

Just diagnosed with leukaemia

You may have just found out that you or someone you love have leukaemia. It can be hard to know where to start and what to do after such a life-changing diagnosis. We are here to support you. Find out about what support is available, where to find information, and things you may need to get in order.

What to do after a diagnosis

Find out about what support is available, where to find information, and things you may need to get in order.

How you might feel

Finding out you have leukaemia is difficult. You may experience a mix of thoughts and emotions like:

- Shock or disbelief
- Uncertainty, anxiety or fear about the future
- Feeling a loss of control
- Worry about other people's reactions
- Guilt, anger, frustration or irritability
- A loss of self-confidence
- Grieving for a major life change
- Feeling alone and ill informed

Everybody reacts differently. You may experience some of these emotions but not others. You might have different feelings at different times. There is no right or wrong way to feel.

It's important to let your medical team know how you're feeling. They can help you access support and may be able to refer you for counselling if you need it.

Here are some other ways you can find emotional support:

- Contact us for advice and support. You can call us on [08088 010 444](tel:08088010444), send a WhatsApp message to [07500 068 065](tel:07500068065) or email support@leukaemicare.org.uk.
- We offer a [counselling service](#) for people with leukaemia and their families.
- The NHS has more information about [mental health services](#).

<https://lcdemo-stage.gb.aldryn.io/about-leukaemia/just-diagnosed/>

Leukaemia Care Registered Charity Number 1183890. Scotland Registered Charity Number SC049802

Helpline: [08088 010 444](tel:08088010444)

- Cancer Research UK has more information on [where to get support for mental health](#).
- Sometimes, coming to terms with your diagnosis can take time. Maggie's have [more information about dealing with a diagnosis](#).
- Sometimes, due to societal pressures, men can find it harder to open up and talk about their emotions. But mental illness can affect anybody. [Man Up](#) is a mental health charity that helps challenge this and help men with their mental health.

Where to get support

Being diagnosed with leukaemia can feel isolating. But you're not alone. It can help to talk to people who know what you're going through.

- Call our helpline on [08088 010 444](tel:08088010444), send a WhatsApp message to [07500 068 065](tel:07500068065) or email support@leukaemiacare.org.uk for more information about the support we can offer you.
- We offer a [buddy service](#) and [support groups](#) so you can connect with people you can relate to.
- Our online support includes [Facebook communities](#) where you can connect with other people in a similar situation.
- Speak to a [navigator](#) at one of our hospital hubs for advice and support.
- Macmillan have [cancer community meet-ups](#). This is where people with cancer can meet each other and socialise together.
- Maggie's have [local centres](#) where people with cancer can get help and information from staff. They also have classes and groups to help people cope with cancer.
- GOV.UK lets you search for [local community support groups and organisations](#).

“I found the Leukaemia Care website a week into my treatment. They provided information about my leukaemia, I attend their online support groups and webinars and they organised a buddy for me with the same kind of leukaemia, all of which helped me through some tough times. It can be difficult, but it was great that this charity was and is there for me.”

Sally, diagnosed with hairy cell leukaemia in 2024

Support for loved ones and carers

If someone you love has been diagnosed with leukaemia it can feel overwhelming. You may feel pressure to 'be strong', but you also might be feeling worried for your loved one.

<https://lcdemo-stage.gb.aldryn.io/about-leukaemia/just-diagnosed/>

Leukaemia Care Registered Charity Number 1183890. Scotland Registered Charity Number SC049802

Helpline: [08088 010 444](tel:08088010444)

You may have taken on extra responsibilities to help care for your loved one. But it's also important to take care of yourself both physically and emotionally.

- Contact us for advice and support. You can call us on [08088 010 444](tel:08088010444), send a WhatsApp message to [07500 068 065](tel:07500068065) or email us support@leukaemiacare.org.uk.
- If you are struggling with your mental health, we offer a [counselling service](#). It is also open to loved ones and carers of people with leukaemia.
- Macmillan has more [information about how you can support someone with cancer](#).
- [Carers UK](#) have lots of information for carers. This includes financial, practical and emotional support. They also have [information about caring for someone with cancer](#).
- Maggie's have [more information about support for carers](#). They also have local centres where you can attend support groups or speak to a cancer support specialist.

