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Chronic Lymphocytic Leukemia Early Detection, Diagnosis, and Staging

Detection and Diagnosis

Finding cancer early often allows for more treatment options. Some early cancers may have signs and symptoms that can be noticed, but that's not always the case.

- [Can Chronic Lymphocytic Leukemia Be Found Early?](#)
- [Signs and Symptoms of Chronic Lymphocytic Leukemia](#)
- [How Is Chronic Lymphocytic Leukemia Diagnosed?](#)

Stages and Outlook (Prognosis)

After a cancer diagnosis, staging provides important information about the extent of cancer in the body and anticipated response to treatment.

- [How Is Chronic Lymphocytic Leukemia Staged?](#)

Questions to Ask About CLL

Here are some questions you can ask your cancer care team to help you better understand your CLL diagnosis and treatment options.

- [Questions to Ask About Chronic Lymphocytic Leukemia](#)
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Can Chronic Lymphocytic Leukemia Be Found Early?

For certain cancers, the [American Cancer Society recommends screening tests](#)¹ in people without any symptoms, because they are easier to treat if found early. But for chronic lymphocytic leukemia (CLL), no screening tests are routinely recommended at this time.

Many times, CLL is found when routine blood tests are done for other reasons. For instance, a person's white blood cell count may be very high, even though he or she doesn't have any symptoms.

If you notice any [symptoms that could be caused by CLL](#), report them to your doctor right away so the cause can be found and treated, if needed.

Hyperlinks

1. www.cancer.org/healthy/find-cancer-early/cancer-screening-guidelines/american-cancer-society-guidelines-for-the-early-detection-of-cancer.html

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Signs and Symptoms of Chronic Lymphocytic Leukemia

Many people with chronic lymphocytic leukemia (CLL) do not have any symptoms when it is diagnosed. The leukemia is often found when their doctor orders [blood tests](#)¹ for some unrelated health problem or during a routine check-up and they are found to have a high number of lymphocytes.

Even when people with CLL have symptoms, they're often vague and can be symptoms of other things. Symptoms can include the following:

- Weakness

- [Feeling tired](#)²
- Weight loss
- Chills
- Fever
- Night sweats
- Swollen lymph nodes (often felt as lumps under the skin)
- Pain or a sense of "fullness" in the belly (this can make someone feel full after only a small meal), which is caused by an enlarged spleen and/or liver

Many of the signs and symptoms of advanced CLL occur because the leukemia cells replace the bone marrow's normal blood-making cells. As a result, people don't have enough red blood cells, properly functioning white blood cells, and blood platelets.

- **Anemia** is a shortage of red blood cells. It can cause tiredness, weakness, and shortness of breath.
- A shortage of normal white blood cells (**leukopenia**) increases the risk of [infections](#)³. You might hear the term **neutropenia**, which refers to low levels of neutrophils (a type of granulocyte needed to fight bacterial infections). People with CLL may have very high white blood cell counts because of excess numbers of lymphocytes (**lymphocytosis**), but the leukemia cells don't fight infection the way normal white blood cells do.
- A shortage of blood platelets (**thrombocytopenia**) can lead to excess bruising, bleeding, frequent or severe nosebleeds, and bleeding gums.

People with CLL have a higher risk of infections. This is mainly because their immune systems aren't working as well as they should. CLL is a cancer of B lymphocytes, which normally make antibodies that help fight infection. Because of the CLL, these antibody-making cells don't work as they should, so they can't fight infections. Infections may range from simple things like frequent colds or cold sores to pneumonia and other serious infections.

CLL can also affect the immune system in other ways. In some people with CLL, the immune system cells make abnormal antibodies that attack normal blood cells. This is known as **autoimmunity**. It can lead to low blood counts. If the antibodies attack red blood cells, it's called **autoimmune hemolytic anemia**. Less often, the antibodies attack platelets and the cells that make them, leading to low platelet counts. Rarely, the antibodies attack white blood cells, leading to leukopenia (low white blood cell counts).

These symptoms and signs may be caused by CLL, but they can also be caused by

other conditions. Still, if you have any of these problems, it's important to see a doctor right away so the cause can be found and treated, if needed.

