

Hairy cell leukaemia (HCL)

What you need to know

leukaemiacare.org.uk

 **Leukaemia Care**

About **Leukaemia** Care

Every day, 28 people in the UK find out they have leukaemia. In that moment, and every moment after, we're here.



Helpline: Contact us for advice, support or a listening ear.

- Call our freephone helpline: **08088 010 444**
(weekdays 9am to 4.30pm)
- Message us on WhatsApp: **07500 068065**
(weekdays 9am to 4.30pm)
- Email [**support@leukaemicare.org.uk**](mailto:support@leukaemicare.org.uk)



Support groups: Connect, share experiences and find comfort from other people who've been affected by HCL.



Buddy support: Chat to someone who's had a similar experience to you and understands what you're going through.



Facebook groups: Connect online with other people with leukaemia or their carers in our closed Facebook groups.



Advocacy and welfare team: Get advice on financial support, housing, employment issues and more.



Leukaemia counselling service: Access up to six sessions of counselling to help you cope with the emotional impact of HCL.



Cost of living service: Apply for a one-off grant to help with essential living costs.



Will service: Write a free, simple Will so you know what happens to your money, property and belongings when you die.



Information: Find reliable information online and in print.

To access our services or find out more:

- Scan the QR code
- Call **08088 010 444**
- Search 'support' at leukaemiacare.org.uk



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This information is aimed at people in the UK. We do our best to make sure it is accurate and up to date but it should not replace advice from your health professional.

There is a lot of information about cancer on the internet. Some of it may not be reliable or up to date. A lot of it may not apply to you. Your doctor or nurse is your best source of information because they know you and your situation. If you want to search for information yourself, look for trustworthy organisations like the NHS or national charities. Check for a quality mark, such as the PIF tick.

This booklet includes addresses and QR codes that link to more information or support online. If you cannot access the links, please email information@leukaemiacare.org.uk or call **08088 010 444**.

Introduction



There is a lot of information in this booklet. Each chapter has a summary at the beginning if you'd prefer a short overview.

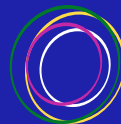
Hairy cell leukaemia (HCL) is a rare type of slow-growing blood cancer. It affects white blood cells called B lymphocytes. It's called hairy cell leukaemia because, under a microscope, the cancer cells look hairy. This booklet covers what HCL is, how it may affect you, diagnosis, and treatment options. We also include practical information about living with HCL.

We'd like to thank the expert reviewers and patient contributors who helped us with this information:

- Claire Dearden, Consultant Haematologist, The Royal Marsden NHS Foundation Trust
- Francesco Forconi, Professor of Haematology, Consultant Haematologist, University of Southampton Hospital Trust
- Helen Knight, Clinical Nurse Specialist, Nottingham University Hospital
- Bruno, Caroline, Gary, Julie, Paul

We'd also like to thank everyone who shared a quotation of their experience of HCL or caring for people with leukaemia.

About hairy cell leukaemia (HCL)



Summary

- Hairy cell leukaemia (HCL) is a rare, slow-growing blood cancer.
- It develops when white blood cells called B lymphocytes grow abnormally. The abnormal cells look hairy under a microscope.
- Hairy cells can gradually build up, usually in your blood, bone marrow, and spleen. When there are too many of them, they start to cause problems.
- HCL can affect adults of any age, but it is more common in middle-aged to older people and in men.
- We do not know the exact cause of HCL. It is not due to something you did or did not do.
- HCL can be controlled and, with treatment, it is not life-threatening.

What is HCL?

Hairy cell leukaemia (HCL) is a 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.

HCL is a chronic blood cancer, which means it's usually a slow-growing condition. At first, it's harmless, but over time, the number of hairy cells grows high enough to cause problems.

Hairy cells can build up in your body, often 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.

Bone marrow and types of blood cells

Blood cells grow and develop in the spongy centre of some of your larger bones. This is called bone marrow.

There are three main types of blood cells:



Red blood cells carry oxygen around your body



White blood cells fight infections



Platelets help your blood clot

With treatment, HCL can be controlled and is not life-threatening. People with HCL can live a normal life.

“ 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



Who gets HCL?

