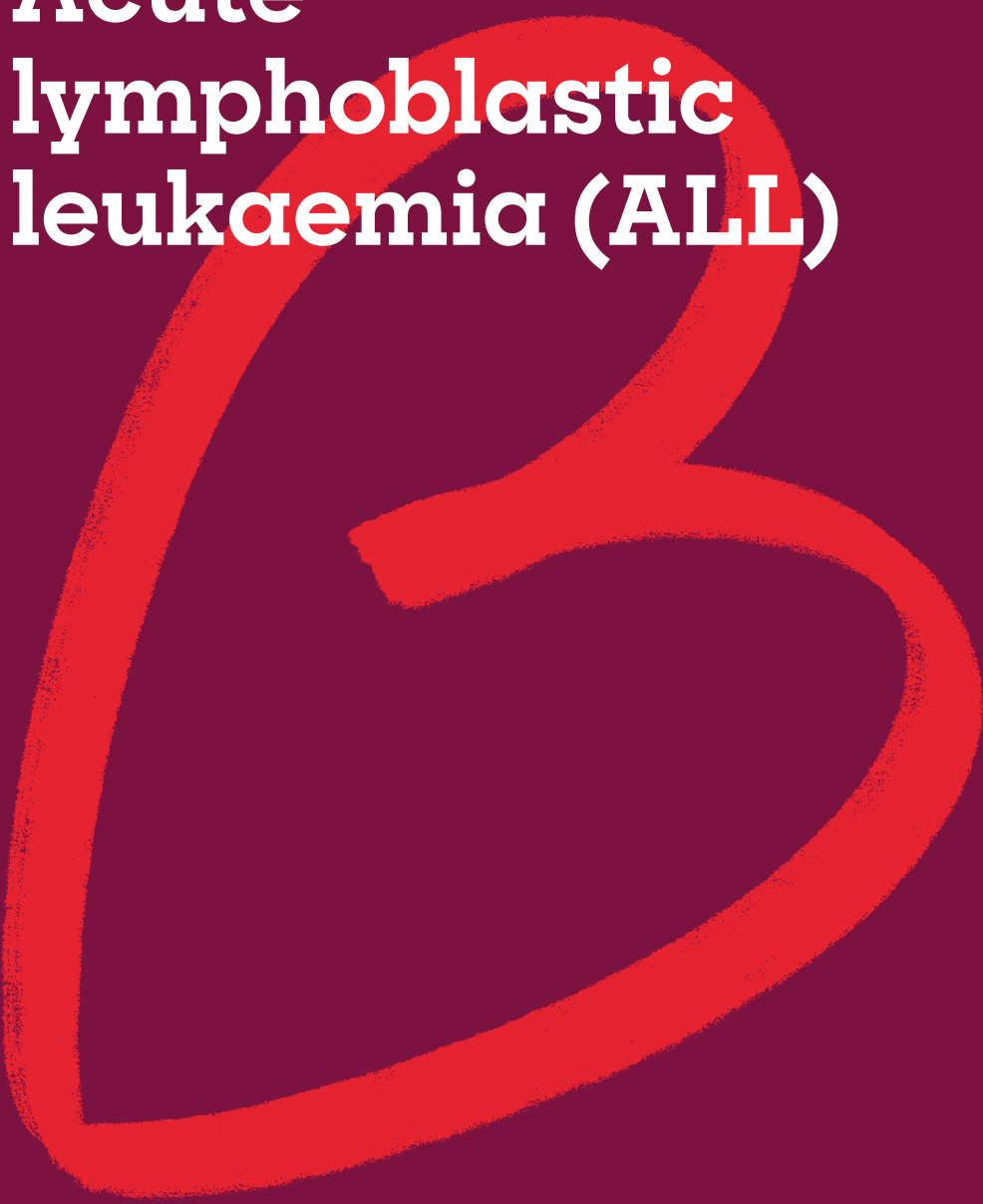


Acute lymphoblastic leukaemia (ALL)



**Blood
cancer
UK**

About this booklet

We have produced this booklet in collaboration with expert medical professionals and people affected by blood cancer. Thank you to Consultant Haematologists Professor Adele Fielding and Dr Clare Rowntree for their support checking the content of this booklet.

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 115.

bloodcancer.org.uk

0808 2080 888

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

support@bloodcancer.org.uk

A list of references used in this booklet is available on request. Please email us at **information@bloodcancer.org.uk**

Disclaimer

We make every effort to make sure that the information in this booklet is accurate, but you shouldn't rely on it instead of a fully trained clinician. It's important to always listen to your specialist and seek advice if you have any concerns or questions about your health. Blood Cancer UK can't accept any loss or damage resulting from any inaccuracy in this information, or from external information that we link to.

The information in this booklet is correct at the time it was printed (February 2019)

Date of next review: 2022

Blood Cancer UK, 39–40 Eagle Street, London WC1R 4TH

020 7504 2200 **hello@bloodcancer.org.uk** **bloodcancer.org.uk**

© All rights reserved. No part of this publication can be reproduced or transmitted without permission in writing from Blood Cancer UK.

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

Contents

2	Introduction
4	Acute lymphoblastic leukaemia (ALL) at a glance
9	Blood, bone marrow and your immune system
19	What is acute lymphoblastic leukaemia (ALL)?
25	What causes ALL?
29	Symptoms
33	Diagnosis
51	Treatment
75	The outlook
79	Living with ALL
93	Places you can get help and support
100	Questions for your healthcare team
106	Glossary
112	Our health information
115	About us
125	My details

Introduction

This is a booklet for adults with acute lymphoblastic leukaemia (ALL), and their family and friends. It's about the most common form of ALL in adults, B-cell ALL.

Being told that you, or a loved one, have any type of cancer can be one of the hardest things you'll ever have to hear.

There's sure to be a lot of information to take in at this time.

We hope this booklet will help you understand your condition and feel more in control. We'll cover the key aspects of diagnosis and care along the way – including symptoms, tests, treatment, living with ALL, and where you can get support.

We have information about ALL in children and young adults on our website. Go to: **[bloodcancer.org.uk/childhood-all](https://www.bloodcancer.org.uk/childhood-all)**



Our Support Services Team offers practical and emotional support for anyone affected by blood cancer. Contact us on **0808 2080 888** or email **support@bloodcancer.org.uk**



If you are the parent of a child or young person with ALL, please read the information on our website about ALL in children and young adults. This explains the treatments available for children and adults from one year up to 24 years old.

Every person is different, with a different medical history. So when you're deciding what's right for you, always talk to your specialist as well as getting information from this booklet and other trustworthy places.

Acute lymphoblastic leukaemia (ALL) at a glance

Anyone can get ALL, but it's more common in younger and older people, and less common in middle age. Generally, most people who have treatment will go into remission (a period where there's no sign of cancer cells) although there is a chance of relapse (the cancer coming back).

What is ALL?

ALL is a type of cancer that affects cells called lymphoid blasts, or lymphoblasts. These develop into white blood cells in the bone marrow (the

spongy material inside some of your bones). ALL happens when your lymphoid blasts don't mature properly and build up in the bone marrow and the blood. 'Acute' means that the leukaemia develops quickly and needs treatment straight away.

Who gets ALL?

ALL is the only type of leukaemia that affects children more often than adults. When it does affect adults, they are more likely to be younger adults, and least likely to be middle-aged. ALL then becomes more common again in older age. We don't know why the risk is different at different ages.

What's the outlook?

The outlook (prognosis) is different for each person with ALL. The best person to talk to about this is your specialist doctor (consultant), or someone else on your healthcare team. Generally, after active treatment, up to nine out of ten people can go into what's called remission or complete remission.


This means that the treatment has worked well and no leukaemia cells can be seen when your blood or bone marrow are looked at under a microscope (although this may not mean you're completely cured).

Once the ALL has gone into remission you will be checked regularly and your healthcare team will tell you if the disease comes back or relapses. Some people never relapse and they remain in remission for the rest of their lives.

What are the treatments for ALL?

The best treatment for you will depend on your individual situation, including your age, general health, and the type of ALL you have.

Anti-cancer drugs (chemotherapy) are the main treatment for ALL. You'll be offered a treatment plan involving chemotherapy drugs and steroids. You'll also have medicines which aim to stop you getting infections during the chemotherapy. In some cases, a stem cell transplant (also known as a bone marrow transplant) will be part of the treatment.



**Stick to trustworthy
information from cancer
charities or the NHS.
Your healthcare team will
tell you the best place
to find it.**

Wendy, diagnosed with blood cancer aged 46

**Knowing the basics
about blood, bone marrow
and your immune system
is useful.**

If you're worried, get in touch on **0808 2080 888**
or email **support@bloodcancer.org.uk**

Blood, bone marrow and your immune system

It's a good idea to know a bit about blood, bone marrow and your immune system as your healthcare team is likely to talk about them.

Your blood

The blood has many important functions:

Transport system

Blood carries food, oxygen and proteins to different parts of your body. It also carries waste chemicals to the kidneys and lungs, so they can get rid of them.

Defence system

White blood cells are part of your immune system, which fights infections.

Communication system

Hormones are your body's chemical messengers. It's their job to give instructions to your organs. These chemicals are carried around in the blood.

Repair system

Your blood contains cells and chemicals that can seal off damaged blood vessels and control bleeding.

Blood cells

Blood contains three types of cells: red blood cells, white blood cells and platelets. Each type has several different jobs to do in the body. You'll learn all the terms below as your treatment goes on. Your healthcare team will talk to you about them regularly.

Red blood cells (erythrocytes) contain a protein called haemoglobin, which carries oxygen to all the tissues of your body. Muscles and other tissues need oxygen to use the energy you get from food.

White blood cells (leukocytes) are an important part of the immune system. Their job is to help fight and prevent infection. There are different types of white blood cell including lymphocytes, monocytes, and granulocytes.

Platelets (thrombocytes) stick together and form clots to stop you bleeding, for example, if you have a cut or a bruise.

Bone marrow and how blood cells are made

All blood cells are made in the soft material inside your bones (your bone marrow). This process starts off with a very basic kind of cell, called a stem cell. Stem cells go through various stages until they mature and change into different types of blood cells.