Hyperlinks

1. www.cancer.org/treatment/understanding-your-diagnosis/tests/understanding-your-lab-test-results.html
2. www.cancer.org/treatment/treatments-and-side-effects/physical-side-effects/fatigue.html
3. www.cancer.org/treatment/treatments-and-side-effects/physical-side-effects/low-blood-counts/infections.html

References

American Society of Clinical Oncology. Leukemia - Chronic Lymphocytic - CLL: Symptoms and Signs (06/2016). Accessed at www.cancer.net/cancer-types/leukemia-chronic-lymphocytic-cll/symptoms-and-signs on April 12, 2018.

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How Is Chronic Lymphocytic Leukemia Diagnosed?

Certain signs and symptoms might suggest that a person has chronic lymphocytic leukemia (CLL), but tests are needed to be sure.

Medical history and physical exam

If you might have leukemia, your doctor will want to take a complete medical history to

check for symptoms and possible risk factors. You'll also be asked about your family medical history and your general health.

A physical exam will be done to look for possible signs of leukemia and other health problems. During the exam, your doctor will pay close attention to your lymph nodes, abdomen (belly), and other areas that might be affected.

Your doctor may also order tests to check your blood cell counts. If the results suggest leukemia, you may be referred to a hematologist, a doctor who specializes in treating blood disorders (including blood cancers like leukemia). This doctor may do one or more of the tests described below.

Tests used to diagnose and classify leukemia

Tests will need to be done on your blood and bone marrow to be certain of a leukemia diagnosis. Other tissue and cell samples may also be needed to help guide treatment.

Blood tests

Blood samples for tests for CLL will be taken from a vein in your arm. Many different tests are done.

Complete blood count and blood cell exam (peripheral blood smear)

The [complete blood count or CBC¹](#) measures the different cells in your blood, such as the red blood cells, the white blood cells, and the platelets. This test is often done along with a differential (or diff) which looks at the numbers of the different types of white blood cells. These tests are often the first ones done when a blood problem is suspected.

People with CLL have too many lymphocytes. (This may be called **lymphocytosis**.) Having more than 10,000 lymphocytes/mm³ (per cubic millimeter) of blood strongly suggests CLL, but other tests are needed to know for sure. You might also have low levels of red blood cells and platelets.

A sample of blood is looked at under the microscope (called a peripheral blood smear). If you have CLL, the blood smear could show many abnormal looking lymphocytes called **smudge cells**.

Flow cytometry

This test is important in diagnosing CLL. It uses a machine that looks for certain substances (markers) on or in cells that help identify what types of cells they are.

This test can be used to see if the lymphocytes in a sample of blood contain CLL cells. Flow cytometry can also be used to look for CLL cells in bone marrow or other fluids.

Flow cytometry can also be used to test for substances called *ZAP-70* and *CD38* on the CLL cells. Studies suggest that people who have few CLL with these substances seem to have a better outlook. This is discussed in more detail in [Chronic Lymphocytic Leukemia Stages](#).

Other blood tests

Other tests may be done to measure the amount of certain chemicals in your blood, but they're not used to diagnose leukemia. In people already known to have CLL, these tests can help find liver or kidney problems caused by the spread of leukemia cells or certain chemotherapy (chemo) drugs. These tests also can check the levels of certain minerals so any imbalances can be treated. If you're going to be treated with the drug rituximab (Rituxan[®]), your doctor may order blood tests to check for previous hepatitis infection. (You can find more on this in [Monoclonal Antibodies for Chronic Lymphocytic Leukemia²](#).)

Your blood immunoglobulin (antibody) levels may be tested to check if you have enough antibodies to fight infections, especially if you've recently had many infections. Another blood protein called beta-2-microglobulin may be measured. High levels of this protein generally mean a more advanced CLL.

Bone marrow tests

Blood tests are often enough to diagnose CLL, but testing the bone marrow can help tell how advanced it is. Because of this, bone marrow tests are often done before starting treatment. They might also be repeated during or after treatment to see if treatment is working.

