Your feelings after a blood cancer diagnosis

Being diagnosed with blood cancer is tough and you probably have a range of feelings at the moment. On this webpage we cover some of the emotions you might feel, suggestions to help you cope and where to get support.

Summary

- Finding out you have blood cancer is tough.
- You may feel overwhelmed, shocked, helpless or struggle to process your diagnosis. You may feel some of these emotions but not others. However you feel is OK.
- Everybody copes with their feelings differently.
- 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.

Download our booklet on coping with your feelings 🗎
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Factsheet: Your feelings after a blood cancer diagnosis 🗎
Factsheet: Your feelings if you need treatment straight away 🗎
Factsheet: Your feelings if you do *not* need treatment straight away 🗎

Your feelings and emotions

You may have just found out that you have a blood cancer, and it can be hard to process such a life changing diagnosis. Coping with your diagnosis can feel overwhelming. We are here to support you.

> **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.**

> "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*

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 that 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*

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*

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*

If you think you may 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.**

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If you need to start treatment straight away

Factsheet: Your feelings if you need 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.

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.

> “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*

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*

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If you don’t need to start treatment straight away

Factsheet: Your feelings if you do not need 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.

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 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 a challenge. 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*

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*

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Coping with your feelings

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

> "I stopped calling it a journey and now refer to it as my rollercoaster and once I accepted 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*

Everybody copes with their feelings differently. There is no right or wrong way to manage your feelings. It can be normal to feel down at times. 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.

> "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*

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Where to get support

Coping with a blood cancer diagnosis can be difficult. You may need support from:

- Your healthcare team
- Family and friends
- Leukaemia Care
- Other charities

We are here to support you.

Our support services include:

Buddy service, where you are matched with someone who's had a similar experience to you

Support groups, which offer a safe place to share your feelings with people who understand

Online support, including Facebook communities where you can connect with other people who know what it's like to have a diagnosis of blood cancer

Counselling service, where you can access up to six sessions of in-person or online counselling, free of charge

We have more information on coping with your feelings and getting support.

We also have information on the practical things when you have just been diagnosed with leukaemia.

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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 →

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