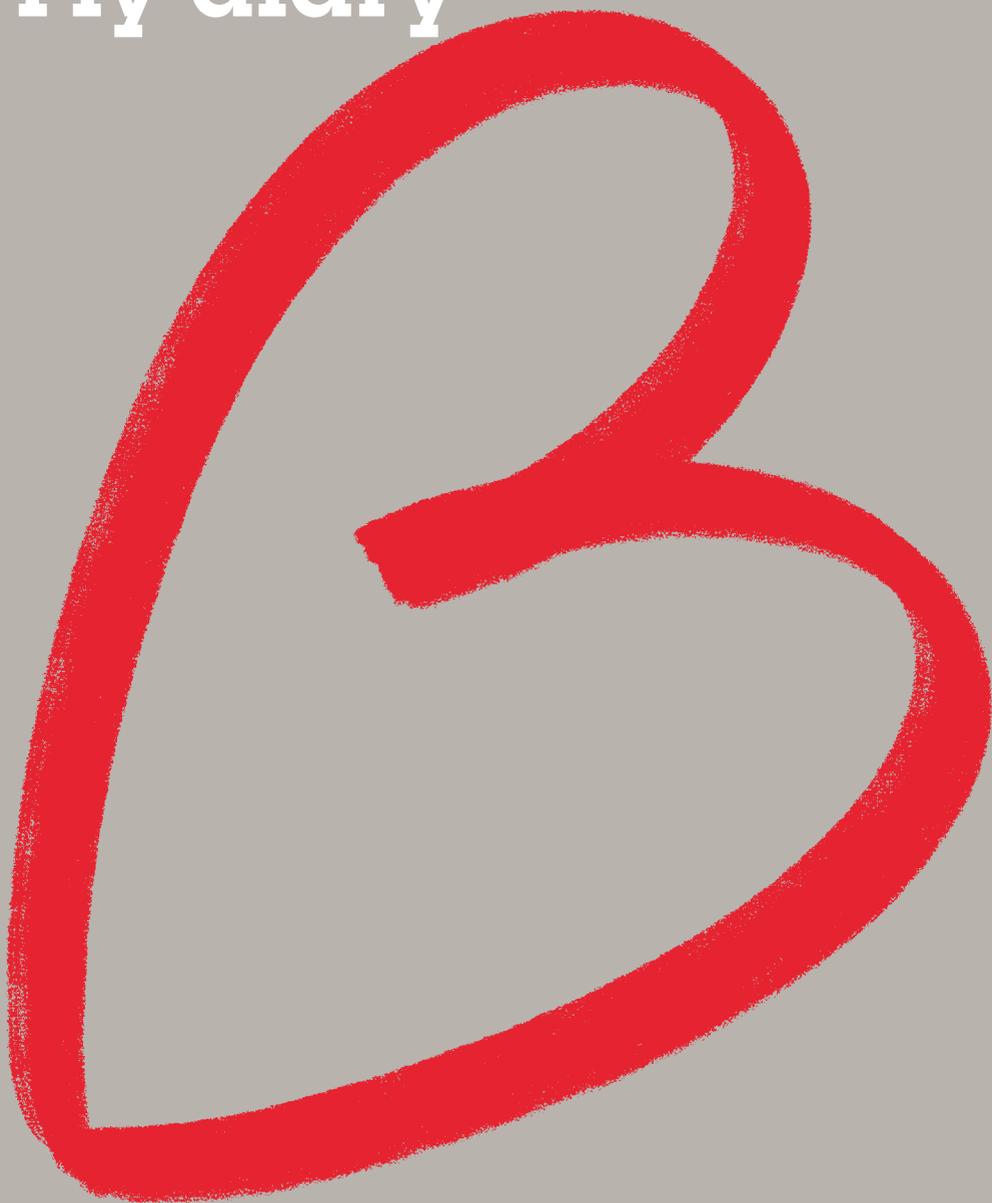


My diary



**Blood
cancer
UK**

About this booklet

This diary is for you. It's your place to write down your thoughts and feelings. You may also like to use this diary to record practical considerations, any side effects you experience or questions you have. You may want to keep its contents private, or you might find it useful to share the notes with your GP or the healthcare team treating you. This is your space, however you wish to use it.

If you would like more information about blood cancer, please go to our website or see page 86.

