

Complications of CLL

Chronic lymphocytic leukaemia (CLL) can cause other health problems. The most common complications of CLL are autoimmune conditions. They happen when your immune system mistakenly attacks your own body. Although less common, it's also possible for your CLL to transform into a more aggressive type of cancer.

Summary

- There are three main complications of CLL: autoimmune haemolytic anaemia (AIHA), immune thrombocytopenia (ITP) and Richter syndrome.
- AIHA causes low levels of red blood cells. Symptoms include feeling tired, dizzy or breathless.
- AIHA is usually treated with steroids, a targeted medicine called rituximab or other targeted treatments for CLL.
- ITP causes low numbers of platelets in your blood. Symptoms include bleeding that is hard to stop and unusual bruising.
- Treatment options for ITP include steroids, intravenous immunoglobulin (IVIg), a targeted medicine called rituximab and medicines that increase your platelet count.
- Richter syndrome is a rare complication of CLL. It happens when your CLL transforms into a type of cancer called lymphoma. Symptoms include sudden swelling of your lymph nodes, fever and night sweats.
- Treatment options for Richter syndrome include chemotherapy, sometimes with an antibody therapy, or a stem cell transplant.

[Download our factsheet on AIHA](#) 

[Download our factsheet on ITP](#) 

[Download our factsheet on Richter syndrome](#) 

About complications of CLL

There are three main complications of chronic lymphocytic leukaemia (CLL). They are:

- Autoimmune haemolytic anaemia (AIHA)
- Immune thrombocytopenia (ITP)
- Richter syndrome

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Here, we cover what they are, symptoms you might get, and how they are treated.

Contact your haematology team if you're worried about any symptoms you have.

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Autoimmune haemolytic anaemia (AIHA)

AIHA is the most common autoimmune complication of CLL. It happens when your immune system attacks your red blood cells. It causes low levels of red blood cells.

It's called secondary AIHA when you have CLL because it follows on from your disease.

Up to 10 in 100 people with CLL develop AIHA. This means more than 90 in 100 do not.

AIHA is most likely to develop when you have advanced-stage CLL, but it can happen at any stage. For some people, AIHA can be the first sign that they have CLL.

AIHA is more common in:

- People with advanced-stage CLL, although it can happen at any stage
- People with certain genetic changes in their CLL cells
- Older people, although it can happen at any age

Types of AIHA

There are two main types of AIHA:

- Warm AIHA, when antibodies that work best at body temperature attack your red blood cells
- Cold AIHA, when antibodies that work best at a cold temperature attack your red blood cells

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Warm-type AIHA is more common than cold-type AIHA. Some people have a mixture of the two.

Both warm-type and cold-type AIHA can cause:

- Destruction of red blood cells (haemolysis)
- Low red blood cells (anaemia)

Symptoms of AIHA

Both warm-type and cold-type AIHA cause symptoms from the breakdown and loss of red blood cells. These include:

- Tiredness and lack of energy
- Dizziness
- Breathlessness
- Yellowing of the whites of your eyes
- Darker pee than usual

AIHA can also cause yellowing of your skin, but this may be less noticeable if you have brown or black skin.

Cold-type AIHA can also cause symptoms triggered by cold temperatures. These include:

- A white or paler colour on the skin of your fingertips or toes
- Pain, numbness, or pins and needles in your fingers or toes

The tips of your nose and ears may also turn a pale or dusky blue colour. This may be harder to see on black or brown skin.

Diagnosis of AIHA

You'll need blood tests to diagnose AIHA. The results of your blood tests may show whether you have warm-type or cold-type AIHA or a mixture of the two.

Some people might need other tests. These might include a bone marrow test or screening for infections.

Treatment for AIHA

There are lots of treatment options for AIHA. Your treatment plan will depend on your symptoms, CLL stage, and general health.

Treatments for AIHA can take several weeks to work. Your haematology team might suggest:

- Steroids, such as prednisolone tablets. This is the usual first treatment for warm AIHA.
- A targeted medicine called rituximab. You have this through a drip into a vein. For warm AIHA, you might have it alongside steroids, or after a course of steroids. For cold AIHA, you might have it as your first treatment.
- Other targeted medicines used to treat CLL or other blood cancers, if you're not already on treatment. These are usually tablets you take by mouth. They are effective against CLL and AIHA and usually have few side effects.
- A [blood transfusion](#), if your red blood cell count is very low. This can help to ease your symptoms.

