



Coping with
your feelings
after a blood
cancer diagnosis

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 blood cancer.



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 blood cancer or their carers in our closed Facebook groups.



Advocacy and welfare: Get support with the practical things in life, like money, work and your rights.



Counselling service: Access up to six sessions of counselling to help you cope with the emotional impact of blood cancer.



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](https://www.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.

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.

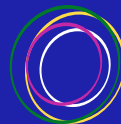
Being diagnosed with blood cancer is tough and you probably have some difficult feelings at the moment. In this booklet, we cover some of the emotions you might feel. We've included quotes from other people who've told us what it was like for them. We also cover things that might help you cope with your feelings and where to get support.

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

- Bryony Tyrell, Charlotte Bloodworth and Joanna Stokes, clinical nurse specialists
- Patient reviewers Abir, Emma and Lisa
- Everyone who shared their own experience so others feel less alone

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**.

Your feelings and emotions



Summary

Getting a diagnosis of blood cancer can be overwhelming, and hard to process. Once you start to process it, you might feel a mix of emotions. There is no right or wrong way to feel. You might feel different things at different times.

We are here to support you.

“ From the uncertainty of diagnosis to the cautious hope of treatment, I’ve learned that resilience isn’t loud – it’s quiet, steady and deeply personal. It’s not always easy, but there is always light to be found in the quiet moments. ”

Abir, living with chronic myeloid leukaemia (CML) since 1998



Your feelings and emotions

Coping with a blood cancer diagnosis can be difficult. It can be overwhelming, and hard to process.

Not everyone is the same. Diagnosis affects everybody differently. You may experience some emotions but not others. You might feel different things at different times. There is no right or wrong way to feel. However you feel is OK even if you are confused about your emotions.

You will probably feel a mix of emotions. At first you might feel shocked or in disbelief. Once you start to process your diagnosis, you might feel scared or anxious about the future, or angry that this is happening to you.

“ I just sat there and said, ‘What, cancer?’ He said yes, and I broke down in tears. ”

Ian, diagnosed with acute myeloid leukaemia (AML) in 2005



Some people say they feel helpless at first, like they've lost control of their life. Or you might feel grief that your life doesn't look now how you expected. Many people worry about how things will change and how they will cope.

Other people might feel relieved to finally get a diagnosis. This might be the case if you've had symptoms for a while and been worried about what was causing them. Now you know the problem, you and your medical team can work together to best treat or manage your condition.

“ With my type of cancer, they don't rush in to treat it straight away, so the wait to get my diagnosis hasn't made any difference physically, but it has meant I struggled mentally. ”

Nicola, living with chronic lymphocytic leukaemia (CLL) since 2015

It is common to worry about how to tell people and how they will react. This can all leave you feeling very alone and lonely.

“ Thoughts and questions started playing over and over in my mind. Am I going to die? What will my family do without me? Will I ever leave hospital? Thankfully, the day of leaving the hospital did in fact come. ”

Brian, living with CML since 2021



You might feel low or sad, which is understandable. But if you feel hopeless, you lose interest or pleasure in life, or you feel low for several weeks, you may have depression. If you feel this way, tell someone you trust.

If you think you might be depressed, contact your GP or nurse specialist. They can help you access the support and treatment that you need. This could be lifestyle changes, talking therapy or antidepressants.

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

If you need to start treatment straight away

Depending on your type of blood cancer, you may need to start treatment straight away. This can make you feel overwhelmed. You may feel like you haven't got time to process what's going on. You may feel like you are just going with the motions and dealing with things a day at a time.

“ I said to my consultant I only want to know what I need to know for today and I have tried to carry that with me every day since. ”

Emma, diagnosed with AML in 2024

Talk to your haematology team about how you feel, even if you say that you are confused about your feelings. They can help you cope and offer you support.

You might hear a lot of medical terms that you haven't heard before. Not understanding what's going on can make you feel anxious or worried. Ask your medical team any questions you have. They will be used to this. There is no such thing as a silly question, so if you are unsure about anything, just ask.

“ I could hear words and phrases being thrown around that I didn't understand. Blood cells... bone marrow... mutations... ”

Zoe, diagnosed with AML in 2019



Some people tell us they feel reassured when having treatment, as they know something is being done to manage their cancer.