We're a community dedicated to beating blood cancer by funding research and supporting those affected. Since 1960, we've invested over £500 million in blood cancer research, transforming treatments and saving lives. To find out more about what we do, see page 89.

bloodcancer.org.uk

0808 2080 888

(Mon, Tue, Thu, Fri, 10am–4pm, Wed, 10am–1pm)

support@bloodcancer.org.uk

Blood Cancer UK, 39–40 Eagle Street, London WC1R 4TH
020 7504 2200 **hello@bloodcancer.org.uk** **bloodcancer.org.uk**

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Registered charity 216032 (England & Wales) SC037529 (Scotland)

My details

My name and hospital number

.....
.....

My NHS number

.....

My condition

.....
.....

My contacts

.....
.....

My consultant

.....

My key worker (usually CNS)

.....
.....

Haematology ward

.....
.....

Haematology clinic

.....
.....

Out of hours

.....
.....

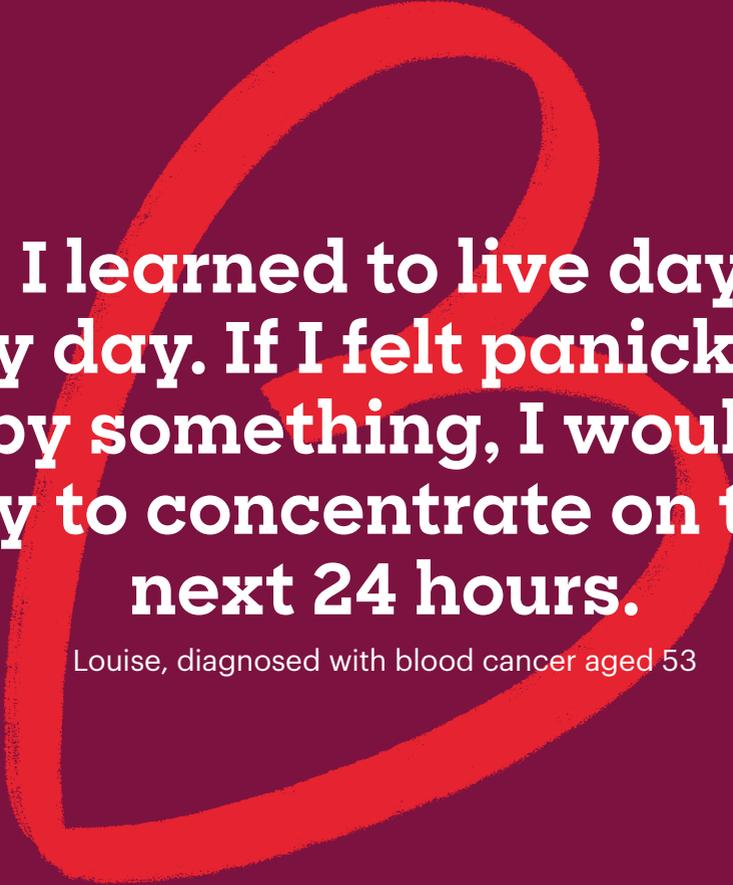
Other contacts

.....
.....
.....
.....
.....
.....

Date:

Date:

Date:



**I learned to live day
by day. If I felt panicked
by something, I would
try to concentrate on the
next 24 hours.**

Louise, diagnosed with blood cancer aged 53

Date:

Date:

Date:



**I remember feeling as if
I was in a weird bubble
with the world going
by on the outside, like a
parallel universe.**

Erica, diagnosed with blood cancer aged 53

Date:

Date:

Date:



