

# Chronic lymphocytic leukaemia (CLL)

Your guide to diagnosis,  
treatment and living  
well with CLL

**Blood  
cancer  
UK**

## Need to talk?

Contact the Blood Cancer UK Support Service with questions or worries about your diagnosis, family, work, mental health, the future.



Call free on **0808 2080 888**

(Monday: 10am to 7pm, Tuesday to Friday: 10am to 4pm  
and Saturday and Sunday: 10am to 1pm)

Email **support@bloodcancer.org.uk**

Visit **bloodcancer.org.uk**

Talk to others **bloodcancer.org.uk/our-forum**

We're the UK's specialist blood cancer charity, supporting anyone affected by any blood cancer. Family and friends can contact us for support too.

## My diagnosis and care

Ask your doctor or nurse to help you fill in this page about you, your diagnosis and key contacts:

### My diagnosis is:

.....

My hospital number is: .....

My NHS number is: .....

### My main point of contact (key worker) is:

Name: .....

Role: .....

Phone no: .....

Email: .....

You should be given a key worker. Ask if you're not sure who this is, or call us.

### My consultant's name is:

.....

Haematology ward/clinic: .....

Phone no: .....

### If I need medical help outside normal hours, I can call:

Name of service: .....

Phone no: .....

# In this booklet

**1**

<b>Finding out you have CLL</b>	<b>5</b>
What happens after diagnosis?	<b>6</b>
Checklist of things you can do	<b>8</b>
Telling people about your diagnosis	<b>10</b>

**2**

<b>Understanding CLL</b>	<b>13</b>
What is CLL?	<b>14</b>
What does the future look like?	<b>16</b>
Your risk of infection	<b>18</b>
Covid-19 and flu vaccinations	<b>20</b>
Looking after your skin	<b>20</b>
If you're feeling overwhelmed	<b>21</b>

**3**

<b>Coping with watch &amp; wait</b>	<b>23</b>
Why am I waiting for treatment?	<b>24</b>
How often will I have check-ups?	<b>25</b>
What happens at a check-up?	<b>26</b>
Waiting for test results	<b>27</b>
Will I need treatment in the future?	<b>28</b>
Coping with your symptoms	<b>31</b>
Coping with your feelings	<b>32</b>
Questions to ask about watch and wait	<b>34</b>
Finding out about treatment	<b>35</b>

## 4

### **If you need treatment** **37**

What to expect	<b>38</b>
Tests you may have	<b>40</b>
Bone marrow biopsies	<b>42</b>
What treatment will I have?	<b>44</b>
How will treatment affect my daily life?	<b>49</b>
Protecting your fertility	<b>50</b>
Treatment side effects	<b>51</b>
Questions to ask about treatment	<b>53</b>
The future of CLL treatment	<b>54</b>

## 5

### **Living well with CLL** **57**

What can I do to help myself?	<b>58</b>
Positive thinking	<b>62</b>
Managing fatigue (tiredness)	<b>64</b>
Keeping active	<b>66</b>
Eating well	<b>67</b>
How to help your family and friends	<b>68</b>
Working when you have CLL	<b>70</b>
Help with money	<b>72</b>
Places to get support	<b>74</b>

# Finding out you have CLL



## **If you have a diagnosis of chronic lymphocytic leukaemia (CLL), this booklet is for you.**

Getting a diagnosis of CLL may have come as a bit of a shock and you're probably feeling there's a lot to take in.

With the help of people who know what it's like to live with CLL, we have written this booklet to give you the basics, so you understand a bit more about what having CLL might mean for you.

Don't feel you have to read it all at once. Keep it handy so you can come back to it when you're ready or show others to help them understand.

This booklet is also for people with small lymphocytic lymphoma (SLL), which develops and is treated in the same way as CLL.

**I found Dr Google full of confusing and frightening information. So ignore it and rely on what you find on good sites like Blood Cancer UK.**

Mel, living with CLL since 2013





## What happens after diagnosis?

Your CLL diagnosis may have come as a shock. Most people are diagnosed with CLL after a routine blood test, so you may not even have thought there was anything wrong.

## Is it normal to feel how I'm feeling?

Being diagnosed with cancer is life-changing and it's a lot to get used to. People talk about feeling stunned, sad, angry, scared, numb...and it can change from minute to minute. So whatever you're feeling now is normal in these difficult circumstances. And you're not alone.

There are around 250,000 people with blood cancer living in the UK, and over 30,000 of them have CLL. So there are other people who will completely understand. You might find it helpful to connect with some of them on our online forum at [bloodcancer.org.uk/our-forum](https://bloodcancer.org.uk/our-forum)

“

**What I've learned is that there's no point fighting your diagnosis. By accepting it you're rolling with the punches and moving forward. But I would never have got to that position without support.**

Kate, living with SLL since 2010





## The next steps

It's useful to know what will happen next after you've been diagnosed, but it can be hard to take in what your doctor or nurse has told you. Don't be afraid to ask questions and ask them to go over things again. In the meantime:

- 1. You should be given contact details of a key worker,** your main point of contact in the hospital team. Usually, this is a clinical nurse specialist (CNS). Sometimes, if you're not having active treatment, your GP will be your key worker. Ask who is responsible for your care and who to contact if you have questions.
- 2. You may have more tests** to find out more about the type of CLL you have, whether you need treatment straight away, and what treatment will work best for you. Ask your team what the tests are for and if you'll have them again.
- 3. Your hospital team will explain your treatment plan** or how you will be monitored if you don't need treatment yet. Ask any questions you like, including how the treatment or your symptoms will affect everyday things like driving, working, housework and gardening. It's also OK to ask for another appointment. Most people need more than one visit to take it all in.

Some people don't feel confident about talking to their hospital team at first. If you find this difficult, call our Support Service who can give you tips on how to build a relationship with your team.

## Checklist of things you can do

The first thing you might want to do is contact us. We can help you start to understand your diagnosis and think about what comes next.

Here are some suggestions of practical things to do to make life a bit easier for you in these early days:

- Put all your appointments in a diary or calendar so you know what's coming up.
- Decide how you will get to face-to-face appointments and consider taking someone with you, if your hospital says it's OK. Many people find this helpful.
- Keep a list of questions to ask at your next appointment or to email to your CNS.
- Choose books, magazines, podcasts or videos to give you something to do if you have to wait.
- Get a folder to keep medical letters and health information in one place.
- If you need to, think about who could help you with things like shopping, cooking, gardening, housework, childcare or caring for someone.
- Follow general advice on healthy eating and try to stay active.

# If you need to talk

If you want to talk about what your diagnosis means, how you're feeling or what to do next, contact our Support Service free on **0808 2080 888** or **support@bloodcancer.org.uk** and tell us that you've just been diagnosed with CLL.

Or talk to people who've been where you are now on our online community forum **bloodcancer.org.uk/our-forum**

## Telling people about your diagnosis

When they hear your news, most people will be supportive and offer help. But here are some tips if you have to handle some more difficult reactions:

- **If people get upset** – Explain that CLL is a slow-growing blood cancer, that you can live with it and have a good quality of life. If you end up having a cry too, that's fine!
- **If people don't know what to say or say nothing** – Next time you see them, bring up the subject so they know it isn't something they need to avoid. Then move the conversation on to other things.
- **If people say unhelpful things** – Point them to the Blood Cancer UK website or give them a copy of this booklet so they'll understand more about what living with CLL is like.

