

Discuss treatments with your doctor if necessary

Step 3

Actively participate in your treatment

When you start treatment for CLL, a team of specialists will provide care and offer support and guidance throughout the process.

Here are some team members you may meet:

Hematologists are physicians who specialize in treating blood disorders. Hematologic oncologists (sometimes referred to as a “heme-onc”) focus on treating blood cancers.

Infusion Nurses specialize in giving medicine and fluids to patients. Specifically, they give these through an intravenous (IV) line, central line, or access port.



Not an actual patient or healthcare provider.

Nurse Practitioners/Physician

Assistants have advanced training in diagnosing and treating illnesses and support physicians in their practice. In some states, these advanced practitioners can prescribe treatments and medicine.

Oncology Nurses specialize in treating people who have cancer.

Oncology Nurse Navigators offer individualized assistance to patients, families, and caregivers to help with decision-making and overcoming barriers in the healthcare system.

Pathologists are physicians who specialize in identifying different types of cancer by studying cells and tissues. Pathology results can inform oncologists about the type of cancer and how fast it is likely to grow and can guide treatment decisions.

Pharmacists are healthcare providers who are medication experts. They work with your doctor to ensure you’re receiving the correct medicines and the right dosage strengths.

Radiation Oncologists are physicians who have special training in using radiation to treat cancer.

Radiologists are physicians who use imaging tests to help make an accurate diagnosis for many types of cancer. Imaging tests include X-rays, CT, MRI, and ultrasound that examine organs and other structures inside the body.

Starting and Continuing Your Treatment for CLL

Step 1

Understand your diagnosis

Step 2

Discuss treatments with your doctor if necessary

Step 3

Actively participate in your treatment

During treatment for CLL, it's important to communicate with your healthcare team. Ask questions to stay informed and actively participate in your treatment.

Knowing what to expect as you begin treatment can help you manage your schedule.



Questions to ask as you begin treatment

- How will treatment fit into my daily life?
- Where will I receive my treatment?
- How often should I receive treatment?
- Will I be able to work while receiving treatment?
- How can my caregivers and family be involved?
- How and when will you monitor my progress?
- When I'm on treatment, can I drink alcohol or take over-the-counter medicines?

Keep asking questions as you continue treatment to help you get the most out of care. Write down any concerns or questions you have as you prepare for appointments.



Not an actual patient.



Questions to ask as you continue treatment

- Is my treatment working?
- How can I manage side effects?
- When should I alert my healthcare team about a side effect?
- Are there any diet recommendations while on treatment?
- Can you recommend a safe exercise program for me?
- Are there limits to the types of physical activities I can pursue?
- How do I care for my mental health and deal with stress?
- Where can I turn for help with financial concerns?
- What additional support resources are available to me?

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Starting and Continuing Your Treatment for CLL (cont'd)

Step 1

Understand your diagnosis

Step 2

Discuss treatments with your doctor if necessary

Step 3

Actively participate in your treatment



Terms your doctor may use as you begin and continue treatment:

Blood cell counts: The number of red and white blood cells and platelets in the blood.

Complete response: When all signs of cancer disappear as a response to treatment. Also known as a complete remission.

Infusion: Also known as intravenous infusion, this is a method of putting fluids, which could include medication, into the bloodstream.

Infusion center: A medical center where infusion/injectable medications are administered.

Partial response: A decrease in the overall size of a tumor or the extent of cancer in the body. This is also known as a partial remission.

Refractory: A condition or disease that does not respond to treatment.

Relapse (Recurrence): The return of a disease or the signs and symptoms of a disease after a period of improvement.

Remission: When the signs and symptoms of cancer disappear or decrease.

Stable disease: Cancer that is neither decreasing in size nor getting worse in severity.

[Click here for additional terms >](#)

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Support Organizations for People Living With CLL

You may feel you need support as you move through treatment. Fortunately, patient advocacy groups are available to you and your loved ones. Advocacy groups offer:

- Support
- The latest news
- Links to co-pay assistance foundations, if you are eligible



American Cancer Society

www.cancer.org



CLL Society

www.cllsociety.org



CancerCare

www.CancerCare.org



Blood Cancer United
(formerly The Leukemia & Lymphoma Society)

www.bloodcancerunited.org



Lymphoma Research Foundation

www.lymphoma.org



National Comprehensive Cancer Network (NCCN)

www.nccn.org/patientresources/patient-resources

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Additional Resources



If you have been prescribed a treatment, you may have questions about your financial options.

Health insurance coverage can help make treatment more affordable. Medicare and Medicaid can also offer assistance for those who qualify.

Consider researching the pharmaceutical company associated with your treatment. Some pharmaceutical companies, like AstraZeneca, have programs that provide people with assistance to help them pay for their treatments.



Not actual patients.

If you would like to learn more about other blood cancers



Download Bringing Clarity to Blood Cancer for a comprehensive overview of blood cancer and a list of additional terms you may encounter.



You may also visit
www.cancer.gov/publications/dictionaries/cancer-terms
for definitions of terms that do not appear in this brochure.

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