



Your blood cancer diagnosis

What happens now?

**Blood
cancer
UK**

Blood Cancer UK Support Service

We're the UK's specialist blood cancer charity, supporting anyone affected by any blood cancer.

Our confidential Support Service offers practical and emotional support for you, your family, friends and work colleagues. Our free phone line is open Monday: 10am to 7pm, Tuesday to Friday: 10am to 4pm and Saturday and Sunday: 10am to 1pm.

Keep this card handy:

Need to talk?

Contact us with questions or worries about: your diagnosis, family, work, mental health, the future.

Call free on **0808 2080 888**

Email **support@bloodcancer.org.uk**

Visit **bloodcancer.org.uk**

Talk to others **bloodcancer.org.uk/forum**

My diagnosis and care

Ask your doctor or nurse to help you fill in this page about you, your diagnosis and key contacts:

My diagnosis is:

.....

My hospital number is:

My NHS number is:

My main point of contact (key worker) is:

Name:

Role:

Phone no:

Email:

You should be given a key worker. Ask if you're not sure who this is, or call us.

My consultant's name is:

.....

Haematology ward/clinic:

Phone no:

If I need medical help outside normal hours, I can call:

Name of service:

Phone no:

3 things you need to know

It might be hard to take in information right now, so here are 3 key things it's useful to know straight away:

1. Thanks to research, treatments are being developed and improved all the time. Thousands of people are treated successfully in the UK every year.
2. If you have a question, or you just need to talk, we're here for you on freephone **0808 2080 888** or **support@bloodcancer.org.uk**
3. When you're ready, **bloodcancer.org.uk** has more information for you and your loved ones about types of blood cancer and living with blood cancer.

Contents

- 5** A message from other people diagnosed with blood cancer
- 7** What is blood cancer?
- 9** Why do I have blood cancer?
- 13** Will I be cured?
- 17** How do I tell people?
- 18** What questions should I ask?
- 23** How can I look after myself?
- 27** What next?
- 31** Where can I get more support?

A message from other people diagnosed with blood cancer



People with blood cancer helped us make this booklet. This is their message to you:

“We know how scary it can be to be told you have cancer. Some of us hadn’t even heard of the type of blood cancer we’d been diagnosed with, which somehow made things even scarier.

What we can tell you is that there are effective treatments for blood cancer. And that we are here, getting on with our lives today. You’ll see some of us sharing our experiences later on in the booklet.

When you’re first diagnosed, you can feel a whole range of emotions, sometimes one after the other. Whatever you’re feeling now, it’s a natural reaction to a very stressful situation. And it’s completely normal to find it hard to take it all in.

That’s why this booklet focuses on the key things you need to know now. But it also tells you where to get more information and support when you’re ready.

One in nineteen people will have blood cancer at some point in their life, so there are more of us than you think. We hope this booklet helps you feel less alone.”

Anita, Jacqueline, Precious, Quentin, Simone and Vij.
All living with different types of blood cancer.

What is blood cancer?



The simplest explanation is that blood cancer is a type of cancer that affects your blood cells.

Blood cells are found in your blood, bone marrow and lymphatic system, which are all part of your immune system.

When you have blood cancer, it means some of your blood cells aren't working properly. This means your body can find it hard to fight off infections. It can also cause symptoms like breathlessness, tiredness, bruising or bleeding, lumps in your glands, fever or pain.

The main types of blood cancer are leukaemia, lymphoma, myeloma, myelodysplastic syndromes (MDS) and myeloproliferative neoplasms (MPNs). There are many more specific types which all need different treatments. If you're not sure what your particular diagnosis is, ask your medical team.

If you want to know more:

- We have more information about how blood cancer starts at bloodcancer.org.uk/what-is-blood-cancer
- We have more information about specific blood cancer types at bloodcancer.org.uk/understanding

If you don't use the internet, call us and we can post you the information.

**Why do I have
blood cancer?**



We still don't really understand why some people get blood cancer and others don't.

We know that blood cancer starts with changes in our genes and DNA. These changes are not usually inherited and can happen to anyone during the course of a lifetime.

We also know that lifestyle choices don't play a big role in the development of blood cancer. And you can't catch blood cancer or give it to someone else.

Everyone reacts differently to their diagnosis. Many people are shocked at first. Some people blame themselves for getting blood cancer. Others feel angry or sad, or want to know, why me? These are difficult but natural feelings, and talking to someone can often help you manage them.