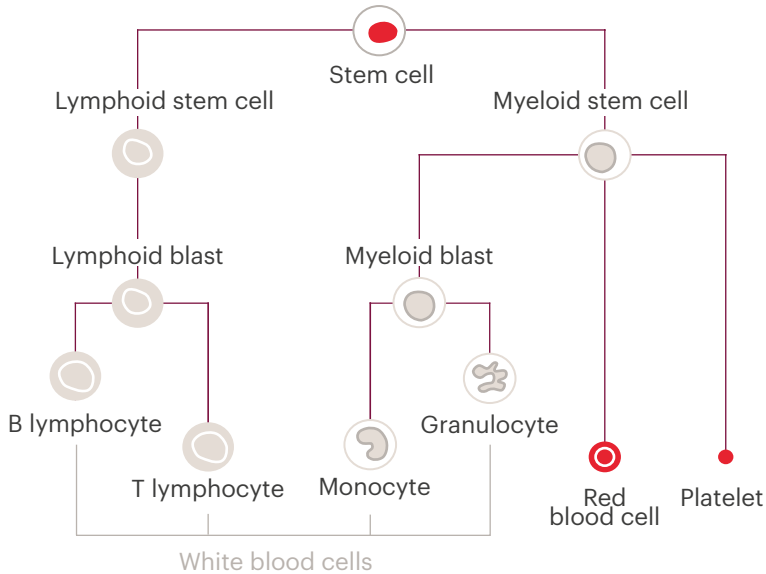
When stem cells first divide, they create two types of more specialised stem cells:

- lymphoid stem cells
- myeloid stem cells

Next, these stem cells go on to form immature blood cells called lymphoid blasts or myeloid blasts.

After developing further, lymphoid blasts eventually end up as a specific type of white blood cell, called a lymphocyte. The myeloid blasts go on to form other types of white blood cell, red blood cells and platelets.

Blood cell production



How many of each type of blood cell should you have?

Your bone marrow produces a huge number of blood cells every second, because your body needs them. If everything's working normally, your body makes the right number of each type of cell to keep you healthy. You may feel unwell if your body is making too many or too few of any type of blood cell.

Everyone has slightly different numbers of each type of blood cell. If you're healthy, the amount you have of each type normally stays more or less the same, with slight changes up and down over time. This table shows the normal ranges for a healthy person:

Blood cell or substance	Levels found in a healthy person
Haemoglobin (Hb) level (for red blood cells)	130–180 g/l (men) 115–165 g/l (women)
Platelets	150–400 x 10 ⁹ /l
White blood cells (WBC)	4.0–11.0 x 10 ⁹ /l
Neutrophils	2.0–7.5 x 10 ⁹ /l
Lymphocytes	1.5–4.5 x 10 ⁹ /l

Your blood values depend on a number of different things, including sex, age, and ethnicity. Also, different laboratories will use different equipment and testing methods, so normal values can vary slightly from hospital to hospital. So this table should only be used as a rough guide. Your healthcare team can explain what your results mean for you.

Your immune system

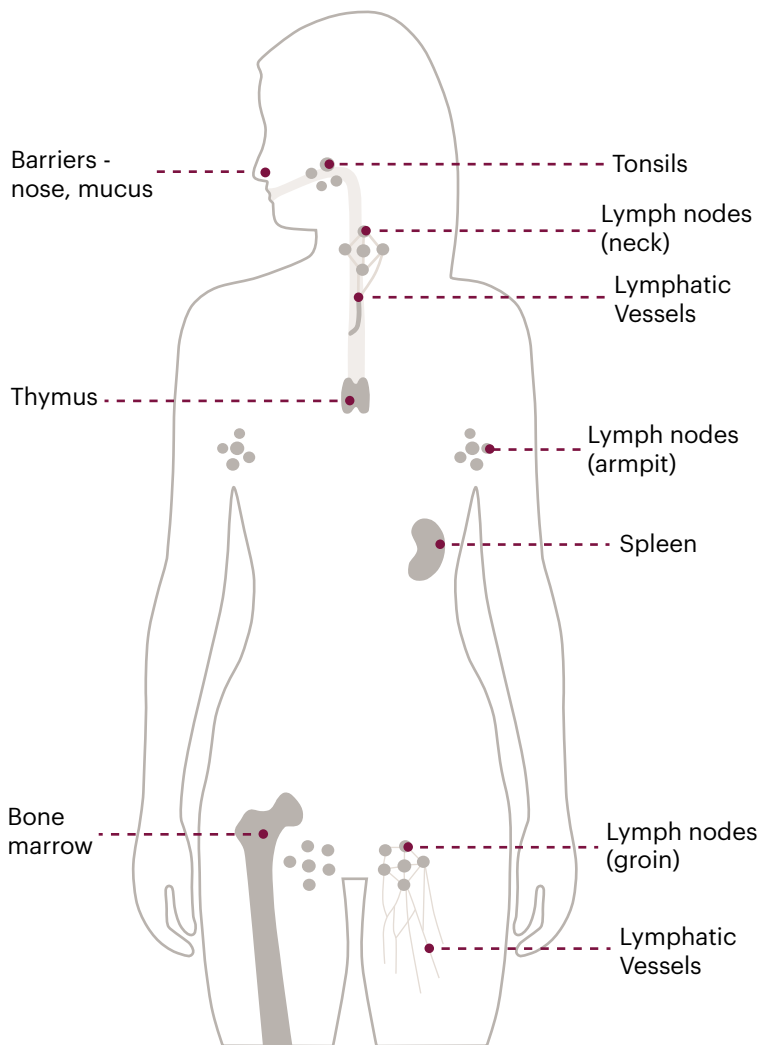
Your immune system is a network of cells, tissues and organs which protects your body against infection. White blood cells called lymphocytes flow around your body in your blood, and play an important role in your immune system's quick reaction to infections. Because both ALL itself and the treatment for ALL affect your immune system and bone marrow, you may be more likely to get infections.

Your lymphatic system

The lymphatic system is an important part of the immune system. A network of thin tubes called lymph vessels runs throughout your body. These vessels collect fluid called lymph and return it to your blood. Lymph fluid bathes all the cells in your body. It contains lots of lymphocytes, carries nutrients which feed the cells and takes bacteria away from infected areas.

Along the lymph vessels are small lumps of tissue called lymph nodes or lymph glands. There are many of these in your body. It may be possible for you to feel normal lymph nodes in your neck and groin (see diagram), particularly if you're slim. If you get an infection when you're healthy these nodes can swell and become tender. People often talk about having 'swollen glands' – this is normal when you have an infection.

Your lymphatic system

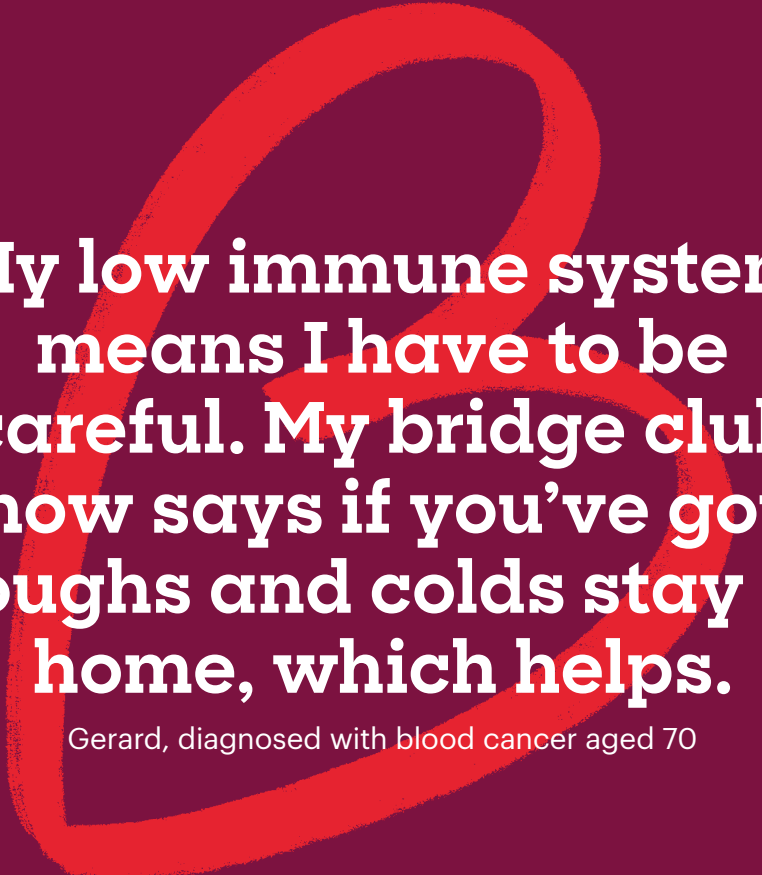


As lymphocytes pass through the lymph nodes, they are changed and triggered to fight certain types of infection.

Your spleen is also part of your lymphatic system. This is a fist-sized organ that sits under your ribs on the left-side of your body, next to your stomach and behind your ribs. It can do some of the same work as the lymph nodes and helps fight infection. It also filters out old or damaged cells from the bloodstream.



For more information about infection risk and tips on how to manage it, we have a fact sheet on **Understanding infection** – see **page 113**.



My low immune system means I have to be careful. My bridge club now says if you've got coughs and colds stay at home, which helps.

Gerard, diagnosed with blood cancer aged 70

Our researchers are continually making new discoveries that help us understand ALL, how it develops and how we can treat it.

If you're worried, get in touch on **0808 2080 888** or email **support@bloodcancer.org.uk**

What is acute lymphoblastic leukaemia (ALL)?

ALL is a fast-developing type of blood cancer that affects cells called lymphoid blasts. These normally produce white blood cells called lymphocytes.

What is leukaemia?

In leukaemia, the lymphoid blast or myeloid blast cells in your bone marrow become cancerous, which means they start to divide and multiply in an unusual way. As more abnormal cells are produced, these start to crowd out the normal blood cells. This affects your ability to fight infection and stay healthy.

Leukaemia can be acute or chronic. Acute means it develops quickly and usually needs treatment straight away. Chronic leukaemia develops more slowly.

What is ALL?

ALL affects cells called lymphoid blasts (or blast cells, for short) in your bone marrow. These are a type of white blood cell, which are a vital part of your immune system. Normally, lymphoid blasts mature and develop into lymphocytes, which fight infection.

Your body needs new lymphocytes all the time, and it usually makes the right amount. When people have ALL, this process goes wrong. The blast cells multiply too quickly, and they don't develop properly. We call these abnormal blast cells leukaemia cells. They build up in your bone marrow until eventually there's no room for normal blood cells to be made there. So your body doesn't have enough white blood cells, red blood cells, or platelets to work properly.

ALL develops more quickly than some other blood cancers, so swift diagnosis and treatment are really important.



For more information on blood cells, see **pages 10–12**.

Types of ALL

There are different types of ALL. The treatment you'll have depends on the specific type you're diagnosed with. There are two types of lymphocytes known as B cells and T cells. When you have ALL, it usually affects one type or the other, so doctors will say you have either B-cell ALL or T-cell ALL.

This booklet is about B-cell ALL, which is more common. If you are diagnosed with T-cell ALL, ask your healthcare team for more information about your treatment and outlook.