“ I was so relieved when I got to the ward I cried; I knew I was safe in their hands. ”

Maria, diagnosed with acute lymphoblastic leukaemia (ALL) in 2018

But it's natural to feel worried about how you will cope with treatment or what side effects you might get. If you need to stay in hospital, away from your friends and family, you may feel scared and lonely. You may even need to stay in a room on your own, which can make you feel isolated and alone. Your medical team are there to support you.

“ The mental health toll of my enforced isolation weighed heavily on me and I was grateful for the support of the Leukaemia Care nurse and the hospital chaplains. ”

Janine, diagnosed with AML in 2019

If you don't need to start treatment straight away

Being told you have cancer but you aren't starting treatment can be difficult. You might feel confused, worried or upset. It probably goes against what you understand about treating cancer. You're often told how important it is to spot cancer early and treat it as soon as possible. But for some types of blood cancer, evidence shows that not starting treatment straight away is a safe and common approach. It's called active monitoring.

We have separate [information on active monitoring](#). Follow the link, scan the QR code or search 'active monitoring' at leukaemiacare.org.uk.



You may feel reassured that you don't need immediate treatment. It can be a relief knowing that you won't have to manage hospital visits and side effects. This can give you time to process things and adjust your life as needed. It also means you have time to prepare yourself physically and emotionally if you need treatment later on.

“ I resigned myself to trying to put it to the back of my mind and get on with my life despite the restrictions that my condition was putting on me. Support from friends and family was there but I don't think people fully understood how I felt both physically and psychologically. ”

Ian, living with CLL since 2012

But adapting to active monitoring can be difficult. Even though your medical team are there for you, it is common to feel a bit isolated from them. It can be hard if you feel unsure or uncertain about what to look out for. Some people tell us they feel anxious or worried about monitoring their symptoms.

“ Being on active monitoring was mentally worse than having treatment... Each day I woke up terrified whether bruising had appeared on my body overnight. ”



Sadie, living with CLL since 2012

Your haematology team should give you details of who to contact if you have any questions or concerns. If they don't, ask them who you can contact if needed. Don't be afraid to reach out, they are there to support you.

People often feel particularly anxious just before their appointments. Over time, things usually get a bit easier. Some centres offer patient-initiated follow-up, where you arrange your own check-ups as-and-when you need them. Some people prefer this, but others do not. You can ask for regular appointments instead.

“ Of course, I feel a degree of anxiety whenever I go for my check-ups, but most of the time, I don't even think about it. ”

Paul, living with CLL since 2016

NHS England have more [information on patient-initiated follow up](#). Follow the link, scan the QR code or search 'patient initiated follow up' at england.nhs.uk



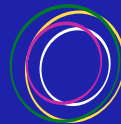
It can also be hard to explain to your friends and family that you have cancer but aren't having treatment. You may come across some misconceptions when you tell people. They might find it hard to understand. It can help to tell the people you trust the most so you don't feel isolated or without support. Being able to explain why you aren't having treatment can help people understand and be there for you.

It can be especially difficult if you feel like your feelings after diagnosis have been dismissed. Some people tell us medical staff have said they are 'lucky' or that 'it's a good cancer to have'. This can make you feel like the emotions you have are not valid.

“ The 'it's a good cancer to have' and 'you look so well' quotes can begin to make you feel like an imposter in the cancer world. This can leave you feeling like you're not entitled to the same concerns and worries. Family and friends begin to forget you are unwell. Empathy for symptoms such as fatigue and anxiety began to wane. ”

Christopher, living with CLL since 2009

Coping with your feelings and getting support



Summary

Everybody copes with their feelings differently. There is no right or wrong way. If you're feeling low, it can seem that nothing will help. But there are things you can try that might help you feel a bit better.

We're here for you if you need support.
Scan the QR code, or select 'support and community' at leukaemiacare.org.uk



“ Everyday will bring something new; the journey is like a rollercoaster. Ensure you reach out for all the support available and don't suffer in silence. ”

Elliot, diagnosed with chronic myelomonocytic leukaemia (CMML) in 2023

Talking about your feelings and getting support from loved ones can really help. Finding and connecting with people who understand what you are going through can help you feel like you have a support network around you.

