



Coping with
your feelings
when you finish
treatment for
blood cancer

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



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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.

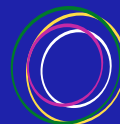
When you finish treatment, it can be a difficult time, and you might not feel how you expected to. In this booklet, we cover how this may make you feel. We've included quotes from other people who've told us what it was like for them. We also cover things that might help you cope with these feelings and adapt to a 'new normal', and where to get support.

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

- Bryony Tyrell, Joanna Stokes and Sarah Blakey, clinical nurse specialists
- Patient reviewers Bethan, Esther and James
- 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

The end of treatment can feel like a whirlwind and hard to process. You may have built it up in your head, but now that it is here, you might not feel how you expected to. You might feel a mix of emotions, or different things at different times. There is no right or wrong way to feel.

We are here to support you.

“ I strongly believe that once your ‘active treatment’ is over people expect you to be back to ‘normal’ and that the mental health side of things is not taken as seriously as the physical side. ”

Emma, diagnosed with acute myeloid leukaemia (AML) in 2024



Your feelings and emotions

Finishing treatment for blood cancer can be an unsettling time.

It's common to not feel how you expected to. You might have thought you would be relieved or happy to go back to normal – and some people are. But finishing treatment can feel anti-climactic. Not feeling how you thought you would can leave you feeling lost.

“ The day I got those final results should have been a day of happiness and celebration, but when the doctor told me I was in complete remission I felt nothing. ”

Esther, diagnosed with AML in 2020



Not everyone is the same. Finishing treatment affects everybody differently. You may experience some of these emotions but not others, or you may feel other emotions altogether. 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.

Your family and friends may be happy for you and expect you to feel like this too, which can be difficult. You may feel like you have to be strong for them or try and 'crack on' with things. Some people tell us this can leave them feeling alone and like no one understands what they are going through.

“ I actually wanted to be in hospital where I felt safe. ”

Ian, diagnosed with AML in 2005



You might have expected life to go back to the way it was before. But this may not be the case. You might feel differently about what is important to you, or want to make some changes. You may have side effects to cope with and appointments to go to. This can be difficult for you and those around you.

These changes can leave you grieving the life you used to have. You might feel upset if you can no longer do the things you did before, or if you struggle more than you used to. You may worry about the future.

“ The cancer may have gone but our lives are still impacted daily by the devastation it has caused to our bodies. ”

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



It takes time to adjust to how you feel and what your body can cope with. Be patient with yourself.

If you started treatment soon after being diagnosed, you may have felt like you were in 'survivor mode' with no time to process things. Some people tell us that they only started to process what they had been through after finishing treatment.

“ It was as if in that moment my brain had suddenly caught up with what had happened to my body. ”

Esther, diagnosed with AML in 2020



It can also feel unsettling not to have as much contact with your doctors and nurses. You may feel anxious or scared at first. You may feel like you no longer have that support network to share your fears, worries or concerns about your cancer. Remember, your team are still there for you if you need them. Ask them how you can contact them if you need to.

“ Whilst you're in hospital you are in a 'protective bubble' and getting used to being outside that is difficult, but the biggest thing I realised is recovery is not linear. ”

Emma, diagnosed with AML in 2024

Some people tell us they feel ‘survivor’s guilt’ for making it through treatment when others may not. This can make you feel that you have to be happy or appreciative of life all the time. You are allowed to feel how you feel. You have been through a lot. You can be happy to have got through it but still feel a mix of challenging emotions too.

“ A friend described it perfectly – it was as if you’d been away to war – everyone thinks you should be happy to be back alive but no-one really understands the trauma you’ve experienced... ”

Esther, diagnosed with AML in 2020



It’s also natural to feel anxious or scared about the cancer coming back. You might feel this before appointments or if you get new symptoms. Over time, it usually gets easier.

“ 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 chronic lymphocytic leukaemia (CLL) since 2016

You may also have lost your self-confidence, especially if you have side effects from treatment like losing or gaining weight or losing your hair. You may also feel less confident if you've been unable to work or look after your family for some time.