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

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

What causes HCL?

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

In HCL, there is 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 does not stop.

Understanding genes and proteins



DNA is like a thread of code in each cell of your body. Your DNA contains lots of different genes.



Genes contain instructions for your cells on how to make proteins. Proteins are important in the normal growth, development, and function of your cells.



Sometimes changes called variants occur within a gene. These variants can cause the cell to make different proteins, which can affect how the cell behaves.

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.

If you have a close relative (parent, brother, sister or child) with HCL, you may have a slightly higher chance of developing it too. The risk is still very low. Most people who have a close family member with HCL do **not** develop HCL.

“ Hopefully, I can give encouragement to others. I am certainly proof that you can survive and live life to the full. ”

David, living with HCL since 2003





Summary

- HCL symptoms depend on where the hairy cells build up in your body.
 - In your bone marrow, they can lower your numbers of healthy blood cells, causing anaemia, increased infections, or unusual bruising or bleeding.
 - In your spleen, they often cause swelling and tummy symptoms, like losing your appetite, feeling full quickly and pain.
 - In other parts of your body, like your liver, they may cause swelling and pain.

Symptoms of HCL

As hairy cells build up in your body, you usually get symptoms. These may be mild at first and worsen over time. If you have symptoms, they may be caused by:

- Hairy cells building up in your bone marrow, spleen or other parts of your body
- A lack of healthy blood cells

Most people with HCL already have symptoms when they are first diagnosed. But it can sometimes be found by chance when you have a blood test for another reason.

Common symptoms of HCL

Hairy cells can take up so much space in your bone marrow that it cannot make enough healthy blood cells. This can cause low blood cell counts.



If you have low red blood cells (anaemia), you may feel tired, dizzy, or breathless.



If you have low white blood cells, you may get infections more often than usual or struggle to get rid of them. This can mean more coughs, colds and other infections like urinary or skin infections.



If you have low platelets, you may have unexplained bruising or bleeding, like nosebleeds, bleeding gums or heavier periods.

Hairy cells often build up in your spleen, which may become swollen. 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

Sometimes hairy cells may build up in other parts of your body, such as your liver or, more rarely, your lymph nodes. These may become swollen and painful.

Signs and symptoms of infection can include:

- A high temperature (38°C or higher)
- A low temperature (below 35°C)
- Shivering
- Chills and sweating
- Feeling generally unwell, confused or disorientated
- Sore throat or sore mouth
- Sneezing, blocked or runny nose, earache
- Cough or shortness of breath
- Skin sores, injuries or intravenous lines that have become swollen or red (this can be harder to see on brown or black skin)
- Diarrhoea or vomiting (being sick)
- Burning or stinging when you pee, or needing to pee more often than usual
- Discharge from your genitals or itching around your genitals
- Unusual or new neck stiffness, along with finding bright lights uncomfortable
- New or worsening pain

General symptoms of leukaemia

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



Fatigue ([page 40](#))



Feeling generally unwell



Unintended weight loss



Night sweats



Fever



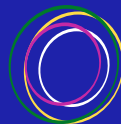
Loss of appetite

“ Looking back, I feel that my energy levels had been very low - like there was no fuel in the tank, for quite some time. ”

Sally, living with HCL since 2023



If you become concerned about new or worsening symptoms at any time, contact your GP or haematology team. You don't have to wait until your next check-up.



Summary

- Your haematology team will diagnose HCL based on:
 - A physical examination
 - Blood tests
 - Bone marrow tests
 - Specialist lab tests
- You may also have a scan to check your spleen, liver and lymph nodes.
- It can be difficult waiting for and coming to terms with test results. We are here for you if you need support. You can:
 - Email us at support@leukaemicare.org.uk
 - Message us on WhatsApp at **07500 068065**
 - Or call our freephone helpline at **08088 010 444**

Diagnosis of HCL

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

You'll be referred to a blood specialist (a haematologist) at the hospital. You usually have a physical exam and tests as an outpatient and go home the same day.

Some tests may be repeated throughout your care to check how your HCL is progressing or how you've responded to treatment.

Tests for HCL

A range of tests are used to diagnose HCL, including blood tests, bone marrow tests and genetic tests.

