About large granular lymphocytic leukaemia (LGLL)

Large granular lymphocytic leukaemia (LGLL) is a slow-growing blood cancer that starts in white blood cells called lymphocytes. Find out what LGLL is, the signs and symptoms and how it is diagnosed.

Summary

- LGLL is a slow-growing blood cancer.
- We do not know exactly what causes it. But it is not because of anything you have or have not done.
- Sometimes you might not have symptoms when you are first diagnosed. You may be diagnosed after a blood test for something else.
- Symptoms of LGLL include exhaustion, repeated infections, bruising or bleeding, and tummy pain or bloating.
- Your haematology team will diagnose LGLL based on blood tests and sometimes bone marrow tests.
- The outcome of LGLL depends on your individual situation, your health history and the way you respond to treatment. As with most cancers, outcomes vary from person to person.
- We are here for you if you need support.

We have separate information about treatment for LGLL.

Download our booklet about LGLL
Download our factsheet about LGLL

What is LGLL?

Large granular lymphocytic leukaemia (LGLL) is a slow-growing blood cancer. It starts in white blood cells called lymphocytes. These become abnormal and don't die when they should. They also produce substances that kill healthy blood cells. This leads to a high level of abnormal lymphocytes and a low level of healthy red and white blood cells.

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There are two main types of LGLL, depending on the exact type of cell it starts in:

- T-cell LGLL starts in lymphocytes called T cells. Most people with LGLL have this type.
- NK-cell LGLL starts in lymphocytes called NK cells. This type of LGLL is less common.

Diagnosis and treatment options are the same whichever type you have.

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Who gets LGLL?

LGLL is a very rare leukaemia. Fewer than 300 people are diagnosed with it each year in the UK. This is why you might not have heard of LGLL or met anyone with it before.

LGLL can affect people of any age, but it is more common in people over 60. It affects men and women equally.

> **Most people with LGLL live for many years.**

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What causes LGLL?

We do not know the exact cause of LGLL. Some scientists think it might start after a reaction to an infection or another trigger, but they are still researching this. LGLL itself is not infectious. You cannot catch it and you cannot pass it on to someone else.

People with LGLL have genetic changes in their leukaemia cells that stop the cells from working properly. However, in most cases we do not know why these genetic changes occur. These changes are not because of anything you have or have not done.

But there are some factors that can increase your chance of getting LGLL. These include:

- Your age: LGLL is more common in people over 60
- Having an autoimmune condition such as rheumatoid arthritis

- If you have or have had a different type of cancer, including blood cancer

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Signs and symptoms of LGLL

You might not have symptoms when you are first diagnosed. Many people are diagnosed after a blood test for something else. But you might get some signs or symptoms over time. The signs and symptoms you might get vary from person to person.

LGLL can cause the following signs and symptoms:

- Feeling tired for no obvious reason (fatigue)
- Infections that last a long time or keep coming back, especially skin, throat or sinus infections
- Feeling tired, breathless or dizzy due to a low red blood cell count (anaemia)
- Bruising or bleeding easily (for example, nose bleeds or bleeding gums when you brush your teeth)
- Tummy pain, bloating or discomfort due to a swollen spleen or liver (you may particularly notice this feeling under your ribs on the left-hand side)
- Fever
- Night sweats
- Losing weight without trying to

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Diagnosis of LGLL

You'll have blood tests and sometimes bone marrow tests to diagnose LGLL. The samples go to the lab for specialist testing.

> **It can be difficult waiting for tests and test results. Our Helpline is here for you if you need support.**

It can sometimes take a while but it is important for your haematology team to make an accurate diagnosis. It also helps them work out the most suitable treatment for you, if you need it.

Blood tests

You will have blood tests to:

- Measure your numbers of red blood cells, white blood cells and platelets. If you have LGLL, you may have high levels of abnormal lymphocytes. You may have low levels of healthy blood cells.
- See how your blood cells look under a microscope. LGLL cells are larger than healthy lymphocytes and contain lots of granules.

You might also have blood tests to:

- Check how well your liver and kidneys are working.
- Look for any signs of autoimmune conditions like rheumatoid arthritis.
- Check if you have any infections that could flare up during treatment.

Bone marrow test

You might have a bone marrow test to confirm the diagnosis, but this may not be needed. This involves taking a sample of your bone marrow, usually from the back of your pelvis, with a local anaesthetic.

Cancer Research UK have more information on having a bone marrow test.

Lab tests

Your doctor will send your blood and bone marrow samples to the lab for specialist tests. They may check what proteins are on the surface of your leukaemia cells, or what genetic changes the cells have. The results can help your doctor work out the most suitable treatment for you.

Other tests

You might have an ultrasound to check for a swollen liver or spleen. Depending on your symptoms, you might have other tests or scans.

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Outcomes of LGLL

LGLL is a slow-growing blood cancer. Treatment aims to control it rather than cure it, but it is often effective.

Most people with LGLL live for many years.

Your outcome can vary depending on your individual situation, your health history and the way you respond to treatment. As with most cancers, outcomes vary from person to person. They depend on lots of different factors, including:

- Your age and overall fitness
- Whether or not you have any symptoms and how severe they are
- Whether or not you have any other medical conditions
- The genetic changes in your leukaemia cells
- The proteins on the surface of your leukaemia cells

> **Your haematology team are best placed to discuss what they expect for you because they know your individual circumstances.**

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Sources we used to develop this information

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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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