Hairy cell leukaemia (HCL)

Hairy cell leukaemia (HCL) is a rare, slow-growing type of blood cancer. It develops when white blood cells called lymphocytes stop developing and working normally. Find out about the signs and symptoms of HCL, tests you might have, and how HCL is diagnosed and treated.

Summary

- Hairy cell leukaemia (HCL) is a rare but treatable, slow-growing blood cancer.
- It develops when white blood cells called B lymphocytes grow abnormally. The abnormal cells look hairy under a microscope.
- We do not know the exact cause of HCL. It is not due to something you did or did not do.
- Hairy cells can gradually build up in different parts of your body, often in your bone marrow and spleen.
- It can lead to low blood counts and problems like anaemia, frequent and long-lasting infections and unexpected bleeding.
- If your spleen is affected, you may have symptoms like bloating, tummy pain and poor appetite.
- Most people have symptoms and need treatment soon after diagnosis. But some people don’t have symptoms and can be regularly monitored instead.
- HCL is usually treated with chemotherapy. You may also have an antibody therapy called rituximab.
- Treatments for HCL are very effective at controlling HCL, so you can get on with your life.
- HCL can come back after successful treatment, so you may need more than one course of treatment for HCL in your lifetime.

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What is HCL?

Hairy cell leukaemia (HCL) is a slow-growing type of blood cancer. It affects white blood cells called B lymphocytes or B cells. These usually help fight infections by making antibodies.

In HCL, the B cells don't develop or function normally. When you look at the cells under a microscope, they have tiny hair-like projections all over them. This is where the name 'hairy' comes from.

"Some people think the name of our condition is a joke. The good news is it's treatable with chemotherapy, and you won't lose your hair!"

— Julie, living with HCL since 1995

> **Hairy cell leukaemia can be controlled and is not life-threatening. With treatment, people with HCL can lead a normal life.**

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Who gets HCL?

HCL is rare. Around 230 people are diagnosed with HCL in the UK each year. This is why you might not have heard of HCL or met anyone with it before.

Most people who get it are white, middle-aged or older adults. It is four times more common in men than in women, but we don’t know why.

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What causes HCL?

We do not know what causes HCL. It’s not because of something you did or did not do. It starts when a genetic change stops a cell from working as it should. This usually happens by chance during your lifetime.

In HCL, there’s a change in a gene called BRAF in your bone marrow. This switches on a protein needed for lymphocyte development and keeps it on. It leads to an abnormal B cell that slowly keeps dividing and doesn’t stop.

This genetic change is only in the hairy cells. You did not get this change from your parents, and you cannot pass it on to any children you may have.

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Signs and symptoms of HCL

At first, HCL is harmless, but over time, the number of hairy cells grows high enough to cause problems.

Hairy cells can build up in your body, usually in your blood, bone marrow, and spleen. They can stop your bone marrow from making healthy blood cells, including red blood cells, white blood cells and platelets.

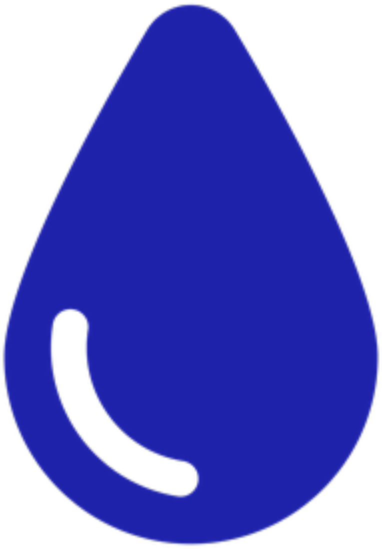
As hairy cells build up in your body, you usually get symptoms. They may be mild at first and get worse over time. Most people with HCL already have symptoms when they are first diagnosed.

Low blood cell counts

Hairy cells can take up so much space in your bone marrow that it cannot make enough healthy blood cells. Your symptoms may vary depending on which blood cells are affected:

Tiredness, dizziness, or breathlessness due to low red blood cells (anaemia)

More frequent and longer-lasting infections, like coughs, colds and skin infections, due to low white blood cells



Unexplained bruising or bleeding, like nosebleeds, bleeding gums and heavy periods, due to low platelets

Swollen spleen

If you have a swollen spleen, you may:

Feel full quickly

Lose your appetite

Feel bloated

Have pain at the top-left of your tummy

Have a higher risk of infections

> “Before treatment, I had general tiredness, breathlessness during exercise, random bruises and several infections that needed antibiotics. My clothes had become tighter and uncomfortable around my chest/spleen area.”
>
> — *Sally, living with HCL since 2023*

Over time, hairy cells may gradually build up in other parts of your body, like your liver and lymph nodes. This can cause swelling and pain.