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

“ 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





You may have blood tests to check your numbers of blood cells and to look for hairy cells under a microscope.



You may have a bone marrow test, which involves taking a sample of bone marrow. This is usually taken from the back of your pelvis, with a local anaesthetic.



Your blood or bone marrow samples will go to the lab for specialist tests. These look for protein or gene changes in your cells. The main test for HCL is called immunophenotyping and checks for protein changes.



You may have an ultrasound or CT scan to check the size of your spleen, liver and lymph nodes. Not everyone needs a scan.

People often need support after their diagnosis. You may benefit from counselling, meeting people at a support group, or talking with a nurse advisor on our helpline on **08088 010 444**.

Find the help you need through our **support services**. Follow the link, scan the QR code or search for 'support' at **leukaemiacare.org.uk**





Summary

- Current treatments for HCL are very effective.
- They aim to control HCL rather than cure it, so you may need more than one course of treatment in your lifetime.
- Most people with HCL need treatment soon after diagnosis.
- If you don't have symptoms, you may not need treatment immediately. You may have regular check-ups and monitor your symptoms instead. This is called active monitoring.
- If you need treatment, you usually have chemotherapy on its own or combined with antibody therapy.
- You may also have other medicines to prevent or manage symptoms or side effects.
- Outcomes are usually very good. Most people with HCL live long lives, similar to people without HCL.

Treatment of HCL

Most people diagnosed with HCL have symptoms and need treatment soon after diagnosis.

Some people do not need treatment immediately and have regular check-ups instead. This is called active monitoring.

You have treatment for HCL whenever your hairy cells build up enough to cause you problems. After or in between treatments, you usually go onto active monitoring.

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

Active monitoring for HCL

If your HCL is not causing you problems, you may not need treatment straight away. Instead, your haematology team will see you for regular check-ups, and you'll monitor your symptoms at home. This is called active monitoring or 'watch and wait'.

It can be confusing and unexpected to hear that you have blood cancer but are not starting treatment. However, research shows no benefit to starting treatment before you need it. Early treatment could do you more harm than good due to the side effects ([page 27](#)). Treatment is available if or when you need it.

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.

“ 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

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'.

“ I strongly advise people on active monitoring to be proactive. Take good care of their general health, watch their weight, exercise, don't smoke, monitor their blood pressure and cholesterol – this also reduces their risk of blood clots, including stroke and heart disease. ”

**Professor Claire Harrison, Haematology
Consultant and Deputy Chief Medical Officer**

We have separate information on **active monitoring**. Follow the link, scan the QR code or search for 'active monitoring' at leukaemiacare.org.uk



Treatments for HCL

Your haematology team is likely to recommend treatment if:

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

Current treatments for HCL are very effective. They aim to keep your HCL under control rather than to cure it. This means that you may need more than one course of treatment for HCL in your lifetime. 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 ([page 27](#)).

HCL is usually treated with chemotherapy. You may also have an antibody therapy called rituximab.

“ Currently, people with HCL who need treatment for the first time in the UK are offered cladribine injections for 5 consecutive days. These can be combined with or followed by rituximab weekly to maximise the depth and duration of response. ”

Professor Francesco Forconi, Professor of Haematology, Consultant Haematologist

Chemotherapy medicines

The main chemotherapy medicines used to treat HCL are called cladribine and pentostatin. They are both very effective at killing hairy cells. You have either one or the other. Cladribine is used more often.

You have them in hospital at a day unit:

- 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.

Unlike some chemotherapies, cladribine and pentostatin **do not** cause hair loss.

Antibody therapy

Rituximab is an antibody therapy designed to stick to proteins called CD20 on the surface of cancer cells. This triggers your immune system to destroy the cells.

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

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

Some people develop a reaction to rituximab, usually the first time they have it. For this reason, you have a low dose at first, and you have it very slowly.

Your body may react to rituximab while having the drip or within 24 hours. It can sometimes be serious. 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.

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.

Other treatment options

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

“ After treatment, HCL is likely to return at some point. But treatments are successful and getting better all the time. In between HCL episodes, you can live a normal life. ”

Julie, living with HCL since 1995



Clinical trials

Your haematology team may ask if you'd like to take part in a clinical trial, if there is one suitable for you. This is a research study that aims to find out what treatments work best for a particular condition.