Even if you don't have physical changes, or these get better over time, you might not feel like yourself. You might feel less independent. You may have a different role in your family or at work. Some people tell us they find it harder to socialise and meet friends, especially when coping with side effects like fatigue.

It can take time before you feel like yourself again. It's important to be kind and patient with yourself.

“ I feel as if my life has been turned on its head. I am not yet back at work and don't know whether I'll be able to go back, and my role as a father and husband has changed too. ”

James, diagnosed with myelofibrosis (MF) in 2023

You might be feeling 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 are struggling, try speaking to someone and getting support.

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.

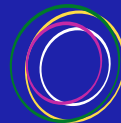
If you need urgent mental health support, call 111 and select the mental health option.

Of course, there are also lots of positives of stopping treatment too. You may feel relieved and hopeful for the future. Knowing that you won't have to stay in hospital or deal with treatment might be something you are looking forward to.

“ It was an amazing feeling, a relief. I didn't care that I had no hair. ”

Sue, diagnosed with AML in 2021

Coping with your feelings and getting support



Summary

Learning to adapt to life when treatment stops can take time. Be kind and patient with yourself. If you're feeling low, it can seem like nothing will help. But there are things you can try that might help you feel a bit better.

“ 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

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



Staying in contact with your medical team 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're not the only one feeling like this.

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

Adapting to life after treatment and learning to cope with your feelings can be difficult. Once you start to settle into things, you may still have good days and bad days. It can take time to adjust, but people tell us it gets easier over time. It is important to be kind and patient with yourself through it all.

“ I have accepted that no two people with blood cancers have the same recovery story and once I stopped comparing it became easier. ”

Emma, diagnosed with AML in 2024

It can be difficult if you are struggling to adapt, feel less supported or feel pressure to be happy. Everybody copes with their feelings differently. There is no right or wrong way to manage your feelings. 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.

Give yourself time to adjust to a new normal

Life after treatment usually involves a lot of change. Some people call this finding their 'new normal'.

There are some things you might have done before that you can try and slowly ease back into. This could include:

- Working or supporting your family
- Doing activities or hobbies that you used to
- Spending more time with family, friends and loved ones

Adjusting to a new normal can take time. You may still do the things that are important to you, it just may look different to before you had cancer. Be kind and patient with yourself, you will get there.

“ I stopped calling it a journey and now refer to it as my rollercoaster and 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

Macmillan have [more information on returning to work after treatment](#). Follow the link, scan the QR code or search 'returning to work' at [macmillan.org.uk](https://www.macmillan.org.uk)



Take things a day at a time

Try not to put pressure on yourself to find your 'new normal'. It takes time and it's important to be patient with yourself. Try not to expect too much of yourself, remember you will have good days and bad days. It can help to take things a day at a time, bit by bit. This can help you focus on the here and now.

“ Plan for the future, live for today. ”

**Emma, diagnosed with AML
in 2024**



Build your self-confidence

After treatment you might no longer feel like your usual self. This can knock your self-confidence.

“ Throughout this time people commented on how well I looked – which just isn’t helpful at times! ”

Emma, diagnosed with AML in 2024

You might no longer be able to do the things you did before, like work or certain hobbies. This can affect how you might feel about yourself. It can be difficult if you don’t know how to fill your time. Some people tell us that volunteering helps them feel a sense of purpose.

Macmillan have [more information about loss of confidence and cancer](#). Follow the link, scan the QR code, or search ‘loss of confidence’ at [macmillan.org.uk](https://www.macmillan.org.uk)



Doing things with your friends and family can help. It can be daunting to start going out and socialising again. You might have fatigue, which can make this even more difficult. Spend time with others in ways that work for you. If you're not feeling up to going out, you could have people come round to relax with you instead. Even just catching up over the phone or video call can help you feel less lonely. Often, being around loved ones and those that care about you can help.