Don't be afraid to tell people how you want to be treated. Most people just want others to behave as normal.

“

**Some people made eye contact, some looked at me sideways and some avoided me. My pet hate was people saying I looked well when I felt absolutely terrible inside.**

Erica, living with CLL since 2003



## Telling children

The first thing is to decide whether you want to say anything. If nothing's changed outwardly, you may decide that the children you're close to don't need to know right now, if at all. But if your symptoms or treatment are likely to cause changes to your routine or appearance, you may think it's better to explain what's happening.

Most people say it's best to be as honest as you can. Children of different ages can react in different ways, but our Support Service can recommend some age-appropriate resources to help you. Or other people with blood cancer will share their experiences at **[bloodcancer.org.uk/our-forum](https://www.bloodcancer.org.uk/our-forum)**

## Telling your workplace

You don't have to tell your employer about your diagnosis, but you might want to, even if you don't need treatment. It means you can discuss adjustments to help you deal with CLL symptoms such as tiredness (fatigue). See page 70 for some examples of adjustments that might help you carry on working, and information about your rights as someone with cancer.

You might also benefit from a workplace risk assessment, as you're likely to be at risk from infections such as covid or flu.

If you want other people at work to know about your diagnosis, you can ask your line manager or HR team to tell work colleagues. Or tell them yourself, it's your choice. Your employer can't tell anyone without your permission.

# Understanding CLL



# Many people find it helps them feel more in control to learn about what CLL is and how it can affect their body.

People often talk about having to learn a whole new language when they're diagnosed with CLL. Different people have different feelings about how much they want to research and read up on their condition, and that's a personal choice. But most would agree there are some things it's good to know straight away.

This section of the booklet gives you a very brief summary of what CLL is and the health risks that come with it. This is so you know what you need to do to enjoy life, while keeping yourself safe.

Knowing more about CLL can also make you feel more confident about asking questions so you can get more out of your appointments at the hospital or with your GP.

**You may not even have heard of CLL before, but you will get used to the new lingo and end up becoming a bit of an expert in your own condition.**

Gerard, living with CLL since 2017





## What is CLL?

CLL is a type of blood cancer. It's a chronic condition which means it's lifelong, but usually progresses very slowly.

CLL affects blood cells called lymphocytes, which normally work as part of your immune system, helping you fight off infections.

When you have CLL, your body makes abnormal lymphocytes that don't work properly and grow too fast. They can't fight infection effectively so your immune system doesn't work as well as it should.

As the number of abnormal lymphocytes rises, the number of normal cells in your blood can drop, causing a range of other symptoms.

When you're diagnosed with CLL, you may have some of the symptoms listed below, or you may not have any:

- extreme tiredness (fatigue)
- swollen glands (lymph nodes)
- repeated infections, such as colds and flu
- losing weight without trying
- high temperature (fever)
- drenching night sweats.

It's important to know that fatigue is very common with CLL. You can have it at any time, even if you feel well otherwise. Find out more about managing fatigue on page 64.

## Small lymphocytic lymphoma (SLL)

If most of the leukaemia cells are in your glands (lymph nodes) rather than your blood, you may be told you have small lymphocytic lymphoma (SLL).

SLL is the same type of blood cancer as CLL and the treatment is the same. So whenever we say CLL, we mean SLL as well.

### Key facts about CLL

1. It's a slow-growing type of blood cancer.
2. You may not need treatment yet, and some people don't ever need treatment.
3. If you do need treatment, there are lots of effective options.
4. Treatment might be daily tablets rather than classic chemotherapy.

## What does the future look like?

After you've been diagnosed with CLL, you may want to know more about your prognosis (what could happen in the future).

Thanks to research, new treatments for CLL have been introduced in recent years and overall, people with CLL have a much better prognosis than previously.

CLL isn't a type of blood cancer that can be cured, but it can be managed so you have a good quality of life. Managing CLL might mean regularly monitoring your symptoms and checking what's happening in your blood. Or it might mean treatment with cancer drugs – either ongoing or just when it's needed.

CLL normally progresses very slowly. For some people, it might progress more quickly. Everyone is different and your prognosis is personal to you.

“

**As for Googling, when I was diagnosed all I could find was a prognosis of 5 to 10 years and 18 years later I am still here.**

Erica, living with CLL since 2003



## If you want to know more

The best people to ask about your prognosis are your hospital team or GP. They know you and your individual situation.

Tell them about any concerns you have for the future. It's helpful for them to know what you're thinking and feeling so they can give you the care that's right for you.

If you want to talk about your prognosis but find it difficult to start the conversation, contact our Support Service to talk through how you could approach it.

You'll find information in this booklet about monitoring (see page 23) and treatment (see page 37). Information about living with CLL starts on page 57.

You may also be interested in our research to improve treatments. Go to **[bloodcancer.org.uk/researching](https://www.bloodcancer.org.uk/researching)**

## Your risk of infection

Having CLL makes it more likely you'll get infections, because the condition affects your immune system. This is the case whether or not you need treatment.

If you get an infection when you have CLL, it can become more serious, because your body might not be able to fight it off effectively. In some cases, an infection can turn into sepsis, which is life-threatening. It's important to be aware of this, because if you act fast when you have an infection, it can be treated before it gets worse.

There are simple things you can do to lower your risk of infection such as washing your hands frequently, staying away from anyone who has an infection, avoiding crowds and wearing a face mask when you're out.

Your doctor will usually recommend a flu jab and possibly a pneumonia jab. If you have CLL, you shouldn't have live vaccines, but the flu, pneumonia and covid-19 vaccines aren't live and so they're safe for you.

There are two important things to do from the start:

- **Find out who you can contact urgently** (and out of hours) if you think you have an infection and write it at the front of this booklet or somewhere you can easily find it.
- **Make sure you know the symptoms of infection** (see the next page), and call your emergency contact number straight away if you have any of these symptoms.

## Symptoms of an infection

These are common symptoms of an infection, but tell your hospital team or GP straight away if you just generally don't feel well.

- fever (temperature of 37.5°C or above)
- low temperature (less than 36°C)
- shivering and sweating
- feeling confused
- sore throat or cough
- rashes or swelling
- frequent watery poos (diarrhoea)
- a burning or stinging sensation when weeing
- unusual stiffness of the neck
- achy, flu-like symptoms

Find out more at [bloodcancer.org.uk/infection](https://www.bloodcancer.org.uk/infection) or call us for printed information.

## Your risk of shingles

You may be at higher risk of shingles when you have CLL. Shingles is a viral infection of a nerve and the skin around it, which you can get if you've had chickenpox in the past.

There is one shingles vaccine called Shingrix that is safe for people with CLL because it isn't a live vaccine. Or you may be given long-term preventive medication such as aciclovir, especially if you have had shingles before.

For more information about shingles and avoiding live vaccines, visit [bloodcancer.org.uk/staying-safe](https://www.bloodcancer.org.uk/staying-safe)

## Covid-19 and flu vaccinations

People with CLL are at higher risk of serious illness from covid-19 (coronavirus) and other viruses like flu. That's why you'll be prioritised for these vaccines. They will give you some protection, although probably not as much protection as for someone who doesn't have CLL.