Philadelphia positive ALL

Around one in four adults with ALL have Philadelphia positive ALL. This means the leukaemia cells develop because of a very specific genetic fault that's only present in the abnormal cells, not throughout your body. It is not the sort of genetic fault that passes from one generation to another.

All cells in your body contain a set of 'instructions' which tell the cell what to do and when to do it. These instructions are stored inside the cells in structures called chromosomes.

Chromosomes are made up of a chemical known as DNA, which is arranged in sections called genes. There are 23 pairs of chromosomes in each cell in your body. When cells divide to form new cells, the chromosomes should stay the same in the new cells.

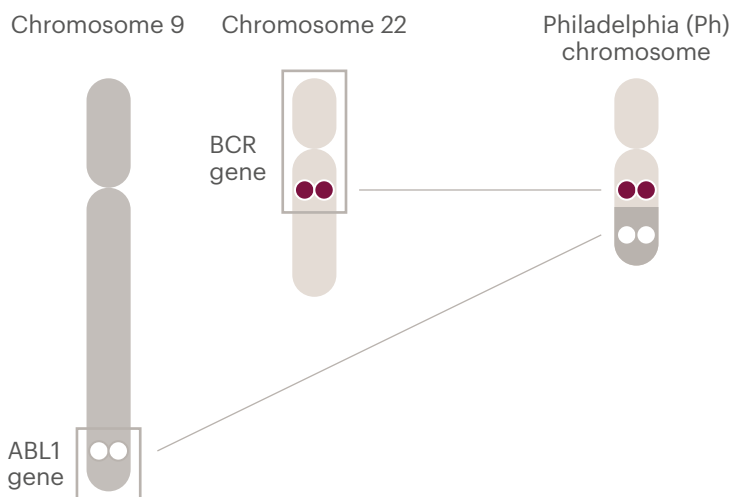
We think Philadelphia positive ALL begins when something goes wrong by chance. A small part of chromosome 9 (the ABL1 gene) gets stuck to a small part of chromosome 22 (the BCR gene) when the cell divides. This forms a new fusion gene called BCR-ABL1, and makes chromosome 22 shorter than normal. This new, shorter chromosome is called the Philadelphia chromosome, because it was discovered in Philadelphia in the USA.

This swapping of genetic material is called a translocation, or chromosomal translocation. This particular translocation is sometimes called t(9;22).

The new BCR-ABL1 gene is important in the development of Philadelphia positive ALL because it makes a new protein known as tyrosine kinase. This protein is a type of enzyme (a substance which speeds up chemical processes), and it causes the leukaemia cells to divide more often and to live longer than usual.

If doctors can spot the BCR-ABL1 fusion gene, it can help them to diagnose ALL, and also monitor how well you respond to treatment. The standard treatment for Philadelphia positive ALL is to take drugs that block the effects of (inhibit) the tyrosine kinase enzyme. These drugs are called tyrosine kinase inhibitors or TKIs.

The Philadelphia chromosome



Other types of ALL

There are many other types of ALL, based on the many different genetic changes that can happen. The outlook for each type varies. At the moment, there are no specific therapies for these different types of ALL and they are all treated in the same way, but scientists across the world are working to develop more targeted treatments. Your doctors are likely to carry out specific genetic tests on your leukaemia cells, but the results might not be available until a few weeks after diagnosis.

**You're not alone: over 800
people are diagnosed with
ALL in the UK each year.**

If you're worried, get in touch on **0808 2080 888**
or email **support@bloodcancer.org.uk**

What causes ALL?

We don't know exactly what causes ALL yet. What we do know is that it's not possible to 'catch' ALL or any other type of leukaemia. We also know there are some things that may make it a bit more likely for someone to get ALL.

Age

ALL is the only type of leukaemia that affects children more often than adults. When it does affect adults, they are more likely to be younger adults, and least likely to be middle-aged. ALL then becomes more common again in older age. We don't know why the risk is different at different ages.

Sex

ALL is slightly more common in men than women. We don't know why.

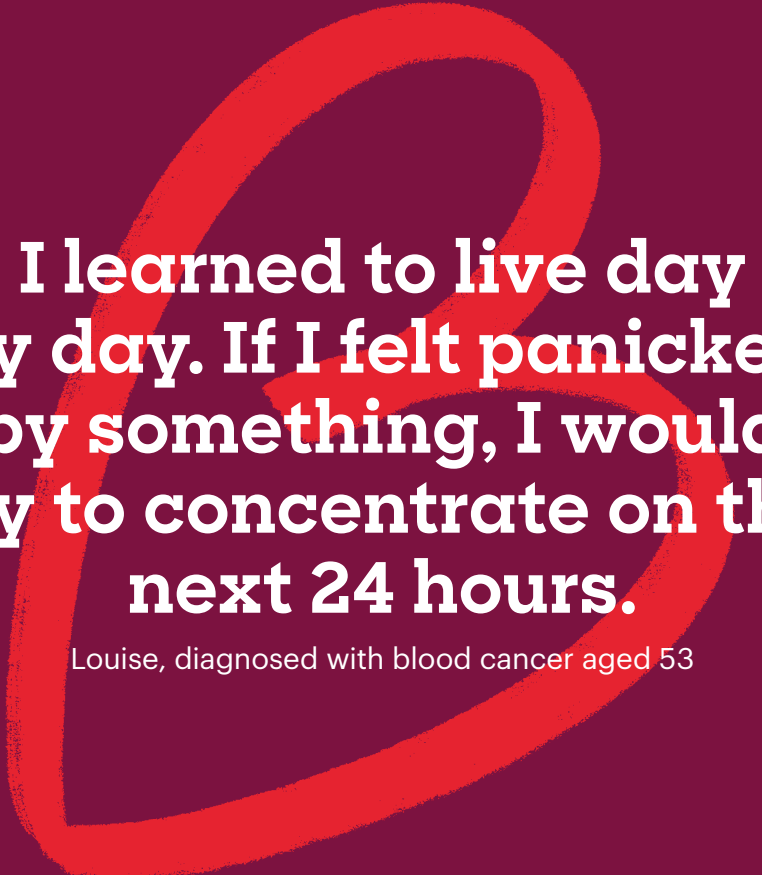
Genetics

Although people with ALL have a genetic fault in the leukaemia cells themselves, this is not something you inherit from your parents or pass on to your children. Some genetic conditions such as Down syndrome carry a higher risk of developing ALL.

Radiation

Radiation in high doses can lead to leukaemia, but it's unlikely to cause many cases in the UK, if any at all.

It's important to remember that none of your lifestyle choices have contributed to this condition.



**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

**It's important to remember
that not everyone will
get all of these symptoms.
Each person is different.**

If you're worried, get in touch on **0808 2080 888**
or email **support@bloodcancer.org.uk**

Symptoms

The main symptoms you get with ALL are caused by not having enough normal blood cells, because there are too many blast cells in your bone marrow. This can lead to a number of symptoms.

Common symptoms of ALL include:

Fatigue (extreme tiredness)

Fatigue is a kind of tiredness that lasts a long time and doesn't improve with rest. It's caused by a low number of red blood cells in your blood (a low red blood cell count). The medical name for this is anaemia.

Anaemia can also make you feel breathless, even when you're resting, and lead to chest pain.

Bruising and bleeding

This is caused by a low number of platelets in your blood (a low platelet count). Platelets are the blood cells that stop bleeding by making the blood clot.

Low platelets can mean:

- bruising easily
- bleeding from your gums or nose
- bleeding from wounds, which is hard to stop
- black, tarry poos or poos that are streaked with red, because of bleeding in your gut
- headaches, difficulty speaking or difficulty moving parts of the body, because of bleeding into the brain.

Infections

This is caused by a low number of white blood cells
A low white blood cell count can lead to infections and fevers that last for longer or happen more often than normal.

Weight loss

This is caused by a high metabolism, which is the rate you burn energy from food. We don't completely understand why the metabolism speeds up in people with ALL.

Other symptoms

You or your doctor may also notice that your lymph nodes (glands) are larger than normal. You may notice these in your neck but they could be in several places around your body, such as your armpit or groin. Your doctor may also feel a swollen liver or spleen (the organ that sits under your ribs and filters your blood) when they examine your stomach area (abdomen). In T-cell ALL, swollen lymph nodes in the chest might show up on an X-ray.

It's important to remember that many of the symptoms seen in ALL can also happen in people who have common conditions which are less serious.

Because leukaemia is rare but the symptoms are common in other diseases, it sometimes takes a week or two to diagnose. But if your doctors suspect leukaemia, they'll act quickly to make sure you get the tests and treatment you need.

**It's important to know
and understand your
diagnosis. You could keep
a record of it on the inside
back cover of this booklet,
so you have it to hand.**

If you're worried, get in touch on **0808 2080 888**
or email **support@bloodcancer.org.uk**

Diagnosis

Your healthcare team will order laboratory tests to confirm whether you have ALL, and what type of ALL you have. They start by looking at the bigger picture, and then focus in on your exact diagnosis.

Tests to diagnose ALL

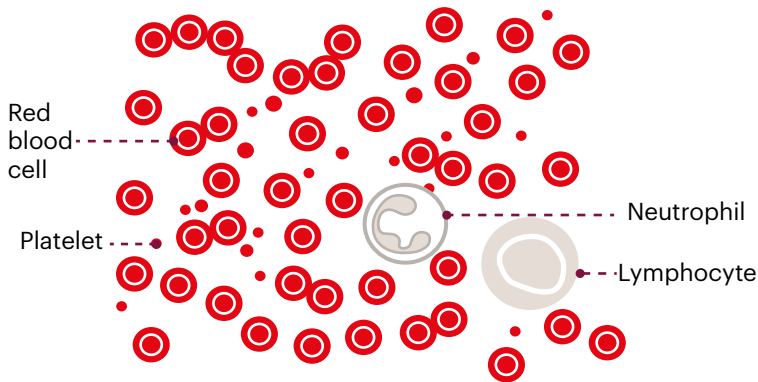
It can be hard to understand how doctors know you have leukaemia, when there's nothing like a lump you can see, as you might get with other cancers. Your doctors diagnose leukaemia by looking at your blood, your bone marrow and your genes. They will need the results of a number of tests to confirm a diagnosis of ALL.

Full blood count (FBC)

This measures the number of each type of cell in your blood: red blood cells, white blood cells and platelets. Your GP may send you for this test because you're unwell and they don't understand why, or you might have one as part of a routine check-up.

You'll have a blood sample taken, then, in the laboratory, automated machines very accurately count your blood cells. If the count is too high or too low, a small drop of your blood is smeared onto a slide and the doctor or a senior scientist will look at it under the microscope.

Normal blood film



Abnormal blood film



If your FBC shows that you may have ALL, you'll need to go to hospital for more tests. If you're diagnosed with ALL, you'll have regular FBCs to monitor your condition during and after treatment.