Taking part in a clinical trial may give you access to treatments that are not routinely available. There are risks and benefits to taking part, which your haematology team should explain to you.

It is your decision whether to join a clinical trial. You can withdraw from a trial at any time.

Cancer Research UK have [more information about clinical trials](#). Follow the link, scan the QR code or visit [cancerresearchuk.org](https://www.cancerresearchuk.org) and search 'find a clinical trial'.



Supportive treatments

You may also have other treatments to help manage symptoms of HCL or side effects of treatment. These supportive treatments help you have a better quality of life. Some help you prepare for treatment, if you need it.

They may include:

- Medicines to prevent or treat infections, like antibiotics
- Growth factor injections to boost blood cell counts
- Vaccinations against infections, such as COVID-19, flu, pneumonia, and shingles
- Blood transfusions to treat low blood cell counts

Irradiated blood

If you've had cladribine or pentostatin for HCL, 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. Show it to your medical team if ever you need a transfusion.

The NHS Blood and Transplant service has **more information for people needing irradiated blood.** Follow the link, scan the QR code or visit **hospital.blood.co.uk** and search 'irradiated blood'.



Side effects

Most medicines have side effects, including treatments for HCL. Some side effects can be temporary while your body adjusts to a medicine. They vary depending on what treatment you're having. They can also vary from person to person, even with the same treatment.

Your haematology team should explain what side effects you might expect and what to do if you get them.

Side effects can make a big difference to your quality of life, and not just while you're being treated. Some may cause health problems months or years after treatment.

The [electronic medicines compendium](#) has more information about the side effects of treatments for HCL. Follow the link, scan the QR code or visit [medicines.org.uk/emc](https://www.medicines.org.uk/emc) and search for your medicine.



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.

Infections

Treatments for HCL often affect blood counts and lower your immune system. People being treated for HCL may develop infections that can lead to serious conditions like pneumonia or sepsis. There are things you can do to reduce your risk of infection before, during and after treatment ([page 38](#)).

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 or pneumonia
- Skin infections, like cellulitis, shingles or herpes
- Eye infections, such as conjunctivitis
- Urinary tract infections
- Fungal infections, like thrush

For a list of signs and symptoms of infection to look out for, **see page 14**.

“ 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

Follow up during and after treatment

Your haematology team will check whether treatment has been successful. You may have:

- Blood tests during treatment and more blood tests when treatment has finished
- A bone marrow test during or after treatment, depending on the treatment you have
- An ultrasound or CT scan of your spleen, liver and lymph nodes

“ 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

If HCL does not respond or comes back after treatment

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 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 ([page 25](#)).

If you'd like to talk to someone who understands what you're going through:

- Call our freephone helpline on **08088 010 444**
- Message us through WhatsApp on **07500 068065**
- Email support@leukaemiacare.org.uk

Outcomes of treatment

Outcomes for people with HCL are usually very good because treatments are so effective.

After a first course of treatment, people often have a long period of remission.

We cannot predict how long you may be in remission, but it could be many years or even decades. During this time, you can focus on living well and doing things you enjoy.

With treatment, people with HCL can expect to live long lives, similar to people without HCL.

If you want to know as much as possible about your long-term outlook, it's best to talk to your doctor or haematology team. They can take into consideration everything they know about you, your HCL, and the care they can offer you.

Some people want to know what might happen to them in their own time. We have further **[information on outcomes for people with HCL](#)**. If you want to see these, scan the QR code or contact the information team at **information@leukaemicare.org.uk** or on **08088 010 444**.





Summary

- Having HCL can affect your day-to-day life and impact you physically and emotionally
- You may experience a variety of emotions. There is no right or wrong way to feel.
- You may want to talk to your friends and family about having HCL. Remember, if or when you tell people is your choice.
- You're more likely to get infections and find it harder to get rid of them when you have HCL or have treatment for HCL. There are steps you can take to reduce your risk of infection.
- You may experience fatigue. Pacing yourself and saving your energy for what matters to you can help.
- Keep active and eat a healthy, balanced diet, if you can, to help your general fitness.
- Having HCL can affect your work and finances. You may need adjustments or support to continue working or studying.
- You probably have lots of questions. Make a list of them for when you see your haematology team.
- If you are struggling, ask for help from friends, family, your haematology team or Leukaemia Care.