There's lots more information about coronavirus and blood cancer on our website at [bloodcancer.org.uk/coronavirus](https://www.bloodcancer.org.uk/coronavirus)

## Looking after your skin

People with CLL have a higher than normal risk of developing skin cancer. This is true whether or not you have treatment for CLL, and means it's important for you to follow standard sun safety advice:

- Stay in the shade between 11am and 3pm when it's sunny.
- Make sure you never burn.
- Cover up with suitable clothing.
- Wear UV protective sunglasses.
- Use sunscreen with high UVB and UVA protection.

It's also a good idea to check your skin regularly and report any changes to your doctor.



## **If you're feeling overwhelmed**

It might feel like there's lots to remember and lots of medical information.

Ask your doctor or nurse how to protect yourself. This helps you feel more in control.

You'll find some ideas to help you cope with stress or anxiety from page 59.

You can also talk to us about any worries you have. Call **0808 2080 888** or email **support@bloodcancer.org.uk**

# Coping with watch and wait



## **Because CLL is slow growing, some people don't need treatment straight away and some never need treatment.**

If your doctor doesn't think you need treatment for CLL, you'll go on watch and wait. This means you'll have regular check-ups to monitor the CLL.

You may also hear this approach called watchful waiting or active monitoring. Some people think active monitoring is a better description because it makes it clearer that your doctor is actively involved in your care, even if you don't need treatment.

It can be hard to find out you have blood cancer but won't be treated. This chapter aims to answer key questions and help you manage your physical and emotional health while you're on watch and wait.

**CLL can be a slow process. There are check-ups and anxious waits in between, but not every change in your blood requires action. You do get used to it.**

Paul, living with CLL since 2020



## Why am I waiting for treatment?

Doctors recommend watch and wait if you have few or no worrying symptoms of CLL. Saving treatment for later is safe in this situation and means the treatment will have more impact if it's needed later. You'll also avoid potential treatment side effects for as long as possible.

But being on watch and wait can be tough emotionally. It's a strange situation to be told you have blood cancer but don't need treatment. It can be hard to explain to others. And people often say their anxiety level rises as their next check-up comes nearer.

We have printed information to help you understand watch and wait and explain it others. You can order or download this from **[bloodcancer.org.uk/watch-wait-booklets](http://bloodcancer.org.uk/watch-wait-booklets)**

## If you feel anxious

Talk to your doctor or nurse if you feel anxious about being on watch and wait. They may be able to put your mind at rest about some of your concerns. They can also refer you for counselling or other professional support, which many people find helpful.

It can also help to talk to people in a similar situation. Online forums like ours at **[bloodcancer.org.uk/our-forum](http://bloodcancer.org.uk/our-forum)** are a good place to find support.

The chapter on living well with CLL (see page 57) has more information and tips on looking after your emotional and physical well-being.

## How often will I have check-ups?

You'll probably have between two and four check-ups in the first year after your diagnosis. If tests show the CLL is stable and your symptoms don't change, you may need fewer check-ups.

It's getting more common now to discuss your test results by phone or video call, which many people find convenient. Whether you have a virtual or face-to-face appointment, make sure you tell your doctor about any changes in your symptoms, and any worries you have. See page 28 for information on things to look out for.

**I like to do my own research on CLL, but I go on the forum to compare notes with other people. There are some truly knowledgeable and supportive folk on there.**

Ann, living with CLL since 2008



## What happens at a check-up?

Your check-up will involve blood tests, which may be done at the hospital or at your GP surgery. A nurse or doctor will take some blood and send it to a laboratory to check:

- how quickly your white blood cell count is going up
- whether you have enough red blood cells and platelets in your blood to keep you healthy
- whether the CLL is stable or progressing.

They will also:

- ask if you have any symptoms, like swollen glands, tiredness, feeling breathless, bruising or bleeding easily, night sweats or weight loss
- check you physically for any swollen glands (lymph nodes) which are common with CLL.

If everything is OK, you can carry on as you are until your next check-up.

If you start to get new symptoms, or your blood tests show the CLL is growing, you might need more tests to decide whether it's time to start treatment.

We have more information about regular tests to monitor CLL at [bloodcancer.org.uk/cll-tests-after-diagnosis](https://www.bloodcancer.org.uk/cll-tests-after-diagnosis)



## Waiting for your test results

It's natural to think or worry about test results before you get them. Here are some tips for managing this:

- **Distract yourself** – Get engrossed in an activity you enjoy, something that's achievable but needs a bit of mental or physical effort, or both. This might be a DIY or craft project, an exercise programme, gardening or reading.
- **Unwind and relax** – If you find it difficult to concentrate, something that needs less effort might work better, like watching TV shows or films, reading magazines or chatting to friends about other things. Anything that will take your mind off your worries for a period of time will help.
- **Say your worries out loud** – you might prefer the more direct approach of talking through the possible outcomes of your test results and your feelings about them. Expressing your worries out loud can often help you manage them.
- **Techniques for managing anxiety** – If you've experienced anxiety in the past, you may already know some self-help techniques you can use. If not, or you need a reminder about different things to try, you'll find a range of ideas at **[bloodcancer.org.uk/mind-emotions](https://www.bloodcancer.org.uk/mind-emotions)**

Anxiety around waiting for test results is a common topic of conversation with our Support Service, and on our online community forum. Contact us if you want to talk through your fears.



## **Will I need treatment in the future?**

Many people stay on watch and wait for years and some people never need treatment. You won't start treatment until your doctor thinks it's the right time.

During your check-ups, your doctor will be looking for signs that show whether the CLL is growing and needs treatment. They will look for changes in your blood test results, for example, the number of abnormal white blood cells going up, or the number of other blood cells going down.

They will also want to know whether you're having certain symptoms. Symptoms to look out for include:

- extreme tiredness (fatigue) that's getting worse
- repeated infections
- new swollen glands (lymph nodes), or bigger swellings
- feeling full after eating small amounts or feeling uncomfortable under the left side of your rib cage – this could mean your spleen is swollen
- symptoms known as “B” symptoms: a high temperature (fever) without any other sign of infection, drenching night sweats and weight loss you can't explain.

## Keep a record of how you feel

Many people find it helpful to note down how they've been feeling in a symptoms diary. This helps you notice if anything changes and makes it easier to report any symptoms to your doctor.

It's important to tell your doctor if anything changes. It doesn't necessarily mean the CLL is progressing – your doctor will look at a range of things before deciding whether you need treatment.

**Knowing what symptoms to look out for is important – it's something active you can do to get involved in your own care.**

Paul, living with CLL since 2020



# More information

You'll find more information at  
**[bloodcancer.org.uk/watch-and-wait](https://bloodcancer.org.uk/watch-and-wait)**,  
including tips on how to cope with anxiety.

If you don't use the internet, call us and we will send  
you information about being on watch and wait.

You can get support from other people on  
watch and wait at **[bloodcancer.org.uk/our-forum](https://bloodcancer.org.uk/our-forum)**

# Coping with your symptoms

## Fatigue (tiredness)

Fatigue is a common symptom of CLL, including for people on watch and wait. It's a type of tiredness that comes on suddenly and can take time to go away.

If you have fatigue, you may need to pace yourself so you can carry on doing the things you want to do. You'll find tips about coping with fatigue on page 64 or on our website at [bloodcancer.org.uk/fatigue](https://www.bloodcancer.org.uk/fatigue)

## Infections

CLL affects your white blood cells, which means it's harder for you to fight off infections. So you need to be aware that you may be at higher risk of infection from germs such as viruses and bacteria.

See pages 18 to 19 for more information on what to look out for, how to manage your risk of infection and what to do if you think you have an infection.