Bone marrow biopsy

Your doctors will probably want to take a bone marrow sample, or biopsy. This is the most accurate way of diagnosing the type and level of leukaemia you have. Sometimes it's not possible to make a diagnosis from a blood sample alone, because there may be leukaemia cells in your bone marrow which aren't circulating in your blood yet. A bone marrow test is also useful at this point because it can be used to compare your blood cells after treatment to see how well the treatment has worked.

You'll lie on your side and a small needle will be used to give some local anaesthetic (which only numbs a particular area of the body) – this needle goes into the skin around the back of your hip bone. A larger needle (an aspirate) is then inserted into the hip bone, and a small amount of bone marrow is taken. This procedure is called a bone marrow aspirate. A piece of bone may also be taken using a different needle, and this is called a bone marrow trephine.

Taking the sample is usually quite quick, but it may feel painful while it's being done. People are usually offered a tablet to make them feel sleepy (a sedative) if they want it. Or you may be offered gas and air (as used during childbirth) to help with the pain. You'll be advised not to take ibuprofen-based painkillers (such as Nurofen) during this time, as they can cause bleeding which can be especially dangerous if you have a low platelet count.

Your doctors will then look at your bone marrow sample under a microscope.

A bone marrow biopsy gives your doctors more information about:

- the structure of your bone marrow
- the types of blood cell in your bone marrow
- the number of blood cells in your bone marrow (too many or too few).

The results can also tell them if the blood cells in your bone marrow are cancerous.

Cytogenetics

Genes are short sections of a chemical called DNA that are found in structures called chromosomes in the cells of your body. Each gene is part of a set of instructions that tells your cells how to behave.

People with any kind of cancer, including blood cancer, will have changes in the genes of cells affected by the cancer. These changes aren't the type to be passed on through families. They are only found in the affected cells, such as leukaemia cells.

The study of these gene changes is called cytogenetics or molecular genetics. Cytogenetic tests are usually done on cells from your blood or from your bone marrow, before you start any treatment.

Information about these gene changes is very important. It's these cytogenetic tests that will tell your healthcare team what type of ALL you have (B-cell, T-cell, Philadelphia positive or negative), and therefore what your treatment is likely to be.

Flow cytometry (immunophenotyping)

Flow cytometry, or immunophenotype analysis, looks at the pattern of proteins on the surface of leukaemia cells. This can confirm a diagnosis of ALL, and tell your doctor exactly which type of ALL you have.

Samples of your bone marrow or blood are combined with some antibodies (proteins that fight infections in your body). As these antibodies stick to the leukaemia cells but not to normal cells, the antibodies 'tag' the leukaemia cells. The sample is then passed through a machine which is able to record the number and type of leukaemia cells.

Other tests

Depending on how well you are after you're diagnosed, your healthcare team may want to do more tests. These tests aren't routine and some aren't necessarily done at diagnosis, so don't worry if your healthcare team doesn't suggest you have them. One test your healthcare team may recommend at this stage is a lumbar puncture.



For more information about different types of ALL, see **pages 21–23**.

Lumbar puncture

Leukaemia cells can get into the fluid that cushions your brain and spinal cord. This fluid is called the cerebrospinal fluid, or CSF. A lumbar puncture is a test to see if there are leukaemia cells in your CSF. To treat this or prevent it happening, the procedure may also involve anti-cancer drugs (chemotherapy) being introduced to your CSF.

The doctor inserts a thin needle into your spine, to collect a sample of the fluid. You'll have a local anaesthetic to numb the area first. After fluid has been collected, drugs used to treat ALL may be injected through the needle. These drugs are safe to give in this way. Your doctor will tell you if you need this treatment.

It's likely that you won't have a sedative to make you feel sleepy during lumbar punctures, as it's useful for patients to be awake to report any symptoms.

Often, you won't need a lumbar puncture when you're first diagnosed, but you'll generally need several during the course of your treatment.

Imaging (scans)

X-ray

X-rays provide very good images of the denser tissues in the body, such as bone. You may have an X-ray when you're first diagnosed, to check for infection or any other chest problems.

Computerised tomography (CT or CAT) scan

A CT scan is a type of X-ray. You'll lie on a table that moves into a doughnut-shaped machine while the pictures are taken. You may need to have a dye injected into one of your veins, to help get a better image. This is not a routine test during the diagnosis and treatment of ALL but there may be specific reasons it needs to be done, such as if you have a swollen liver or spleen when you are diagnosed.

Magnetic resonance imaging (MRI) scan

Another type of scan is an MRI scan. This scan shows up soft tissues (non-bony parts) and uses radio waves rather than X-rays. You'll be asked to lie on a table, which will move you through the scanner. You may need to have an injection of some dye.

An MRI scan is not a routine test during diagnosis and treatment of ALL, but there may be specific reasons for having one. For example, it may be done



to check if there are signs of ALL in the brain or the fluid around the brain.

Positron emission tomography (PET) scan

A PET scan is similar to an MRI scan, but you're injected with a radioactive sugar. The levels of radiation used are very small and won't harm you, but you may be told to stay away from pregnant women, babies and young children for a few hours after your scan. It's rare to have this test, but it may be done if doctors suspect there are leukaemia cells in your lymph nodes (glands), liver or spleen.

Blood tests

Liver function tests

This is a blood test to check if your liver is working normally. It's very important if you need chemotherapy, as many drugs are broken down in the liver. If your liver isn't working normally, it might be necessary to adjust your doses.

Urea and electrolytes test

This is a blood test to check how well your kidneys are working. The results will help your doctors work out the doses of drugs you need. It'll also show if you're lacking fluids (dehydrated), and show any damage that may have been caused either by the cancer or your treatment. You'll usually have your kidneys checked every time you have an appointment at the hospital.

Infection screening

When you're diagnosed with ALL, you'll also have a general health check-up. This will help work out if you'll be particularly vulnerable to side effects from treatment. You'll have a range of tests to check your heart, liver and kidneys. It's also routine to be tested for HIV, hepatitis B and hepatitis C, so that if you have these conditions without knowing, they can be treated at the same time as the ALL.

Tissue typing

Tissue typing is a blood test that's routinely done when someone's diagnosed with ALL. It checks your white blood cells for proteins called HLA markers. If you need a stem cell transplant using cells from another person (a donor) as part of your treatment, this information is used to make sure the donor's stem cells are a close match to your own, which lowers the risk of problems following the transplant.

Your healthcare team

If you're diagnosed with ALL, your hospital will give you the names and contact details of your specialist doctor (consultant), clinical nurse specialist (CNS) and other members of your healthcare team. There's space to write them at the back of this booklet if you want to. You can then use these details to contact your team if you have any questions you want to ask when you're not at the hospital.

Your specialist doctor (consultant)

Most people with a blood cancer are treated by a consultant haematologist – a doctor who specialises in treating patients with blood diseases. All adults diagnosed with ALL should be treated in a haematology centre, so your local hospital may refer you on to a bigger centre in the region for specialist care, particularly at the start of your treatment.

You may at times be looked after by a more junior doctor, such as a senior house officer or a registrar. These are qualified doctors who are training to be consultants. They'll be able to answer many of your questions, but if they can't then they'll ask the consultant. All doctors in training are supervised closely by more senior colleagues.

Your clinical nurse specialist (CNS)

People with cancer are normally given a key worker, usually a clinical nurse specialist (CNS). They're your point of contact with the rest of your healthcare team. You may like to have a meeting with them when you're first diagnosed, to discuss your condition. Your CNS will be with you every step of the way, so do make use of their help and expertise if and when you need it.

If you have a stem cell transplant as part of your treatment, your key worker may change. This shouldn't alarm you in any way, as there will always be a proper handover.

Research nurse

It is very common for patients with leukaemia to be offered the chance to take part in the UK's national clinical trials. Your doctors and the research nurses who work on the trials will give you information about this. If you decide to take part, the research nurses will be heavily involved in your care.

Your multidisciplinary team (MDT)

Your condition should be discussed at regular MDT meetings. An MDT brings together doctors, nurses and other specialist staff who will be looking after you, as well as the laboratory staff who help to make the diagnosis. They'll discuss the best treatment for you and every aspect of your care, including any changes in your condition.

If you have questions about your care

If you're unhappy with any aspect of your care, speak to someone in your healthcare team. Or, ask your hospital or treatment centre who is best to speak to outside of the team.

Sometimes, asking your doctor or another member of the team to explain your diagnosis again can clear up any concerns you may have.

You can also ask for a second opinion from another doctor at any stage – before, during or after treatment.

There are services that provide support and information for people who have concerns about their healthcare. In England this is the Patient Advice and Liaison Service (PALS), in Scotland it's the Patient Advice and Support Service (PASS), and in Wales it's the Community Health Councils (CHCs). In Northern Ireland, you need to ask your hospital for a copy of their complaints procedure.

Talking to other people with blood cancer

You might want to ask your CNS if you can talk to someone who's had the same diagnosis and treatment as you. If you do this, remember that someone else's experience won't always be the same as yours. For example, some people will experience side effects from a drug and others won't.

You may also want to contact a support organisation – many provide patient meetings or further online support – see pages 93–98.

Your other healthcare professionals

It's definitely worth telling other healthcare professionals you see (like your dentist or optician) about your diagnosis and any medication you're taking. They may need to check with your specialist or GP before giving you some types of treatment.



You can talk to other people with blood cancer or read their experiences on our online community forum:
forum.bloodcancer.org.uk

There's a list of questions you may want to ask your healthcare team on **pages 100–104**.

Finding out more

After you've been diagnosed, it's worth taking time to think about what information you want to know, when and how. For some people, this is a way to have some control over what's happening.

- Let your consultant and CNS know how much information you'd like, and in what form. You can always ask for more information later.
- Write down any questions you have and keep them handy for when you see your consultant or CNS. If they can't answer your questions, they'll be able to tell you who to speak to.
- You might prefer to ask your CNS questions rather than your consultant, but do whatever works for you.
- Most people say they find it useful taking someone with them to appointments. If you think you'd find it helpful, you could ask them to take notes while you listen. You can choose who to take – it doesn't have to be a family member.
- If you're staying in hospital it might be harder to have someone with you when you speak to your consultant. It might be useful to ask in advance what time the consultant is likely to see you, so you can try to arrange for someone to be with you at that time.

- Some people find that joining a patient support group is helpful. It may be easier to talk to someone outside of your family about your situation. Being able to share similar experiences might also help you.

Telling people

Many people tell us that keeping in touch with loved ones throughout their illness keeps them going. However, some people may find it stressful having to discuss their condition lots of times with family, friends and colleagues.

