Your feelings if blood cancer comes back or does not respond to treatment

Sometimes blood cancer may not respond to treatment. This is called refractory cancer. Sometimes, it can come back after successful treatment. This is called a relapse.

Finding out you haven't responded to treatment or that your blood cancer has come back is difficult. Here we cover some of the emotions you might feel, how to cope with your feelings and where to get support.

Summary

- Finding out you haven't responded to treatment or that your blood cancer has come back is tough.
- You may feel overwhelmed, shocked, angry or devastated. You may feel some of these emotions but not others. Or you may feel something else entirely. However you feel is OK.
- Everybody copes with their feelings differently.
- If you're feeling low, it might seem that nothing will help. But there are things you can try that might help you feel a bit better.

Factsheet: Your feelings if cancer comes back or does not respond

Worrying that you might have relapsed

Worrying that your cancer has relapsed or not responded to treatment can be challenging. You may be dealing with a lot of difficult emotions.

You might be concerned about symptoms you've noticed. Or something small might have triggered a memory of your diagnosis or treatment, which can make you worry you've relapsed. Perhaps the uncertainty of a possible relapse makes you feel anxious or scared for the future. Or maybe you wake up worrying in the night, with thoughts going round your head.

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Some people feel especially anxious around the time of check-ups or while waiting for blood test results. Certain times of the year like the anniversary of your diagnosis, or special occasions like birthdays and Christmas can also make you feel worried about relapse. You may feel a mixture of fear you've relapsed and hope that you have not, or swap between the two.

This can all leave you feeling vulnerable and less secure than you used to.

> **Not everyone is the same. Fear of relapse 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.**

You may try to ignore your concerns or put them down to something else. This might mean you delay speaking to your medical team. But it can be easy to get lost thinking about what may be wrong.

> "I was in remission and could return to some sense of routine. Well, up until I grazed my fingers down the side of my neck and felt something unusual. A lump. I remember the horror I felt when I found it there. I struggled telling anyone about it; saying it out loud made it all feel so real."
>
> *— Bethan, diagnosed with chronic lymphocytic leukaemia (CLL) in 2015 and relapsed in 2021*

It can be difficult to talk about your worries because it can make them feel more real. But it is important to speak to your medical team. They can address your concerns, help you access support or arrange tests, depending on what you need. It can help to know that there is a plan.

Worrying about relapse can feel very lonely. Some people tell us they don't want to tell others how they feel. You might feel like it would be a burden for your loved ones, or that you have to be strong for them. Being able to talk to someone can help you feel less alone. They can help support you.

You may prefer to speak to someone independent. This might help you discuss how you feel and find a way to manage your feelings.

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Finding out you have relapsed or not responded to treatment

Finding out you haven't responded to treatment or your blood cancer has come back can be difficult to cope with. It can be overwhelming and hard to process.

> **Not everyone is the same. Finding out you've relapsed or not responded to treatment 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.**

At first you might feel shocked or in disbelief. You might have similar feelings to when you were first diagnosed, but these emotions may feel more intense now. Or you might react differently this time.

> "The next thing I remember is being in a room with my family at the hospital and my haematologist telling me that the cancer was back and I just remember wailing."
>
> *— Ellen, diagnosed with acute promyelocytic leukaemia (APL) in 2005 and relapsed in 2008*

Even if you expected to relapse at some point, you still might feel disappointed. It can be hard if you hoped to stay in remission for longer. This can leave you feeling low and resigned. Be kind to yourself and take the time you need to process it all.

> "I walked into the consultation room a few days later and burst into tears. 'I'm pretty sure I'm relapsing!' I managed to say through the sobs. My consultant sat me down, ran a few tests, and agreed with me. In an odd sort of way, I felt relieved I was right, but it didn't stop the tears. I felt sad. Fearful. Angry. How do you tell your friends and family that it's all starting again?"
>
> *— Bethan, diagnosed with CLL in 2015 and relapsed in 2021*

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You may feel angry or upset that you need more treatment. You might feel 'why me?' or blame yourself. It's important to remember that it is **not** your fault.