## Other symptoms

CLL can affect the balance of cells in your blood and cause a range of symptoms. A low level of red blood cells (anaemia) can make you feel tired and out of breath. You might also bruise or bleed more easily because of a low number of clotting cells called platelets. Medicine or a blood transfusion can help so do tell your doctor if you're affected by these or any other symptoms.

## Coping with your feelings

It's natural to have mixed feelings about being on watch and wait. On the one hand, it's good that you don't need treatment. With a few adjustments, you should be able to carry on with life as before. If you're working, that includes staying in your job (see page 70 for more information on your rights at work).

On the other hand, it's hard to take in, and explain to others, that you have cancer but aren't being treated for it. And waiting for test results or looking out for new symptoms can cause a rollercoaster of anxiety.

## Managing difficult feelings

Some people talk about feeling like a "fake" cancer patient. Others say they feel they're not in control, because they don't know if and when they'll need treatment.

There are things you can do to manage these difficult feelings. We have advice on coping with waiting for test results on page 27. You'll find a checklist of simple things to do to protect your mental health on pages 59 to 61, and more things to try at [bloodcancer.org.uk/mind-emotions](https://www.bloodcancer.org.uk/mind-emotions)

Other people with blood cancer are also a great source of tips and advice. Visit our online community forum at [bloodcancer.org.uk/our-forum](https://www.bloodcancer.org.uk/our-forum) and search "watch and wait" to see what's helped others adjust to their new situation.



## Kate

### How do you cope with being on watch and wait?

"I try to take something positive from every single day, and I'd say I have a new-found love of life. I don't sweat the small stuff any more and I've realised that sometimes you can get by without planning everything."

Read Kate's story at [bloodcancer.org.uk/kate](https://bloodcancer.org.uk/kate) or call us and we'll post you a copy.

## Questions to ask about watch and wait

It's a good idea to write down questions for your hospital team or GP as people say their mind sometimes goes blank when they're in an appointment, and they don't get the answers they need.

Here are some suggestions for questions to ask about watch and wait, or you can write your own on page 78:

- Why don't I need treatment?
- When will I need treatment?
- How often will I have check-ups?
- What are the check-ups for?
- What tests will I have?
- How long will it take to get the results?
- What symptoms should I look out for?
- Who's responsible for my care?
- Who can I contact if I'm anxious or feel ill?

66

**I find it helpful to write down all my questions before I go to an appointment so I make sure I cover them all and I am satisfied with the answers I get.**

Erica, living with CLL since 2003





## Finding out about treatment

If you're on watch and wait, you may not want to find out about treatments for CLL just yet – if so, save the next chapter on starting your treatment for another time.

For now, the most important thing is to be aware that if the time comes, there's a range of effective treatments for CLL and more are being developed all the time.

If you do want to know more about what's involved in treating CLL, the next chapter will give you a general overview. When you're ready, you'll find detailed information about the latest treatments for CLL at **[bloodcancer.org.uk/cll-treatment](https://www.bloodcancer.org.uk/cll-treatment)**

**If you need  
treatment**



# If you need treatment for CLL, there are effective drugs, and new ones are being developed all the time.

Sometimes, treatment can put you into remission, and you could go back on watch and wait again. Other times, you might need to stay on treatment. Many long-term CLL treatments can be taken as daily tablets.

There are lots of options for CLL treatment. Treatment affects everyone differently but most people cope well with it. It's often possible to carry on with daily life, including working, during treatment.

**They told me CLL is treatable but not curable. That was a shock at first, but after a while, you take comfort that there are effective treatment options when you need them.**

Johanna, living with CLL since 2009



## What to expect

This chapter gives you an overview of the different types of treatment and what they involve. It also outlines some of the tests you may need.

As you read this chapter, write down questions for your hospital team. Three key questions to ask would be:

- Which treatment will I have?
- What is the aim of this treatment?
- How will I take the treatment?

There are more suggested questions on page 53 and space to write your own on page 78.

“

**It's really important to ask questions and build up a rapport with your doctor, as they're in the best position to allay any fears or concerns.**

Kate, living with SLL since 2010



## The aims of treatment

Some treatments aim to put you into remission, where the level of CLL is low again. If this happens, you could go back on watch and wait (see page 23). You might not need treatment again for some time.

Sometimes, you might need to start treatment and stay on it. Many long-term CLL treatments can be taken as daily tablets. This aims to keep the CLL under control.

## When will treatment start?

If the CLL begins to grow more, starts causing symptoms or makes you unwell, then you might need to start treatment.

There are a lot of different things doctors will consider when deciding whether it's time to start treating you. They will look at your blood test results and how these have changed over time. They will also take into account any symptoms that are new or getting worse – see page 28 for symptoms to look out for.

For more information about how doctors decide when you will need treatment, see our online information about watch and wait for CLL at [bloodcancer.org.uk/cll-watch-wait](https://bloodcancer.org.uk/cll-watch-wait)

If you don't use the internet, please call us free on **0808 2080 888** and we will print and send you the information.

## Tests you may have

When it's time to start treatment, you will need tests to monitor the CLL and check how the treatment is working. You may also have tests to check on your general health.

These tests will usually be done on a sample of your blood, or sometimes a sample of your bone marrow (see page 42). You might also have a scan to check on certain symptoms, although this isn't routine.

Waiting for test results can be hard, but there are some ideas on page 27 about how you can reduce the stress of it.

## Genetic tests

Genetic tests look for specific changes (mutations) in the genes of CLL cells. They are done using a blood or bone marrow sample.

The main genetic changes doctors are looking for involve genes called p53 and IgHV. Knowing about these changes can give your doctors an idea of:

- how your CLL might progress (your prognosis)
- which treatments might work best for you.

If you have genetic tests, your doctor will explain what the results mean. We have more information about genetic tests at [bloodcancer.org.uk/cll-tests-after-diagnosis](https://www.bloodcancer.org.uk/cll-tests-after-diagnosis)

# Find out more

We have more information about tests you may have before and after a CLL diagnosis on our website:

**[bloodcancer.org.uk/ctl-symptoms-diagnosis](https://bloodcancer.org.uk/ctl-symptoms-diagnosis)**

Our online community forum at **[bloodcancer.org.uk/our-forum](https://bloodcancer.org.uk/our-forum)** is a great place to get support and tips from people who know what it's like to wait for test results and treatment.

## **Bone marrow biopsies**

You may have a bone marrow biopsy before or after treatment if your doctors believe it will give them essential information. They tend to be more common if you are being treated through a clinical trial.

Bone marrow is a soft tissue found inside your larger bones. It is where blood cells are made, and it is where CLL starts.

A bone marrow biopsy involves removing a sample of bone marrow to look at under a microscope. This gives your hospital team an idea of:

- how fast the CLL is growing
- which treatments might be best to use
- if you're on treatment, how well it is working.

### **What happens in a bone marrow biopsy?**

A doctor or nurse will normally take two samples from the back of your pelvis (the ring of bones between your waist and your legs). You'll be asked to curl up on your side to make this easier. You might need to change into a hospital gown.

You'll have a local anaesthetic to numb the area where the needle goes in. Then they will insert one needle to draw some cells out of the bone marrow, and insert a second needle to take a sample of bone marrow tissue (a core).



The procedure can take up to half an hour, but removing the bone marrow sample only takes a few minutes. Your samples are sent to a laboratory and the results usually come back in one to two weeks.