You might find it easier to ask a trusted family member or friend to be your 'information person' and ask them to keep people updated on your behalf. Another idea is setting up a blog or Facebook page, so you or other people can post information on it that everyone can read. You might not want to tell many people – or anyone at all – about your condition. This is ok too, whatever works for you.

Talking to children and teenagers

Talking to children and teenagers about your condition can be a difficult thing to do. There are organisations to support you and offer advice about how to explain cancer to children of different ages.

Telling your GP

Your team at the hospital will keep your GP informed about your condition and any treatment you're having. They'll usually send your GP a letter with this information. As the patient, you'll often be sent a copy too. These letters can have a lot of medical terms in them which you might not have heard before, or there might be something in one which worries you. If this is the case, let your hospital or GP know – a quick chat with them might help to reassure you.

Cancer and work

Consider telling someone at work about your diagnosis. It can be hard asking for time off at short notice if no one knows about your illness, and your colleagues and HR department might be able to offer support.



We have more information about money and work when you have blood cancer on our website:

[bloodcancer.org.uk/living-well](https://www.bloodcancer.org.uk/living-well)

Macmillan Cancer Support has information on talking to children about cancer. Go to **[macmillan.org.uk](https://www.macmillan.org.uk)** then search for 'talking to children and teenagers'.

**Your treatment will
depend on your individual
condition, your general
health and your wishes.**

If you're worried, get in touch on **0808 2080 888**
or email **support@bloodcancer.org.uk**

Treatment

Throughout your treatment, your healthcare team will always discuss your treatment options with you. They'll want to hear what you think, answer your questions, and explain anything you're unsure about.

Treatment planning

It's very important to start treatment soon after you've been diagnosed, because ALL can develop quickly. It may feel like things are happening too fast to keep up with the change to your life, but many people find that starting treatment straight away is reassuring.

Some people find it hard to fully understand the details of their treatment when they're trying to cope with the stress of being diagnosed with leukaemia. There isn't a single 'best' way to deal with this situation or a right way to feel. Don't be afraid to ask as many questions as you need to.

Your doctor will recommend a treatment plan and talk to you about what it will involve. Treatment plans are tailored to each individual, so if you meet someone else with ALL, they might be having different treatments. Some treatment programmes (also called protocols) are very intensive (concentrated), while others are less intensive. What's right for you depends on your age, general health and the type of ALL you have.

ALL becomes more difficult to cure as people get older. We don't know the reason for this – it could be that the disease itself is different in older people, or it could be because it's harder for older people to cope with intensive treatment.

Treatment decisions are never based on age alone, but on general health and fitness. Your wishes are always taken into account.



There's more information about treatment planning and making treatment decisions on our website:

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

Your treatment plan may need to change at any point. If this happens, your healthcare team will explain why, and talk to you about the different options available to you.

Most people in the UK who are diagnosed with ALL are invited to join a clinical trial.

Steroids

Most people will begin steroid treatment while their treatment plan is being confirmed. The steroids will start working to get rid of the leukaemia cells.

Types of treatment

The best treatment for you will depend on your individual situation. Generally, treatment for ALL can be divided into:

- Active treatment, which aims to get rid of the leukaemia cells and help your bone marrow work normally again.
- Supportive care, which helps you feel better and supports your body through some of the problems caused by ALL and its treatment.

Everyone will receive supportive care, whether they have intensive or less intensive treatment. Some people may choose not to have any active treatment, or the doctors might not recommend it as the best option.

If this is the case for you, an approach called palliative care will help control the symptoms of ALL, and improve your quality of life. The palliative care team will be able to support both you and your family.

Clinical trials

All new drugs and treatments are thoroughly tested before they're made available. After tests in a laboratory, they're tested on people. Research studies which involve testing new drugs and treatments on people are called clinical trials.

Clinical trials are done for several reasons, including to look for new treatment options and to improve existing treatments. Taking part in a clinical trial has many advantages, such as the opportunity to have a new test or treatment which may not be given outside of the trial.

Your safety and wellbeing are always the first priority when taking part in a clinical trial. You'll be very closely monitored and have detailed follow-up. You can choose to withdraw at any time.

The UK has a proud history of conducting clinical trials in ALL, which have contributed significantly to developing and improving treatments for patients with the disease. It's highly likely that you will be approached by your healthcare team to consider taking part in one of the ongoing major national

trials. The trial you're offered will depend on your age and general level of fitness, for example, younger adults are likely to be offered the chance to enter the trial designed for children and young people aged up to 24 years old. Specific information about suitable trials will be given to you at the time.

If you're not given information about one of the national trials and you think you would be interested, speak to your healthcare team.

Taking part in a clinical trial does come with uncertainties and risks, and there's no guarantee the new treatment will be better than the best current treatment. If you don't want to be in a trial, or there isn't a suitable trial available, you'll be offered the best treatment available which is appropriate for your individual condition.

Treatment stages

Chemotherapy is the main active treatment for ALL. You'll be offered a combination of chemotherapy drugs as set down in your treatment plan (your healthcare team may call this a protocol or regimen).

Your treatment will be divided into three phases, or 'blocks'. This section gives an overview of the different phases of treatment.

Your healthcare team will explain to you in detail which drugs you'll have and when during each phase. They may be able to give you a chart with this information on too.

Remission induction

The aim of this first phase of treatment is to get you into remission (also called complete remission or CR), where there's no sign of leukaemia.

This involves using several chemotherapy drugs in combination. The goal is to clear the leukaemia cells completely from your blood and bone marrow. This works for about nine out of ten people.

The length of this treatment stage depends on your individual situation, but usually lasts between four weeks and two months.

Because there's a risk of infection or bleeding, you're likely to spend all, or most, of this stage in hospital, with your healthcare team close by.

Remission induction for Philadelphia positive ALL

If you have this type of ALL, your treatment will be different. Doctors use drugs called tyrosine kinase inhibitors (or TKIs) to treat it. These drugs target the abnormal protein (tyrosine kinase) produced by the leukaemia cells. When used alongside standard chemotherapy, TKIs can significantly increase

the chance of a cure for people with Philadelphia positive ALL.

The TKI that most people with Philadelphia positive ALL will be given is called imatinib.

Intrathecal chemotherapy

Around this time, you may also have what's called intrathecal chemotherapy to give extra protection to your brain and spinal cord. Chemotherapy drugs will be injected into the cerebrospinal fluid (CSF) that surrounds your spine to try and prevent leukaemia cells from entering the fluid. This procedure is the same as a lumbar puncture. After some CSF has been removed from your spine using a needle, the chemotherapy drugs are carefully introduced.

Testing for remission

When your initial chemotherapy is finished, doctors will look at samples of your blood and bone marrow under a microscope. If they can't see any leukaemia cells, this means you're in remission (CR).

Minimal residual disease tests

You may also have a minimal residual disease test (MRD) to check how complete your remission is.



For more information about Philadelphia positive ALL, see **pages 21–23**.

When your doctors look at blood cells through a microscope, the lowest level of leukemia they can detect is if around one in every 20 cells is a leukaemia cell. The MRD test is much more sensitive and can detect leukaemia cells at levels as low as one leukaemia cell in 100,000 cells. This gives your healthcare team more accurate information which can help with planning the next phase of treatment.

Consolidation

This phase is sometimes called post-induction or post-remission therapy.

It's usual for some leukaemia cells to remain after your initial chemotherapy, even if doctors can't see any under the microscope. So when the remission induction phase is finished, you'll have more chemotherapy to clear any leukaemia cells that might remain in your blood and bone marrow.

This stage usually lasts for several months. It involves several rounds (known as blocks) of intensive therapy, which are similar to the treatment you get at the remission induction stage.

You might be able to have some of this treatment as an outpatient, which means you won't always have to stay in hospital overnight. But you should be prepared to spend quite a bit of time in hospital.

Stem cell transplant

Some people may be offered a stem cell transplant (also called a bone marrow transplant) during this stage of treatment.

Transplants can make you feel very unwell and can cause complications, so doctors look at a number of things before offering you a transplant, including your age and general health, and how well the first phase of your treatment worked.

A transplant aims to give you healthy stem cells, which then produce normal blood cells.

There are two types of stem cell transplant:

- allogeneic or allograft – this uses stem cells from another person (a donor)
- autologous or autograft – this uses your own stem cells but is rarely used for ALL.

If you have a stem cell transplant, you will not need the next phase of treatment (maintenance), but will have careful follow-up once you have left hospital.



For more information on lumbar punctures, see **page 39**.

We also have another booklet, **Blood stem cell and bone marrow transplants: the seven steps** – see **page 112**.

Maintenance

Maintenance therapy aims to prevent relapse (the cancer coming back) and usually involves low doses of chemotherapy and steroids. The maintenance phase is really important because without it, there's a higher chance that the ALL could come back, even if you seem to be in full remission. We don't know why this happens, but we do know that having maintenance therapy gives much better results in the long term.

This stage usually takes about two years.

Unless you get an infection or have a relapse, you shouldn't need to stay in hospital and most people on maintenance therapy can start getting back to normal, including going back to work or college. You will still be at risk of infection at this time, so if you have any symptoms of infection, tell your healthcare team straight away so they can give you the treatment you need.

Although you may feel relieved that the more intensive stages of your treatment are over, you may also feel concerned about seeing your healthcare team less often. If you are worried, talk to your CNS.



See **page 69** for a list of symptoms to watch out for that may be a sign of infection.

Your CNS can refer you for counselling if you would like more support.

Treatment of relapsed ALL

As many as nine out of ten adults with ALL will go into remission (although this doesn't necessarily mean that they're cured).

Unfortunately, some people relapse (the ALL comes back). Relapse happens because some leukaemia cells remain, often because they've become resistant to the drugs people are being treated with. If you do relapse you may be offered the opportunity to go on another clinical trial looking at new treatments for relapsed ALL.

Usually, the first step in treating relapsed ALL is to repeat the remission induction programme. This treatment might need to be more intense than the first time around. In trials, a second go at remission induction using chemotherapy has worked for around four out of ten people (40%).

There are two new drugs called blinatumomab and inotuzumab which have recently become available on the NHS for relapsed ALL. These drugs are known as monoclonal antibodies – they work by attaching themselves to the leukaemia cells, so your immune system can find these cells and kill them. They have shown promising results in clinical trials, and tend to have fewer unpleasant side effects.

If your treatment is successful this time round and you go into remission (CR), your healthcare team may recommend a stem cell transplant.

Some people may decide not to have active treatment any more. Instead they can ask for palliative care, which focuses on relieving their cancer symptoms and improving their quality of life.

Treatment for relapsed Philadelphia positive ALL

If you have Philadelphia positive ALL and you relapse after chemotherapy with imatinib (or it doesn't put you in remission in the first place), your healthcare team may offer you more chemotherapy with a different TKI (tyrosine kinase inhibitor). Dasatinib is a TKI that can be used for people who have relapsed or not responded to treatment including imatinib. Ponatinib is another option that doctors can recommend.

