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# The Emotional Impact of a Blood Cancer

A Guide for  
Patients

**Leukaemia Care**  
YOUR Blood Cancer Charity

# Introduction

**It must be noted that this information is mainly written in the context of acute leukaemia and is for those who are receiving intensive treatment. However, anyone with a blood cancer diagnosis may find this information useful. If you are unsure about anything in this booklet, speak to your doctor.**

This booklet describes some of the more challenging emotional responses you may experience as you adjust to life following a diagnosis of blood cancer. Everyone is different and what follows may or may not apply to you. There is no right way or wrong way to live with a blood cancer. As you gradually adjust to this major change in your life you will find what is most helpful and feels

right for you.

This booklet was compiled by Anne Crook and peer reviewed by Dr Robert Marcus and Dr Steve Knapper. We are also grateful to Julie Quigley for her contribution as a patient reviewer.

If you would like any information on the sources used for this booklet, please email [communications@leukaemiacare.org.uk](mailto:communications@leukaemiacare.org.uk) for a list of references.

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# About Leukaemia Care

**Leukaemia Care is a national charity dedicated to ensuring that people affected by blood cancer have access to the right information, advice and support.**

## Our services

### Helpline

Our helpline is available 9.00am - 10.00pm on weekdays and 9.00am - 12.30pm on Saturdays. If you need someone to talk to, call **08088 010 444**

### Nurse service

We have two trained nurses on hand to answer your questions and offer advice and support, whether it be through emailing **nurse@leukaemicare.org.uk**, over the phone on **08088 010 444** or via LiveChat.

### Patient Information Booklets

We have a number of patient information booklets like this available to anyone who has been affected by a blood cancer. A full list of titles – both disease specific and general information titles – can be found on our

website at **www.leukaemicare.org.uk/resources/filter-by-resource-type/information-booklets**

### Support Groups

Our nationwide support groups are a chance to meet and talk to other people who are going through a similar experience. For more information about a support group local to your area, go to **www.leukaemicare.org.uk/our-support-groups**

### Buddy Support

We offer one-to-one phone support with volunteers who have had blood cancer themselves or been affected by it in some way. You can speak to someone who knows what you are going through. For more information on how to get a buddy call **08088 010 444** or email **support@leukaemicare.org.uk**

## Online Forum

Our online forum, [www.healthunlocked.com/leukaemia-care](http://www.healthunlocked.com/leukaemia-care), is a place for people to ask questions anonymously or to join in the discussion with other people in a similar situation.

## Patient and carer conferences

Our nationwide conferences provide an opportunity to ask questions and listen to patient speakers and medical professionals who can provide valuable information and support.

## Website

You can access up-to-date information on our website, [www.leukaemicare.org.uk](http://www.leukaemicare.org.uk), as well as speak to one of our care advisers on our online support service, LiveChat (9am-5pm weekdays).

## Campaigning and Advocacy

Leukaemia Care is involved in campaigning for patient well-being, NHS funding and drug and treatment availability. If you would like an update on any of the work we are currently doing or want to know how to get involved, email [advocacy@leukaemicare.org.uk](mailto:advocacy@leukaemicare.org.uk)

## Patient magazine

Our free quarterly magazine includes inspirational patient and carer stories as well as informative articles by medical professionals. To subscribe go to [www.leukaemicare.org.uk/resources/subscribe-to-journey-magazine](http://www.leukaemicare.org.uk/resources/subscribe-to-journey-magazine)

# Feelings

Living with a blood cancer is often described as feeling like being on an emotional rollercoaster ride because of the range of emotions felt at different times.

From the shock of being told about the diagnosis, facing the challenges of going through treatment and to then adjusting to life after treatment ends, your emotions can catch you by surprise and may sometimes feel overwhelming. It is common to feel low, sad, angry or anxious. Feeling down or worried is a normal reaction and does not mean that you are weak or failing to cope. Your feelings may come and go. There may be times when you are not sure how you are feeling and other times when you feel okay.