A bone marrow biopsy is done as a day patient, so you can go home afterwards.

## Does it hurt?

People's experiences of having a bone marrow biopsy seem to vary. Some people feel a pulling or pushing sensation or find it uncomfortable. Others find it painful, even with a local anaesthetic.

Taking paracetamol before and after can help. You can also ask whether you can take something to make you feel sleepy, or have gas and air. Different hospitals have different policies, so ask what pain relief is available.

Some people find their back is sore afterwards, so think about how you'll get home after the biopsy.

**I met another patient who said biopsies did not trouble him and he never bothers with anaesthetic, but I always make sure I have a local anaesthetic and that it's taken effect.**

David, living with CLL since 1997



”

## What treatment will I have?

Treatment for CLL involves drugs that destroy the CLL cells or stop them growing.

Not everyone's CLL is the same. There are different genetic changes that can happen in CLL cells, and different drugs work better for each of these. Your drug treatment will be tailored to your CLL and your body.

The main types of drugs are:

- cancer growth blockers (inhibitors)
- monoclonal antibodies (immunotherapy)
- chemotherapy drugs

These work in different ways, but they all aim to destroy CLL cells or stop them growing.

Thanks to research, new drugs for CLL are being developed and made available to more people. Often these have fewer side effects.

This means information about drug treatments changes regularly, so we can't include detailed information about specific drugs in this booklet. But you will find up-to-date information on current treatment options at

**[bloodcancer.org.uk/ctl-treatments](http://bloodcancer.org.uk/ctl-treatments)**

If you would like this information but don't use the internet, we will print it out and send it to you. Please call us free on **0808 2080 888**.

## Clinical trials

Many people who start treatment for CLL have their treatment as part of a clinical trial, which offers the chance to have a newer treatment.

Find out more at [bloodcancer.org.uk/clinical-trials](https://www.bloodcancer.org.uk/clinical-trials) or contact us for details of our clinical trials support service.

## How and where will I have treatment?

This depends on which drugs you are having. Many of the latest CLL drugs are tablets you can take at home, so you might not need to visit the hospital for treatment.

For some drugs you might need to visit hospital, to have them through a drip into your vein (by infusion or IV). You can often do this as an outpatient, meaning you can go for treatment and come home on the same day.

You might have a combination of hospital treatment and home treatment. Many people find they can continue with their daily lives while having CLL treatment.

## Should I give up smoking?

It may be hard, but if you're a smoker, it's important to do your best to give up. Smoking can increase your risk of side effects from treatment and your chance of developing a second cancer or lung problems in the future.

Search "NHS stop smoking" for ideas and services to help you quit.

## How long will treatment take?

Some treatments are given for a set period of time, usually over several months. The aim is to get the CLL back to a low level of abnormal cells (remission). Then you can finish treatment and go back on watch and wait (see page 23). You'll keep having blood tests to check you are staying in remission.

Other treatments are long-term treatments, so you can keep taking them for as long as you need them. These treatments are mostly taken as tablets.

## What if the CLL continues to grow?

Generally, CLL progresses very slowly, and treatments can be effective at keeping it under control.

There are many different treatments for CLL, so if one stops working, there are others to try.

For the most up-to-date information on CLL treatment, visit **[bloodcancer.org.uk/cll-treatment-side-effects](http://bloodcancer.org.uk/cll-treatment-side-effects)** or call our Support Service to ask for printed information.

## Key things to know

Your treatment will be managed by a hospital team who are specialists in blood cancer.

- **You should be given a named key contact**, and a phone number or email in case you have any questions or worries. This is often a clinical nurse specialist (CNS), but it may be your doctor or someone else. If you don't know yours, ask your team. You can also call us and we'll help you find out.
- **Your doctor and the rest of your hospital team are there to answer your questions** – Don't be afraid to ask them whatever you want to know. It's their job to make sure you understand your treatment and what's happening. We have suggestions for questions to ask on pages 34 and 53.
- **You can contact us for help preparing for your next appointment** – This is something we talk to people about a lot. So if you don't feel confident about talking to your hospital team, please get in touch on **0808 2080 888**

# More information

We have more information about CLL treatment on our website: **[bloodcancer.org.uk/cll-treatment](https://bloodcancer.org.uk/cll-treatment)**

We also have information about research we're funding so we can understand and treat CLL better: **[bloodcancer.org.uk/researching](https://bloodcancer.org.uk/researching)**

If you don't use the internet,  
please call us on **0808 2080 888**.

## How will treatment affect my daily life?

Many people say they're surprised by how busy things can get during treatment. You might be visiting the hospital for treatment, or you might be going for lots of tests.

Knowing what to expect will help. Ask your hospital team how much you'll be coming to the hospital and when. Then you can plan ahead for how you'll get to hospital, and things like work, childcare or other commitments in your life. Getting organised helps – use the checklist on page 8.

Treatment affects everyone differently. Some people say it doesn't affect their life too much. Other people find it harder. Treatment might affect you physically, emotionally, or both. It's also common for people to get tired more easily.

Many people continue doing things like working, seeing family and friends, and hobbies. They say that even with treatment and side effects, CLL doesn't stop you doing most things you want to.

**It can get very busy, attending appointments, having tests. Ask questions so you know what to expect and can prepare.**

Johanna, living with CLL since 2009



## **Protecting your fertility**

Some blood cancer treatments can affect your ability to have children in the future. If this is an issue for you, talk to your doctor or nurse about it before you start your treatment.

For women, it may be possible to freeze eggs or embryos (fertilised eggs) before you start treatment. It may also be possible to freeze some tissue from your ovaries.

If you're a man, you may be able to freeze sperm for use when you're ready to have children.

Ask your doctor or nurse about ways to protect your fertility.

## **Talk to us**

If you are hoping to have children, being told your treatment may affect your fertility is a very difficult thing to cope with. You can talk to your hospital team but you can also talk to us about it if you prefer.

Contact our Support Service and we'll help you get the support and information you need.



## Treatment side effects

Drugs for CLL can have side effects, but everyone is different, and you won't get all of the possible side effects. When you start treatment, your doctor or nurse should tell you about common side effects of the drugs you're having.

The most important thing to do is tell your doctor or nurse if you notice any changes in your body or how you're feeling during treatment. There are things you can do to reduce most side effects, if you tell your doctor or nurse about them straight away.

Whatever type of treatment you're having, as someone with CLL you're particularly at risk of infection. So if you feel at all unwell, tell your hospital team immediately. See page 19 for what to look out for.

We have more information about treatment side effects at [bloodcancer.org.uk/cll-side-effects](https://bloodcancer.org.uk/cll-side-effects)

**When I was diagnosed, treatment involved chemotherapy which often had extremely unpleasant side effects. Now many of the targeted therapies are much kinder and offer a good quality of life.**

David, living with CLL since 1997



”

# More information

For general information about side effects and how to manage them, visit [bloodcancer.org.uk/side-effects](https://bloodcancer.org.uk/side-effects)  
Or call us on **0808 2080 888**.

Other people with CLL have tips to share about what worked for them. Find out more at [bloodcancer.org.uk/our-forum](https://bloodcancer.org.uk/our-forum)

## Questions to ask about treatment

You can also write down your own questions on page 78. It can help to jot things down as they come to you, so you remember what you wanted to ask.