CAR-T cell therapy

There is a new treatment called CAR-T therapy, which is available for some adults with relapsed ALL. T cells (a particular type of white blood cell) are removed from the body and altered in a lab to make them more effective at killing leukaemia cells. They are then put back into the body. In clinical trials, CAR-T therapy has been very successful, and could offer people with hard-to-treat ALL another treatment option.

How chemotherapy is given

Most chemotherapy for ALL will be injected into the bloodstream through a vein (known as intravenous infusion).

Drugs will usually be given directly into a tube, known as a central line, which is inserted into a large blood vessel. This line is kept in over the whole period that you have treatment, so there's no need for repeated injections.

There are different types of central line. These include:

- a PICC line or Peripherally Inserted Central Catheter – a central line that's put into your arm (the most commonly used central line)
- a Hickman® line – a central line that can be put under the skin in your chest.



For more information on stem cell transplants see **page 59**.

To find out more about CAR-T therapy, visit **bloodcancer.org.uk/what-is-car-t-therapy**

Supportive care

At the same time as you're having active treatment for your illness, you will also be offered supportive care (which is different from palliative care).

Supportive care involves help with preventing infections, blood transfusions, mouth care, dietary advice, pain management and dealing with complications you may get from the ALL and its treatment.

Here are some examples of supportive care you might be offered while you have active treatment:

Drugs to protect your kidneys

When leukaemia cells are destroyed, they release a chemical called uric acid, which can damage the kidneys. Drugs called allopurinol and rasburicase can help. It's also important to drink plenty of fluids to reduce the risk of kidney problems.

Platelet transfusion

At the start of active treatment, the main side effect is that you produce fewer blood cells. This is known as bone marrow suppression. This can result in a low platelet count, which can lead to heavy bleeding. A platelet transfusion can help to protect you against this.

Red blood cell transfusions

Another result of bone marrow suppression is low levels of a protein called haemoglobin, which can cause anaemia. This can make you feel tired and out of breath, but regular blood transfusions can help.

Preventing infections

Because ALL and its treatment reduce your white blood cell count, you'll be more vulnerable to infections. So your healthcare team will take care to protect you from infection at all times. They will give you an antibiotic to lower your risk of getting pneumonia (a serious chest infection), and a drug called acyclovir to stop you getting shingles, a virus that affects the skin around a nerve.

You may also be offered a treatment called a growth factor (commonly known as G-CSF). This stimulates your bone marrow to make more white blood cells called neutrophils, and helps you to recover from the effects of treatment.



For more information about shingles see **pages 84–85**.

We also have fact sheets on **Blood transfusions** and **Understanding infection** – see **pages 113**.

Fertility

Before your treatment starts, you should talk to your healthcare team about how it might affect your ability to have children, if that's relevant and important to you.

Active treatment can affect your fertility. Because treatment for ALL has to start so quickly, there usually isn't time to preserve a woman's eggs. Men sometimes have a chance to freeze their sperm for the future.

If you do go on to have children, studies have shown that the treatment you've had won't affect their health. Similarly, the likelihood of your child getting ALL would be no greater than for any other child. Your healthcare team will be able to discuss your options with you, and refer you to a fertility department, if appropriate.

Side effects

There are some potential side effects from treatment for ALL.

Different people have different responses to their treatment. Even if two people are having the same treatment, they may have a different experience. So you might not get all of these side effects – try to bear this in mind when you read about them. You may also like to talk to your healthcare team about possible side effects.

Short term side effects from chemotherapy

You may experience some short-term side effects from chemotherapy treatment. They could include:

- an achy flu-like feeling
- difficulty pooing (constipation)
- frequent watery poos (diarrhoea)
- bruising and bleeding
- extreme tiredness (fatigue)
- hair loss
- infections
- rashes
- a sore mouth or mouth ulcers (mucositis)
- feeling and being sick (nausea and vomiting)
- headache (this can also happen after a lumbar puncture)
- leg or chest pain, redness or swelling or breathlessness caused by blood clots

- damage to the nerves which causes a burning feeling or pins and needles, or a loss of feeling, often in the hands and feet (peripheral neuropathy)
- abnormal changes in your liver – this doesn't usually result in any symptoms, but sometimes causes the build-up of a substance called bilirubin in your body, which makes your skin look yellow (jaundice).

It's important to remember that any side effects you get are only temporary. If you do have side effects, tell your healthcare team, as they may be able to help you manage them. There are medicines you can take to help with feeling sick, for instance.

Neutropenic sepsis

Chemotherapy can cause a low level of white blood cells called neutrophils, which means that your body can't fight off infections as well as it should.

This is called neutropenia, or being neutropenic.

If you are neutropenic and get an infection, then you are at risk of a serious condition called neutropenic sepsis, which can be life-threatening.

If you think you have an infection, you should contact your healthcare team straight away. Symptoms to look out for include:

- a raised temperature (usually above 38°C)
- a temperature below 36°C
- coughing or a sore throat
- confusion or agitated behaviour, especially if this comes on suddenly (this is more common in older people)
- rapidly feeling more poorly
- fast heartbeat and breathing
- difficulty weeing (passing urine) or producing little or no urine
- pain which comes on quickly and gets worse
- shivering or shaking and feeling cold.

Long-term side effects from chemotherapy

With any type of chemotherapy, there's always some risk of long-term side effects (also called late effects). These could include problems with the thyroid (a gland in your neck), heart or lungs. Some chemotherapy drugs raise the risk of developing other types of cancer later on, but this is very rare. Your ability to have a child (your fertility) may also be affected by chemotherapy.

The risk of long-term side effects will depend on how many cycles of treatment you've had, the intensity (strength) of the treatment and whether you've had a transplant or not. Every case is individual, so your healthcare team will talk to you about this in more detail.

Short-term side effects from steroids

Steroids can cause side effects such as:

- increased appetite
- mood changes and feeling irritable
- weight gain
- muscle weakness (especially in the legs).

Again, if you have any of these side effects it's worth discussing this with your healthcare team, as they may be able to help.

Follow-up

Going to your follow-up appointments is really important if you've had ALL. Your healthcare team will stay on the lookout for any signs of relapse, or complications from your treatment. The appointments can also help you adjust to everyday life again – it can feel very different once you've had ALL and your treatment has finished.

In some ways, you can think of your follow-up care as starting during the maintenance phase of your treatment. At this stage, you'll have blood checks every one or two weeks. Then it'll be more like every two or three months. Gradually, your checks will become less frequent, until you're only having them once a year.



For more information on side effects, see our fact sheets **Understanding infection, Managing sickness and vomiting,** and **Sore mouth or gut (mucositis)** – see **page 113**.

When you're in complete remission, and have moved on to maintenance treatment, your lifestyle can get back to normal in almost every way. You should be able to return to work and take up your regular activities again. You should also be able to enjoy a healthy diet and drink alcohol within sensible limits.

You won't normally need to stay in hospital any more, unless you relapse or get a severe infection. If someone you live with catches an infection, you might want to ask your healthcare team whether you need to take any special precautions.

After treatment, you can also travel and go on holiday. You might be able to have travel vaccinations (jabs), but check it's ok with your consultant first. In particular if you're taking steroids or you've had a stem cell transplant, you should never have a vaccination without talking to your consultant.

If you're having treatment from any doctor who isn't your main consultant or GP, make sure you tell them that you're having treatment for ALL, or that you've had it in the past.



When Tony first had symptoms of ALL, he thought it was just old age creeping up. By the time he was diagnosed, his blast level was almost 80%, but he responded well to treatment and is now in remission.

The treatment is hard, but it's working. Being there for my son's wedding was a big thing for me and enjoying life with my three grandchildren is a joy beyond compare.

**Every person is different,
so your consultant and
healthcare team are
the best people to ask
about your likely outlook
(prognosis).**

If you're worried, get in touch on **0808 2080 888**
or email **support@bloodcancer.org.uk**

The outlook

The outlook (prognosis) is different for each person with ALL. The best person to talk to about your individual outlook is your consultant, or someone else in your healthcare team.

There are a number of things which may affect your outlook. The main ones your healthcare team will look at are:

- your age and general health – ALL is typically easier to treat in younger people
- the type of ALL you have
- the result of your minimal residual disease (MRD) test after remission induction treatment.

If you want to find out more

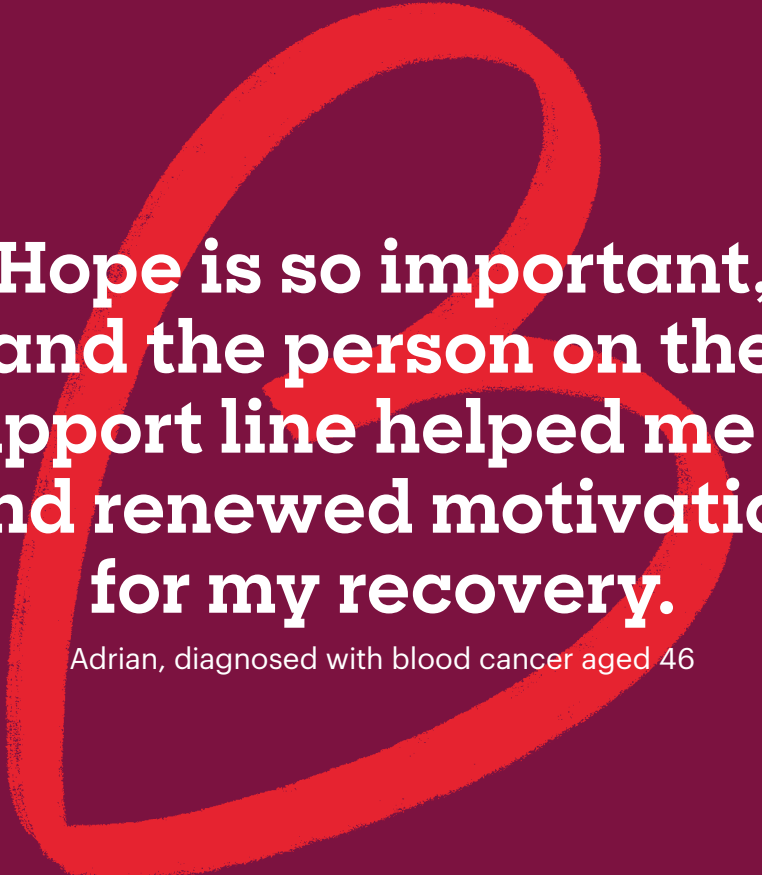
If you would like more detailed information on the general outlook for ALL, go to cancerresearchuk.org and search 'survival ALL'. Remember that statistics can only give an overall picture. Your own outlook is individual to you and will depend on your age, general health and specific condition.