## Hope and determination

Hope and determination will help you to face blood cancer, identify your reasons to get through treatment and remind yourself of them when you feel that you are struggling. Notice what helps you to feel strong. Set yourself realistic goals to help you get through treatment and the recovery process. Your treatment may go on for quite some time and so it will be important for you to draw on the support of others. We are very resilient beings and with time and good support, you can adjust to this enormous change in your life.

Leukaemia Care offers nationwide support groups for people affected by a diagnosis of a blood or lymphatic cancer. Visit [www.leukaemiacare.org.uk](http://www.leukaemiacare.org.uk), or call **08088 010 444**, to find out more and to find a group near you.



# Anger

**Anger is an emotion that we naturally feel when we are challenged and under threat and so it is not unusual for illness to provoke an angry response.**

You may feel angry with your body for becoming ill in the first place. Thoughts like, 'Why me? It's not fair, I don't deserve this' can make you feel angry. You may be annoyed with healthcare professionals and with the lack of control over your life. It may be frustrating that it is taking so long to get through your treatment or to recover from it all. This is particularly so if you have had a stem cell transplant and are struggling with physical weakness and fatigue, or you are having maintenance therapy and are having to juggle treatment with day to day life.

Anger makes us feel uncomfortable. Some of us shout and stomp around, but for others, feeling and expressing anger is a struggle. It can be a physical feeling of restlessness and frustration and of not being able to settle. It may leak out as irritability or impatience with the people around us.

It helps to acknowledge your anger at the time rather than hold on to it and let it build up, otherwise, it may burst out and leave you feeling helpless and out of control. Buy yourself some time to let the tension go by leaving the room, getting some fresh air, listening to some loud music, doing something physical or put your angry thoughts down on paper. Try and identify what it is that is making you angry, so you can direct the energy that comes with anger in ways that help you to feel more in control of things. This could be setting some recovery goals for yourself, doing some exercise or physical activity to shift your pent-up tension or talking through your frustrations with someone who is a good listener.

# Feeling alone

**There are times when you are going through your blood cancer journey that you may feel alone. This can be despite having good support from your family, friends and healthcare team.**

Worrying about how others might respond if you tell them what's really on your mind, feeling that you need to hide your feelings to protect others or because they may not understand can leave you feeling isolated and alone. Feeling different from those around you whose lives are continuing as before can be a challenge.

You will most likely have your treatment in hospital in an 'isolation' room. You won't be in complete isolation as you will be able to have some visitors and the staff will be in and out of your room. But when your blood counts are low, and the time seems to be going by slowly, you may sometimes feel very vulnerable and alone.

When you are receiving your treatment, you become used to the hospital environment and the healthcare team looking after you. Afterwards or during the less intensive or maintenance phases, it can feel disconcerting to be on

your own and not have the same reassurance and support on hand. Some people describe this period as feeling lost and abandoned.

If you are having maintenance chemotherapy, you may find that you are having to combine feeling like "a patient" on treatment days with trying to get on with living your life, going to work and reassuming family responsibilities the rest of the time. This can be a challenge - give yourself time to adapt to this new routine. The treatment will come to an end at different times according to the protocol you are following. Mark this out in your calendar if you feel this will help you cope.

The transition after treatment is another big adjustment to make so give yourself time to regain your self-confidence and take stock of all you have come through.

# Loss, sadness and depression

The experience of blood cancer brings with it many losses. You might pine for the life that you had before the illness, and for the hopes and plans that have been put on hold for now, due to the loss of control over your life you feel whilst going through treatment. There may be activities and people that you miss. You may feel a sense of loss for the healthy person you were before and feel sad and vulnerable because of the changes to your body. It is normal to grieve for these losses and to feel sad when you think about the impact that a blood cancer has had on you and those close to you. Give yourself permission to allow these feelings of grief to surface. It isn't self-indulgent or weak to feel sad as you adjust to your new reality.

Sadness can often make our mood feel low. People sometimes worry that feeling low can affect their recovery from a blood cancer. They can put themselves under pressure or are encouraged by others to remain 'positive' and to 'fight' the illness. This becomes a way of coping for some people and it works well for them. It is

important, though, to know that everyone copes in their own way and that you don't have to be positive all the time. A hopeful and determined outlook will help you to get through the challenges but it is alright to feel low from time to time, particularly when your energy is low, or you experience setbacks.