Living with HCL

Being diagnosed with HCL can feel overwhelming. It can affect you both physically and emotionally. Your symptoms, side effects of treatment, and hospital appointments can all impact your day-to-day life. Here, we cover some practical information about living with HCL and where to get support.

Managing your emotions

Being diagnosed with blood cancer can be very upsetting. You may experience a range of complex thoughts and emotions, which may be strange and unfamiliar to you.

You may feel anxious, depressed, uncertain about your future, or relieved that you have an explanation for how you've been feeling. Everyone is different. There is no right or wrong way to feel. Your feelings may also change if or when you start treatment or go onto active monitoring.

Whatever stage you're at, support is available. Even though you have a rare leukaemia, you can still talk to other people living with HCL.

We have separate [**information on the emotional impact of leukaemia**](#). Follow the link, scan the QR code or search for 'emotional impact' at [**leukaemicare.org.uk**](http://leukaemicare.org.uk)



You are not alone

Sometimes it can help to talk to someone who really understands what you're going through. Our support groups, Facebook groups, and buddy service can connect you with people who've been there too. If you'd like to talk to someone who has the same condition or a similar condition as you:

- Call our freephone helpline on **08088 010 444**
- Message us through WhatsApp on **07500 068065**
- Email support@leukaemiacare.org.uk

“ I really appreciate Leukaemia Care's buddy service. I first spoke to my buddy after my initial treatment. Talking to someone who'd had HCL for 30 years was incredible. I felt so much more confident about my own future. If either of us needs treatment again, we'll support each other through it. ”



Caroline, living with HCL since 2024

Sadness and depression

You might be feeling anxious and low, which is a natural effect of your diagnosis and can be caused by some treatments for HCL. However, you may have depression if:

- Your low mood persists for several weeks
- You feel hopeless
- You lose interest and pleasure in life

If you think you may be depressed, contact your GP. They can help you access the support and treatment you need.

If you need urgent mental health support, call 111 and select the mental health option.



“ I believe in staying positive. I take each day as it comes with a relaxed and positive attitude, which has certainly helped me through the difficult times. ”

Peter, living with HCL since 1989



Telling people

When you're first diagnosed with HCL, there is a lot to take in. You may need time to adjust before deciding when and how you tell others about it. There will be some people that you want to tell and others you prefer not to. It's up to you who you speak to and how much you tell them.

People may be anxious to know what's happening, particularly if you need treatment straight away. You may feel under pressure to tell them as a result. Let them know you need time to process the information yourself before you're ready to talk about it.

In conversation with your loved ones, you might want to:

- Explain that you have a rare, slow-growing condition that affects your white blood cells and your blood cell numbers.
- Tell them what symptoms you get and how they affect you.
- Explain what treatment you might be offered. You might want to talk about the possible outcomes of treatment.
- Explain your needs. Your family and friends may be happy to know they can support you by helping around the house or doing the food shop.
- Be open and honest about how you feel. Often people will want to help you as best as they can.
- Have a print-out or factsheet handy so you don't have to remember everything your friends and family might want to know. Or you could give them a copy of this booklet.

Reducing your risk of infection

If you have HCL, you're more likely to get infections than other people. If you get infections, they can be harder to get rid of than usual or more severe. This is because the hairy cells in your body stop your immune system from working properly.

You may have low levels of some types of white blood cells, which usually fight infections. If you're on treatment for HCL, it can also reduce your immunity.

“ It's best if your GP is informed how vulnerable you are to infection and has it flagged on the system. This may help you get an appointment more quickly and, hopefully, avoid waiting in crowded waiting rooms. ”

Gary, living with HCL since 2005

Contact your haematology team straight away if you have any signs or symptoms of infection ([page 14](#)). It's important to get prompt treatment, so don't wait until your next appointment.

The International COVID-19 Blood Cancer Coalition has more information on personal risk and [steps you might take to avoid infection](#). Follow the link, scan the QR code or visit icbcc.info and search for 'campaign materials'.