General symptoms of leukaemia

You may have other, more general symptoms of leukaemia. They happen because your body is working hard to combat the effects of HCL. They may include:

Fatigue

Feeling generally unwell

Losing weight without trying to

Night sweats

Fever

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Diagnosis of HCL diagnosed

Your doctor may suspect you have HCL based on your symptoms or from a blood test for something else. You'll need a check-up and further tests to make sure their diagnosis is right.

You'll be referred to a blood specialist (a haematologist) at the hospital for this. You usually attend the day unit and go home the same day. You may have:

Blood tests. These are used to measure your numbers of red blood cells, white blood cells and platelets. They're also used to look for hairy cells under a microscope.

Bone marrow test: This involves taking a sample of liquid or spongy tissue from the centre of a large bone. The samples are sent to the lab for testing.

Specialist lab tests: Your haematology team send your blood or bone marrow samples to the lab for specialist tests. These look for protein changes in your cells.

Scans: You may have an ultrasound or CT scan to see if HCL is affecting your spleen, liver, or lymph nodes. Not everyone needs a scan.

"It was a concern having to go through the tests, but they happened very quickly. It meant that HCL was diagnosed swiftly, which triggered the right treatment and recovery."

— *Sally, living with HCL since 2023*

Your haematology team will use your symptoms and test results to decide whether you need treatment straightaway.

It can be difficult waiting for and coming to terms with test results. If you need support, call our freephone Helpline on 08088 010 444.

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Treatment for HCL

HCL is usually treated with chemotherapy. You may also have an antibody therapy called rituximab. You have these treatments as an outpatient in a haematology day unit.

> **Some people only ever need one course of treatment. While others may have many months, years or even decades between treatments.**

You have treatment for HCL whenever your hairy cells build up enough to cause you problems. Most people need treatment soon after diagnosis. Some people don't need treatment for HCL straight away and go on to active monitoring instead.

Your haematology team is likely to recommend treatment if:

- You have troublesome symptoms, like fatigue and night sweats
- Your spleen, liver or lymph nodes become very swollen
- Your blood tests show low blood cell numbers

If you need to start treatment, your haematology team will discuss your options with you. They will recommend treatments based on:

- Your preferences
- Your symptoms
- Your blood counts
- Any genetic changes or markers in your hairy cells
- Your age, general health, and any other health conditions you may have

They will also discuss the side effects of treatment with you.

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Active monitoring

If you don't have any symptoms and your HCL is not causing you problems, you may be offered regular monitoring instead. This is called active monitoring or 'watch and wait'.

It can be confusing and unexpected to hear that you have HCL but not be offered treatment. However, research shows no benefit to starting treatment before you need it. Early treatment could do you more harm than good due to side effects. Treatment is available if or when you need it.

> "I was relieved to be put on active monitoring and not to need treatment for HCL right away. It helped me get used to this new condition that I was suddenly diagnosed with."
>
> *— Diana, living with HCL since 2023*

You can be on active monitoring immediately after diagnosis. You can also be on active monitoring after treatment, or in between periods of treatment for HCL.

While you're feeling well and on active monitoring, it's an opportunity to improve your general health. This can help you feel better and prepare for treatment. This approach is called 'prehabilitation'.

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Chemotherapy

There are two main chemotherapy medicines used to treat HCL:

- **Cladribine**: You usually have this as an injection under the skin of your tummy every day for 5 days.
- **Pentostatin**: You have this as a slow injection or through a drip over about 30 minutes. You usually have it once every 2 to 3 weeks for eight to ten treatments.

Both cladribine and pentostatin are very effective at killing hairy cells. You have either one or the other. Cladribine is used more often.

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Antibody therapy

Rituximab is an antibody designed to stick to certain proteins on the surface of cancer cells. This triggers your immune system to destroy the cells.

Rituximab can be used alongside cladribine or pentostatin. Adding rituximab to your treatment may help HCL stay under control for longer. Some people cannot have chemotherapy and have rituximab on its own instead.

If you need it, you have rituximab through a drip into a vein, usually once a week.