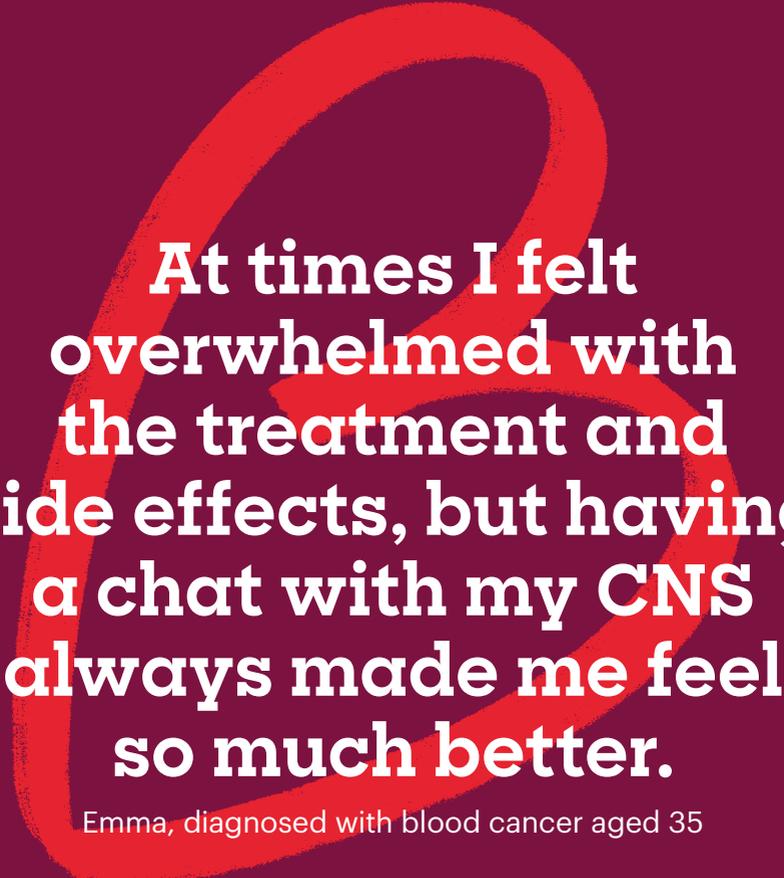
**A large part of my job
is listening and talking to
patients about their fears
and other emotions.
It's as important as the
clinical care.**

Darren, Clinical Nurse Specialist

Date:

Date:

Date:



**At times I felt
overwhelmed with
the treatment and
side effects, but having
a chat with my CNS
always made me feel
so much better.**

Emma, diagnosed with blood cancer aged 35

Date:

Date:

Date:



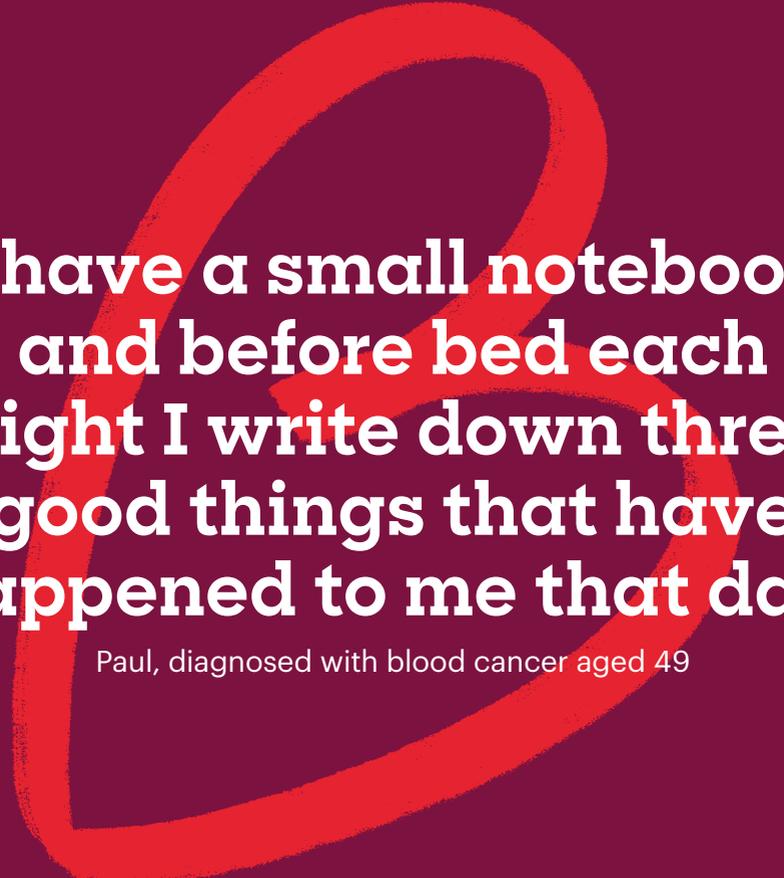
**The Blood Cancer UK
Online Community Forum
means I never feel alone
because there's always
someone there to talk to,
who really understands.**