Tips to reduce your risk of infection

There is always a balance between taking care and living a fulfilling life. Everyone is different, and what one person is happy to compromise on, another person isn't. These tips are a guide to things you can do to reduce your chance of infection, if you choose to:

- Stay away from people who have infections and avoid crowded places where infections can spread more easily.
- Inform your workplace that you need help to avoid infections at work.
- Have vaccinations your haematology team recommend and encourage people you live with to have vaccinations they're eligible for too.
- Take medicines or supplements that your haematology team recommend to help prevent infections.
- Wash your hands regularly and keep your body clean too.
- Brush your teeth well and go to the dentist regularly.
- Store and prepare food safely. Avoid eating undercooked food or food that has passed its use-by date.
- Avoid cuts and grazes if you can. Wear protective clothing, shoes and gloves when you're gardening. If you shave, consider swapping from a razor to an electric shaver.

Coping with fatigue

Many people with HCL experience extreme tiredness or lack of energy that doesn't get better with rest. This can interfere with your usual activities and can be frustrating. After treatment for HCL, fatigue sometimes gets better over time.

Tell your haematology team if you have fatigue. They may be able to suggest things to help or refer you for support if you need it.

Tips for coping with fatigue

Plan activities and pace yourself:

- Prioritise things that are important to you and save energy for these
- Accept help where you can

Balance rest and exercise:

- Take regular, gentle exercise
- Rest when you need to
- Try yoga or meditation, as these can help

Keep to a regular sleep schedule:

- Try to go to bed and wake up at around the same time each day
- Keep your bedroom quiet and at a comfortable temperature
- Avoid eating or drinking alcohol, coffee, tea, or chocolate before bedtime
- Avoid using electronic devices before going to bed

Healthy living

It is important to look after yourself well when you have HCL. Living healthily has many benefits. It can improve the quality of your life and help you cope with fatigue and other effects of HCL.

Adopting a healthier way of living is about making small, manageable changes to your lifestyle. If your current lifestyle is less than ideal, it's best to pace yourself and avoid changing too much at once.

“ I'd put on a lot of weight. But having my brush with HCL, I decided I'd be crazy to mess it up myself. So, I adopted a healthier lifestyle and, through diet and exercise, I lost 12 stone. I kept the weight off and decided to take early retirement to enjoy life to the full. ”



David, living with HCL since 2003

Diet

If you can, try to eat a healthy, well-balanced diet. This will help you:

- Feel stronger
- Have more energy
- Cope better with treatment if you need it

Side effects from some treatments, such as sickness and diarrhoea, can make it difficult to eat a healthy diet. If you are struggling, ask your haematology team for advice.

Exercise

Exercise can improve your general health, quality of life and wellbeing. It can also help to reduce some of the side effects and symptoms you may be experiencing, such as fatigue.

You may not feel like being active, especially if you are experiencing fatigue. Remember, even a gentle walk can help. Choose a level of exercise that works for you and how you're feeling.

The NHS website has [information and guidance on eating well and exercise](#). Scan the QR code, or go to the 'healthy living' section at [nhs.uk](https://www.nhs.uk)



Sun safety

HCL can make you more vulnerable to skin cancer, and so can some treatments, including cladribine and pento-statin. You need to protect yourself from the sun and be particularly mindful of any skin changes.

Tips for preventing skin cancer

- Keep to the shade between 11 am and 3 pm on sunny days.
- Cover your skin with clothes, including a hat, shirt and sunglasses.
- Use a high-protection sunscreen of at least SPF 30 with UVA protection too. Apply it generously and often.
- Get to know what's normal for your skin by checking it regularly.
- Tell your doctor about any changes to a mole or any new or unusual marks on your skin that haven't gone away within 2 months.
- Go for annual skin checks if you're referred for them.

Work and education

Being diagnosed with HCL and having to juggle work or education with hospital or GP appointments can be challenging. Your diagnosis, managing symptoms or side effects, or going to appointments may mean you need time off from work.

You are entitled to reasonable adjustments at work. Your haematologist or GP can write letters to your employer to confirm your diagnosis and how this may affect your work life. This can help your employer have arrangements in place for when you need time off and to discuss how else they can support you.