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 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.

When cancer comes back or doesn't respond to treatment, it's common to feel overwhelmed, even if you had always thought it might happen. It's important to allow yourself the time you need to accept and process it.

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Feelings about the impact on your life

Adapting to a 'new normal' can be hard, and relapse can leave you feeling like you have to start again. You might be recovering from everything you have already been through, and it can be daunting feeling like you have to face it all over again. This might leave you feeling helpless or like you have lost control of your life again.

> "I had 2 years of being cancer free. Then I started experiencing pains in my spleen and just when we thought life could get back to some normality, I relapsed."
>
> *— Leanne, diagnosed with acute lymphoblastic leukaemia (ALL) in 2017 and relapsed in 2022*

Often, things that helped you cope the first time, can help again now, like trying to take things a day at a time.

It is natural to feel worried, scared or anxious about treatment options or what your outcomes may be. Ask your medical team any questions you have. This can help reduce uncertainty and focus on a way forward that works for you.

Many people worry about how things will change and how they will cope. Using support networks you have from before can help you feel less alone and better able to cope.

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Feelings about treatment

It can be hard to face further treatment, especially if you are worried about how you will cope with it, or if you will have side effects. Remember, your team are there to support you and can help you with any questions or concerns you may have.

> "The cycle began again. Treatment is complicated to begin with and it feels like you can never get away from hospital, but it gets easier. I've learnt that it is OK to admit when you need help and it is empowering to be able to do that."
>
> *— Bethan, diagnosed with CLL in 2015 and relapsed in 2021*

Your previous experience of treatment can affect how you feel. You might have coped well with treatment before, which can help you feel like you can get through it. Or, you may have struggled with treatment and side effects, which can leave you feeling terrified or worried about having to face it again

> "I'd also obviously been through treatment before, so I knew what was coming. Once again treatment began…Once again, I lost my hair and all the horrible side effects returned."
>
> *— Ellen, diagnosed with APL in 2005 and relapsed in 2008*

You may have different treatment options this time around. Or you may be scared that there are no suitable options left for you. Some people do not want to have more treatment.

If you need to stay in hospital for treatment, you might feel anxious about being lonely or isolated. You may be worried about not being there for the people you love. If you have further treatment at home, you might be worried about not having a medical team around you to support you.

However you feel, it is important to talk to your medical team about your concerns and your treatment options. Ask any questions you have. You may want to discuss it with family members or friends. But it is your decision to make.

> "Emotionally, it has been really tough on both me and my family; I still see a psychologist regularly… I am very fortunate to have a really great support system of family and close friends. I couldn't have got through all this without them."
>
> *— Ellen, diagnosed with APL in 2005 and relapsed in 2008*

You might feel under pressure to have more treatment for your blood cancer, but the treatment you have is your choice. It's important to remember that whatever you decide, you will still have treatment to manage your symptoms and side effects, to help maintain your quality of life.

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Feelings about telling family and friends

Some people tell us that they feel anxious about telling family and friends they have relapsed or not responded to treatment. You may worry about how they will react to facing it again, or feel like you are reliving when you were first diagnosed.

It can be hard to tell them. But talking about what is going on, how you feel and your worries can help them understand and be there for you.

It's OK to give yourself time to adjust and take things in before deciding to tell others. Remember, it is up to you who you tell, how you tell them and how much you share. It can help to make a list and plan what you want to say.

Macmillan have more information on talking about cancer.

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Coping with your feelings

Learning how to cope with your feelings if your cancer has come back or not responded to treatment can take time. Even when you have effective 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 still have many hurdles to overcome, both physically and mentally, but I am grateful that I now have another chance at life and I will be making the most out of it. Tomorrow is not promised."
>
> *— Leanne, diagnosed with ALL in 2017 and relapsed in 2022*

It can be difficult if you feel like you are going through it all again or are struggling to process what it means for you. Everybody copes with their feelings differently. There is no right or wrong way to manage your feelings.

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

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Where to get support

Coping with a relapsed or refractory blood cancer 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 when blood cancer comes back

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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.

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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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