Questions you might want to ask

After your diagnosis, you are likely to have a lot of questions. Make sure you ask them. If you don't understand something, ask your medical team to explain. They will be used to this. You could take notes on your phone or on paper to help you remember. Or you could ask your doctor or nurse to write things down. You can also ask them if they're happy for you to record the conversation.

Questions that you might want to ask include:

- What have my tests found?
- Do I need any more tests?
- Where can I find information about my condition and treatment?
- What are my treatment options?
- Why would you recommend this treatment option for me?
- How will I have my treatment? How long will it last?
- What might the side effects be? How likely are these side effects?
- How might this treatment affect my fertility?
- What other treatment options are there?
- Will I need to stay in hospital? If so, for how long?
- Who can I contact if I have any further queries or concerns after my appointment?

<https://lcdemo-stage.gb.aldryn.io/about-leukaemia/just-diagnosed/>

Leukaemia Care Registered Charity Number 1183890. Scotland Registered Charity Number SC049802

Helpline: [08088 010 444](tel:08088010444)

- Do I have a clinical nurse specialist? If yes, how do I contact them?
- Who can I contact if I feel unwell during my treatment?
- What might my outcome be?
- How will I know if my treatment has worked?
- Are there any food or medicines that I need to avoid?
- Do I need to take any steps to prevent getting an infection?
- Will I be able to go back to work, school or university?
- Where can I get financial help?
- Where can I get help dealing with my feelings?

Your medical team

Your medical team might include:

- A consultant (senior doctor), which could be
 - A haematologist, a blood specialist
 - An oncologist, a cancer specialist
- A clinical nurse specialist (CNS)
- Other doctors and nurses
- A pharmacist
- A physiotherapist
- A dietician
- Other health professionals

Telling people

When you are first diagnosed with leukaemia, it is important to give yourself time to adjust before deciding when and how to tell others. You might feel under pressure to share as people want to know what's going on, but it is okay to let them know you need time to adjust.

Your diagnosis may leave you feeling vulnerable and less independent. You may need emotional and practical support. It can be hard to open up about your needs but taking that step can help you feel supported and understood.

Telling your family and friends

It is up to you who you tell about your diagnosis, how you tell them and what you share. It can help to make a list and plan what you want to say.

<https://lcdemo-stage.gb.aldryn.io/about-leukaemia/just-diagnosed/>

Leukaemia Care Registered Charity Number 1183890. Scotland Registered Charity Number SC049802

Helpline: [08088 010 444](tel:08088010444)

When you tell your loved ones you might want to:

- Explain your condition and how it affects your body.
- Explain what symptoms you get.
- Explain your needs.
- Be open and honest about how you feel.
- Address any concerns or questions they have. You might not be able to answer all their questions but you may be able to give them more information as diagnosis and treatment progresses.
- Signpost them to support groups or other available support should they need it.

Having [information about your condition](#) on hand can make the conversation easier. Repeating yourself can be draining, so you can ask your friends and family to tell other people for you.

[Blood Cancer UK](#) and [Macmillan](#) have more information about telling your friends and family you have blood cancer.

Telling children

It's natural to want to protect children from knowing that someone they care about is ill. But children may notice changes in their routine and start to pick up that something is wrong. Being open and honest with them can help them cope. Knowing that adults they trust are there if they want to talk about it can help.

- Macmillan have more [information about talking to children and teenagers](#).
- Cancer Research UK have more [information about talking to children](#).
- The Fruitfly Collective have many [resources to help with navigating family life and supporting children](#). They have free online information but there is a charge for their physical packs and resources.

What to pack for a hospital stay

Depending on your diagnosis and treatment, you might need to stay in hospital.

Here's a list of things you might want to pack. You may need to ask someone else to bring them in for you.