Feeling low from time to time is normal and these feelings usually pass. But if your low mood persists over a couple of weeks, you feel depressed and it is affecting your day to day life, you may be suffering from depression. It can be hard to separate out the physical and psychological causes, but the feeling of depression is deeper, longer and more unpleasant than the short episodes of feeling low and unhappy that everyone sometimes experiences. Some people find that their mood is affected when they take steroids. Do tell your medical team if you feel low or your mood seems unusual for you.

Some of the common symptoms of depression include:

- Feeling sad or low, most of the time
- Losing interest or enjoyment in people and things
- Finding it harder to concentrate or make decisions
- Feeling helpless, hopeless or worthless
- Feeling restless, agitated and irritable
- Feeling easily moved to tears
- Thinking negative thoughts about yourself, the world and the future
- Difficulty getting to sleep or waking up very early
- Having thoughts of self-harm or suicide

Depression does not mean that you can't cope or are weak. It is a common medical condition and complication of many types of cancer therapy and there is support available to help you get through it. You can't simply 'snap out of it' or 'pull yourself together'.

Talk to your GP or healthcare team if you think that you may be depressed. Depression can

be treated with both medication and talking therapies such as cognitive behavioural therapy (CBT) and counselling. Your doctor may also recommend self-help books or an online course. Depression can make you feel less inclined to ask for help, so be guided by those close to you.

If you are having suicidal thoughts or feelings, you can call the Samaritan 24-hour helpline on **116 123**.

**[www.mind.org.uk](http://www.mind.org.uk)** and **[www.nhs.uk](http://www.nhs.uk)** have further information and links to support.

# Anxiety and worrying about your health

A diagnosis of a blood cancer brings with it the challenge of living with uncertainty. What will happen to me? Will the treatment work? Will the blood cancer come back? It is natural to feel anxious when faced with fears for ourselves.

Anxiety is like an internal alarm system going off. Being anxious will not affect the blood cancer or harm your recovery but do ask for support if it is making it difficult for you to have medical procedures.

We feel anxious when we feel threatened. The brain uses adrenaline to tell the body to run away from or to fight a danger and this is called the 'fight-flight response'. It is helpful when we need to escape quickly from a physical threat such as a fire, but less helpful when the brain interprets stressful life events like illness in the same way. Because we can't physically run away (although we may feel like it), those same fight-flight physical symptoms can persist and make you feel uncomfortable.

It causes that familiar feeling of lying awake at night and the mind won't switch off because it's focused on the threat, and with it comes a racing heart, tight chest and tense muscles. When we feel constantly stressed we struggle to relax, it is difficult to concentrate, and we can feel impatient, irritable and restless.

Worrying is something we do to try and cope with uncertainty. We try to predict and control future events by thinking about them, perhaps to try and prepare ourselves if the worst happens. Worry can be useful when it helps us to take action to sort out a difficult problem. But more often, these 'What if ...' thoughts or images focus on things that could go wrong in the future. All that worry does is keep our attention focused on the threat and this keeps the anxiety going. It's helpful to remember that our brain is responding to the threat of something that may happen in the future. It hasn't happened yet, and it may never happen.

When we are faced with a threat

like blood cancer, our alarm system can become a bit too sensitive and lots of things can trigger our anxiety and keep it going. We are always on the lookout for threats. Each pain, niggle, clinic appointment or wait for test results can set off fearful thoughts about your health. This is normal and gradually eases as you get further from treatment. Your consultant and specialist nurse will be able to guide you about any physical symptoms that you need to watch out for.

If you notice that you are constantly checking, seeking reassurance or you avoid doing things, it may be a sign that anxiety is becoming a problem. If you feel that the uncertainty is making you feel so anxious and worried that it is affecting your daily life, you may find it helpful to talk to your healthcare team.