Carina, diagnosed with blood cancer aged 43

Date:

Date:

Date:



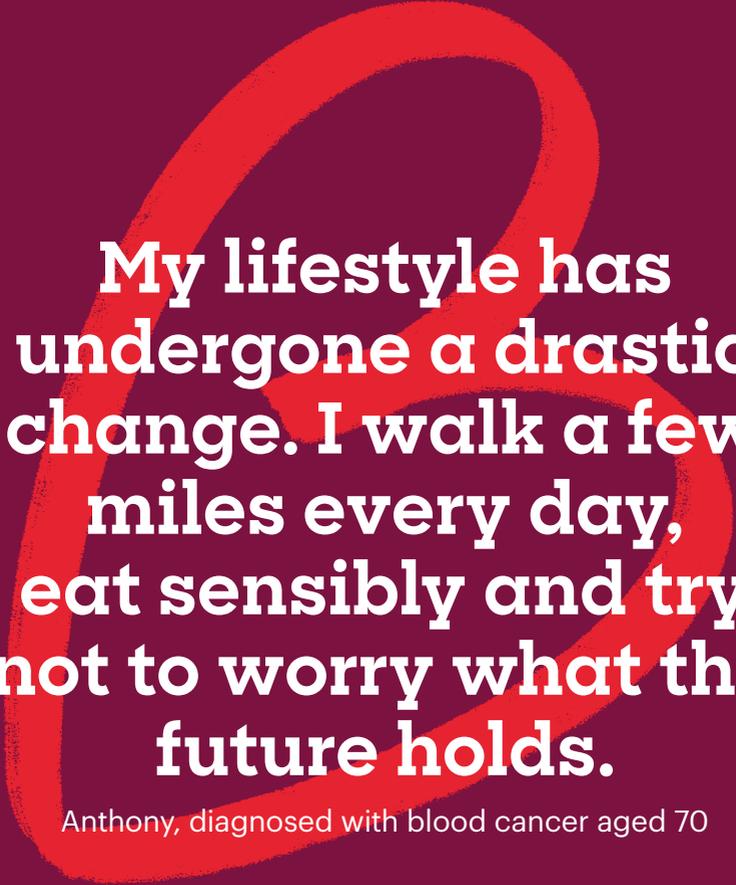
**I have a small notebook
and before bed each
night I write down three
good things that have
happened to me that day.**

Paul, diagnosed with blood cancer aged 49

Date:

Date:

Date:



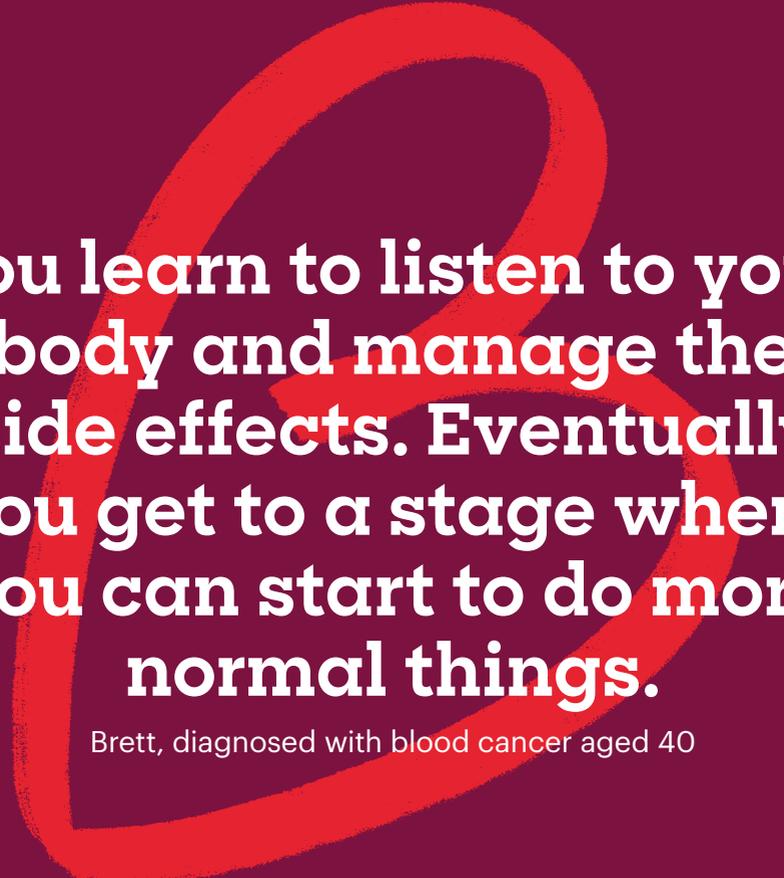
**My lifestyle has
undergone a drastic
change. I walk a few
miles every day,
eat sensibly and try
not to worry what the
future holds.**