Tell your doctor or nurse how you are feeling, or get in touch with our Support Service if you prefer. You can also talk to other people with blood cancer who've been through it themselves at **[bloodcancer.org.uk/forum](https://www.bloodcancer.org.uk/forum)**

If you need to talk

If you want to talk about your diagnosis, what it means, how you're feeling, or what to do next, contact our Support Service free on **0808 2080 888** or **support@bloodcancer.org.uk** and tell us that you've just been diagnosed.

Or talk to people who've been where you are now on our online community forum:
bloodcancer.org.uk/forum



Jacqueline

How did you feel when you were first diagnosed?

“My initial reaction was, ‘It’s the wrong diagnosis!’ The idea just didn’t sink in. Then I thought, if I start crying or panicking, it’s not going to help. And it’ll make my family feel worse. I wanted to save my energy for getting better.”

Read Jacqueline’s story at bloodcancer.org.uk/jacqueline or call us and we’ll post it to you.

Will I be cured?



Thanks to research, treatments for blood cancer are being developed and improved all the time.

With some blood cancers, treatment aims to put you into remission. This means there's no sign of cancer left, or the level is so low it's no longer a problem. Some people stay in remission and can consider themselves cured. Others may need more treatment later on.

For other blood cancers, treatment aims to manage the condition so you can live with it and enjoy a good quality of life. Sometimes, slow-growing blood cancers don't need treatment straight away, just regular checks-ups. This approach is called "watch and wait", or "active monitoring". Some people are on watch and wait for many years.

Talk to your doctor or nurse

Ask your specialist doctor or nurse about the aims of your treatment, and what's likely to happen in the future (your prognosis).

Your prognosis is individual to you. It'll depend on the type of blood cancer you have and things that are personal to you, such as your overall health. Try to avoid googling because everyone is different. Read trustworthy information from the NHS or from us, and use it to ask your doctor or nurse questions.

If you want to know more

We have information about different types of blood cancer, including the general prognosis for each type:
bloodcancer.org.uk/understanding

We also have information about research to improve treatments and find new ones:
bloodcancer.org.uk/research-info

If you don't use the internet,
call us free on **0808 2080 888**.
We can post what you need.



Simone

What are your tips on telling people you have blood cancer?

“You have to gauge each person – there’s no blanket way of dealing with everyone. So you may need to tell people separately and be prepared for different reactions. Some people cried, some asked some very direct questions!”

Read Simone’s story at bloodcancer.org.uk/simone or call us and we’ll post it to you.

How do I
tell people?



It can be stressful telling family and friends about your diagnosis when you're trying to understand it yourself.

Decide who you want to tell. Many people say that being open about it helps, but you don't have to tell anyone if you don't want to.

Be prepared for different people to react in different ways. If you're anxious about telling someone, call our Support Service so we can help you plan what to say.

It's quite common for people to ask lots of questions, so it might help if you give people this booklet. You can get more free copies from **[bloodcancer.org.uk/booklets](https://www.bloodcancer.org.uk/booklets)**

Telling children

If you tell children, it's generally best to be as honest as you can. Think through what you want to say, but be prepared to be flexible. If things don't go to plan, remember it's a conversation you'll come back to. Our Support Service can recommend some age-appropriate resources which you might find helpful.

Telling work

You don't have to tell your employer, but if you need time off or changes to how you work, you might want to. The information will be confidential, so it's up to you who else you tell at work.

What questions should I ask?

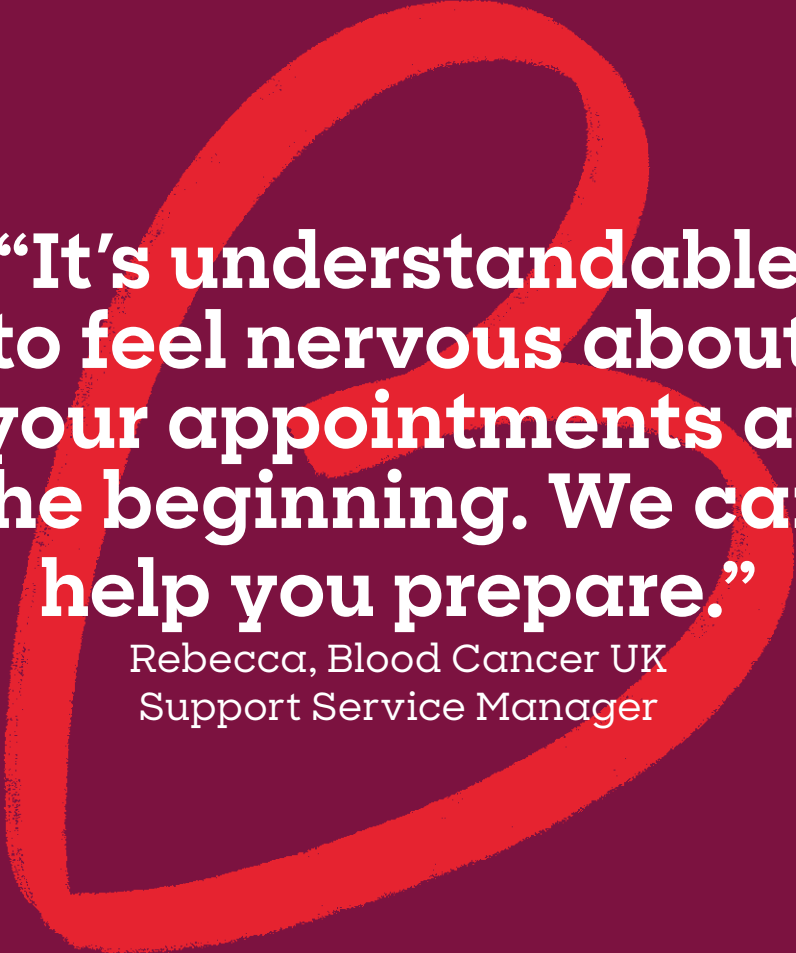
Once you've had a chance to think, you'll probably have questions. Getting answers might help you feel a bit more in control, but you don't have to ask everything at once.

