

# Chronic Lymphocytic Leukemia (CLL): Overview



## What is chronic lymphocytic leukemia (CLL)?

Cancer starts when cells change (mutate) and grow out of control. The changed (abnormal) cells often grow to form a lump or mass called a tumor. Leukemia is different from most other types of cancer.

Leukemia cells don't often form tumors. Leukemia is cancer that starts in the bone marrow. The bone marrow is where new blood cells are made. It's the thick, sponge-like tissue in the center of certain bones.

When a person has leukemia, the body makes too many abnormal blood cells. They can crowd out healthy cells in the bone marrow. This leads to not making enough of all the different types of blood cells. Leukemia cells travel throughout your body in your blood. So leukemia can affect organs all over your body.

Chronic lymphocytic leukemia (CLL) is also called chronic lymphoid leukemia.

CLL starts when changes happen in very early or immature forms of white blood cells called lymphocytes. These are a type of white blood cell that helps fight infections. People with CLL have too many lymphocytes in their blood, but these cells aren't normal and don't help fight infection. In fact, people with CLL are more likely to get infections. And because the abnormal lymphocytes fill up the bone marrow, people with CLL can also have low levels of other blood cells, such as red blood cells and platelets. This leads to other problems. Not having enough red blood cells is called anemia. It can cause tiredness (fatigue). Low platelet levels can lead to easy bleeding and bruising.

## Who is at risk for chronic lymphocytic leukemia?

A risk factor is anything that may increase your chance of having a disease. The exact cause of someone's cancer may not be known. But risk factors can make it more likely for a person to have cancer. Some risk factors may not be in your control. But others may be things you can change.

The risk factors for CLL include:

- Being exposed to the chemical Agent Orange during the Vietnam War
- Having a family history of CLL
- Being older in age
- Being a man

Talk with your healthcare provider about your risk factors for CLL and what you can do about them.

## Can chronic lymphocytic leukemia be prevented?

There's no sure way to prevent CLL.

## Are there screening tests for chronic lymphocytic leukemia?

There are currently no regular screening tests for CLL. Screening tests are done to check for disease in people who don't have symptoms.

## What are the symptoms of chronic lymphocytic leukemia?

CLL tends to grow slowly. Many people with CLL don't have any symptoms when it's first found.

Common symptoms of CLL can include:

- Feeling very tired or weak

- Fevers with no clear cause
- Night sweats
- Frequent infections
- Enlarged lymph nodes, often felt as lumps beneath the skin
- Pain or fullness in the upper left belly (abdomen) from an enlarged spleen
- Losing weight without trying
- Bleeding and bruising easily
- Shortness of breath

Many of these may be caused by other more common health problems. But it's important to see a healthcare provider if you have these symptoms. Only a healthcare provider can tell if you have cancer.

## How is chronic lymphocytic leukemia diagnosed?

CLL is often found when blood tests are done for another reason, like part of a routine physical. If your healthcare provider thinks you may have CLL, exams and tests will be needed to be sure. Your healthcare provider will ask you about your health history, symptoms, risk factors, and family history of disease. A physical exam will be done.

You may also have 1 or more of these tests:

- Blood tests (many different kinds)
- Bone marrow aspiration and biopsy

After a diagnosis of CLL, you'll likely need other tests. These help your healthcare providers learn more about your cancer. They can help determine the stage of the cancer. The stage is how much and how far the cancer has spread, or metastasized, in your body. It's one of the most important things to know when deciding how to treat the cancer.

Once your cancer is staged, your healthcare provider will talk with you about what the stage means for your treatment. Be sure to ask your healthcare provider to explain the stage of your cancer to you in a way you can understand.

## How is chronic lymphocytic leukemia treated?

Your treatment timing and choices depend on a number of factors. These include:

- The kinds of chromosome changes in the CLL cells
- The speed at which the CLL cells are growing
- Other test results
- Your age
- Your overall health
- Stage of the cancer

The goal of treatment may be to control the cancer or help ease problems caused by the cancer. There's no cure for CLL at this time. Talk with your healthcare team about your treatment choices, the goals of treatment, and what the risks and side effects may be.

Types of treatment for cancer are either local or systemic. Local treatments remove, destroy, or control cancer cells in one area. Surgery and radiation are local treatments that may be used in certain cases of CLL.

Systemic treatment is used to destroy or control cancer cells that have traveled around your body. When taken by pill or injection, chemotherapy and targeted therapy are systemic treatments.

CLL tends to grow slowly and often doesn't need to be treated right away. Your healthcare team may keep track of your condition to see if treatment is needed. This is called watchful waiting. If and when treatment is needed, you may have just 1 treatment or a combination of treatments. Tests will be done during treatment to see how well it's working.

Treatments for CLL include:

- Chemotherapy
- Targeted therapy
- Immunotherapy
- Radiation therapy
- Stem cell transplant

Talk with your healthcare providers about your treatment choices. Make a list of questions. Think about the benefits and possible side effects of each choice. Talk about your concerns with your healthcare provider before making a decision.

## What are treatment side effects?

Cancer treatment can damage normal cells. This causes side effects like hair loss, mouth sores, skin changes, appetite loss, diarrhea, and vomiting.

Talk with your healthcare provider about side effects linked to your treatment. Be sure you know what to watch for. There are often ways to manage and even prevent side effects.

## Coping with chronic lymphocytic leukemia

Many people feel worried, depressed, and stressed when dealing with cancer. Getting treatment for cancer can be hard on your mind and body. Keep talking with your healthcare team about any problems or concerns you have. Work together to ease the effect of cancer and its symptoms on your daily life.

Here are tips:

- Talk with your family or friends.
- Ask your healthcare team or social worker for help.
- Speak with a counselor.
- Talk with a spiritual advisor, such as a minister or rabbi.
- Ask your healthcare team about medicines for depression or anxiety.
- Keep socially active.
- Join a cancer support group in person or online.

Cancer treatment is also hard on the body. To help yourself stay healthier, try to:

- Eat a healthy diet, with a focus on high-protein foods.
- Drink plenty of water, fruit juices, and other liquids.
- Keep physically active.

- Rest as much as needed.
- Talk with your healthcare team about ways to manage treatment side effects.
- Take your medicines as directed by your team.

## When should I call my healthcare provider?

Your healthcare provider will talk with you about when to call. You may be told to call if any of the following occur:

- New symptoms or symptoms that get worse
- Signs of an infection, such as a fever or chills
- Side effects of treatment that affect your daily function or don't get better with treatment

Ask your healthcare provider what signs to watch for and when to call. Know how to get help after office hours and on weekends and holidays.

## Next steps

Tips to help you get the most from a visit to your healthcare provider:

- Know the reason for your visit and what you want to happen.
- Before your visit, write down questions you want answered.
- Bring someone with you to help you ask questions and remember what your provider tells you.
- At the visit, write down the name of a new diagnosis and any new medicines, treatments, or tests. Also write down any new instructions your provider gives you.
- Know why a new medicine or treatment is prescribed and how it will help you. Also know what the side effects are.
- Ask if your condition can be treated in other ways.
- Know why a test or procedure is recommended and what the results could mean.
- Know what to expect if you do not take the medicine or have the test or procedure.
- If you have a follow-up appointment, write down the date, time, and purpose for that visit.
- Know how you can contact your provider if you have questions.

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