Our Support Services Team can talk to you about any questions you have about outlook.

Contact us on **0808 2080 888** or
support@bloodcancer.org.uk



For information about MRD tests, see **pages 57–58**.



**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

**Your healthcare team
should look after your
emotional needs, as well
as your physical ones.**

If you're worried, get in touch on **0808 2080 888**
or email **support@bloodcancer.org.uk**

Living with ALL

If you've been diagnosed with ALL you might experience a range of emotions at different times. There can be a physical impact on your day-to-day life too.

Looking after yourself emotionally

Being told that you have cancer can be very upsetting and will almost certainly bring many different emotions. Friends and family may be able to offer support, but it may be harder for them to understand the long-term emotional impact that you might experience.

Your healthcare team should discuss your emotional, spiritual, social, practical and physical needs with you and talk about how they can be met. This is called a holistic needs assessment. You should have one a few times throughout the course of your treatment and beyond, as your needs might change.

Looking after yourself physically

Changes in your condition

You might need to live with symptoms for a long time, but your healthcare team will be able to give you advice on how to cope with them.

When you've finished your treatment it's important to contact your healthcare team at the hospital straight away if you notice any new symptoms. Don't wait for your next check-up.



You can talk to other people living with blood cancer or read their experiences at **forum.bloodcancer.org.uk**

We have more information and tips about coping with emotions and keeping active on our website at **bloodcancer.org.uk/living-well**

Symptoms to watch out for include:

- swollen glands
- bleeding/bruising
- frequent infections
- a constantly sore mouth
- an unexplained temperature (fever)
- fatigue (extreme tiredness) that gets worse
- night sweats.

Keeping active

You might feel tired a lot (fatigued). This might be caused by the ALL or its treatment and isn't the same as normal tiredness which improves with rest and sleep.

While even the idea of doing something can be tiring if you've got fatigue, try to keep as active as you can because evidence shows that this could help to reduce the symptoms of fatigue.

Although there's no evidence that any particular exercise programme can improve your condition or how you respond to treatment, we do know that staying active is good for your general physical wellbeing and your mood.

Eating well

There's no evidence that any special diet will improve your condition or how well your treatment works.

Chemotherapy can make you lose your sense of taste and your mouth may be sore. In time, this will go back to normal, but you may find you don't enjoy food you previously liked and might even enjoy food you didn't like before. You may not have much appetite and might not feel like eating full meals. So it's important to make sure there are plenty of snacks around that you like. You could also try eating small meals more often throughout the day.

While you're having treatment, don't worry too much about trying to eat healthily, even if that's what you normally do. The important thing is to get as much energy as possible, and that means eating whatever you feel like eating.

You will need to take care to avoid infections that you might get from food, because your immune system may not be working as normal. This means that your body won't be able to destroy germs and fight off infection as easily, so follow basic food hygiene rules like paying attention to use-by dates and keeping raw meat separate from ready-to-eat foods in the fridge. You may also be advised to be careful about takeaway food and eating out while you're having treatment.

A diet for people with a weakened immune system is known as a neutropenic diet. Your healthcare team will advise you on any changes you need to make to your diet to help you avoid infections.

If you notice any changes in your appetite or reactions to certain foods following treatment, tell your healthcare team so they can advise you.

Other infection risks

If you're having chemotherapy, speak to your healthcare team about whether it's ok for you to do gardening and housework. Some gardening jobs such as raking leaves or cutting down dead bushes can put you at risk of fungal infection. You should also avoid touching fresh cut flowers, changing the water in vases and changing cat litter, because these activities could also bring you into contact with germs.



There's more information and practical tips about eating well on our website at [bloodcancer.org.uk/living-well](https://www.bloodcancer.org.uk/living-well)

Our booklet **Eating well with neutropenia** has advice on how to avoid infections from food – see **page 112**.

Shingles

Shingles is the infection of a nerve and the skin around it. It's caused by the same virus that causes chickenpox. It can only affect you if you've had chickenpox in the past – even if you had it a long time ago – as the virus can lie dormant (stay inactive) in your body for years.

You're more likely to get shingles if your immune system isn't working well, for example, if you have ALL. That's why all patients being treated for leukaemia are given a drug called acyclovir, which can prevent shingles. It's important not to stop taking acyclovir until your healthcare team tell you your immune system has recovered from the effects of chemotherapy.

Shingles has some quite obvious symptoms. If you think you have it, let your GP or consultant know as quickly as possible (within 24 hours of the rash appearing is best). If it's treated early, the symptoms won't be as bad. Symptoms include:

- a rash (with blisters filled with fluid which burst, form sores and then crust over), usually on one side of the body
- pain where the rash is
- an itching, tingling or burning feeling.

You can't catch shingles from someone who has it, but you can catch chickenpox from someone with an open shingles sore, if you haven't had chickenpox already.

Try to avoid direct physical contact with people who have shingles or chickenpox. If you do have contact, please let your healthcare team know right away.

Vaccination

It's a good idea for everyone with ALL to have the flu vaccine each year. Your GP might contact you about this, but if they don't then you can request the vaccine yourself. It might not work as well for people with ALL but will still offer some protection. It's also sensible for the people you live with to be vaccinated against flu.

If you have ALL, avoid having any live vaccines while you're having active treatment. Fortunately only a few vaccines used in the UK are live. The most commonly used ones are MMR (measles, mumps and rubella) and shingles. The yellow fever vaccine, occasionally needed for travel to certain areas, is also a live vaccine.

Smoking

If you smoke, it's best to give up. Smoking is especially harmful to those who've previously had chemotherapy and it increases your risk of developing a new, second cancer or lung problems in the future.

Of course, when you're stressed it's even more difficult than usual to stop smoking. Talk to your healthcare team as they can prescribe nicotine patches if you decide to give up.

Sex and pregnancy

If you're a woman having chemotherapy, it's essential to avoid becoming pregnant while you're having treatment. Once you're in remission, talk to your doctor if you are planning to have a child.

People who are having chemotherapy should use condoms (and continue to do so for a week after their treatment has finished) because chemotherapy drugs can be present in all bodily fluids. We also do not fully understand what effect chemotherapy may have on sperm.

Complementary therapies

Complementary therapies are treatments like massage, meditation or acupuncture that are used alongside standard medical treatments with the aim of making you feel better.

There's no evidence to suggest that these therapies can treat or cure blood cancer, but there's some that suggests some of them may help you manage your symptoms or the side effects of your treatment. Other therapies may just help you relax or improve your general sense of wellbeing.

Alternative therapies

There's an important difference between complementary therapies, which are used alongside standard medical treatments (like chemotherapy and radiotherapy), and alternative therapies, which are offered instead of these treatments. We don't recommend that you use any alternative therapy in place of proven medical care, but you may be interested in using complementary therapies alongside your treatment.

Keeping yourself safe

If you're thinking about using complementary therapies, you should let your healthcare team know, so you can discuss what's safe for you. They may advise you to avoid certain therapies because of specific risks to do with your condition or the treatments you're receiving. In other cases, they may say a therapy is ok as long as you take specific precautions, like visiting a complementary therapist who's a member of the relevant professional association or register. Your healthcare team can explain how to check this.

Some hospitals will have a complementary therapies team that offers sessions free of charge, while others might have a specialist who visits once or twice a week. Sometimes these therapies are there for your partner or close relatives, too. Your healthcare team will be able to tell you what's on offer.

If your hospital doesn't offer complementary therapies, there may be a local cancer centre or charity that you could visit instead. Speak to your healthcare team to see if they can recommend anywhere nearby. Some people choose to see an independent complementary therapist. If you do this, it's important to make sure they will keep you safe. Speak to your healthcare team about what you need to keep in mind when finding a therapist.

Practical support

Your work, education and home arrangements

If you work or are studying you might want to contact your employer or college, or ask someone to do it for you.

You might need to make a short-term arrangement with your employer or college when you're first diagnosed, so you can have time off when you need to be at the hospital. When you have to stay in hospital for the first phase of your treatment,

or if you're not well enough to go to work or college, you'll probably need to make a more formal agreement.

You might also need to make arrangements about your home life. It would be good to have a family member, friend or someone else look into sick pay and other benefits you might be entitled to, and make sure your bills get paid while you're being treated.

You may need to show written proof of your diagnosis from your healthcare team, which makes clear the effect ALL could have on your ability to work or study.

If you're a parent or a carer, you may need support throughout your treatment. You might have unplanned stays in hospital because of infection, for example. It's helpful to have plans in place just in case.



We have more information and practical tips about dealing with work when you have blood cancer at **[bloodcancer.org.uk/living-well](https://www.bloodcancer.org.uk/living-well)**.

Cancer and the law

People with a disability are protected by the Equality Act 2010 in England, Scotland and Wales, and the Disability Discrimination Act 1995 in Northern Ireland. For the purposes of these Acts, cancer is considered a disability. This means that employers and places of study are required by law to make reasonable adjustments for people with cancer and can't discriminate against them. An example of a reasonable adjustment would be allowing you time off to go to hospital for treatment.

Getting to hospital

If you're being treated as an outpatient (not staying overnight) you might need to be at the hospital a lot over a long period of time. If you find this hard because of transport or any other reason, you can ask your consultant if you can have any of your treatment nearer to where you live. It might not always be possible but sometimes it is – it depends on the healthcare facilities close to your home and the type of treatment you're having.

If this isn't possible and transport is a problem, you can ask about hospital transport. You might also be able to apply for support with travel costs. If you'd like to find out more about this support, you can speak to your team at the hospital or a benefits advisor.

Financial support

There are lots of places you can get help and advice if you are worried about money.

Your hospital will normally have social workers or welfare rights (benefits) advisors who can advise on which benefits you might be able to receive. This might be especially useful if you're on a low income or are unemployed. If you're worried, ask to speak to an advisor as soon as possible after your diagnosis. Alternatively, your hospital may be able to arrange for an advisor from somewhere else to visit you.

If you normally pay for your prescriptions but are being treated for cancer (including the effects of cancer or its treatment) you can apply for a medical exemption certificate for any drugs you need to support your care. Application forms are available from your GP surgery or hospital clinic.



We have more information and tips on dealing with the financial impact of cancer on our website at **[bloodcancer.org.uk/living-well](https://www.bloodcancer.org.uk/living-well)**

Blood Cancer UK offers information and support to anyone affected by blood cancer. You'll find other useful organisations listed here as well.

If you're worried, get in touch on **0808 2080 888** or email **support@bloodcancer.org.uk**

Places you can get help and support

Blood Cancer UK

We are here for anyone affected by blood cancer, whether it's you who's been diagnosed or someone you know.

