

Information + Taking Control = Best Outcome



Oncology

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Hematology

Fast Facts Information Sheets for Patients

Chronic Lymphocytic Leukemia

Chronic lymphocytic leukemia

You or a family member have been diagnosed with chronic lymphocytic leukemia (CLL). This leaflet gives you some basic information about the condition and may help answer some of your questions.

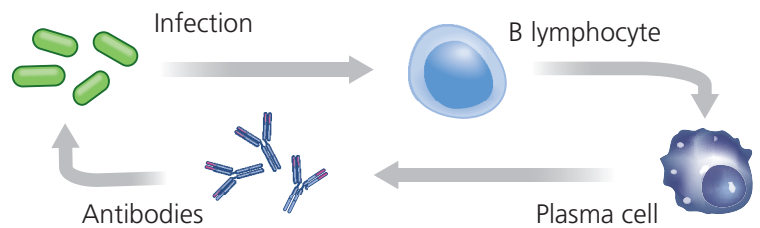
What is CLL?

CLL is a slow-growing blood cancer. It is the most common form of blood cancer in adults. It happens when a type of blood cell in your body develops in an unusual way. CLL is usually caused by changes (mutations) in the genes of a blood cell. These changes are typically caused by ageing. The blood cells involved in CLL are a type of white blood cell called a **lymphocyte**. There are 3 types of lymphocyte: natural killer cells, T cells and B cells. In CLL, large numbers of abnormal B cells (also called B lymphocytes) are produced.

Is there a cure for CLL?

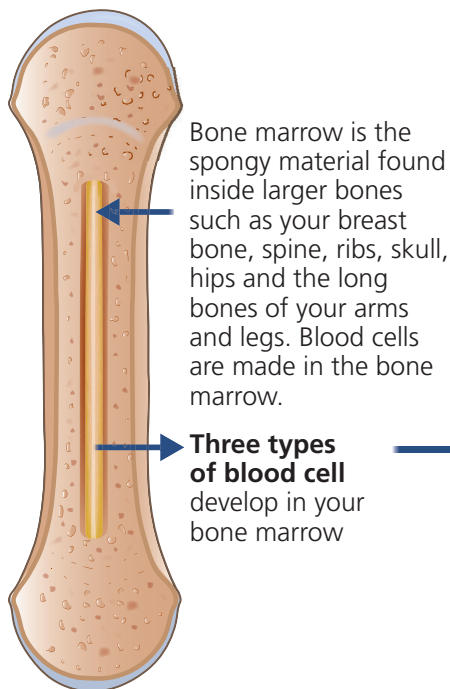
There is currently no cure but CLL is a treatable condition. There are promising new therapies being developed and it's usually possible to keep the disease under control for long periods. Many people with CLL have a normal lifespan and a good quality of life.

What do B lymphocytes do?



Once a B lymphocyte is activated, it turns into a plasma cell and starts to make **antibodies**. An antibody is a protein that the body makes to defend itself against something harmful like a virus or bacteria.

More about normal blood cell production



Red blood cells

carry oxygen around your body



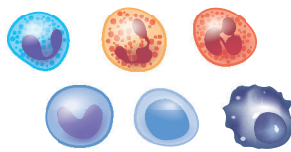
Platelets

help your blood to clot



White blood cells

fight infection. There are several different types which are important for immunity. One of these types is the lymphocyte



What happens in CLL?

In CLL, B lymphocytes don't develop properly and cannot produce antibodies. This means that people with CLL are more likely to develop infections and to have more difficulty fighting them.

Abnormal B lymphocytes also build up in the immune system, crowding out the normal cells.

The overcrowding prevents normal cell production and the normal functioning of red and white blood cells and platelets.

The problems this causes include anemia, blood clotting problems and swelling in glands.

How will CLL affect me?

Symptoms vary from person to person depending on how the disease develops but as many as one third of people diagnosed with CLL never have any symptoms. Other people have no symptoms for many years.

You may have:

- **swollen glands.** Most often in your neck or under your arms. This is often the first symptom that people notice.
- **repeated infections** or difficulty shaking off an infection, such as flu.
- **fatigue.** One of the causes of fatigue is anemia. Anemia in CLL is caused by not having enough red blood cells.
- **bleeding or bruising easily.** This can happen if you don't have enough platelets to help clot your blood.
- **pain under the ribs on your left side.** This happens if an organ called the spleen fills up with abnormal B cells.