[Bone marrow aspiration and biopsy³](#) are done to get bone marrow samples for testing. They're usually done together. The samples are usually taken from the back of the pelvic (hip) bone, but sometimes they may be taken from other bones.

For a bone marrow **aspiration**, you lie on a table (either on your side or on your belly). After cleaning the skin over your hip, the doctor uses a long thin needle to put in a drug that numbs the area and the surface of the bone. This may cause brief stinging or

burning. A hollow needle is then put into the bone, and a syringe is used to suck out a small amount (about 1 teaspoon) of the thick, liquid bone marrow. Even with the numbing medicine, most people still have some brief pain when the marrow is removed.

A bone marrow **biopsy** is usually done just after the aspiration. A small piece (core) of bone and marrow (about 1/16 inch in diameter and 1/2 inch long) is removed with a larger needle that's twisted as it's pushed down into the bone. Even with the numbing medicine, this can cause a feeling of pressure or tugging, but it usually doesn't hurt. After the biopsy is done, pressure will be put the site to help prevent bleeding.

Routine microscopic exams

A pathologist (a doctor specializing in lab tests) looks at the bone marrow samples under a microscope. They may also be reviewed by your hematologist/oncologist (a doctor specializing in blood diseases and cancer).

The doctors will look at the size, shape, and other traits of the white blood cells in the samples. This helps to classify them into specific types.

An important factor is if the cells look mature (like normal blood cells that can fight infections). CLL cells usually look mature, while cells of acute leukemias look immature.

A key feature of a bone marrow sample is its cellularity or cellular makeup. Normal bone marrow has a certain number of blood-forming cells and fat cells. Marrow with too many blood-forming cells is said to be hypercellular. This is often seen in bone marrow of a person with CLL. Doctors also look to see how much of the normal cells in the bone marrow are replaced by CLL cells.

The pattern of spread of CLL cells in the bone marrow is important, too. A pattern where the cells are in small groups (called a nodular or interstitial pattern) often means a better outlook than if the cells are scattered throughout the marrow (a diffuse pattern).

Stains and/or antibody tests such as cytochemistry, immunocytochemistry, immunohistochemistry, and flow cytometry may be used on the bone marrow samples to diagnose CLL. You can learn more about these tests at [Tests Used on Biopsy and Cytology Specimens to Diagnose Cancer](#)⁴.

Gene tests

Cytogenetics

For this test, bone marrow cells (or sometimes cells from the blood or other tissues) are grown in the lab, then their chromosomes are examined under a microscope. Because it takes time for the cells to start dividing, this test usually takes weeks to complete. Normal human cells contain 23 pairs of chromosomes, but sometimes CLL cells have chromosome changes that can be seen under the microscope.

In some cases of CLL, part of a chromosome may be missing. This is called a **deletion**. The most common deletions occur in parts of chromosomes 13, 11, or 17. Deletion of part of chromosome 17 is linked to a poor outlook. Other, less common chromosome changes include an extra copy of chromosome 12 (trisomy 12) or a translocation (swapping of DNA) between chromosomes 11 and 14 [written as t(11;14)].

This information may be helpful to determine a patient's prognosis (outlook), but it needs to be looked at along with other factors, such as the stage of CLL. The loss of part of chromosome 13 is usually linked with a slower-growing disease and a better outlook, while defects in chromosomes 11 or 17 often indicate a poorer outlook. Trisomy 12 doesn't seem to have much of an effect on prognosis.

Fluorescent in situ hybridization (FISH)

This chromosome test can be used to look at the cells' chromosomes and DNA without having to grow the cells in the lab. It uses special fluorescent dyes that only attach to specific parts of particular chromosomes. FISH is used to look for certain genes or chromosome changes (not just any change). It can be used on regular blood or bone marrow samples, too. Because the cells don't have to grow in the lab first, you can usually get the results more quickly than cytogenetics, often within a few days.

Molecular tests

Immunoglobulins, the antibodies that help your body fight infections, are made up of light chains and heavy chains. Whether the gene for the immunoglobulin heavy chain variable region (IGHV or IgV_H) has changed (mutated) can help your doctor know how aggressive your CLL is. That gene is looked at in a test called *cDNA sequencing*.