There is more information about anxiety and helpful links on the NHS website: [www.nhs.uk/Conditions/stress-anxiety-depression/Pages/low-mood-stress-anxiety.aspx](http://www.nhs.uk/Conditions/stress-anxiety-depression/Pages/low-mood-stress-anxiety.aspx)

# Managing stress

You cannot remove the stress of blood cancer completely but there are some things that you can do to help yourself manage when you are feeling stressed:

- Exercise is an excellent way to reduce the impact of stress. It could be any physical activity – walking, exercise or dance classes, yoga, gardening, housework etc. It helps us to use up some of that extra adrenaline that comes from worrying, helping us to feel calm.
- Relaxation and breathing exercises can help to calm the mind and release muscle tension.
- Doing an activity that you enjoy can help you to stay in the present moment and enjoy life in the now rather than jumping ahead in your mind to predicting the future.
- Talking about what's on your mind to someone who is a good listener or writing worries or thoughts down on paper can make them feel less

overwhelming. When we hear ourselves out loud, we are more able to rationalise and put worries into perspective. We can ask: "Is this a problem that I can do something about or is this an uncertainty that may never happen? Am I concentrating on negative fears for the future at the expense of hope and enjoying life again today?"

- Mindfulness is a great way to be in the present. It is simply bringing our attention into the present moment and being fully aware of what we are experiencing - noticing what is going on using your senses rather than thinking about the past or worrying about the future. We are observers of our thoughts and feelings, allowing them to come and go without getting caught up in them. When we bring our attention into the present moment rather than our imagined future, we realise that we are coping, and getting on with life the best we can. If you have experienced trauma in the past, mindfulness may not be helpful, so seek

advice.

- Complementary therapies can help you relax and feel more in control, but make sure you are seeing a qualified therapist who has experience of treating people with cancer.
- Talking therapies such as counselling can help you to talk through your experience to try and make sense of it all. Talking to someone you don't know and in confidence can be helpful to understand and process feelings as normal responses to a difficult situation. Counselling may be available through your doctor or local cancer support centre.
- Connect with others who have been affected by blood cancer through a support group or online forum. Each person's experience is unique, but it can help to hear from others who know what it is like to have a blood cancer.
- Do the things that work for you – maintain the activities and hobbies that were important to

you before your diagnosis and try to keep these interests going if they are not too tiring and you are still enjoying them.

- See the people you want to see and talk about what you feel comfortable with. It is fine to change the subject if you don't want to talk about something.

# A new normal

Reaching the end of treatment can bring a whole set of new challenges as you begin to recover from the physical, practical and emotional demands that treatment brings. It will probably feel like a relief that the intense treatment has ended even though there may be ongoing side effects to deal with. Getting through treatment can take up all of your energy and it is only when it has stopped that you may begin to deal with the emotional impact of it all. Your family and friends might expect you to feel back to normal once your treatment finishes, but your body and your emotions need time to recover and to work through all that has happened to you. You may have gone through treatment with the goal of getting your life back to normal. Now, it is not so much 'getting back to normal' as finding out what is normal for you now, your 'new normal'.

Having a blood cancer is an extraordinary experience and it may seem hard to imagine life ever feeling ordinary again. You might miss the support from

the doctors and nurses at the hospital. Some people say they feel a bit abandoned as they see their hospital team less frequently than before. If you have had a transplant or are having maintenance therapy, your recovery may be taking much longer than you hoped and this can be disheartening. It helps to set small and achievable goals.

You can feel very out of touch with your life before blood cancer because so much has happened. The emotions which have been building up as you have been going through the intense treatment may now come bubbling up and catch you by surprise. The impact of a blood cancer is not something that can be forgotten or left behind but needs to be incorporated into your life story. This is a process that takes as long as it takes and can't be rushed, no matter how impatient you feel to leave the illness behind.

Some of your relationships may feel stronger whereas other relationships have changed.

Perhaps you have discovered that you or those around you are more resilient than you ever imagined.

Your life may have a very different outlook because of your blood cancer and you may be faced with making difficult adjustments. Continue to seek support from those close to you. You might find that making decisions and plans with those around you helps you feel more prepared for what the future may hold.

Coming through successful treatment brings hope for the future, and life inevitably takes on a new meaning. People sometimes think about what is most important to them in life and make changes for the better. As you work through your process of recovery, you can gradually incorporate all that you have experienced because of your blood cancer into your new view of yourself and your life. Eventually, you might even want to consider offering help and support to others undergoing the same therapy.