- What tests will I have before and during treatment?
- How long will it take to get the results?
- What are the tests for?
- What treatment will I have?
- What is the aim of my treatment?
- Is there a clinical trial I can join?
- How and where will I be given the treatment?
- How long will the treatment take?
- What might the side effects be?
- How can I manage these side effects?
- How will treatment affect my daily life?
- What's the best outcome I can hope for?
- Who do I contact if I don't feel well?
- Who do I contact out of hours?

## The future of CLL treatment

In the past ten years, there have been many developments in CLL treatment, and this is set to continue.

Research has made drugs like monoclonal antibodies (immunotherapy) and cancer growth blockers (inhibitors) available to people with CLL, offering treatment options that are both effective and have fewer side effects.

New drugs and new drug combinations are tested thoroughly in the laboratory before being used in clinical trials. A large number of people with CLL are treated through a clinical trial, where they will have either an effective current treatment, or a newer treatment that may be even better.

These trials and other research projects bring the hope of more breakthroughs in the near future.

“

**While CLL is still incurable, researchers have made great progress and, for the first time, many experts are talking about the possibility of finding a cure in the future.**

David, living with CLL since 1997



# Research and clinical trials

For more information about the CLL research we're funding visit [bloodcancer.org.uk/researching](http://bloodcancer.org.uk/researching)

For more information about joining a clinical trial, go to [bloodcancer.org.uk/clinical-trials](http://bloodcancer.org.uk/clinical-trials)

If you don't use the internet,  
call us on **0808 2080 888**.

# Living well with CLL



# Having CLL doesn't stop you from being you, or from living your life.

We've talked to lots of people with CLL to get their thoughts on what has helped them cope with their diagnosis and enjoy life to the full.

This section is about how to live with CLL, and continue to get the most of out of life. It covers:

- What can I do to help myself?
- Checklist: 10 things that can help
- Positive thinking
- Managing fatigue (tiredness)
- Keeping active
- Eating well
- How to help your family and friends
- Working when you have CLL
- Help with money
- Places to get support

**People hear leukaemia and think that people are just going to rot away. But it's important to know, it's not all doom and gloom - there is life with CLL.**

Gerard, living with CLL since 2017



## What can I do to help myself?

Looking after your physical and mental health is important. When we say mental health, we just mean how you feel about your daily life and what's happening.

Everyone reacts differently to their diagnosis. Some people feel sadness, fear, guilt or anger. Many find themselves asking, "Why me?"

Some people don't have strong emotions or are able to accept the diagnosis quite quickly. Others feel shocked, or like it isn't really happening.

Whatever you're feeling is normal. For now, it's just important to take care of yourself in any way that works for you. The next few pages have some ideas to try.

“

**Looking after yourself is empowering. Do things to put yourself in the best shape - quit smoking, reduce drinking, take up exercise. OK you've got CLL, but you can still have some control.**

Paul, living with CLL since 2020





## Checklist: 10 things that can help

This section is about small, simple things you can do that can make a big difference. These are all things that have helped other people with blood cancer at different times:

- 1. Focus on the here and now** – Focusing on the present moment can help if you feel overwhelmed. Try focusing on your breathing for a minute, or engaging your senses (listen to the sounds around you, feel the texture of something in your hands, or simply look at the objects around you and notice their shapes and colours). Exercises like this can help calm you if you feel stressed, and you can do them anywhere.
- 2. Give yourself time to absorb and ask questions** – You don't have to learn everything at once. Take time to read information, write down all your questions, and then take them to your hospital team, GP or our Support Service.
- 3. Listen to your body** – If you're tired, the housework can wait, and most plans can be changed. You're going through a lot, so it's OK to say no to people and take time out. People will understand. If you're having a good day, going on a walk or doing some exercise can help. Do what feels right for you, and take one day at a time.

- 4. Keep up your hobbies, or start one you can do at home** – Anything you enjoy and which keeps your mind occupied can give you a break and lift your mood. A hobby can be something you find relaxing, or something that motivates you. Getting engrossed in something that requires some mental or physical effort can help. Gardening, DIY, drawing or crafting can take you out of your head.
  
- 5. Have goals or a focus** – Goals can keep you going, provide motivation, and help you feel positive. While there is a lot you can't control right now, try to think about things you can control. Whether it's planning the next place you want to visit when you're able, having mini goals for each day, or simply keeping a photograph of someone special to look at – find something that can motivate you to get through this.
  
- 6. Keep a diary or log** – Record your goals, things you've achieved, things that have helped you, and how you're feeling each day. It can be helpful and motivating to look back at how far you've come.
  
- 7. Try to stay active** – Physical activity can help you sleep better, release feel-good hormones and help manage stress, anxiety and depression. Even a five-minute walk can help you feel better. Exercise also helps by giving you something to focus on and a sense of achievement.

**8. Keep connecting with other people** – While it’s OK to say no when you don’t feel like seeing people, it’s also important not to withdraw too much. Seeing or talking to other people about things that are not related to blood cancer can really help to lift your mood.

**9. Talk to someone** – Trying to keep things to yourself can add extra pressure and make things harder. Talking about things can make them feel more normal and less scary, even when that thing is blood cancer. Be open with close friends and family if you can – many people say this is their biggest support. Or contact our Support Service and talk to us – we are here to talk about anything that’s bothering you, even if you just want a chat.

**10. Keep doing things that make you smile** – Many people with CLL say it’s important to carry on as much as you can with the things you enjoy, and that life should not stop because of CLL. There might be some things you can’t do right now, but try to focus on the things you can still do.

There are more tools on our website to help you try some of these practical tips, including some videos to help you relax, at **[bloodcancer.org.uk/mind-emotions](http://bloodcancer.org.uk/mind-emotions)**

If you don’t use the internet, call us and we can send you some resources.

## Positive thinking

Many people say that staying positive is really important for coping with blood cancer. This doesn't mean being positive all the time – everyone has bad days and it's important to accept these and not put pressure on yourself to be fine all the time. But sometimes just looking at something differently or changing what you focus on can help.

Our thoughts affect our feelings. So while it's difficult to change feelings (emotions) directly, changing our thought patterns can actually change how we feel about things.

You can spot unhelpful thoughts because they are often very unbalanced (things are either all good or all bad) or catastrophic (worst-case scenarios). Sometimes these thoughts don't relate to what your hospital team or GP has actually told you – that's completely understandable, but it is possible to turn these thoughts around.

“

**You've got to come out of it with positivity. Never have any negative thoughts at all. Don't hide it, talk about it. Just say, 'I have leukaemia but I'm OK.'**

Eirwen, living with CLL since 2021



Thinking about things differently can change your outlook to a more balanced and positive one.

Examples of balanced thinking:

**It might be hard, but I have coped with challenges in life before, and I can find a way to cope with this.**

**My hospital team said there was a good chance of treatment working for a long time.**

**Life will be different, but there are still things I can enjoy.**

**There are good things in my life, and I can focus on these.**

**If I feel lonely, I know there are people out there who understand. I can contact Blood Cancer UK.**

**Rather than dwelling on things I can't change, I'm going to concentrate on what I can control, like keeping active.**

## Managing fatigue (tiredness)

Fatigue is a type of tiredness that many people with blood cancer get. It's different from normal tiredness.

It can affect you mentally and physically, and it can come on suddenly. You might feel like you are totally drained.

It's important to know:

- **You're not alone** – Fatigue is a common symptom of blood cancer and a side effect of treatment.
- **There are lots of things that can help** – It might seem strange, but being physically active reduces fatigue.