If you are diagnosed with HCL while you're attending college or university, you should contact them. They might be able to offer you extra support, pause your studies, or defer your attendance for a while if you need it.

Money and financial help

Your HCL diagnosis may affect your finances, whether you are working or not. Being diagnosed with HCL can come with extra costs, such as travel to and from hospital, childcare costs or parking charges.

You should be able to get free NHS prescriptions as a person with cancer. Your haematology team or GP can tell you how to apply.

We have a range of **services that can help you**, including a welfare service and cost of living hub. Follow the link, scan the QR code or search 'support and community' at leukaemiacare.org.uk



Macmillan also have **information on benefits and financial support**. Follow the link, scan the QR code or search for 'benefits and financial support' on macmillan.org.uk for more information. Or contact them on **0808 808 0000** to discuss your eligibility for benefits, grants and support available.



Going to appointments

Hospital and GP appointments often involve a lot of waiting around. You could download a podcast or TV programme to keep you occupied while you wait. Or take something physical like a book or travel game.

Once you're in your appointment, it can be hard to take in everything your doctor or nurse is telling you.

Here are some tips to help you get the most from your appointment:

- It can help to take a family member or friend with you for support.
- Ask any questions you have. If you don't understand something, ask your haematology team to explain. They will be used to this.
- You can take notes on your phone or paper to help you remember. You can always ask your doctor or nurse to make notes for you, or ask if they are happy for you to record the conversation.
- Be open and honest when discussing your symptoms and how you are coping. You and your haematology team are working together to keep you well.

“ Sometimes your brain's not in the right place. The first time I needed treatment, I was feeling too ill to think straight. I had very low blood counts and couldn't fully absorb what I was being told. Looking back, it led to some questionable decision-making on my part! ”

Gary, living with HCL since 2005

Questions for appointments

Sometimes it can be hard to know what to ask in your appointments. Questions you might want to ask include:

- What tests will I need?
- What might these tests show?
- How long will it take to get the results back?
- How will I get my results? By phone, letter or email?
- Will I need treatment?
- What treatment will I need and how long for?
- How will I know if my treatment is working?
- What might the side effects be?
- Are there any foods or medicines I need to avoid?
- Will I be able to go to work?
- Where can I get help claiming benefits and grants?
- Where can I get help dealing with my feelings?

Words you might see or hear



Antibody: an immune system protein that helps fight infections by sticking to targets on the surface of cells that don't belong in your body.

Antibody therapy: a lab-made antibody that sticks to targets on cancer cells, so your immune system can kill the cells.

BRAF gene: the gene that codes for the BRAF protein, which helps control growth, development, and survival of cells.

Cancer: an illness that happens when abnormal cells grow and divide uncontrollably.

Chemotherapy: medicine that kills cancer cells or stops them dividing and multiplying.

Clinical nurse specialist (CNS): an experienced nurse who has specialised in a particular area of nursing. They can offer you advanced care, support, advice and guidance.

CT scan: a scan that uses X-rays and a computer to make detailed pictures of the inside of your body.

Growth factor: a type of medicine that boosts your blood cell counts.

Haematologist: a doctor who specialises in diseases of the blood.

Haematology: the branch of medicine that deals with diseases of the blood and bone marrow.

Liver: a large organ in your body that sits under your ribs on the right. It helps fight infection and disease, balances your hormones, cleans your blood and processes food.

Lymphocyte: a type of white blood cell that helps fight infections.

Lymph nodes: small, bean-shaped structures in your neck, armpits, groin and other parts of the body that are part of your immune system. They may become swollen when you are unwell.

Prehabilitation (prehab): a way of getting ready for treatment before it starts by improving your general health.

Proteins: the building blocks of every cell, tissue and organ in your body. Your body needs proteins for growth, repair, and to fight infections.

Refractory: cancer that does not respond well to your first treatment.

Relapse: when cancer comes back after successful treatment.

Remission: when tests or scans after treatment can find little or no cancer left in your body.

Spleen: a fist-sized organ that sits under your ribs on the left side. It filters and stores blood and makes some blood cells.

Transfusion: having blood or blood products through a drip into a vein.