- Contact details of your next of kin, GP, social worker or carer if you have one
- Any medicines you take, including:
 - Prescription medicines and repeat prescription lists
 - Over the counter medicines

<https://lcdemo-stage.gb.aldryn.io/about-leukaemia/just-diagnosed/>

Leukaemia Care Registered Charity Number 1183890. Scotland Registered Charity Number SC049802

Helpline: [08088 010 444](tel:08088010444)

- Herbal remedies
- Contraceptive pills, hormone replacement therapy and inhalers
- Details of any allergies and medical alert-ID bracelets
- Loose pyjamas or loose-fitting comfortable clothes
- Socks, slippers and underwear
- A bag to put dirty clothes in
- Your own pillow
- Your mobile phone, laptop or tablet and the chargers for them
- Headphones
- Sleep mask, ear plugs
- Tissues and baby wipes
- Something to help pass the time
 - You may want to download a TV series or a few films on your phone, tablet or laptop
 - A book, magazines, games or crafts
- Credit or debit card, small amounts of change or cash
- Something comforting, like a photo, a favourite blanket or jumper or a stuffed toy
- Toiletries (hairbrush and hair care products, deodorant, body wash, shampoo, moisturiser, razor, shaving foam)
- Period products
- Toothbrush and toothpaste
- Dentures, mouthguards or braces if you use them
- Hand and bath towels
- Glasses, contact lenses and solution
- Hearing aid
- Walking stick or orthopaedic shoes if you use them
- Your favourite tea, coffee or squash flavour

If you have a special diet, ask if the hospital can cater for this, or if family and friends can bring in food for you.

The NHS have [information on staying in hospital as an inpatient](#).

Looking after children

After your diagnosis you may need to adjust to changes in your routine. You may be admitted to hospital, or have to go often for tests, appointments or treatment.

<https://lcdemo-stage.gb.aldryn.io/about-leukaemia/just-diagnosed/>

Leukaemia Care Registered Charity Number 1183890. Scotland Registered Charity Number SC049802

Helpline: [08088 010 444](tel:08088010444)

There might be long periods of time when you aren't at home. So, you may need to arrange care for your children.

If you ask someone to look after your child, there are some important details they might need to know. This may include:

- Contact details for you and your emergency contact
- Contact details for your child's GP surgery
- Any medicines your child takes, including inhalers and repeat prescriptions
- Details of any allergies and medical alert-ID bracelets
- Details of any special diets and foods they like or don't like
- Contact details for their teacher and school
- Their school timetable, after-school clubs and school uniform
- Passwords to collect children from nursery or school
- School lunches, what they normally have, and how to order school lunches
- Access to any online parent portals from school to access newsletters, pay for school trips etc
- Your child's usual routine, including rules around chores, bedtime, screentime and snacks

There are several places where you can seek support with arranging childcare.

- Your friends and family may be able to help look after children on a short-term or long-term basis. [Kinship](#) is a charity that has information, support and advice for family and friends.
- Your child's school may be able to offer support like breakfast clubs and after school clubs.
- Your [local council](#) will have more information about social and childcare services in your area.
- If you, your partner, or child's parent work, talk to your employer about childcare. They may be able to offer flexible working or unpaid leave.
- [Home-Start](#) is a charity that offers support and help with young children.
- [Carers Trust](#) is a charity that offers support with childcare.
- [Gingerbread](#) is a charity that offers support for single parents.
- [Macmillan](#) have more information about childcare and cancer.
- [GOV.UK](#) have more information about looking after someone else's child and financial help.

Caring for pets

<https://lcdemo-stage.gb.aldryn.io/about-leukaemia/just-diagnosed/>

Leukaemia Care Registered Charity Number 1183890. Scotland Registered Charity Number SC049802

Helpline: [08088 010 444](tel:08088010444)

If you're admitted to hospital, you may need to organise care for your pets. Your family or friends may be able to help look after your pet in the short-term. Or neighbours may be able to pop in to check in on your pet or help with dog-walking.

If you're struggling to arrange pet care, there are a few places that may be able to help.

- Your [local vet](#) might have information about local services that can help.
- The [Cinnamon Trust](#) are an organisation that help with pet care for people over 65 or people who have a terminal illness.
- The [Carers Trust](#) have more information about arranging pet care.
- [Macmillan](#) have more information about cancer and arranging pet care.

Looking after your home and vehicle

Depending on your diagnosis and treatment, you might need to stay in hospital, or go for tests, appointments or treatment.

There might be long periods of time when you aren't at home. So, you may need to sort out your household and vehicle.