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.co.uk

Coping with your feelings and getting support

Learning how to cope with your feelings can take time. Even when you have ways of dealing with your emotions, you may still have good days and bad days. It is important to be kind and patient with yourself.

“ I refer to it as my rollercoaster. Once I accepted my life was going to be very different in so many ways, I was able to look at things differently. ”

Emma, diagnosed with AML in 2024

There is no right or wrong way to manage your feelings. Everybody copes differently. It's normal to feel down at times and sometimes it may seem nothing helps. But there are things to try that may help you feel a bit better.

Take things one day at a time

It's common to feel worried, anxious or uncertain. Try taking things a day at a time. This can help you focus on what you need now, without worrying about the future.

“ Plan for the future, live for today. ”

Emma, diagnosed with AML in 2024

It can help to write down your worries, rather than keep them in your head. This lets you rationalise them. Some worries can come from thinking the worst. Noting your concerns and asking your team about them can help.

Talk about your feelings

It can be hard to speak openly and honestly about your feelings. You may feel like you have to stay strong for your loved ones, and don't want to burden them. You might not feel comfortable telling your medical team about your mental health.

“ Emotionally, it has been really tough on both me and my family; I saw a psychologist regularly for years and now have sessions when needed. My health is still like a rollercoaster, it's very up and down, but I treasure the well days. ”



Ellen, diagnosed with acute promyelocytic leukaemia (APL) in 2005

Some people find it can help to speak to someone independent, so you can open up about how you are feeling and coping.

We can help you **access up to six sessions of remote or in-person counselling**, free of charge. Follow the link, scan the QR code, or search 'counselling service' at **leukaemiacare.org.uk**



Tell the important people in your life

It's important to give yourself time to adjust before deciding when and how to tell others. Your diagnosis can leave you feeling vulnerable and less independent. You might need emotional and practical support. Opening up to your loved ones can help you feel supported and understood.

We have more information about telling people about your diagnosis on our [newly-diagnosed webpage](#). Follow the link, scan the QR code or search 'just diagnosed' at leukaemiacare.org.uk



It can be hard to open up about your needs. You might be worried about how people will react. It can be easier to tell the person or people you trust the most. They can tell others for you, so you don't have to tell everybody yourself. Remember, it is up to you who you tell, how you tell them and what you share.

Macmillan have more [information on talking about cancer](#), including with children and at work. Follow the link, scan the QR code or search 'talking about cancer' at macmillan.org.uk



Get help with the practical things

Having blood cancer can impact your day to day life. It can be daunting trying to organise everything yourself, which might make you feel anxious.

It can help to make a list of things you may need to arrange, such as childcare, time off work, and managing appointments. You can ask a family member or friend to help you, or delegate things to those willing to help you.

Your medical team may also be able to signpost you to relevant, local support.

We have more information about the practical things you might need to arrange on our [**newly-diagnosed webpage**](#). Follow the link, scan the QR code or search 'just diagnosed' at [**leukaemiacare.org.uk**](http://leukaemiacare.org.uk)



You may also be worried about how your diagnosis may impact your finances. It can help to see what support is available for you.

[**Our welfare team**](#) are here to support you. Follow the link, scan the QR code or search 'welfare service' at [**leukaemiacare.org.uk**](http://leukaemiacare.org.uk)



Connect with other people with blood cancer

You may be feeling alone and like no one understands what you are going through. Being able to connect with someone who can understand and relate to your experience can make you feel seen and heard.

“ It can feel terribly lonely on this journey, and I do have bouts of low mood and anxiety when thinking about my future. But other people in a similar situation are a source of both inspiration and comfort. ”



Brian, living with CML since 2021

They may have had the same diagnosis, the same treatment and even shared the same worries, concerns or hope.

“ The mental side of leukaemia is tough, so having someone who understood exactly what I was going through was a great support. ”

Janine, diagnosed with AML in 2019

We have specific support services for people with different conditions or experiences. These include:



Buddy service where you are matched with someone who has a similar experience to you



Support groups where you can share your experiences with people who understand



Our **online support**, including Facebook groups moderated by trained volunteers

We're here for you if you need support.
Scan the QR code, or select 'support and community' at leukaemiacare.org.uk



Look after yourself

You might find it hard, but it is important to allow yourself to look after and care for yourself. Being stressed or worried all the time can be exhausting, try and allow yourself to switch off.