Useful contacts



Here are some organisations you might find helpful.

Leukaemia Care

- Helpline: **08088 010 444**
(weekdays 9am to 4.30pm)
- WhatsApp: **07500 068065**
(weekdays 9am to 4.30pm)
- [leukaemiacare.org.uk](https://www.leukaemiacare.org.uk)
- support@leukaemiacare.org.uk

Hairy Cell Leukemia Foundation

- Leading US charity dedicated to HCL education and research.
- [hairycellleukemia.org](https://www.hairycellleukemia.org)

Blood Cancer UK

- Leading charity into the research of blood cancers.
- **0808 2080 888**
- [bloodcancer.org.uk](https://www.bloodcancer.org.uk)

Macmillan

- Provide free, practical, medical and financial support for people facing cancer.
- **0808 8080 000**
- **macmillan.org.uk**

Cancer Research UK

- Leading charity dedicated to cancer research.
- **0300 1231 022**
- **cancerresearchuk.org**

Maggie's

- Offer free practical, emotional and social support to people with cancer and their loved ones.
- **0300 1231 801**
- **maggies.org**

Carers UK

- Offers advice, information and support for carers.
- **0808 808 7777**
- **carersuk.org**

How you can help us

We've built an active community centred around emotional care, practical guidance, and raising awareness. We help people spot the signs, get diagnosed earlier, and feel supported through it all.

We can't do this alone. Whether you can give your money, effort, time or kindness, it matters. Your generosity means more people feel seen, understood, and less alone.

On the next few pages are some of the ways you can help.

For more information:

- Scan the QR code or visit leukaemiacare.org.uk
- Call **08088 010 444**
- Write to **Leukaemia Care, One Birch Court, Blackpole East, Worcester, WR3 8SG**
- Email the addresses listed on the following pages





Tell us what you think

Follow the link or scan the QR code to complete **a short survey** about how we can improve our information. You can also contact us for a list of sources we used.



- Email information@leukaemicare.org.uk

Share your story

Real stories shape our work. Sharing your story can help others in a similar situation. It can also help people understand HCL better.

- Email communications@leukaemicare.org.uk

Volunteer with us

Our volunteers are at the heart of everything we do. Whether you can give a few minutes online or commit to a regular role, there are many ways you can get involved.

- Email volunteering@leukaemicare.org.uk

Fundraise for us

Every fundraising activity or event, big or small, helps support people affected by leukaemia, MDS and MPN.

- Fancy the chance to win £25,000? Join our weekly lottery from as little as £1 a week.
- Ask your society, group or sports club about their charity of the year partner.
- Does your employer make charitable grants or donations to good causes?
- Organise your own event. You could host a quiz night or bake sale with friends, at work or school.
- Prefer to get outdoors? Take on one of our challenges of varying levels. Walk, run – or, for the more adventurous, a skydive?

Contact our fundraising team:

- Email fundraising@leukaemiacare.org.uk





Donate to us

Whether you can give a little or a lot, your donation means faster diagnosis, all-rounded care, and better days ahead. There are so many ways you can give. Find one that fits you!

- By bank transfer
 - Account name: **Leukaemia Care**
 - Sort code: **20-98-61**
 - Account number: **80823805**
- By cheque
 - Please make your cheque payable to **Leukaemia Care**
 - Post it to **Leukaemia Care, One Birch Court, Blackpole East, Worcester, WR3 8SG**
- Online
 - Visit leukaemicare.org.uk
- By phone
 - Call **08088 010 444** to donate by debit or credit card



Every day, 28 people in the UK find out they have leukaemia. In that moment, and every moment after, we're here.

At Leukaemia Care, we support anyone affected by leukaemia because leukaemia can affect anyone. Whether you're living with it, loving someone through it, or coping with the impact of it, you're not alone.

Want to talk?

- Call our freephone Helpline: **08088 010 444**
(weekdays 9am to 4.30pm)
- Message us on WhatsApp: **07500 068065**
(weekdays 9am to 4.30pm)
- Visit leukaemiacare.org.uk
- Email support@leukaemiacare.org.uk

Leukaemia Care, One Birch Court,
Blackpole East, Worcester, WR3 8SG



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