Leukaemia Care offers one-to-one buddy support for people affected by blood cancer. Call **08088 010 444** or email **support@leukaemicare.org.uk** to find out more.

# Glossary

## Acute Leukaemia

Leukaemia is cancer of the white blood cells. Acute leukaemia means it progresses rapidly and aggressively, and usually requires immediate treatment.

## Chemotherapy

It is a type of cancer treatment that uses one or more drugs with powerful chemicals to kill growing cancer cells.

## Chronic leukaemia

A type of blood cancer that affects the white blood cells. This tends to progress over many years.

## Complementary therapies

These are treatments used alongside conventional western medicine.

## Fatigue

Extreme tiredness, which is not alleviated by sleep or rest. Fatigue

can be acute or come on suddenly or chronic and persist.

## Leukaemia

A cancer of the bone marrow/ blood with many different subtypes. Some forms are acute (develop quickly) and others are chronic (develop slowly). Leukaemia is an excess number of abnormal cells in the bone marrow, usually white blood cells, which stop the bone marrow from working properly.

## Stem cell transplant (SCT)

A stem cell transplant is a treatment for some types of cancer as well as other blood diseases of the immune system. A stem cell transplant involves the administration of chemotherapy plus or minus radiotherapy as conditioning followed by infusion of stem cells. The stem cells engraft and form a new immune

## Tell us what you think!

If you would like to give us some feedback about this patient information booklet, please hover over the code to the right using your phone or tablet's camera. Click the link as it appears and this will take you to a short web form to fill in.

Suitable for Android, iPhone 7 and above.



# Useful contacts and further support

There are a number of helpful sources to support you during your diagnosis, treatment and beyond, including:

- Your haematologist and healthcare team
- Your family and friends
- Your psychologist (ask your haematologist or CNS for a referral)
- Reliable online sources, such as Leukaemia Care
- Charitable organisations

There are a number of organisations, including ourselves, who provide expert advice and information.

## Leukaemia Care

We are a charity dedicated to supporting anyone affected by the diagnosis of any blood cancer.

We provide emotional support through a range of support services including a helpline, patient and carer conferences, support group, informative website, one-to-one buddy service and high-quality patient information. We also have a nurse on our help line for any medical queries relating to your diagnosis.

Helpline: **08088 010 444**  
**[www.leukaemicare.org.uk](http://www.leukaemicare.org.uk)**  
**[support@leukaemicare.org.uk](mailto:support@leukaemicare.org.uk)**

## Bloodwise

Bloodwise is the leading charity into the research of blood cancers. They offer support to patients, their family and friends through patient services.

**020 7504 2200**  
**[www.bloodwise.org.uk](http://www.bloodwise.org.uk)**

## Cancer Research UK

Cancer Research UK is a leading charity dedicated to cancer research.

**0808 800 4040**  
**[www.cancerresearchuk.org](http://www.cancerresearchuk.org)**

## Macmillan

Macmillan provides free practical, medical and financial support for people facing cancer.

**0808 808 0000**  
**[www.macmillan.org.uk](http://www.macmillan.org.uk)**

## Maggie's Centres

Maggie's offers free practical, emotional and social support to people with cancer and their families and friends.

**0300 123 1801**  
**[www.maggiescentres.org](http://www.maggiescentres.org)**

## Citizens Advice Bureau (CAB)

Offers advice on benefits and financial assistance.

**08444 111 444**  
**[www.adviceguide.org.uk](http://www.adviceguide.org.uk)**

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Leukaemia Care is a national charity dedicated to providing information, advice and support to anyone affected by a blood cancer.

Around 34,000 new cases of blood cancer are diagnosed in the UK each year. We are here to support you, whether you're a patient, carer or family member.

## Want to talk?

Helpline: **08088 010 444**

(free from landlines and all major mobile networks)

Office Line: **01905 755977**

**[www.leukaemiacare.org.uk](http://www.leukaemiacare.org.uk)**

**[support@leukaemiacare.org.uk](mailto:support@leukaemiacare.org.uk)**

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**Leukaemia Care**  
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