Lymph node biopsy

In a lymph node biopsy, all or part of a lymph node is removed so it can be examined under the microscope to see if it contains cancer cells. This is often done to diagnose lymphomas, but only rarely needed for CLL. It may be done if a lymph node has grown very large and the doctor wants to know if the leukemia has changed (transformed) into a more aggressive lymphoma.

In an **excisional** lymph node biopsy, an entire lymph node is removed through a cut in the skin. If the node is near the skin surface, this is a simple operation that can be done by first numbing the skin, but if the node is inside the chest or abdomen (belly), general anesthesia (where the patient is asleep) is used. If the lymph node is very large, only part of it may be removed. This is called an **incisional** biopsy.

Lumbar puncture (or spinal tap)

This procedure is used to test the fluid that surrounds the brain and spinal cord (the cerebrospinal fluid or CSF). It's not often needed for people with CLL. It's only done if the doctor suspects leukemia cells may have spread to the area around the brain or spinal cord (which is rare), or if there might be an infection in those areas.

For this test, the doctor first numbs an area in the lower part of the back over the spine. A small, hollow needle is then placed between the bones of the spine and into the space around the spinal cord to collect some of the fluid.

Imaging tests

Imaging tests use x-rays, sound waves, or magnetic fields to create pictures of the inside of the body. Imaging tests are not done to diagnose CLL, but they may be done for other reasons, for instance to help find a suspicious area that might be cancer, to learn how far a cancer may have spread, or to help see if treatment working.

Computed tomography (CT) scan

The [CT scan](#)⁵ can help tell if any lymph nodes or organs in your body are enlarged. It isn't usually needed to diagnose CLL, but it may be done if your doctor suspects the leukemia is growing in an organ, like your spleen.

Sometimes a CT scan is combined with a PET scan in a test known as a PET/CT scan. For a PET scan, glucose (a form of sugar) containing a radioactive atom is injected into the blood. Because cancer cells grow rapidly, they absorb large amounts of the radioactive sugar. A special camera can then create a picture of the areas of radioactivity in the body. The PET/CT scan combines both tests in one machine. This test allows the doctor to compare areas of higher radioactivity on the PET scan with the more detailed appearance of that area on the CT.

Magnetic resonance imaging (MRI) scan

[MRI scans](#)⁶ are most useful in looking the brain and spinal cord, but they're not often needed in people with CLL.

Ultrasound

[Ultrasound](#)⁷ can be used to look at lymph nodes near the surface of the body or to look for enlarged organs (like the liver and spleen) inside your abdomen.

Hyperlinks

1. www.cancer.org/treatment/understanding-your-diagnosis/tests/understanding-your-lab-test-results.html
2. www.cancer.org/cancer/chronic-lymphocytic-leukemia/treating/leukopheresis.html
3. www.cancer.org/treatment/understanding-your-diagnosis/tests/testing-biopsy-and-cytology-specimens-for-cancer/biopsy-types.html
4. www.cancer.org/treatment/understanding-your-diagnosis/tests/testing-biopsy-and-cytology-specimens-for-cancer/special-tests.html
5. www.cancer.org/treatment/understanding-your-diagnosis/tests/ct-scan-for-cancer.html
6. www.cancer.org/treatment/understanding-your-diagnosis/tests/mri-for-cancer.html
7. www.cancer.org/treatment/understanding-your-diagnosis/tests/ultrasound-for-cancer.html

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How Is Chronic Lymphocytic Leukemia Staged?

For most cancers, staging is the process of finding out how far the cancer has spread. Stages are often useful because they can help guide treatment and determine a person's outlook. Most types of cancer are staged based on the size of the tumor and how far the cancer has spread.

Chronic lymphocytic leukemia (CLL), on the other hand, does not usually form tumors. It's generally in the bone marrow and blood. And, in many cases, it has spread to other organs such as the spleen, liver, and lymph nodes by the time it's found. The outlook for a person with CLL depends on other information, such as the results of lab test and imaging tests.

