

Patient information from BMJ

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Leukaemia (chronic lymphocytic)

Chronic lymphocytic leukaemia 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.

You can use our information to talk to your doctor about the best treatment for you.

What is chronic lymphocytic leukaemia?

Chronic lymphocytic leukaemia (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 under 40.

Leukaemia 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 carry oxygen around the body
- white cells help fight infection
- platelets 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 that 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.

We're not completely sure what causes CLL, but it's probably genetic.

What are the symptoms?

Once CLL starts to spread and cause symptoms, these can include:

- swollen lymph glands. You might notice this swelling in the neck, armpits, and groin
- weight loss

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- night sweats
- fever
- chills, and
- fatigue (tiredness).

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

If you have a blood test that shows that you have CLL, you will have more blood tests to see how far the cancer has progressed. If it has not started to spread, you probably won't need any treatment for now.

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 need.

What treatments work?

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 any problems.

There is no benefit in starting treatment before CLL reaches the point where it is causing problems. So, unlike with many medical problems, early treatment won't help.

But you will need to have treatment straight away if tests show that you have begun to have problems including:

- a shortage of red blood cells (anaemia)
- a shortage of platelets (thrombocytopenia)
- physical symptoms such as painful swollen glands, fever, and weight loss
- white blood cells multiplying very rapidly, and
- swollen lymph glands on your liver or spleen.

Your doctor might talk to 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.

Chemotherapy

Treatment for CLL is **chemotherapy**. Chemotherapy drugs are medicines that kill cancer cells. The usual treatment is to use several chemotherapy drugs together, for treatment cycles lasting several weeks.

Depending on what drugs you need, you might be able to take some of them as tablets at home, while others might need to be given as IV infusions in hospital.

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Your doctor will explain exactly how your treatment will work, and you should ask any questions that you want to, at any time.

The drugs you need might depend on what stage your cancer has reached.

CLL is not curable, even with chemotherapy. But 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 chemotherapy within a few years.

Chemotherapy for CLL can cause unpleasant side effects, including:

- extreme tiredness
- nausea
- anaemia, which can lead to a feeling of weakness and shortness of breath
- hair loss, and
- a weakened immune system, which can make you more likely to get infections.

Most of these side effects stop when you have stopped having chemotherapy.

If your first course of chemotherapy doesn't work, or if it works but your symptoms come back quickly, your doctor will recommend trying different chemotherapy 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 a donor and putting them into your bone marrow.

But this treatment is complex and is not commonly available. It is also more likely to work in people who are younger and in fairly good general health. So some people might not be strong enough to have this treatment.

What will happen?

Between 25 and 50 in 100 people will be free of symptoms (in remission) after their first course of chemotherapy.

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 chemotherapy to stop them again.

Some people choose not to have any more treatment because they find the side effects of chemotherapy so unpleasant. This is your decision to make, and no one can make you have any treatment that you don't want.

If you decide to stop treatment, your healthcare team will talk to you about what's called palliative care. It means making you as comfortable as possible when you have a condition that can't be cured.

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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. 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
- 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's lymphoma
- anaemia.

CLL is not uncommon, and there is a lot of help available. There are many charities and support groups for people with CLL and their families and carers. For example, in the UK, the CLL Support Association (cllsupport.org.uk) offers information, advice, and support.

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

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