About CLL

Chronic lymphocytic leukaemia (CLL) is a slow-growing type of blood cancer. It develops when white blood cells called lymphocytes stop working properly and grow out of control. Find out about the signs and symptoms of CLL, tests you might have, and how CLL is diagnosed.

Summary

- CLL is a slow-growing type of blood cancer. It starts when white blood cells called lymphocytes grow out of control and build up in your blood and bone marrow.
- We do not know exactly what causes CLL. It is not because of anything you have or have not done. You cannot catch CLL or pass it on to anyone else.
- The signs and symptoms of CLL vary from person to person. Many people have no symptoms and are diagnosed after a blood test for something else.
- CLL is diagnosed by a blood test. You might also have a bone marrow test or other tests to see how CLL is affecting your body.
- If your CLL is not causing you any problems you might not be offered treatment immediately. Instead, you'll be on 'active monitoring', sometimes called 'watch and wait'.
- The outlook for most people with CLL is good. Most people live with CLL for many years, and some people never need treatment.
- We have separate information about treatment for CLL and active monitoring.

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What is CLL?

CLL is a slow-growing type of blood cancer. It happens when white blood cells called lymphocytes stop working properly and grow out of control. These abnormal cells build up in your blood and bone marrow.

Because it is a slow-growing type of blood cancer, it can take a while for CLL to affect you.

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Who gets CLL?

About 4,500 people are diagnosed with CLL every year in the UK. It's one of the most common blood cancers in adults, which means you are not alone.

It is more common in people over 60 years old, and rare in young people. The average age at diagnosis is 72 years old.

CLL affects nearly twice as many men as women. It is also more common in white people than people of Asian, African or Hispanic heritage.

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What causes CLL?

We do not know exactly what causes CLL. It is not because of something you did or didn't do. You cannot catch CLL or give it to someone else.

CLL develops when the genetic code (DNA) inside your lymphocytes changes. This stops the cells from responding to signals that usually keep them under control. They divide when they shouldn't or live on when they should die off. These abnormal cells stop working properly and build up in your body as CLL cells.

It usually takes several different DNA changes to cause CLL. Most of the time these changes happen by chance, although some factors might make them more likely. These include:

- **Age.** The older you are the more likely you are to develop CLL. This is because genetic changes become more common as you age.
- **Sex.** Men are more likely to develop CLL than women.
- **Family history**. Although CLL is not passed from parent to child, close relatives of someone with CLL have a higher than usual chance of getting it themselves. But the chance is still low.
- **Monoclonal B-cell lymphocytosis (MBL).** This condition is fairly common in people over 60 years. It happens when there are low levels of abnormal lymphocytes in your blood with no other signs of CLL. Each year, around 2 out of 100 people with MBL go on to develop CLL.

- **Chemicals.** People who are exposed to high levels of industrial chemicals may be slightly more likely to develop CLL.

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Signs and symptoms of CLL

Most people have no symptoms when they are diagnosed with CLL. It's usually found by chance when you have a blood test done for another reason. Your first sign of CLL is often high levels of white blood cells (lymphocytes) found in your blood test results.

As CLL cells build up, you may start to get mild symptoms, although some people never do. If you get symptoms, they usually worsen over months or years.

Signs and symptoms vary from person to person depending on where in your body CLL cells build up. You may feel generally unwell or notice some of the following:

- Swollen glands – if the cells build up in your lymph nodes, you may feel lumps under your skin. You often find them in your neck, armpits or groin, although they can swell up anywhere in your body.
- Swollen tummy – if the cells build up in your spleen or liver, you may feel full quickly or lose your appetite. You may feel bloated or have pain at the top-left of your tummy (abdomen).
- Fatigue – you might feel exhausted even when you've had plenty of sleep and rest.
- Frequent infections – you may get infections more often than usual or find it hard to get rid of them.
- Fever – you might have a high temperature (above 38°C or 100.4°F) that comes and goes.
- Night sweats – you may sweat so much at night that your bedclothes and sheets become soaked and need changing.
- Weight loss – you may lose weight without trying to.