You can put questions to anyone in your medical team, but it's worth knowing you should have contact details for a named key contact. This is often a clinical nurse specialist (CNS) but not always. Ask if you don't know who yours is.

If you feel unsure about anything to do with your appointments, contact our Support Service for help.

We've made a list of questions you might want to ask, or you can write your own on the opposite page.

- Do I need more tests?
- How long will it take to get the results?
- Who will explain the results?
- Will I need to have treatment? If so, when?
- What's the aim of my treatment?
- What does the treatment involve?
- How effective is it likely to be?
- Will the treatment affect my ability to have children?
- How could treatment affect my everyday life?
- Who do I contact if I feel unwell?
- Who do I contact if I have any questions?
- Who do I contact if I feel anxious or low?



**“It’s understandable
to feel nervous about
your appointments at
the beginning. We can
help you prepare.”**

Rebecca, Blood Cancer UK
Support Service Manager



Quentin

How important was good communication with your medical team?

“I needed a proper understanding of what was happening to me. I might be unusual in the level of detail I wanted from my medical team, but everyone will have questions to ask. And getting clear answers can make all the difference.”

Read Quentin’s story at [bloodcancer.org.uk/quentin](https://www.bloodcancer.org.uk/quentin) or call us and we’ll post it to you.

How can I look after myself?



Here are some things you can do to take care of yourself in the first days and weeks after your diagnosis.

- Try to take things one day at a time. If you can, carry on doing things you enjoy and keep social activities going.
- You might find it helps to talk about your diagnosis. Many people talk to family or friends. But if you don't have anyone you feel comfortable talking to, call us free on **0808 2080 888** and tell us you've just been diagnosed.
- Keep a list of questions or worries that come to mind, so you can ask your doctor or nurse next time you see them (see page 18 for some suggestions).
- Try to stay as active as you can, even if you're in hospital. Getting outside, especially being in nature, can help you keep moving and lift your mood.
- Our Support Service can talk to you about how to look after yourself, whether that's dealing with how you're feeling, trouble sleeping, what you should eat or worries about family or work. Your family and friends can talk to us too.

Above all, do what feels best for you. There's no right or wrong in this situation.

Find out what your hospital can offer

Your hospital may offer other services to help you to cope with what's happening. This might involve:

- support from a counsellor or clinical psychologist
- the chance to connect with other people who've been diagnosed with cancer
- complementary therapies like massage and aromatherapy – these can't treat cancer but they can help with symptoms and improve your mood.

You may not be ready for these things yet, but it's good to find out what's available for the future. Ask your nurse or anyone in your medical team.

What's offered will vary from place to place, but most hospitals aim to support your general well-being as well as treating the cancer. If they don't offer services themselves, they should be able to point you to somewhere that does.

More advice on living well

We have information about how to look after your mental and physical health, including personal stories from people affected by blood cancer:

bloodcancer.org.uk/live-well

If you don't use the internet,
call free on **0808 2080 888**.

We can post what you need.

What next?



When you're ready, you may want to find out more about your condition.

You can order or download a range of free information from bloodcancer.org.uk/booklets or call us free on **0808 2080 888**.