“ After shielding before, during and for 6 months after treatment I became increasingly anxious about going out. With some help from the Cancer Psychology Team at my hospital I am now back to my 'normal' pre planning and enjoying being out and about. ”



Jane, living with CLL since 2004

Macmillan have [more information on cancer and fatigue](#). Follow the link, scan the QR code, or search 'tiredness' at [macmillan.org.uk](https://www.macmillan.org.uk)



If you're struggling to adapt to changes in your appearance, you might find it helpful to say positive things that you like about yourself in the mirror. Maybe you like your eyes, your smile or your laughter. You could also place sticky notes with kind messages to yourself on your mirror to help you through it.

Cancer Research UK have [more information about coping with changes in your appearance](#). Follow the link, scan the QR code or search 'changes in your appearance' at [cancerresearchuk.org](https://www.cancerresearchuk.org)



Macmillan have [beauty advisors at Boots](#) to help with the visible side effects of treatment. Follow the link, scan the QR code or search 'beauty advisors' at [macmillan.org.uk](https://www.macmillan.org.uk)



Know when and how to contact your medical team

Even after you finish treatment, it's important to remember that your medical team are still there to support you.

It can help to ask your medical team any questions you have before your treatment ends. They can help you with any worries you might have. They can also tell you who to contact if you have any concerns or queries.

“ 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

Talk to your medical team if you are struggling to adjust. Let them know if you have any medical worries or if you have new symptoms or side effects. They are there to support you, address any of your concerns and can help put your mind at ease. Your GP can also help you access support and treatment if you are struggling with your mental health.

“ I feel very lucky...having the support and knowledge from an amazing haematologist makes the journey a lot better. ”

Carrie, living with chronic myeloid leukaemia (CML) since 2018



Finding the information you need

It's natural to feel worried about what to look out for, what to expect and how to cope with side effects. Having the information you need can help you feel on top of things.

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



Ask your medical team any questions you have. You can ask them to give you printed information if you struggle with looking online. They can also make notes for you in appointments, to help you remember key bits of information.

Look after yourself

You might find it hard, but it is important to care for yourself. Adapting to a 'new normal' can be tiring, try and allow yourself to switch off.

Try and spend time doing 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 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, or crafts, and try to add it into your weekly if not daily schedule. ”

**Elaine, diagnosed with ALL
in 2016**



It's important to look after yourself physically too. This can also help you feel better emotionally.

Try to eat a well-balanced diet. This should help you feel stronger, have more energy and cope better with any side effects you have.

The NHS website has [information and guidance on eating a healthy, balanced diet](#). Scan the QR code, or search 'eat well' at [nhs.uk](https://www.nhs.uk)



“ Having a routine and having a purpose for me helped me find the way forward to a positive place. ”

Elaine, diagnosed with ALL in 2016



Staying active can improve your wellbeing, quality of life and physical health. Exercise can also help you cope with your emotions. You don't have to overexert yourself, even a gentle walk can help. Choose a level of exercise that works for you and how you are feeling.

The NHS have [more information on exercise for different ages and abilities and examples of different exercises](#). Follow the link, scan the QR code, or search 'exercise' at [nhs.uk](https://www.nhs.uk)



Connect with people who understand

Being able to connect with someone who understands and relates to your experience can make you feel seen and heard. It can help to hear that you're not the only one feeling this way after treatment.

“ 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



Talk about your feelings

It can be hard to speak openly and honestly about your feelings. You may feel like others expect you to feel happy. But some people tell us it can be difficult if you don't feel like this.

Talking to your loved ones about how you feel can help them understand and be there for you. It can also be helpful to write down your feelings, worries and concerns rather than letting them stay in your head.

“ 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 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



Words you might see or hear



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.

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

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

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

Myelofibrosis (MF): a type of cancer where your bone marrow becomes filled with scar tissue, which stops it making enough healthy blood cells.

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 887911**
- [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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