People with blood cancer suggest:

- **Balance activity and rest** – You need both to fight fatigue. Light exercise can actually help.
- **Learn what's doable for you** – Plan time to rest in between activities or days out.
- **Go easy on yourself** – If you need a rest day, have one. You're not being lazy.
- **Tell your hospital team or GP** – They need to know about any symptoms you are having.

Visit [bloodcancer.org.uk/fatigue](https://www.bloodcancer.org.uk/fatigue) for more tips.



## Erica

### What strategies do you have for dealing with fatigue?

“I’m coming round to thinking that fresh air and gentle exercise can actually help lift my energy levels. It takes my mind off the fatigue, too. I try and declutter my life, organise myself as much as I can.”

Read Erica’s story at [bloodcancer.org.uk/erica](https://bloodcancer.org.uk/erica) or call us and we’ll post you copy.

## Keeping active

Being physically active can improve your fitness and strength, reduce fatigue and improve your mood. That's not just what the research says – many people with blood cancer have found it to be true.

- **Walking is good exercise** – If you don't normally walk far, start with 5 or 10 minutes a day and slowly build up.
- **Goals are motivating** – Set yourself goals and tick them off when you've done them. Order a free activity planner from us, or use an app like Habit Tracker or Done.
- **Do something you enjoy** – If you choose an activity you like, you're more likely to keep it up. If you're not sure what to do, ask other people for recommendations and try something new.
- **Make it social** – This usually helps people stick to their plans. Find an exercise buddy (your partner, a friend, a neighbour) and follow a plan together.
- **Get tips from other people with blood cancer** – Join our online community forum and find out how other people with CLL are staying active.

Find exercise videos for people with blood cancer at [bloodcancer.org.uk/keeping-active](https://www.bloodcancer.org.uk/keeping-active)



## Eating well

Eating well is important, as it will give you the nutrients and energy you need to stay healthy. Here are some general tips to bear in mind:

- **No diet, supplement or “super food” can cure cancer** – in fact, cutting out too many foods could mean you’re not getting everything you need.
- **It’s best to follow a healthy, balanced diet** – Ask your hospital team or GP if there’s anything specific you need to eat more or less of.
- **You need carbohydrates** – Wholewheat pasta, wholegrain bread or potatoes with skin on will release energy through the day. Carbs should make up around a third of a meal.
- **Eat lots of fruit and veg** – They’re packed with vitamins, minerals, and are a good source of fibre. Boost your intake by adding extra vegetables into sauces.
- **Protein helps your body grow and repair** – Try beans, peas, lentils, fish, meat, dairy, eggs and vegetarian and vegan alternatives such as Quorn or tofu.
- **Iron is vital for energy** – As well as meat, you can get iron from beans, nuts, dried fruit, wholegrains, and dark-green leafy vegetables.

We have more tips for making cooking and eating easier if you’re tired at [bloodcancer.org.uk/eating-well](https://www.bloodcancer.org.uk/eating-well)

## How to help your family and friends

If you've told people about your diagnosis, you might find you're now getting asked lots of questions.

If you haven't told people about your diagnosis, you might be worried about how you're going to tell them, and how it might make them feel.

It might be hard to deal with different people's reactions. We have some ideas about how to deal with difficult or unexpected reactions on page 10.

Here are some suggestions about ways you can help your family and friends come to terms with your CLL diagnosis so you can make sure they're OK, and that life for everyone goes on as normally as possible.

“

**My husband wanted to wrap me up in cotton wool. I said, 'Treat me normal. If you want a barney have a barney. I'm no different from how I was before.'**

Eirwen, living with CLL since 2021



- **Help your family and friends get information** – If they want to know more about CLL, tell them not to google but to use information from trustworthy sources. Googling can cause a lot of unnecessary worry as not everything on the internet is true or balanced or up to date. You might want to give them copies of this booklet which you can order for free from [bloodcancer.org.uk/our-booklets](http://bloodcancer.org.uk/our-booklets)
- **Tell them where to find a listening ear** – If they are finding it hard to cope with your diagnosis, they are very welcome to call our Support Service to ask questions or just talk things through.
- **Be honest** – Talking openly about CLL to other people can make you and them feel better. It's not something you have to hide. People often worry about things more when they don't feel they know what's going on.
- **Let family and friends help you** – It's common to feel like asking for help is a sign of weakness, but this isn't true. Asking for support is a positive way to help yourself, and it also makes family and friends feel better if they have a role to play.
- **Talk to us about it** – We often talk to people about the impact their diagnosis is having on their family or friends. We can also help you prepare to tell people, whether they are family, friends, children or your employer.

## Working when you have CLL

If you are working or studying when you are diagnosed with blood cancer, you should know:

- **You're protected** – Even if you're on watch and wait, you are entitled to support.
- **You have rights** – Cancer is classed as a disability in UK law, so you are protected against discrimination.

If you're worried about going to work because of the risk of infection, or you are finding it hard to do your job, your employer has to consider "reasonable adjustments" to help you stay in work. Examples include:

- having time off for medical appointments
- taking more breaks
- changing your duties or hours to help you manage fatigue
- changing your hours so you can travel when it's quieter
- supporting you to work from home.

Contact our Support Service for help talking to your employer about managing at work. We also have a fact sheet about blood cancer you can share with your employer. You can order or download it for free from **[bloodcancer.org.uk/our-booklets](http://bloodcancer.org.uk/our-booklets)** or give us a call.



## Mel

### How did your employer help you to carry on working?

“My immune system was low, but my employer gave me my own office space so I wasn’t in constant contact with other people. They were also happy for me to work from home when I wanted to.”

Read Mel’s story at [bloodcancer.org.uk/mel](https://www.bloodcancer.org.uk/mel) or call us and we’ll post you a copy.

## Help with money

If you're worried about money, make sure you get the financial support you're entitled to:

- **Benefits** – Whether you're in or out of work, if you're on a low income, you may be able to claim benefits like Universal Credit, Employment and Support Allowance (ESA), or Personal Independence Payment (PIP).
- **Sick pay** – If your GP or hospital team believe you're not able to work because of the CLL or any other illness, they can give you a fit note (previously called a sick note) which gives you access to your company's sick leave policy and pay, or Statutory Sick Pay (SSP).

## Ways to save money on health costs

- **Parking** – At all hospitals in Wales and most hospitals in Scotland parking is free. In England and Northern Ireland, some hospitals offer free parking to people with cancer in certain circumstances – check with your hospital.
- **Prescriptions** – These are free in Scotland, Wales and Northern Ireland. In England, they are free if your prescription is related to cancer. If you live in England, ask your GP for an exemption certificate.
- **Travel to hospital** – If you have a low income, or get certain benefits, you may be able to get refunds for your travel to hospital. Speak to your doctor or nurse to find out more.

## Help paying bills

Talk to your suppliers about energy bills, council tax and mortgage payments. There is usually support available for people with cancer. Get help from Citizens Advice at **[citizensadvice.org.uk](https://citizensadvice.org.uk)**

## Do you have insurance?

Could you make a claim on income protection insurance or critical illness cover? Contact your insurance provider to find out.

## Help from charities

Many charities offer grants that you don't have to pay back, including Leukaemia UK and Macmillan Cancer Support.