If your AIHA does not respond, your team might suggest other treatments.

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Immune thrombocytopenia (ITP)

ITP is the second most common autoimmune complication of CLL. It happens when your immune system attacks blood cells called platelets.

Up to 5 in 100 people with CLL develop ITP. More than 95 in 100 do not.

ITP causes low numbers of platelets in your blood (thrombocytopenia). You need platelets for your blood to clot. If you don't have enough platelets, it can cause unusual or heavier bleeding than normal for you.

ITP is more common in:

- People with advanced-stage CLL
- People with certain genetic types of CLL
- Older people

Symptoms of ITP

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You may not have any symptoms of ITP, but it can cause bleeding that's hard to stop. This may be underneath your skin, from your skin or inside your body. It can sometimes be serious.

You may notice:

- Bruising easily
- Unusual bruising
- Swelling under your skin that looks or feels like a lump
- Nosebleeds
- Bleeding gums
- Blood in your pee or poo
- Heavier or longer periods than usual
- Extreme tiredness

Unusual bruising may look like tiny spots under your skin. These may look red or purple on white skin or purple or darker brown on black or brown skin.

Diagnosis of ITP

You'll need blood tests to diagnose ITP. Your haematology team will use your platelet numbers and your symptoms to diagnose you.

It can be difficult to be sure of the diagnosis. Your haematology team might need to do other tests to check for other causes of low platelets. You might need to have a bone marrow test.

Treatment for ITP

There are lots of treatment options for ITP. Your treatment plan will depend on your symptoms, general health and preferences.

These may include:

- Steroids, such as prednisolone tablets. This is usually the first treatment for ITP.
- Intravenous immunoglobulin (IVIG). These are donor antibodies that you have as an injection or through a drip into a vein.
- Medicines to boost your platelet count (eltrombopag or romiplostim). You may have these as tablets, as liquid medicine or an injection.
- A targeted medicine called rituximab. You have this through a drip into a vein.

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Depending on your blood test results and your medical history, you might need to stay in hospital to have your treatment.

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Richter syndrome

Richter syndrome is a rare complication of CLL. It happens when CLL progresses into a fast-growing type of lymphoma. It is also known as Richter transformation.

Most people with CLL do not develop Richter syndrome. About 1 in 200 people with CLL develop it each year. This means 199 in 200 do not.

Richter syndrome is more common in:

- People with advanced-stage CLL
- People who have had multiple treatments, particularly chemoimmunotherapy
- People with certain genetic changes in their CLL cells
- Older people with other health conditions

Lymphoma is a type of cancer. It affects white blood cells called lymphocytes in your lymphatic system.

There are many different types of lymphoma. Most people with Richter syndrome develop a type called diffuse large B-cell lymphoma. This is a type of non-Hodgkin lymphoma. Some people with Richter syndrome develop other types of lymphoma.

Lymphoma Action has [more information about lymphoma](#).

Symptoms of Richter syndrome

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Richter syndrome causes symptoms that get worse quickly. You may experience new symptoms including:

- Sudden swelling of your lymph nodes
- Unexplained fever
- Night sweats
- Weight loss
- Tummy pain or fullness

Diagnosis of Richter syndrome

You'll need to have a lymph node biopsy to diagnose Richter syndrome. You may also have:

- Blood tests
- Bone marrow tests
- A special scan called a PET scan

Treatment for Richter syndrome

Richter syndrome is a serious condition and can be very hard to treat. Depending on your test results and general health, your treatment options may include:

- Chemotherapy, sometimes alongside antibody therapy.
- [Stem cell transplant](#). This intensive treatment replaces damaged or abnormal blood-forming cells in your bone marrow with healthy ones.
- Treatment as part of a [clinical trial](#).
- Palliative care. This aims to reduce symptoms and side effects and improve your quality of life.

Lymphoma Action has [more information on treatment for lymphoma](#).

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Questions to ask your doctor

When you're told you have a complication of CLL, it can be hard to think straight. You might want to ask your doctor questions like these:

- What treatment is best for me and why?
- How will treatment affect my daily life?
- Are there any other treatments I may need?

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- Is there anything I should avoid doing while I have this condition?
- What is the outlook for my condition?

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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.

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