Anthony, diagnosed with blood cancer aged 70

Date:

Date:

Date:



**You learn to listen to your
body and manage the
side effects. Eventually
you get to a stage where
you can start to do more
normal things.**

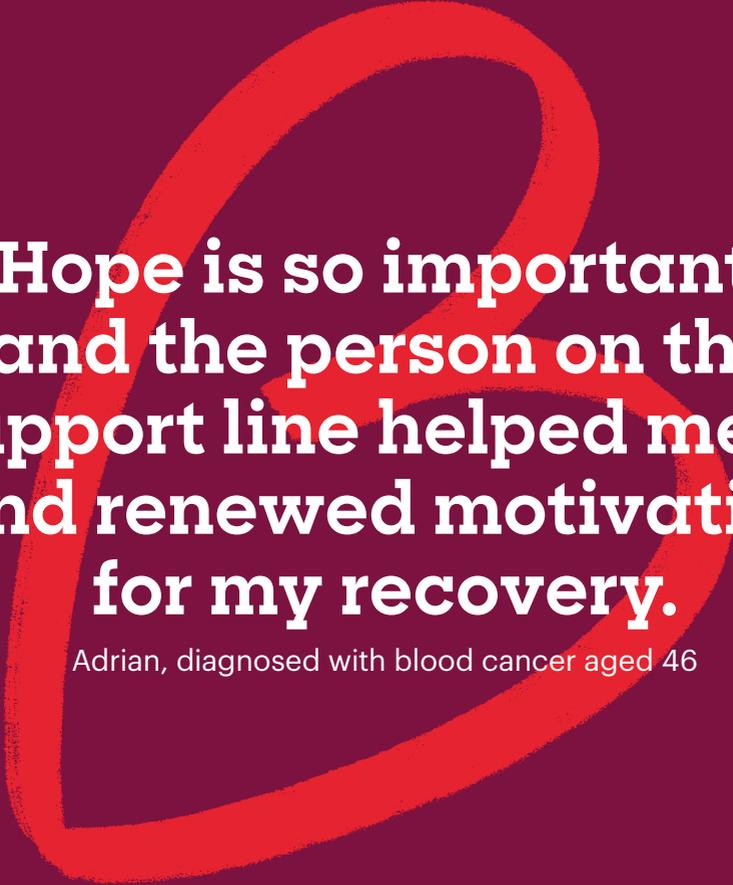
Brett, diagnosed with blood cancer aged 40

Date:

.....

Date:

Date:



**Hope is so important,
and the person on the
support line helped me to
find renewed motivation
for my recovery.**

Adrian, diagnosed with blood cancer aged 46

Date:

Date:

Questions for your healthcare team

It can be a good idea to write down any questions you have before your next appointment. Here are some things you might want to ask while you're waiting to receive your diagnosis, or once you've been diagnosed.

Questions you may want to ask your treatment team:

Who should I contact if I start to feel unwell or have any questions?

Why am I being offered this treatment?
What is the expected effect of it?

If I am not starting treatment straight away, how will I know when I need to start it?

What effect is treatment likely to have on my daily life?

Will I have to stay in hospital or how often will I need to attend as an outpatient?

What will I need to bring with me to hospital?

Will I be able to carry on working/studying?

What is the best outcome I can hope for?

Questions parents may want to ask their treatment team:

Who should I contact if my child starts to feel unwell or if I have any questions?

Where will they be treated?

Will my child have to stay in hospital?

What will they need to bring with them to hospital?

What will I need to bring with me to hospital?

Will I be able to carry on working?

How will their treatment affect them?

Will they be able to cope?

Why are they being given this treatment?

Where can I get help and support?

Questions you may want to ask if someone close to you has blood cancer:

How will I be able to help?

