Bloodwise

For adults and children with blood cancer

bloodwise.org.uk

My diary

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 healthcare team treating you. This is your space, however you wish to use it.

If you would like more information about blood cancer or related conditions, please go to our website, where you can also find the details of other organisations that can offer information and support: bloodwise.org.uk.

If you have any questions, worries or concerns, please contact your consultant or clinical nurse specialist.

My details

Name and hospital number

My NHS number

My condition

My contacts

My consultant

My key worker (usually your CNS)

Haematology ward

Haematology clinic

Out of hours

Other contacts

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.

Date:

My diary

How I feel: emotionally, practically and physically.

Date:

Date:

Date:

Date:

Date:

Date:

Date:

I found it really helpful to talk to someone else about how I was feeling – whether that was a family member, friend, or someone from an organisation which offers support.

Date:

My diary

How I feel: emotionally, practically and physically.

Date:

Date:

Date:

Date:

Date:

Date:

Date:

If I had any questions, my treatment team were always on hand to help me.

Date:

My diary

How I feel: emotionally, practically and physically.

Date:

Date:

Date:

Date:

Date:

Date:

Date:

There's no right or wrong way to feel – I experienced a lot of different emotions.

Date:

My diary

How I feel: emotionally, practically and physically.

Date:

Date:

Date:

Date:

Date:

Date:

Date:

Whenever I had a question, I spoke to my clinical nurse specialist or consultant – even in between my hospital appointments.

Date:

My diary

How I feel: emotionally, practically and physically.

Date:

Date:

Date:

Date:

Date:

Date:

Date:

I joined a support group – I found it really helpful to speak to someone in a similar situation.

Date:

My diary

How I feel: emotionally, practically and physically.

Date:

Date:

Date:

Date:

Date:

Date:

Date:

In between my appointments, I found it helpful to write down any questions I had, so that I could have them handy when I talked to my consultant or clinical nurse.

Date:

My diary

How I feel: emotionally, practically and physically.

Date:

Date:

Date:

Date:

Date:

Date:

Date:

Everyone is different and we'll all have different experiences – even if the diagnosis looks similar.

Date:

My diary

How I feel: emotionally, practically and physically.

Date:

Date:

Date:

Date:

Date:

Date:

Date:

When I was diagnosed, I found it hard to think straight. When I had to make important decisions about treatment or tests, I tried to take some time to consider my options.

Date:

My diary

How I feel: emotionally, practically and physically.

Date:

Date:

Date:

Date:

Date:

Date:

Date:

“Everyone deals with a cancer diagnosis in a different way. I found that speaking openly and honestly with my friends and family really helped.”

Date:

My diary

How I feel: emotionally, practically and physically.

Date:

Date:

Date:

Date:

Date:

Date:

Date:

I contacted a few different organisations after my diagnosis whilst I was being treated – I found it helpful to speak to other experts or people in a similar situation.

Date:

My diary

How I feel: emotionally, practically and physically.

Date:

Date:

Date:

Date:

Date:

Date:

Date:

I found it helpful to speak with a counsellor about my diagnosis – it was really useful to speak to someone who has a different perspective.

Date:

My diary

How I feel: emotionally, practically and physically.

Date:

Date:

Date:

Date:

Date:

Date:

Date:

Date:

My diary

How I feel: emotionally, practically and physically.

Date:

Date:

Date:

Date:

Date:

Date:

Date:

Questions to consider

You might have some questions which you'd like to ask your treatment team. We've provided some suggested questions which you could use, or which might prompt questions of your own – we've left some space for these too.

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?

You might also like to write down any of your own questions here.

Your questions:

About us

We're Bloodwise, the UK's specialist blood cancer charity.

We're here to make things clear

We send our patient information for free to anyone who needs it. Whether you have blood cancer yourself or care for someone with blood cancer, we have a range of booklets, fact sheets and online information to support you and help you make sense of it all.

We're here to listen, support and connect

Our Support Line team are just a call or email away. Call us on 0808 2080 888 Mon–Fri 10am–4pm, email **support@bloodwise.org.uk** or visit us at **bloodwise.org.uk** to join our online community.

We're here to beat blood cancer

We fund the research that gets results: research that tells us more about blood cancer and improves the lives of those with blood cancer. We've invested over £500 million in world-class research since 1960 – but we won't stop until every single person with blood cancer can live their life to the full.

Go to > **bloodwise.org.uk** for more information

Getting involved

Help us beat blood cancer.

We have lots of exciting opportunities for you to get involved and help us to beat blood cancer.

Give a gift

Whether it's a regular or one off donation, every gift – big or small – will make a difference.

Take on a challenge

Every stride, stroke and pedal gets us closer to beating blood cancer. Whatever the event, make every mile matter.

Beat blood cancer locally

Join one of our regional branches and fundraising groups to discover how you can make a difference.

Jump online

Every like, share, tweet and mention could mean someone finds out about our services and raises awareness of blood cancer.

facebook.com/bloodwise.uk
twitter.com/bloodwise_uk

Partner with us

We're always looking for companies who share our vision and energy.

Get in touch

Visit **bloodwise.org.uk/get-involved**, call **0207 504 2200** or email **hello@bloodwise.org.uk**

Your feedback

We're always looking for ways to improve the information we provide for people with blood cancer.