Sorting out your household

If your home is going to be empty for a long period of time, you may want to:

- Give a trusted person a key to your home. If you have an alarm, make sure they know how to set it and deactivate it.
- If you live in a shared house, ask someone to look after any valuables.
- Have someone check on your home or room regularly to make sure everything is OK. They can tell your neighbours or housemates how often they will come and share contact details in case of emergency.
- If you have a landlord, tell them how to contact you if you won't be at home.
- Check your home insurance about what happens if no-one is home for a long period of time.
- Cancel any food deliveries and pause any subscriptions.
- Redirect deliveries to someone you trust.
- Cancel external maintenance like window cleaning or arrange for someone you trust to be there.
- Ask someone to empty bins, put them out for collection and remove perishable food.
- Ask someone to turn off your water, gas and electricity at the mains.

<https://lcdemo-stage.gb.aldryn.io/about-leukaemia/just-diagnosed/>

Leukaemia Care Registered Charity Number 1183890. Scotland Registered Charity Number SC049802

Helpline: [08088 010 444](tel:08088010444)

- Ask someone to water any indoor plants and the garden.
- Arrange for someone to collect your post and bring it to you.
- Ask someone to close your blinds or curtains in the evening and turn lights on and off in the evening. You could arrange for a timer for your lights instead.
- Ask someone to restock your fridge, freezer and food cupboards with some essentials for when you will be coming home.

If you have a repeat prescription, you may need to ask someone to order it for you. The NHS has more information on [how to order a repeat prescription](#).

Sorting out your vehicle

Your diagnosis may impact your ability to drive. You might need to [tell the DVLA](#) about your diagnosis. GOV.UK have more information about [cancer and driving](#).

It's important to make sure your car still has its MOT, tax and insurance. If you're in hospital for a while, you may want to ask a friend or family member to start your car and run the engine for a few minutes every few weeks. This helps maintain the battery. They should not drive it unless they are covered by your insurance.

If you're not using your car or you will be in hospital for a long time, you can declare your car as off the road. This is also known as a [SORN](#) (statutory off-road notification).

- Cancer Research UK have more [information about cancer, driving and insurance](#).

Help with money and finances

Having leukaemia may affect your finances. You may need to stop working or reduce your hours. You may also have extra costs like heating, travel to and from hospital and childcare.

Talking about money and managing your finances can be overwhelming. We are here to support you. Call our helpline on [08088 010 444](tel:08088010444) or email advocacy@leukaemicare.org.uk to speak to our Welfare team about finances or help with money.

After your diagnosis you may be eligible for benefits and government support. If you already claim benefits, there might be other benefits that you are now also eligible for. You may also be able to get other financial support.

People with cancer are eligible for [free prescriptions](#), if you do not already have them where you live. You can ask your haematology team or GP about how to apply. You can also ask them about other financial support you might qualify for.

- We offer a [cost of living fund](#) to adults affected by [leukaemia](#), [myeloproliferative neoplasms](#) (MPN) or [myelodysplastic syndrome](#) (MDS).
- You can call our helpline on [08088 010 444](tel:08088010444) or email us at advocacy@leukaemiacare.org.uk to talk to about benefits, financial support, and how to apply.
- GOV.UK have more [information about benefits](#).
- Macmillan have more [information about benefits and cancer](#).
- You can contact Citizens Advice to [discuss benefits and financial support](#).
- If you are employed, ask about sick pay or company benefits you may be entitled to.
- Ask your hospital if they have any reductions or schemes in place to help with parking costs if you have regular appointments or visits.

It can be helpful to see how your diagnosis may impact your finances. This can help you work out what financial support you may need.

- Money Helper have a [budget planner](#) to help you create a financial plan.
- Cancer Research UK have more [information about managing your money](#). This includes [information about financial planning](#) and a [list of organisations you can contact to talk to about money and finances](#).
- Macmillan have more [information on managing your money](#).
- You might want to discuss your finances with someone else. The Financial Conduct Authority have a [register of advisors](#) that can help you manage your money.

If you have income protection or critical illness insurance, you may be able to make a claim. You can use the money from either type of claim as you need. Contact your insurance provider or visit their website to find out how to make a claim.

- Money Helper have more [information about critical illness cover](#).
- Macmillan have more [information about protection insurance and cancer](#).

Support with work or education

Being diagnosed with leukaemia can affect your work or education. You may need time off for hospital stays, appointments or if you are feeling unwell.