Chronic lymphocytic leukemia... *contd*

What tests will I have?

You will have regular **blood tests** to monitor your general health and to measure the level of CLL cells in your body.

You may also have **bone marrow tests**. Bone marrow tests can give more information about the progression of the cancer. The test is usually done at a hospital.

Tests can also be done to look for **gene changes (mutations)** in cells. These tests generally use a blood sample or bone marrow sample. They can help your doctor understand more about your disease and make decisions about your treatment.

What is the treatment for CLL?

What treatment you need – or whether you need any at all – depends on how far CLL has developed and other factors, like your health or age. Many people will never need any treatment.

For most patients, the aim of treatment is to achieve a ‘remission’ with well-tolerated treatment. Remission means the signs and symptoms of CLL are reduced.

Treatment for CLL is generally

- **targeted therapies**
- **chemotherapy**

Most people will receive a combination of both.

Targeted therapies work by ‘targeting’ the proteins that cause cancer cells to grow and divide.

Chemotherapy works by killing cells that multiply rapidly. This includes cancer cells.

A very small number of people may be offered a stem cell transplant.

After diagnosis: what next?

When you receive a diagnosis of CLL your doctors will ‘stage’ the cancer. Staging is a description of where the cancer is, if and where it has spread, and what other parts of the body are affected. Knowing the stage of the cancer can help your healthcare team decide whether to begin treatment and what treatment may be beneficial for you.

Your healthcare team may decide to begin treatment or you may be one of the many people with CLL who are on **active monitoring**. This is also called ‘watch and wait’.

What is active monitoring?

On active monitoring, you will see your doctor every 3–6 months. You will have regular check-ups and blood tests. Your doctor will look for any signs that CLL is developing (progressing).



What now?

If you're on active monitoring you will probably see a **hematologist-oncologist** (a doctor who specializes in blood cancers) every few months. You will often be assigned a key worker, usually a **clinical nurse specialist**.

If you're having treatment, your care team will be made up of a specialist team of healthcare professionals. Who you see will depend on your symptoms.

You may also see

- a consultant hematologist (a specialist in blood diseases)
- your primary care physician
- a counselor or clinical psychologist.

Where you go for your appointments depends on where you live. You may go to a clinic specializing in CLL or to the hematology department in your local hospital.

More help and information

CLL Society
cclsociety.org

Lymphoma Action UK
lymphoma-action.org.uk

Leukemia and Lymphoma Society
lls.org

Blood Cancer UK
bloodcancer.org.uk

CLL Support Association UK
cclsupport.org.uk

Leukaemia Foundation
leukaemia.org.au

Chronic lymphocytic leukemia... contd

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Chemotherapy works by killing cells that multiply rapidly. This includes cancer cells.

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More help and information

- CLL Society cllsociety.org
- Blood Cancer UK bloodcancer.org.uk
- Lymphoma Action UK lymphomaaction.org.uk
- CLL Support Association UK cllsupport.org.uk
- Leukemia and Lymphoma Society lls.org
- Leukemia Foundation leukemia.org.au

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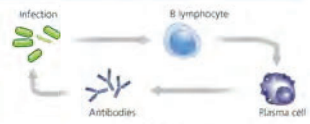
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Red blood cells

Red blood cells carry oxygen around your body.

Platelets help your blood to clot.

White blood cells fight infection. There are several different types of white blood cells that are important for your immunity. One of these is the lymphocyte.



What happens in CLL?

In CLL, B lymphocytes don't develop properly and cannot produce antibodies. This means that people with CLL are more likely to develop infections and to have more difficulty fighting them.

Abnormal B lymphocytes also build up in the immune system, crowding out the normal cells.

The overcrowding prevents normal cell production and the normal functioning of red and white blood cells and platelets.

The problems this causes include anaemia, blood clotting problems and swelling in the lymph nodes.

How the disease develops but as many as one-third of people have no symptoms for many years.

Swelling in your arms. This is often the first symptom that people notice.

Other symptoms, such as flu, can be caused by CLL. CLL is caused by not having enough red blood cells, which means you don't have enough platelets to help clot your blood.

As the spleen fills up with abnormal B cells, it can become enlarged.

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