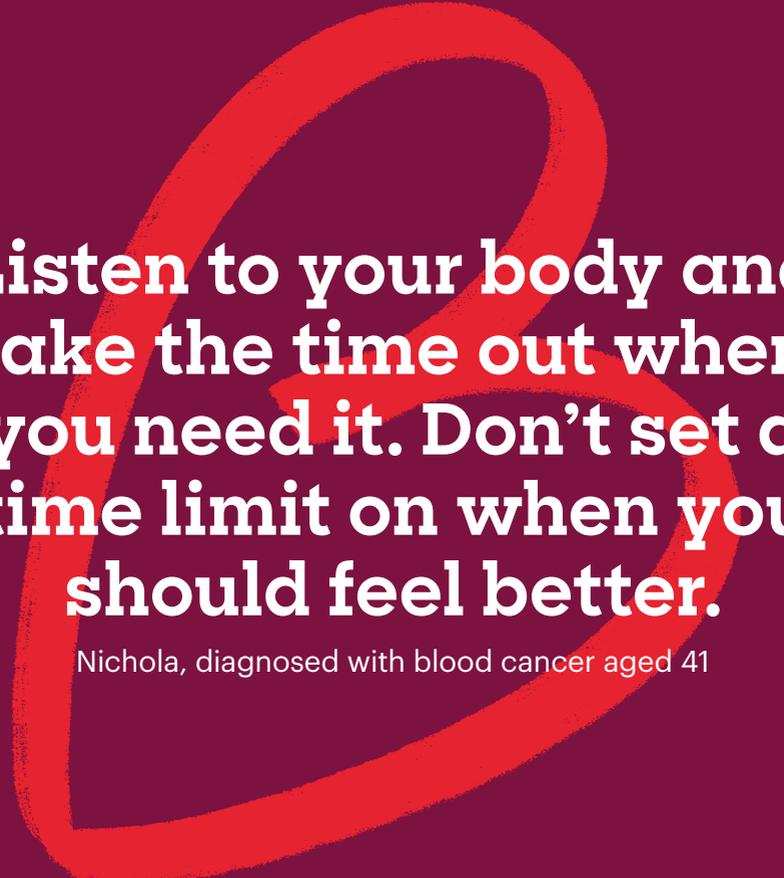
What is the best outcome I can hope for?

What effect is treatment likely to have on their daily life?

Will I need to stop working so that I can look after them?

Will they be able to get financial help?

How much time will they have to spend in hospital?



**Listen to your body and
take the time out when
you need it. Don't set a
time limit on when you
should feel better.**

Nichola, diagnosed with blood cancer aged 41

Glossary

B lymphocyte or B cell

A type of lymphocyte normally involved in producing antibodies to fight infection.

Blood count, full blood count or FBC

A blood test that counts the different types of cells in your blood.

Bone marrow

A spongy material inside long bones, which produces your blood cells.

Chemotherapy

Treatment using anti-cancer drugs; it can be a single drug or a combination of drugs. Chemotherapy is used to kill cells or stop them growing and dividing. Although it's aimed at the cancer cells, the treatment also affects normal cells which divide quickly, such as those in the hair and gut.

Clinical nurse specialist (CNS)

A qualified nurse who specialises in a particular clinical area. Some may specialise in myeloma, lymphoma or leukaemia. Your nurse specialist can provide support, information and expert advice about your condition and treatment.

Clinical trial

A planned medical research study involving patients. They can be small trials involving only a few patients or large national trials. Clinical trials are always aimed at improving treatments and reducing any side effects they cause. You'll always be told if your treatment is part of a trial.

Cytogenetics

The study of the structure of chromosomes. Cytogenetic tests (or FISH tests) are carried out on samples of blood and bone marrow taken from patients. They aim to find any changes which could be linked to the disease. They can also help doctors to decide on the treatment you'll have.

Fatigue

Fatigue is a feeling of extreme tiredness which doesn't go away after rest or sleep. It might be caused by the disease itself or might be a side effect of treatment. It's one of the most common problems that patients with cancer have.