<https://lcdemo-stage.gb.aldryn.io/about-leukaemia/just-diagnosed/>

Leukaemia Care Registered Charity Number 1183890. Scotland Registered Charity Number SC049802

Helpline: [08088 010 444](tel:08088010444)

It's important to know that having cancer is a protected characteristic. This means that you have certain [rights](#) and cannot be [discriminated](#) against due to your illness.

You are entitled to [reasonable adjustments at work](#) or your [place of education](#). These are changes with work or your education to keep you working or studying, if you are well enough to.

You may want to talk to someone about your needs and adjustments. This could be your manager, HR, occupational health, workplace union, teacher or student union. When talking to them you might want to:

- Explain what your condition is, and how it may affect your work or education
- Talk about if you want other people at work or place of education to know
- Discuss what changes they may be able to make to help you
- Ask about sick pay, occupational health and other policies in place at work
- Ask what support they may have or can offer you
- Give them [information about your condition](#) and [how they can support you](#)

There are a few places that may be able to support you with work or education.

- Call our [advocacy team](#) on [08088 010 444](tel:08088010444) or email us at advocacy@leukaemiacare.org.uk. We can explain your rights at work and in education and help you apply for any support you need.
- GOV.UK have more [information about work and your rights as an employee](#).
- Macmillan have more [information about talking to your employer](#).
- Young Lives vs Cancer have more [information about managing your education when you have cancer](#).
- Teenage Cancer Trust have more [information about going to university after cancer treatment](#).

Support with questions or concerns about your care

Our [advocacy services](#) are here for you. We can help with employment, housing and financial issues. We can also help you access support and make decisions about your treatment and care.

If you don't understand your care and support, or struggle to speak up for yourself, an [advocate](#) can help.

Making treatment decisions

Your medical team will recommend treatment for you based on many factors.

<https://lcdemo-stage.gb.aldryn.io/about-leukaemia/just-diagnosed/>

Leukaemia Care Registered Charity Number 1183890. Scotland Registered Charity Number SC049802

Helpline: [08088 010 444](tel:08088010444)

You should feel included in decisions about your care. Make sure you ask any questions you have so you understand what your options are.

- Our [advocacy team](#) are here to help if you'd like support with any aspect of this.
- The [NHS](#) and [National Institute for Health and Care Excellence \(NICE\)](#) have more information about shared decision making.

Asking for a second medical opinion

If you wish to, you have the right to ask for a second opinion. This can mean asking another doctor if they agree with your diagnosis and treatment plan. You might have to go to a different hospital for this.

You might want to ask for another appointment or a second opinion if:

- You are unsure about your diagnosis
- You don't understand everything that has been said to you
- You want to make sure that the treatment you are offered is the best option for you
- You are unhappy with the treatment that has been recommended
- You find it difficult to talk to your doctor or hospital medical team

If you are considering getting a second opinion:

- Our [advocacy team](#) are here to help if you'd like support seeking a second opinion.
- [Macmillan](#) and [The Patients Association](#) have more information about getting a second opinion.

Complaining about your treatment or care

Sometimes, you might have problems or issues with your treatment or care. There are services in place, if this happens. These can help with many aspects of your care, including:

- Getting help with health-related questions
- Getting help with concerns or problems using the NHS
- Being more involved in your own healthcare

There are different services that can help you, depending on where you are in the UK.

- England – [Patient Advice and Liaison Service](#)
- Scotland – [Patient Advice and Support Service](#)

<https://lcdemo-stage.gb.aldryn.io/about-leukaemia/just-diagnosed/>

Leukaemia Care Registered Charity Number 1183890. Scotland Registered Charity Number SC049802

Helpline: [08088 010 444](tel:08088010444)

- Wales – [NHS Wales complaints and concerns](#)
- Northern Ireland – [NI direct government services](#)

Finding information about your condition

You might want to find out more about your condition, including symptoms you might have, what to expect from treatment, and how to cope with side effects.

There is a lot of information on the internet, and it can be difficult to know what to trust.

- We have lots of [online information](#) about different types of leukaemia. You can use our accessibility tool to translate this or listen to it in audio format.
- You can also download our information or [order copies in print](#).
- When you're first diagnosed, our [A-Z of words that you might hear](#) might be helpful.
- The [NHS](#) has lots of reliable health information. They also have some [information about trusted health information websites](#).
- [Macmillan](#) have lots of cancer-related information. They also have some information about [finding reliable health information online](#).
- If you search for information yourself, look for organisations that have the [PIF tick](#). This is a UK quality mark for health information. The PIF tick has a [list of organisations and individuals that produce trusted health information](#).