Abnormal blood counts

If the cells build up in your bone marrow, they can stop healthy blood cells from growing. You may have:

- Low red blood cells (anaemia), which can make you feel tired and perhaps dizzy.

- Low platelets (thrombocytopenia), which can make you bruise or bleed more easily than usual.
- Low numbers of a type of white blood cell called neutrophils (neutropenia). This can make you more likely to pick up infections and make it harder for you to recover from them.
- High levels of lymphocytes, which usually fight infections, but they may not work properly.

About 1 in 10 people with CLL/SLL develop low blood counts caused by an autoimmune reaction. This happens when your immune system attacks and destroys healthy blood cells by mistake. This can cause:

- Low red blood cells (autoimmune haemolytic anaemia or AIHA)
- Low platelets (immune thrombocytopenic purpura or ITP)

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Diagnosis of CLL diagnosed

Your haematology team will diagnose CLL based on:



Blood tests. A blood test called a full blood count measures the number of red blood cells, platelets and different types of white blood cells you have. If you have CLL, this usually shows high levels of white blood cells called lymphocytes. A specialist also looks at a sample of your blood under a microscope to check for CLL cells.

It usually takes a few minutes to have a blood sample taken. You may have other blood tests to:

- Measure your antibody levels
- Check whether your liver and kidneys are working well
- Check for viral infections



Bone marrow tests. If you have low blood counts, you may have a bone marrow biopsy to check for CLL cells in your bone marrow. It involves taking a sample of liquid or spongy tissue from the centre of a large bone.

To have a bone marrow test:

- You have an injection to numb the area first.
- Then a doctor uses a special needle to take samples of your bone marrow, usually from the back of your pelvis.
- They send the samples to the lab for testing.



Genetic tests. Your haematology team sends your blood or biopsy samples to the lab for specialised tests. These look for particular proteins or genetic changes. Some of these changes affect how CLL cells respond to treatments and help decide which treatments are best for you. The most important changes they'll look for are:

- Del17p or TP53 – changes to genes that usually stop tumours from growing
- IGHV –variations in genes called immunoglobulin genes



CT scan. CT scans can help your haematology team find out which parts of your body are affected by CLL. You might have one to check the size of your lymph nodes, spleen and liver.

It can be difficult waiting for test results. If you need support, call our freephone Helpline on **08088 010 444**.

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Staging CLL

Your haematology team use your test and scan results to work out how widespread your CLL is and how it is affecting you. This is called staging.

Your CLL stage is based on your blood counts and whether your lymph nodes, spleen or liver are swollen. There are three stages from A to C:

- Stage A – You have fewer than three areas of 'lymphoid swelling' (swollen liver or spleen, or swollen lymph nodes in your neck, armpits or groin)
- Stage B – You have three or more areas of lymphoid swelling
- Stage C – You have a low red blood cell count, a low platelet count or both, with any number of swellings.

Staging is an important step in your diagnosis because it helps your haematology team plan the best treatment for you, if you need it, and when to start it.

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Outcomes of CLL

> **Your consultant is the best person to advise you on your outlook. They can take account of your individual circumstances and test results.**

CLL usually grows very slowly, and most people live with CLL for many years. It's hard to predict how long it might be until you need treatment or whether you'll ever need treatment.

- About 1 in 3 people need treatment straight away
- About 1 in 3 need treatment later
- About 1 in 3 never need treatment

Outcomes vary from person to person and depend on many different factors. Some people have genetic changes in their CLL cells that make them grow faster. In these cases, CLL needs more frequent treatment.

Rarely, CLL changes into a faster-growing cancer of the lymphatic system. This is called Richter syndrome or Richter transformation. It happens to about 1 in every 100 people with CLL each year. Richter syndrome can be more difficult to treat.

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Need support?

You are not alone. We're here for you whether you have a diagnosis yourself or know someone who has. If you'd like advice, support, or a listening ear, call our freephone helpline on 08088 010 444 or send a WhatsApp message to 07500 068 065.

Helpline and WhatsApp →

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