Reaction to the drip

Some people develop a reaction to rituximab while having the drip or within 24 hours. It can sometimes be serious.

If you're going to react, it usually happens the first time you have it. For this reason, you have a low dose at first, and you have it very slowly.

If your body reacts to rituximab, you may have symptoms like:

- Breathlessness
- Wheezing, coughing or tightness of the chest
- Rapid heart rate, restlessness and confusion

Your haematology team will monitor you closely for any signs of a reaction. This may include blood tests or a chest X-ray.

Tell the day team immediately if you develop any symptoms while you're having a rituximab drip. Or contact the hospital or call 999 if it starts afterwards at home.

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Other treatment options

Some people may need a different treatment called interferon. This medicine is a protein that helps your body fight viruses. You may have interferon if you're pregnant.

Your doctor may ask if you'd like to take part in a clinical trial. These are research studies to find out what treatments work best for people with HCL. They can give you access to treatments that are not routinely available, such as:

- New medicines
- New ways to use existing medicines, such as different combinations or doses

Your haematology team should explain the risks and benefits of taking part. It is completely up to you whether you'd like to take part, and you can withdraw from a trial at any time.

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Treatments to help with symptoms

Your haematology team may offer you supportive treatments. These help you manage symptoms of HCL or side effects of treatment. They can help you have a better quality of life, and some help you prepare for treatment.

They may include:

- Medicines to prevent or treat infections, like antibiotics
- Growth factor injections to boost your white blood cell count
- Vaccinations against flu, pneumonia, respiratory syncytial virus (RSV), shingles, and COVID
- Blood transfusions to treat low blood cell counts

If you’ve had treatment with cladribine or pentostatin, you should have irradiated blood whenever you need a blood transfusion for the rest of your life. This prevents a reaction called graft-versus-host disease (GvHD). Your haematology team should give you a patient alert card with this information. Carry it with you and show it to your medical team whenever you need a transfusion.

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Coping with side effects

Most medicines have side effects, including treatments for HCL. They vary depending on what treatment you’re having. They can also vary from person to person, even with the same treatment.

Side effects can affect your quality of life, and not just during treatment. While some side effects can be temporary, as your body adjusts to a medicine, others can cause health problems months or years later. These are called late effects.

Treatments for HCL often affect your blood counts and immune system. People being treated for HCL may develop infections that can lead to serious conditions like pneumonia or sepsis. Your haematology team should talk to you about ways to reduce your risk of infection before, during and after treatment.

"Like most, I was apprehensive before starting cladribine as to what my side effects would be. However, after the 5 days of injections, I did not react and just waited for my bloods to return to normal."

— Bruno, living with HCL since 2022

When to get help for side effects

Call 999 if you develop:

- Confusion, slurred speech, or you're not making sense
- Blue, grey or pale, blotchy skin, lips or tongue (on black or brown skin, look on the palms of the hands or soles of the feet)
- A meningitis-like rash, which does not fade when you roll a glass over it
- Breathing difficulties, such as breathlessness or rapid breathing

Contact your haematology team immediately if you think you have an infection. This includes:

- Respiratory or chest infections, like colds, flu, and pneumonia
- Skin infections, like cellulitis, shingles and herpes
- Eye infections, such as conjunctivitis
- Urinary tract infections
- Fungal infections, like thrush

> **Go to 111.nhs.uk, call 111 or speak to your haematology team if you're worried about symptoms during or after treatment. You don't have to wait until your next appointment to get help.**

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Outcomes of treatment

Your haematology team will check whether treatment has been successful. You may have blood tests, bone marrow tests and scans to check this. Most people respond well to treatment and have very good outcomes.

When HCL does not respond to treatment or comes back

It's rare for current treatments not to work. If this happens, it's called 'refractory' HCL. It's more common for HCL to come back, sometimes years or even decades later. When HCL comes back after successful treatment, it's called 'relapsed' HCL.

If you have refractory or relapsed HCL:

- Your team might suggest another round of treatment.
- They might offer you a different treatment from before. You may swap from cladribine to pentostatin or vice versa or have rituximab. Or they might suggest treatment as part of a clinical trial.

> “Treatments have changed drastically and improved so much over the years. I’m proof that you can survive and live life to the full. I’m now in my 15th year of remission. Although I insist on regular 6-monthly blood tests, I’m thankfully doing well.”
>
> *— David, living with HCL since 2003*

Find out more about outcomes for people with HCL.

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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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