Online information after diagnosis

There's more information on our website for people recently diagnosed. Aim your phone camera at the QR code and follow the link, or go to bloodcancer.org.uk/just-diagnosed



If you don't use the internet, call us free on **0808 2080 888**

The Blood Cancer UK website

Go to our website for more information about:

- what you need to know after your diagnosis
bloodcancer.org.uk/just-diagnosed
- information and support for your family and friends
bloodcancer.org.uk/someone-i-know
- living well with blood cancer
bloodcancer.org.uk/live-well
- blood cancer and coronavirus
bloodcancer.org.uk/coronavirus
- blood cancer in general and specific types
bloodcancer.org.uk/understanding
- being diagnosed when you're a young adult (16 to 25)
bloodcancer.org.uk/young-adults
- our research to beat blood cancer in a generation
bloodcancer.org.uk/research-info
- the chance to connect with others with blood cancer
bloodcancer.org.uk/forum

If you don't use the internet, call us free on **0808 2080 888**
– we can print and post you the information.



Vij

How did finding trustworthy information help you?

“It was very reassuring to find online information from Blood Cancer UK and other reputable charities. It helped me put together a list of sensible questions, which made me feel more confident about talking to my doctor.”

Read Vij’s story at bloodcancer.org.uk/vij or call us and we’ll post it to you.

**Where can I get
more support?**



If you need emotional or practical support at any time after a blood cancer diagnosis, here's where you can find it:

1. Your medical team are there to explain your condition, answer your questions about blood cancer and help you deal with its impact on your life. Don't be afraid to ask them as many questions as you like.
2. Talking to someone who doesn't know you can help. You can talk through a decision, say how you're really feeling, or ask any question without judgement or guilt. Your family or friends can talk to us too. Contact our Support Service free on **0808 2080 888** or **support@bloodcancer.org.uk**
3. You may also find it helpful to connect with other people with blood cancer. You can chat with other people, ask questions, or just read the posts that interest you at **bloodcancer.org.uk/forum**
4. More and more people are finding support on social media. Find Blood Cancer UK on Facebook – many people get and give support to each other in comments on our posts. You can also find us on Instagram and Twitter.
5. If you want professional support such as counselling, now or later on, ask your medical team or GP. They won't be surprised – they understand the need to take care of your mind as well as your body.

Because we face it together

Finding out you have blood cancer can have a big impact on your life. But we hope it helps to know that there's a community of people out here ready to support you.

Everyone needs help at one time or another. And the most important thing to take away from this booklet is that you can get help from us when you need it, and in a way that suits you.



bloodcancer.org.uk



0808 2080 888 (calls are free and confidential)



support@bloodcancer.org.uk



bloodcancer.org.uk/forum



Blood Cancer UK



[@bloodcancer_uk](https://www.instagram.com/bloodcancer_uk)



[@bloodcancer_uk](https://twitter.com/bloodcancer_uk)



Blood Cancer UK

Thank you to our blood cancer community

Blood Cancer UK is the UK's specialist blood cancer charity. But we're much more than that – we're a community of people with blood cancer, friends, family, medical professionals, researchers and everyone who works for the charity.

Many thanks to everyone involved in making this booklet. To Anita, Jacqueline, Precious, Quentin, Simone and Vij, for their insights into what it's like to be diagnosed with blood cancer, and for steering us in the right direction. To Dr Kevin Boyd, Dr Steven Knapper and Clinical Nurse Specialists Vicki Kitchker and Kirsty Crozier for checking the medical content. And to the many people in the blood cancer community who took the time to give us their feedback.

A list of references used in this booklet is available on request. Please email [**information@bloodcancer.org.uk**](mailto:information@bloodcancer.org.uk)

Disclaimer

We make every effort to ensure that the information in this booklet is accurate, but you should always seek advice from your doctor if you have any concerns or questions about your health. As far as applicable by law, Blood Cancer UK cannot accept responsibility for any loss or damage resulting from any inaccuracy in this information, or in external information that we link to.

By law, this disclaimer cannot limit or exclude our liability for death or personal injury resulting from negligence, or any other liabilities that cannot be excluded under applicable law.

Who are Blood Cancer UK?

We're the UK's specialist blood cancer charity, working to beat blood cancer within a generation.

Since 1960, we've invested over £500 million in research, improving treatments for leukaemia, lymphoma, myeloma, MDS and MPNs. Thanks to generous donations from our supporters, we:

- fund ground-breaking research to improve survival and quality of life
- campaign for better access to treatments and services for people with blood cancer
- provide information and support for anyone affected by any blood cancer.

Find out more at bloodcancer.org.uk

Or call us free on **0808 2080 888**

Monday: 10am to 7pm, Tuesday to Friday: 10am to 4pm and Saturday and Sunday: 10am to 1pm.



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The information in this booklet was correct at the time it was printed (August 2021). Date of next full review: August 2024.

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