

# Patient information from BMJ

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## Leukemia (chronic lymphocytic)

Chronic lymphocytic leukemia is a type of cancer that affects the blood cells. It usually only affects older people. It is not totally curable but there are treatments that can often stop the symptoms for several years.

### What is chronic lymphocytic leukemia?

Chronic lymphocytic leukemia (CLL) is a type of cancer that starts in the bone marrow. It usually only affects middle-aged and older people and is very rare in people younger than 40.

Leukemia is often called "cancer of the blood" because it affects blood cells. Blood cells are made in bone marrow in the middle of our long bones (like the thigh bone), and we have three types:

- Red cells, which carry oxygen around the body
- White cells, which help fight infection
- Platelets, which help with blood clotting when we have a wound.

If you have CLL, the white blood cells grow out of control so that there are too many. But they are weak and don't work properly, so they can't fight infection as well as they should. This makes you more likely to get serious infections.

CLL tends to grow and spread very slowly. Doctors call this type of slow-growing cancer an "indolent" cancer. It can sometimes spread so slowly that it doesn't actually cause you any problems during your lifetime.

It is not completely clear what causes CLL, but it's probably genetic.

### What are the symptoms?

Once CLL starts to spread it can cause symptoms. These can include:

- Swollen lymph glands (you might notice this swelling in the neck, armpits, and groin)
- Weight loss
- Night sweats

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- Fever
- Chills, and
- Fatigue (tiredness).

But many people find out that they have CLL years before it starts to cause them any problems. This happens when they have a blood test called a CBC (complete blood count) for a reason that has nothing to do with CLL.

If those results show you have CLL, you will need further blood tests to see how far the cancer has progressed. If it has not started to spread, you probably won't need any treatment at that point.

Your doctor might also suggest that you have a test called a bone marrow biopsy. This involves using a needle to take a small sample of the soft tissue from inside one of your bones - often the pelvis (hip bone).

A bone marrow biopsy is not needed to diagnose CLL. But it can help to show what kind of treatment you might need.

### When is treatment needed?

Many people find out that they have CLL long before they will need any treatment. This is because you can have CLL for years before it starts to cause problems.

There is no benefit in starting treatment before CLL reaches the point where it is causing problems.

But you will need to have treatment right away if you have:

- A shortage of red blood cells (anemia)
- A shortage of platelets (thrombocytopenia)
- Physical symptoms such as painful swollen glands, fever, and weight loss
- White blood cells multiplying very rapidly, and
- Rapidly enlarging glands, liver, or spleen.

Your doctor might talk with you about what **stage** your cancer has reached. Staging is a way of describing how much the cancer has affected your blood cells, and the types of problems it is causing. It also helps guide what treatment you might need.

### What treatments work?

Treatment for CLL will depend on a few factors such as:

- What stage your cancer has reached
- How fit you are
- Whether you have other medical conditions
- The genetic status of the cancer.

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There are a few treatment options for CLL which include: **immunotherapy**, **chemotherapy**, and **targeted medications**. Some of these options could be combined.

Your doctor will give you advice about which treatments are best for you. They will also explain exactly how your treatment will work.

But CLL is usually not curable, even with treatment. The treatment can lead to what's called **remission**, which is when the cancer is no longer active and you don't have symptoms.

But most people will have symptoms again and need more treatment within a few years.

Depending on your treatment, you may experience unpleasant side effects. For example, chemotherapy drugs can cause extreme tiredness, nausea, and a weakened immune system, which can make you more likely to get infections. And some targeted medications can cause heart-related side effects like abnormal heart rhythms and high blood pressure.

Most of these side effects stop when your treatments stop.

If your first course of treatment doesn't work, your doctor may recommend trying different drugs for your next round of treatment.

### Stem cell transplant

Some people might be able to have a treatment called a stem cell transplant. This involves taking healthy bone marrow cells from another person (a donor) and putting the cells in your bloodstream.

But this treatment is complex and not commonly available. It is also more likely to work in people who are younger and in fairly good general health.

### What will happen to me?

Your first course of treatment may leave you free of CLL symptoms (in remission).

But this isn't a cure and, even if you are in remission your symptoms will usually return after a few years. You will then need more treatment to stop them again.

Some people choose not to have any more treatment because they find the side effects unpleasant and difficult to deal with.

If you decide to stop treatment, your healthcare team will talk with you about palliative care. This is care that makes you as comfortable as possible when you have a condition that can't be cured.

It's not possible to say what will happen to an individual, but most people with CLL are still alive more than five years after being diagnosed.<sup>[1]</sup> And many people live fairly healthy and normal lives for some years after treatment for CLL.

But having CLL can cause serious complications, including:

- A weakened immune system. Both the condition and chemotherapy can affect your immune system so that you're more likely to get infections

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- A greater chance of other cancers. For example, people with CLL are more likely to get skin, stomach, bowel, and lung cancers, as well as a type of lymphatic cancer called non-Hodgkin lymphoma
- A type of anemia called autoimmune hemolytic anemia. This is where your body starts attacking your red blood cells.

CLL is not uncommon, and there is a lot of help available. There are many charities and support groups for people with CLL as well as their families and caregivers.

Your doctor might be able to put you in touch with a group in your area, or you could search online.

1. National Cancer Institute. Surveillance, Epidemiology, and End Results (SEER) Program. Cancer stat facts: leukemia - chronic lymphocytic leukemia (CLL). 2022 [internet publication].

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