Staging systems for chronic lymphocytic leukemia

A staging system is a standard way for the cancer care team to describe cancer. There are 2 different systems for staging CLL:

- **Rai system:** This is used more often in the United States.
- **Binet system:** This is used more widely in Europe.

Both of these staging systems are helpful and have been in use for many years.

Rai staging system

The Rai system is based on lymphocytosis. The patient must have a high number of lymphocytes in their blood and bone marrow that isn't linked to any other cause (like infection).

For a diagnosis of CLL, the overall lymphocyte count does not have to be high, but the patient must have at least 5,000/mm³ monoclonal lymphocytes (sometimes called a monoclonal lymphocytosis). Monoclonal means that the cancer cells all came from one original cell. This causes them to have the same chemical pattern which can be seen with special testing.

This system divides CLL into 5 stages based on the results of blood tests and a physical exam:

- **Rai stage 0:** Lymphocytosis; no enlargement of the lymph nodes, spleen, or liver; red blood cell and platelet counts are near normal.
- **Rai stage I:** Lymphocytosis; enlarged lymph nodes; spleen and liver are not enlarged; red blood cell and platelet counts are near normal.
- **Rai stage II:** Lymphocytosis; enlarged spleen (and maybe an enlarged liver); lymph nodes may or may not be enlarged; red blood cell and platelet counts are near normal.
- **Rai stage III:** Lymphocytosis; lymph nodes, spleen, or liver may or may not be enlarged; red blood cell counts are low (anemia); platelet counts are near normal.
- **Rai stage IV:** Lymphocytosis; enlarged lymph nodes, spleen, or liver; red blood cell counts may be low or near normal; platelet counts are low (thrombocytopenia).

Doctors separate the Rai stages into low-, intermediate-, and high-risk groups when determining treatment options.

- Stage 0 is low risk.
- Stages I and II are intermediate risk.
- Stages III and IV are high risk.

These risk groups are used later in [Treatment of Chronic Lymphocytic Leukemia](#).¹

Binet staging system

In the Binet staging system, CLL is classified by the number of affected lymphoid tissue groups (neck lymph nodes, groin lymph nodes, underarm lymph nodes, spleen, and liver) and by whether or not the patient has anemia (too few red blood cells) or thrombocytopenia (too few blood platelets).

- **Binet stage A:** Fewer than 3 areas of lymphoid tissue are enlarged, with no anemia or thrombocytopenia.
- **Binet stage B:** 3 or more areas of lymphoid tissue are enlarged, with no anemia or thrombocytopenia.
- **Binet stage C:** Anemia and/or thrombocytopenia are present. Any number of lymphoid tissue areas may be enlarged.

Prognostic factors for chronic lymphocytic leukemia

Along with the stage, there are other factors that help predict a person's outlook. These factors are not part of formal staging systems (at least at this time), but are often taken into account when looking at possible treatment options.

- Factors that tend to be linked with shorter survival time are called **adverse prognostic factors**.
- Those that predict longer survival are **favorable prognostic factors**.

Adverse prognostic factors

- Diffuse pattern of bone marrow involvement (more widespread replacement of normal marrow by leukemia)
- Advanced age
- Deletions of parts of chromosomes 17 or 11
- Trisomy 12 in the CLL cells
- High blood levels of certain substances, such as beta-2-microglobulin
- Lymphocyte doubling time (the time it takes for the lymphocyte count to double) of less than 1 year
- Increased fraction of prolymphocytes (an early form of the lymphocyte) in the blood
- High proportion of CLL cells containing ZAP-70 (20% or more) or CD38 (30% or more)
- CLL cells with unchanged (not mutated) gene for the immunoglobulin heavy chain variable region (IGHV)
- CLL cells don't have the TP53 gene

Favorable prognostic factors

- Non-diffuse (nodular or interstitial) pattern of bone marrow involvement
- Deletion of part of chromosome 13 (with no other chromosome abnormalities)
- Low proportion of CLL cells containing ZAP-70 (less than 20%) or CD38 (less than 30%)
- CLL cells with a mutated gene for IGHV

Certain prognostic factors such as the presence or absence of ZAP-70, CD38, and a mutated gene for IGHV help divide cases of CLL into 2 groups, slow growing and fast growing. People with the slower growing kind of CLL tend to live longer and may be able to delay treatment longer as well.