We welcome your feedback on this booklet and our other patient information. Any improvements you suggest mean we can make better information for other blood cancer patients and people close to them.

Email us at **information@bloodwise.org.uk** with your feedback.

More information

We offer patient information on many blood cancer types and topics, online and in free printed booklets.

They cover everything from symptoms and diagnosis through to treatment and living with your condition.

For our patient information, go to >
bloodwise.org.uk/information-and-support

Information booklets

Booklets which are available free of charge:

Reference	Description
	Leukaemia
BWALL	Acute lymphoblastic leukaemia (ALL)
BWAML	Acute myeloid leukaemia (AML)
BWAPL	Acute promyelocytic leukaemia (APL)
BWCLL	Chronic lymphocytic leukaemia (CLL)
BWCML	Chronic myeloid leukaemia (CML)
	Childhood leukaemia
BWCHALL	Acute lymphoblastic leukaemia (ALL) in children and young adults up to 16 years
BWCHAML	Acute myeloid leukaemia (AML) in children and young adults up to 16 years
	Lymphoma
BWHL	Hodgkin lymphoma (HL)
BWNHLHIGHGRADE	High-grade non-Hodgkin lymphoma (NHL)
BWNHLLOWGRADE	Low-grade non-Hodgkin lymphoma (NHL)
	Other
BWMM	Myeloma
BWMDS	Myelodysplastic syndromes (MDS)
BWMPN	Myeloproliferative neoplasms (MPN)
	Treatment and beyond
BWBMT	Bone marrow and stem cell transplantation – for children and adults
BWCHEMO	Chemotherapy – what do I need to know?
BWCT	Clinical trials
BWDONSC	Donating stem cells
BWDLI	Donor lymphocyte infusion
BWSEVEN	The seven steps – blood & bone marrow transplantation
BWHD	Undergoing high dose therapy and autologous stem cell transplant
BWDAPN	Eating well with neutropenia
BWMYDIARY	Diary for anyone affected by blood cancer

Fact sheets

We have the following fact sheets available online at **bloodwise.org.uk**

- Burkitt lymphoma
- Chronic myelomonocytic leukaemia (CMML)
- Hairy cell leukaemia (HCL)
- Large granular lymphocytic leukaemia (LGLL)
- Monoclonal gammopathy of unknown significance (MGUS)
- Mucositis
- Plasma cell leukaemia
- Solitary plasmacytoma
- T-cell acute lymphoblastic leukaemia
- Transformation of chronic lymphocytic leukaemia (CLL)
- Treatment decisions
- Waldenstrom macroglobulinaemia
- What to expect from your appointments

Bloodwise
The **blood cancer research** charity

Please donate today to help Bloodwise beat blood cancer

- Go to **bloodwise.org/donate** › Call us on **0808 2080 888**
- Or complete and send this form to us freepost using the address:
  FREEPOST PLUS RTRS-GCXY-SYKJ, 39-40 Eagle Street, London, WC1R 4TH

First name ..... Surname .....

Address .....

Postcode ..... Email ..... Phone .....

I'd like to donate ☐ **£10** ☐ **£25** ☐ **£50** ☐ **Other** .....

☐ I enclose a cheque/CAF voucher made payable to Bloodwise

OR please debit my ☐ Visa ☐ Maestro ☐ MasterCard ☐ CAF card

Cardholder's name .....

Card number ☐☐☐☐ ☐☐☐☐ ☐☐☐☐ ☐☐☐☐ (Maestro only) ☐☐☐

Start date ☐☐☐☐ Expiry date ☐☐☐☐ Issue no ☐☐

Make your donation worth 25% more at no extra cost to you *giftaid it*

Please treat as Gift Aid donations all donations I have made over the past four years and all donations I make in the future (unless I notify you otherwise).

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

We would like to update you about how you're helping us beat blood cancer

☐ Yes, please update me by email ☐ Yes, please update me by telephone

We may like to write to you in future with news and information on how we spend your money. If you would prefer us not to, please let us know by ticking this box ☐

Bloodwise. Registered charity 216032 (England & Wales) SC037529 (Scotland) Ref:PINFO

More information from Bloodwise

You can order more information by:

- visiting **bloodwise.org.uk**
- emailing **information@bloodwise.org.uk**
- calling **0808 2080 888** (freephone)
- or completing and sending this form to us freepost using the address:
  FREEPOST PLUS RTRS-GCXY-SYKJ, 39-40 Eagle Street, London, WC1R 4TH

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.

Please send me some information

Title ..... First name ..... Surname .....

Address .....

Postcode ..... Email ..... Phone .....

Please write the reference numbers of the booklets that you would like to be sent to you (free of charge) in the spaces provided below:

....

....

....

....

....

Keep in touch

We would like to update you about how you're helping us beat blood cancer

☐ Yes, please update me by email ☐ Yes, please update me by telephone

We may like to write to you in future with news and information on how we spend your money. If you would prefer us not to, please let us know by ticking this box ☐

Bloodwise. Registered charity 216032 (England & Wales) SC037529 (Scotland) Ref:PINFO

Bloodwise

The **blood cancer research** charity

39 – 40 Eagle Street, London WC1R 4TH
bloodwise.org.uk
020 7504 2200 (Reception); 0808 2080 888 (Support Line)

Registered charity 216032 (England & Wales) SC037529 (Scotland)
MYDIARY/0617