Try and give yourself time to do something you enjoy. You might want to go for a walk, practise mindfulness or just do something that makes you happy, like cooking or gardening. Or things like drawing, watching sports, reading or listening to a podcast if you're in hospital or don't have much energy.

It's also important to see family and friends. If you're not able to meet in person, you could catch up by phone or video call.

“ Try to find the thing that lifts your spirits, be that music, singing, people, crafts, and try to add it into your weekly if not daily schedule. ”

Elaine, diagnosed with ALL in 2016



Reach out to your medical team

It's natural to have questions, concerns or fears about your condition. Make sure to ask any questions you have. Your medical team will be used to this.

Usually, you will also be given contact details of a clinical nurse specialist. Don't be afraid to make use of your point of contact, it's what they are there for.

“ I trusted my medical team completely but always asked questions to clarify or to try and understand information or guidance. Don't be afraid to speak up. ”

Paul, living with CLL since 2016

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



You should feel included in decisions about your care. Make sure you understand what your options are. If you're not sure, ask.

“ I am blessed to have a great consultant who works with me to ensure the best possible care. As my treatment wasn't urgent, he allowed me to decide when to start. This helped me maintain some control of my life. ”



Jane, living with CLL since 2004

Sometimes, you might have concerns about your care or treatment. There are services in place, if this happens.

Our advocacy team can support you with treatment decisions or seeking a second opinion. Follow the link, scan the QR code or search 'advocacy support' at leukaemiacare.org.uk



Find out more about your condition

You might want to find out more about your condition, symptoms, what to expect from treatment and how to cope with side effects. Having the information you need can help you feel more in control.

Ask your medical team any questions you have. You can also ask them to give you printed information if you struggle with looking online.

When you're diagnosed with a blood cancer, you might hear a lot of medical terms that you haven't heard before. This can leave you feeling worried.

We have **online information**, as well as information you can **download** or **order in print**. Follow the links, scan the QR codes, or select 'about leukaemia' at leukaemiacare.org.uk



Words you might see or hear



Active monitoring: a way of monitoring your health when you have a blood cancer that doesn't need immediate treatment. You have regular check-ups and you also monitor your own symptoms.

Acute lymphoblastic leukaemia (ALL): a fast-growing type of blood cancer that affects blood cells called lymphoblasts.

Acute myeloid leukaemia (AML): a fast-growing type of blood cancer that starts in blood-forming cells called myeloid stem cells.

Acute promyelocytic leukaemia (APL): a rare subtype of acute myeloid leukaemia.

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

Chronic lymphocytic leukaemia (CLL): a slow-growing type of blood cancer that affects blood cells called lymphocytes.

Chronic myeloid leukaemia (CML): a slow-growing type of blood cancer that starts in blood-forming cells called myeloid stem cells.

Chronic myelomonocytic leukaemia (CMML): a rare type of blood cancer that mainly affects blood cells called monocytes. It can also affect other blood cells.

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

Fatigue: extreme tiredness or lack of energy that can interfere with your usual activities and doesn't get better when you rest.

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

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

Blood Cancer UK

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

MPN voice

- Provides information, community and advocacy for MPN patients, their families and carers.
- **07711 887 911**
- [mpnvoice.org.uk](https://www.mpnvoice.org.uk)

MDS UK

- Provides support to patients with MDS.
- **0207 7337 558**
- **mdspatientsupport.org.uk**

Macmillan

- Provides 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

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

NHS

- National health service that has information on many health-related topics.
- **111**
- **nhs.uk**

Mind

- Leading mental health charity that offers information and support.
- **0300 1233 393**
- **mind.org.uk**

Hub of hope

- Provides a directory of community mental health services, so you can find local support.
- **hubofhope.co.uk**

Samaritans

- Offers 24/7 help and support if you are having a mental health crisis.
- **116 123**
- **samaritans.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@leukaemiacare.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 how to cope with their feelings better.

- Email communications@leukaemiacare.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@leukaemiacare.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.
- Find out if your employer makes 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 leukaemiacare.org.uk

By phone

- Call **08088 010 444** to donate by debit or credit card

By text

- Text **LEUKCARE** to **70490** to donate £5



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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