“When I received my diagnosis, I was so overwhelmed, I felt like my world had ended and I didn't know where to turn or what my life was going to look like. Resources like this really helped me understand what was going to happen and just how much support was out there for me and my loved ones. Leukaemia Care really lived up to their name and the Leukaemia Care navigator at my local hospital was helpful, informative and a smiling face for me during a time when I found it hard to be positive.”

Tara, diagnosed with acute lymphocytic leukaemia in 2023

How to get information if you can't get online

If you don't have access to the internet, it can make it harder for you to find information.

- You can call our helpline on [08088 010 444](tel:08088010444) to get more information about your condition.
- Some GP practices in the UK have services where you can borrow a laptop. You can also [search for a local library](#) where you can access the internet and sign up for computer courses.

<https://lcdemo-stage.gb.aldryn.io/about-leukaemia/just-diagnosed/>

Leukaemia Care Registered Charity Number 1183890. Scotland Registered Charity Number SC049802

Helpline: [08088 010 444](tel:08088010444)

- You can call a charity, such as Leukaemia Care, and ask us to send you some information in print.
- You can ask your haematology team if they can give you printed information.

Sources we used to develop this information

Evans Webb M, Murray E, Younger ZW, Goodfellow H, Ross J. The supportive care needs of cancer patients: a systematic review. *Journal of Cancer Education* 2021;1-0.

Howell DA, McCaughan D, Smith AG, Patmore R, Roman E. Incurable but treatable: Understanding, uncertainty and impact in chronic blood cancers—A qualitative study from the UK's Haematological Malignancy Research Network. *PLoS One* 2022;17(2):e0263672.

LeBlanc TW, Fish LJ, Bloom CT, et al. Patient experiences of acute myeloid leukemia: a qualitative study about diagnosis, illness understanding, and treatment decision-making. *Psycho-Oncology* 2017;26(12):2063-8.

McCaughan D, Roman E, Sheridan R, et al. Patient perspectives of 'Watch and Wait' for chronic haematological cancers: Findings from a qualitative study. *European Journal of Oncology Nursing* 2023;65:102349.

Nørskov KH, Overgaard D, Lomborg K, Kjeldsen L, Jarden M. Patients' experiences and social support needs following the diagnosis and initial treatment of acute leukemia-A qualitative study. *European Journal of Oncology Nursing* 2019;41:49-55.

Pasek M, Suchocka L, Gašior K. Model of social support for patients treated for cancer. *Cancers* 2021;13(19):4786.

Sheridan R, McCaughan D, Hewison A, et al. Experiences and preferences for psychosocial support: a qualitative study exploring the views of patients with chronic haematological cancers. *BMJ Open* 2023;13(8):e070467.

Yogaparan T, Panju A, Minden M, et al. Information needs of adult patients 50 or older with newly diagnosed acute myeloid leukemia. *Leukemia Research* 2009;33(9):1288-90.

Need support?

You are not alone. We're here for you whether you have a diagnosis yourself or know someone who has. If you'd like advice, support, or a listening ear, call our freephone helpline on 08088 010 444 or send a WhatsApp message to 07500 068 065.

[Helpline and WhatsApp →](#)

<https://lcdemo-stage.gb.aldryn.io/about-leukaemia/just-diagnosed/>

Leukaemia Care Registered Charity Number 1183890. Scotland Registered Charity Number SC049802

Helpline: [08088 010 444](tel:08088010444)

Help us improve our information

We aim to provide information that's reliable, up-to-date, and covers what matters to you. Please complete our short survey to help us improve our information and make sure it meets your needs.

[Complete our short survey →](#)

About our information

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. Find out more [about our information](#).

Page last reviewed: 31 May 2025

Updated February 2026

Next review due: 31 May 2028



<https://lcdemo-stage.gb.aldryn.io/about-leukaemia/just-diagnosed/>

Leukaemia Care Registered Charity Number 1183890. Scotland Registered Charity Number SC049802

Helpline: [08088 010 444](tel:08088010444)