## Who can help?

- Ask your GP, specialist doctor or nurse.
- Ask a family member or friend to help you look into it.
- MoneyHelper offers free webchat, WhatsApp and phone advice on all money matters at **[moneyhelper.org.uk](https://moneyhelper.org.uk)**
- You could also contact Citizens Advice. Visit **[citizensadvice.org.uk](https://citizensadvice.org.uk)**
- Call Macmillan on **0808 808 00 00**.

## Places to get support

### Blood Cancer UK Support Service

We can talk to you about anything that's on your mind, or even if you just fancy a chat with someone.

People contact us about:

- understanding their condition
- treatment
- living with blood cancer
- impact on family and friends
- work issues
- mental health
- how they're feeling.

Call our confidential support line free on **0808 2080 888** or email **[support@bloodcancer.org.uk](mailto:support@bloodcancer.org.uk)**

### Blood Cancer UK website

Our website has more information about CLL and blood cancer in general, plus regular news articles and stories from people affected by blood cancer. Explore **[bloodcancer.org.uk](http://bloodcancer.org.uk)**

### Blood Cancer UK publications

If you prefer your information in printed form, browse our booklets about conditions, watch and wait, treatment and side effects and living with blood cancer. Go to **[bloodcancer.org.uk/our-booklets](http://bloodcancer.org.uk/our-booklets)**



## Blood Cancer UK online community forum

Talking to other people with CLL helps. They understand, and will have tips from their own experience. You can ask questions, or just read other people's posts. You don't have to create an account and you can remain anonymous.

Visit **[bloodcancer.org.uk/our-forum](http://bloodcancer.org.uk/our-forum)**

## Local groups

These give you the chance to meet other people affected by blood cancer face to face.

- Ask your hospital or GP what support groups are available in your area.
- Enter your postcode on the NHS website and find support groups near you: **[www.nhs.uk/service-search/other-services/cancer-information-and-support/LocationSearch/320](http://www.nhs.uk/service-search/other-services/cancer-information-and-support/LocationSearch/320)**
- Contact Blood Cancer UK on **0808 169 5155** to see if we have a branch in your area. Our branches are for fundraising and volunteering, but you might find that doing things with other people with blood cancer helps.
- Leukaemia Care and CLL Support Association (CLLSA) run support groups together. Visit **[leukaemicare.org.uk/support-and-information/support-for-you/find-a-support-group](http://leukaemicare.org.uk/support-and-information/support-for-you/find-a-support-group)** or call **08088 010 444**. They also offer a telephone buddy scheme for people with CLL: **[leukaemicare.org.uk/support-and-information/support-for-you/one-to-one-buddy-support](http://leukaemicare.org.uk/support-and-information/support-for-you/one-to-one-buddy-support)**

## Social media

Some people find support in Facebook groups or other social media platforms.

- Find Blood Cancer UK on Facebook – many people get and give support to each other in comments on our posts. You can also find us on Instagram and Twitter.
- Search online or on Facebook for CLL support groups.

## Counselling services

Many people find talking to a trained counsellor helps them come to terms with difficult emotions or life changes.

To find a free NHS counsellor:

- Ask your hospital team how you can access counselling. Some hospitals offer this themselves.
- Tell your GP you'd like to try counselling.
- You can self-refer online in England ([www.nhs.uk/service-search/find-a-psychological-therapies-service/](http://www.nhs.uk/service-search/find-a-psychological-therapies-service/)) and Scotland ([www.breathingspace.scot/living-life/](http://www.breathingspace.scot/living-life/)). In Wales and Northern Ireland, you need to go through your GP.

To find a private counsellor:

- Find a qualified counsellor anywhere in the UK at **BACP.co.uk** or call them on **01455 883300**.

## Travel advice

People often wonder if they can still travel and get travel insurance once they're diagnosed with CLL.

- You can call our Support Service on **0808 2080 888** to talk through your plans and where to get more information about travel insurance.
- Macmillan Cancer Support offers online information about buying travel insurance at **[macmillan.org.uk/cancer-information-and-support/impacts-of-cancer/travel/buying-travel-insurance](https://www.macmillan.org.uk/cancer-information-and-support/impacts-of-cancer/travel/buying-travel-insurance)**
- MoneyHelper has information on travel insurance for people with cancer and other health conditions: **[moneyhelper.org.uk/en/everyday-money/insurance/travel-insurance-if-you-have-a-medical-condition](https://www.moneyhelper.org.uk/en/everyday-money/insurance/travel-insurance-if-you-have-a-medical-condition)**





# Because we face it together

Finding out you have blood cancer can have a big impact on your life. But we hope it helps to know that there's a community of people out here ready to support you.

Everyone needs help at one time or another. And the most important thing to take away from this booklet is that you can get help from us when you need it, and in a way that suits you.



[bloodcancer.org.uk](http://bloodcancer.org.uk)



**0808 2080 888** (calls are free and confidential)



[support@bloodcancer.org.uk](mailto:support@bloodcancer.org.uk)



[bloodcancer.org.uk/our-forum](http://bloodcancer.org.uk/our-forum)



Blood Cancer UK



@bloodcancer\_uk



@bloodcancer\_uk



Blood Cancer UK

# Thank you to our blood cancer community

Blood Cancer UK is the UK's specialist blood cancer charity. But we're much more than that – we're a community of people with blood cancer, friends, family, medical professionals, researchers and everyone who works for the charity.

Many thanks to everyone involved in making this booklet. To Ann, David, Eirwen, Erica, Gerard, Johanna, Kate, Mel and Paul for their insights into what it's like to be diagnosed with CLL, and for steering us in the right direction. To Professor Adrian Bloor, Dr Piers Patten and Clinical Nurse Specialists Vicki Kitchker and Lianne Palmer for checking the medical content.

A list of references used in this booklet is available on request. Please email [information@bloodcancer.org.uk](mailto:information@bloodcancer.org.uk)

## **Disclaimer**

We make every effort to ensure that the information in this booklet is accurate, but you should always seek advice from your doctor if you have any concerns or questions about your health. As far as applicable by law, Blood Cancer UK cannot accept responsibility for any loss or damage resulting from any inaccuracy in this information, or in external information that we link to.

By law, this disclaimer cannot limit or exclude our liability for death or personal injury resulting from negligence, or any other liabilities that cannot be excluded under applicable law.

# Who are Blood Cancer UK?

We're the UK's specialist blood cancer charity, working to beat blood cancer within a generation.

Since 1960, we've invested over £500 million in research, improving treatments for leukaemia, lymphoma, myeloma, MDS and MPNs. Thanks to generous donations from our supporters, we:

- fund ground-breaking research to improve survival and quality of life
- campaign for better access to treatments and services for people with blood cancer
- provide information and support for anyone affected by any blood cancer.

Find out more at [bloodcancer.org.uk](https://bloodcancer.org.uk)

Or call us free on **0808 2080 888**

Monday: 10am to 7pm, Tuesday to Friday: 10am to 4pm and Saturday and Sunday: 10am to 1pm.



**Blood  
cancer  
UK**

The information in this booklet was correct at the time it was printed (February 2022). Date of next full review: February 2025.

©2022 All rights reserved. No part of this publication can be reproduced or transmitted without permission in writing from Blood Cancer UK.

Blood Cancer UK is a trading name of Bloodwise, 39-40 Eagle Street, London, WC1R 4TH. A company limited by guarantee 738089 (registered in England and Wales). Registered charity 216032 (England and Wales) SCO37529 (Scotland) © 2022 CLL/0222