Staging for hairy cell leukemia

There is no standard staging system for hairy cell leukemia.

Monoclonal B-lymphocytosis

Some people have monoclonal lymphocytes in their blood, but not enough to make the diagnosis of CLL. If someone has less than 5,000 monoclonal lymphocytes (per mm³), normal counts of red blood cells and platelets, and no enlarged lymph nodes (or enlarged spleen), they have a condition called monoclonal B-lymphocytosis (MBL). MBL doesn't need to be treated, but about one patient of every 100 with this condition will go on to need treatment for CLL.

Small lymphocytic lymphoma

The cancer cells of small lymphocytic lymphoma (SLL) and CLL look the same under the microscope and have the same marker proteins on the surface of the cells. Whether someone is diagnosed with SLL or CLL depends largely on the number of lymphocytes in the blood. To be diagnosed with CLL, there must be at least 5,000 monoclonal lymphocytes (per mm³) in the blood. For it to be called SLL, the patient must have enlarged lymph nodes or an enlarged spleen with fewer than 5,000 lymphocytes (per mm³) in the blood. Still, since SLL and CLL can be treated the same, the difference between them isn't really important.

Hyperlinks

1. www.cancer.org/cancer/chronic-lymphocytic-leukemia/treating.html

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Questions to Ask About Chronic Lymphocytic Leukemia

As you cope with chronic lymphocytic leukemia (CLL) and treatment, you need to have honest, open discussions with your doctor. You should feel comfortable asking about anything, no matter how small it might seem. Here are some questions you might want to ask. Nurses, social workers, and other members of the treatment team may also be able to give you answers.

When you're told you have chronic lymphocytic leukemia

- What is the [stage](#) (risk group) of the CLL, and what does that mean for me?
- Will I need to have other [tests](#) before we can decide on treatment?
- How much experience do you have treating this type of cancer?
- Should I get a second opinion ?

When deciding on a treatment plan

- Should I start treatment now? Why or why not?
- What are my [treatment choices](#)¹?
- What do you recommend, and why?
- What are the risks and side effects with the treatments that you recommend?
- How often will you test my blood or bone marrow to see how treatment is working?
- What should I do to be ready for treatment?
- How long will treatment last? What will it be like? Where will it be done?
- How will treatment affect my daily activities?
- What is the outlook for my survival?

During treatment

Once treatment begins, you'll need to know what to expect and what to look for. Not all of these questions may apply to you, but getting answers to the ones that do may be helpful.

- How will we know if the treatment is working?
- Is there anything I can do to help manage side effects?
- What symptoms or side effects should I tell you about right away?
- How can I reach your office on nights, holidays, or weekends?
- Are there any limits on what I can do?
- Can you suggest a mental health professional I can see if I start to feel overwhelmed, depressed, or distressed?

After treatment

- What symptoms should I watch for?
- What will we do if the treatment doesn't work or if the leukemia comes back?
- What will my options be if the leukemia comes back?
- What type of [follow-up](#)² will I need after treatment?
- When can I return to work?

Be sure to write down any questions you have that are not on this list. For instance, you might want information about how you'll feel so that you can plan your work schedule. Or you may want to ask about qualifying for [clinical trials](#)³.

Taking another person with you and/or recording your talks with your doctor can be helpful. Collecting copies of your medical records, pathology reports, and radiology reports is a good idea too.

Hyperlinks

1. www.cancer.org/cancer/chronic-lymphocytic-leukemia/treating.html
2. www.cancer.org/cancer/chronic-lymphocytic-leukemia/after-treatment/follow-up.html
3. www.cancer.org/treatment/treatments-and-side-effects/clinical-trials.html

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Written by

The American Cancer Society medical and editorial content team
(www.cancer.org/cancer/acs-medical-content-and-news-staff.html)

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