Leukaemia

Often referred to as 'cancer of the blood', leukaemia is divided into many different types – some which develop faster (acute), and others which develop more slowly (chronic). People with leukaemia have large numbers of abnormal blood cells, usually types of white blood cell, which take over the bone marrow and often spill out into the blood stream. Other areas that may also be affected are lymph nodes, spleen, liver, testes, the membranes surrounding the brain and spinal cord (meninges), gums and skin.

Lymph node or lymph gland

A bean-shaped organ that acts as a filter to catch viruses, bacteria and other foreign materials. It contains white blood cells that fight infection.

Lymphocyte

A type of white blood cell which is involved in fighting infection.

Lymph vessels

Small tubes which make up a network which runs around your body. They carry a fluid called lymph.

Mutation

A small genetic change to DNA. These changes can be caused by exposure to hazardous chemicals or copying mistakes when a cell was dividing. If the mutation affects the way cells normally work it can lead to a disease.

Spleen

An organ that filters the blood. It sits under your ribs on the left hand side of your body. The spleen has two main jobs: to remove old red blood cells and to help protect your body from infections.

Stem cells

Cells that are able to develop into other cell types. Stem cells act as a repair system for your body and replenish other cells.

T lymphocyte or T cell

A type of white blood cell which matures in the thymus (this is why they're called a T cell). They're involved in controlling immune reactions and fighting infections. The uncontrolled production of this type of cell causes T-cell leukaemia or lymphoma.

Radiotherapy

The use of radiation in treatment. Radiotherapy kills cancer cells in the area of the body being treated, so it can be an effective treatment for diseases which affect a particular part of the body.

Our health information

Find out more about blood cancer, its treatments and living with blood cancer. All our information is produced with expert medical professionals and people affected by blood cancer. It's available to anyone to download or order for free.

Symptoms guide

A credit-card sized guide that folds out to explain the symptoms of blood cancer.

Booklets

Leukaemia

- Acute lymphoblastic leukaemia (ALL)
- Acute myeloid leukaemia (AML)
- Acute promyelocytic leukaemia (APL)
- Chronic lymphocytic leukaemia (CLL)
- Chronic myeloid leukaemia (CML)

Lymphoma

- Hodgkin lymphoma (HL)
- High-grade non-Hodgkin lymphoma (NHL)
- Low-grade non-Hodgkin lymphoma (NHL)

Other blood cancers

- Myeloma
- Myelodysplastic syndromes (MDS)
- Myeloproliferative neoplasms (MPN)

Treatment and beyond

- Blood stem cell and bone marrow transplants: the seven steps
- Eating well with neutropenia
- Diary for anyone affected by blood cancer

My information folder

An A5 folder to keep your information in.

Fact sheets

Conditions

- Burkitt lymphoma
- Monoclonal gammopathy of undetermined significance (MGUS)
- Waldenström macroglobulinaemia (WM)

Treatments

- Blood transfusions
- Donating stem cells
- What is CAR-T therapy?
- Watch and wait - What you need to know
- Watch and wait - My blood counts
- Watch and wait - A quick guide for partners, carers, family and friends
- Watch and wait - A quick guide for employers
- Watch and wait - A toolkit for GPs and practice nurses

Side effects

- Managing sickness and vomiting
- Sore mouth or gut (mucositis)
- Understanding infection

Living with blood cancer

- If your employee or colleague has blood cancer
- My activity planner

To order or download information

Visit [bloodcancer.org.uk/information](https://www.bloodcancer.org.uk/information)

Call **0808 2080 888** (Mon, Tue, Thu, Fri, 10am–4pm, Wed, 10am–1pm)

Email support@bloodcancer.org.uk

Or use the order form on **page 96**



**We're a
community
dedicated to
beating blood
cancer.**

About us

We're the scientists who dedicate our careers to finding cures.

We're the nurses who find the right words in the darkest moments.

We're the campaigners and volunteers standing up for the people we love.

We're the bucket-collectors, race-runners and cake-bakers who make our research possible.

We're the friends, parents, children and grandparents affected by blood cancer.

Why?

Because we've invested over £500 million in life-saving research.

Because the finish line's in sight.

Because it's time to beat blood cancer.

Because we give people the support they need

People with blood cancer and their family and friends have unique support needs.

We offer free and confidential support by phone or email, provide information about blood cancer and life after a diagnosis, and have an online forum where you can talk to others affected by blood cancer.

bloodcancer.org.uk

0808 2080 888

(Mon, Tue, Thu, Fri, 10am–4pm, Wed, 10am–1pm)

support@bloodcancer.org.uk

forum.bloodcancer.org.uk

Because our research is saving lives

The money raised by our community has meant we've been able to invest £500 million in research, which has changed the outlook for people with blood cancer. Our research has led to better treatments that have dramatically increased survival rates. Right now, we're funding research projects across the UK that are finding out more about blood cancer and the best way to treat it.

Find out more: **bloodcancer.org.uk/research**



Because we campaign for better treatment and care

We work to make sure people affected by blood cancer are at the heart of Government and NHS decision-making.

We're campaigning to end delays to diagnosis, improve access to the latest treatments and help people with blood cancer get the mental health support they need.

Find out more: [bloodcancer.org.uk/campaigns](https://www.bloodcancer.org.uk/campaigns)

Because we'll beat it together

Donate

A quick way to help. Every pound brings us one step closer to beating blood cancer:

bloodcancer.org.uk/donate

Fundraise

Sign up to one of our events, or do something you enjoy with family and friends – there are lots of ways to fundraise: **bloodcancer.org.uk/fundraise**

Join your local community group

Local community groups raise money and awareness in their local area. Volunteer for yours to meet new people and get involved in local activities:

bloodcancer.org.uk/local-community-groups

Volunteer

Give your time, meet new people and experience new things by volunteering with us. There are lots of ways you can help, from your own home or in your local community: **bloodcancer.org.uk/volunteer**

Get your organisation involved

From funding a project, to becoming a corporate partner, find out how your organisation can help us:

bloodcancer.org.uk/corporate-partnerships

Or call us on **0808 169 5155**



**I love being part of the
Blood Cancer UK family.
Being involved has
helped me and my family
cope with my diagnosis.**

Anna, diagnosed with blood cancer age 39



Go to **bloodcancer.org.uk/donate**, call us on **0808 169 5155** or complete and send this form to us freepost using the address: **FREEPOST PLUS RTSU-XAYE-XZYK, Blood Cancer UK, 111 George Street, Edinburgh, EH2 4JN**

Full Name

Address

Email Phone



As a supporter, you're at the heart of everything we do. We'd love to keep you updated about our exciting work and the ways you can help, including campaigns and events that you might be interested in. We promise to respect your privacy and we will never sell or swap your details.

I'm happy for Blood Cancer UK to contact me by: Email Phone SMS

Don't contact me by post:

You can change how we communicate with you at any time.

Contact us on **0808 169 5155** or email **hello@bloodcancer.org.uk**

I'd like to donate £10 £25 £50 Other

I enclose a cheque/CAF voucher made payable to Blood Cancer UK

OR please debit my Visa Maestro Mastercard CAF card

Cardholder's name

Card number (Maestro only)

Start date Expiry date Issue number

Make your donation worth an extra 25p for every £1 at no extra cost to you!

giftaid it

I'd like Blood Cancer UK to claim Gift Aid on this donation and any donations I make in the future or have made in the past 4 years.

*By ticking this box I confirm that I'm a UK taxpayer and I understand that if I pay less Income Tax and/or Capital Gains Tax than the amount of Gift Aid claimed on all my donations in that tax year, it's my responsibility to pay any difference.

*Today's date

If you stop paying tax, change your name or address, or if you have any further questions about Gift Aid, please contact our Supporter Relations Team on **0808 169 5155**.

*Information required for Gift Aid declaration to be valid.

Order information from Blood Cancer UK

All of our information is free to people affected by blood cancer, but if you would like to include a donation with your order, please fill in the donation form over the page.

You can order more information by:

- visiting **bloodcancer.org.uk/information**
- Emailing **support@bloodcancer.org.uk**
- calling **0808 2080 888**
- or completing and sending this form to us freepost using the address: **FREEPOST PLUS RTSU-XAYE-XZYK, Blood Cancer UK, 111 George St, Edinburgh, EH2 4JN**

Please send me some information

Full Name

Address

Email

Phone

Please tell us the publications you would like us to send you, free of charge (see page 86)

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Keep in touch

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Because we face it together

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- Information about blood cancer and life after diagnosis
- An online forum for people affected by blood cancer

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support@bloodcancer.org.uk

forum.bloodcancer.org.uk



**Blood
cancer
UK**

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