We offer free and confidential support by phone or email. We provide information about blood cancer and life after a diagnosis. And we 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

General information and support

Macmillan Cancer Support

Offers practical, medical, financial and emotional support.

- 0808 808 0000
- macmillan.org.uk

Cancer Research UK

Offers information about different conditions, current research and practical support.

- 0808 800 4040
- cancerresearchuk.org

Leukaemia Care

Offers patient information, a support line and support groups for people affected by leukaemia, lymphoma, myeloma and other blood disorders.

- 08088 010 444
- support@leukaemiacare.org.uk
- leukaemiacare.org.uk

African Caribbean Leukaemia Trust (ACLT)

Aims to increase the number of black, mixed race and ethnic minority people on UK stem cell registries by raising awareness and running donor recruitment drives.

- 020 3757 7700
- info@aclt.org
- aclt.org

Anthony Nolan

Runs the UK's largest stem cell register, matching donors to people with leukaemia and other blood-related disorders who need a stem cell transplant.

- 0303 303 0303
- anthohnolan.org

Maggie's

Has centres across the UK, run by specialist staff who provide information, benefits advice and psychological support.

- 0300 123 1801
- enquiries@maggies.org
- maggies.org

Marie Curie

Runs nine hospices throughout the UK and offers end-of-life support to patients in their own homes, free of charge.

- 0800 090 2309
- mariecurie.org.uk

Cancer on Board

Supplies 'cancer on board' badges to people with cancer, to help with public transport journeys.

- canceronboard.org

Shine Cancer Support

Provides support to adults in their 20s, 30s and 40s who have experience of a cancer diagnosis.

- shinecancersupport.org
- hi@shinecancersupport.org

MedicAlert

Offers personalised jewellery which provides vital medical information to emergency professionals.

- 01908 951045
- info@medicalert.org.uk
- medicalert.org.uk

Tenovus (Wales)

Provides an information service on all aspects of cancer, plus practical and emotional support for people with cancer and their families living in Wales.

- 0808 808 1010
- tenovuscancercare.org.uk

Financial advice

Citizens Advice

Offers advice on benefits and help with filling out benefits forms.

- 03444 111 444 (England)
- 03444 77 20 20 (Wales)
- in Scotland or Northern Ireland, contact your local Citizens Advice
- citizensadvice.org.uk

Department for Work & Pensions (DWP)

Responsible for social security benefits. Provides information and advice about financial support, rights and employment.

- gov.uk/government/organisations/department-for-work-pensions

Travel insurance

Macmillan Cancer Support

Provides information about what to consider when looking for travel insurance, along with recommendations from the Macmillan online community.

- 0808 808 0000
- macmillan.org.uk

British Insurance Broker's Association (BIBA)

Offers advice on finding an appropriate BIBA-registered insurance broker.

- 0370 950 1790
- enquiries@biba.org.uk
- biba.org.uk



I talked a lot about my experience and emotions throughout my treatment. It helped me to process how I was feeling.

Emma, diagnosed with ALL aged 35

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.

Tests

What tests will I have?

What will they show?

Where will I have them done?

Are there any risks associated with the tests?

Will any of the tests be painful?

Do I need to know anything about preparing for the tests, for example, not eating beforehand?

How long will it take to get the results?

Who will explain the results?

What is my exact diagnosis?

Treatment - general

Will I need to have treatment? If so, when?

What does the treatment do?

Is there a choice of treatments?

Is there a clinical trial that I could join?

What's likely to happen if I decide not to have the treatment my healthcare team recommend?

Who do I contact if I feel unwell?

Who can I contact if I have any questions?

Type of treatment

Chemotherapy

What type of chemotherapy will I have?

Will I have to stay in hospital?

If not, how often will I need to go to hospital as an outpatient?

What chemotherapy treatment will I be given?

Will I be given it by mouth, injection or drip (into a vein)?

How long will my treatment last?

Will my treatment be continuous or in blocks of treatment (with breaks in between)?

What side effects could I get from my treatment?

Can side effects be treated or prevented?

Will they affect me all the time or only while I'm taking certain drugs?

What are the fertility risks with treatment and what options are available to protect my fertility?

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

Will I be able to carry on working/studying?

Will I need to take special precautions, for example against infection?

Will I be able to plan taking drugs around my meal times, or will I need to change when I eat?

Stem cell transplant

Is a transplant an option for me?

If I'm having a transplant:

How long will I be in hospital for?

Do I have to be in isolation?

How long will it be before I get back to normal?

Choosing the right treatment for you

If you're asked to choose between treatments, you might like to ask your consultant these questions about each one:

What's the best outcome I can hope for?

How might the treatment affect my quality of life?

Follow-up

How will the cancer be monitored after my treatment?

How often will I need to have follow-up appointments?

Is there anything I need to watch out for after my treatment?

Who can I contact if I have any questions or worries?

Relapse

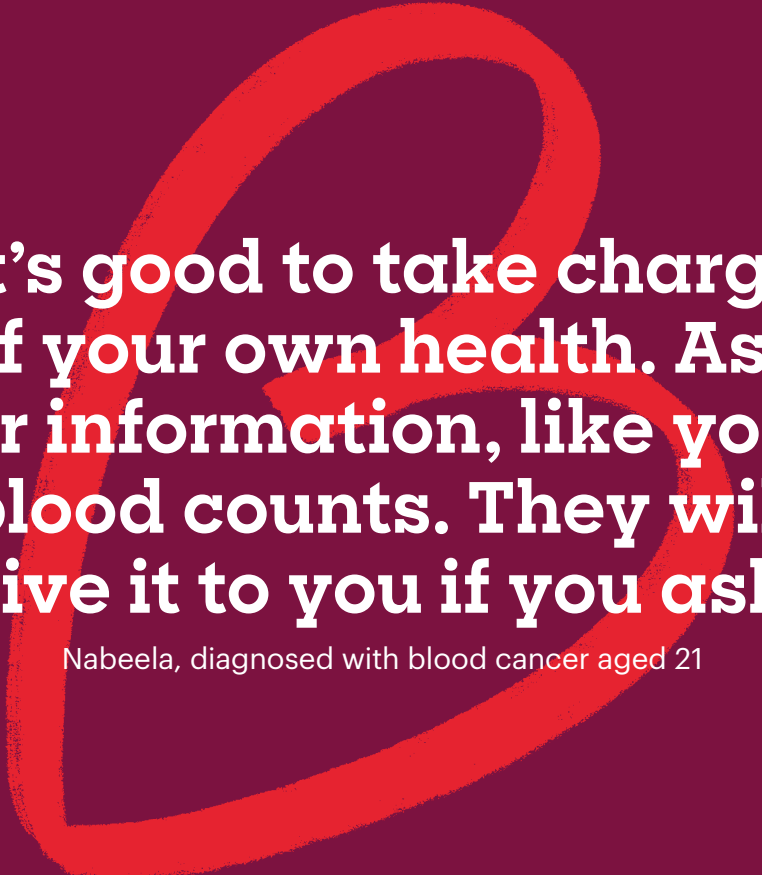
How will doctors know if the cancer is progressing?

What are the options for more treatment?

What will the treatment involve? Will it be different from my initial treatment?

Will there be any side effects from more treatment?

Is my outlook likely to change with more treatment?



**It's good to take charge
of your own health. Ask
for information, like your
blood counts. They will
give it to you if you ask.**

Nabeela, diagnosed with blood cancer aged 21

Glossary

Cancer can sometimes feel like it has its own language. Here are some of the most common words you might hear:

Anaemia

Anaemia is where you don't have enough haemoglobin (found in red blood cells) in your blood. This can mean that your muscles don't get as much energy as they need, most commonly leading to tiredness or shortness of breath.

Blood count, full blood count or FBC

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

Blast cells

Blood cells that haven't developed properly (immature blood cells). It's often used as a shorthand to describe leukaemia cells.

Bone marrow

The spongy material inside your long bones that produces blood cells.

Chemotherapy

Treatment using anti-cancer drugs. It can be a single drug or a combination of drugs. Chemotherapy is used to kill cancer cells or stop them growing and dividing. Although it's aimed at the cancer cells, the treatment also affects normal cells. This causes side effects.

Clinical nurse specialist (CNS)

A qualified nurse who specialises in a particular clinical area. Some deal with all blood cancers, while others may specialise in leukaemia, lymphoma, myeloma, or another specific area. Your CNS can provide information and expert advice about your condition and treatment and can be a good link between you and your doctors.

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 need to sign a consent form to take part in a clinical trial, so you'll always be aware if your treatment is part of a trial.

Cytogenetics

The study of the structure of chromosomes (which are made up of genes). Cytogenetic tests are carried out on samples of blood and bone marrow taken from people with leukaemia. They aim to find any genetic changes that could be linked to the disease. They can also help doctors to decide on the best treatment to recommend.

Fatigue

Fatigue is a feeling of extreme tiredness which doesn't go away after rest or sleep. It may be caused by the ALL itself or it might be a side effect of treatment. It's one of the most common problems that people with cancer can have. If you experience fatigue, your healthcare team should be able to offer guidance on helpful ways to manage it.

Flow cytometry (immunophenotyping)

A test that shows how many leukaemia cells are present in the blood and what type they are.

Intrathecal

A way of giving drugs by injecting them into the fluid in your spine (cerebrospinal fluid or CSF), which bathes and protects the brain and spinal cord.

Lymph node or lymph gland

Bean-shaped organs that act as a filter to catch viruses, bacteria and other potentially harmful particles that enter your body. They contain white blood cells, which fight infection.

Lymphocyte

A type of white blood cell which normally fights infection.

Neutropenia/neutropenic

An abnormally low number of neutrophils (a type of white blood cell that helps fight off infections) in your blood.

Spleen

A fist-sized organ that filters the blood. It sits under your ribs on the left-hand side of your body, next to your stomach and behind your ribs. The spleen has three main jobs: to control the level of blood cells in your body, to remove old red blood cells and to help protect your body from infection.

Stem cells

Cells that develop into other cell types. Stem cells act as a repair system for your body and create a new supply of cells to replace the ones that die. Blood stem cells are found in the bone marrow.

Steroids


Steroids are made naturally in the body, but they can also be made artificially. Steroids are usually used with chemotherapy to treat ALL. Some steroids are taken as tablets. Others are given by injection into a vein (intravenously).

T lymphocyte or T cell

A type of white blood cell normally involved in controlling the reaction of the immune system and fighting viral infection.

TKIs

Tyrosine kinase inhibitors (TKIs) are drugs used to treat Philadelphia positive ALL. They work by blocking the effects of (inhibiting) a substance called tyrosine kinase, which makes leukaemia cells divide faster and live longer. Imatinib, dasatinib and ponatinib are all examples of TKIs.



**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

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 124**



**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:

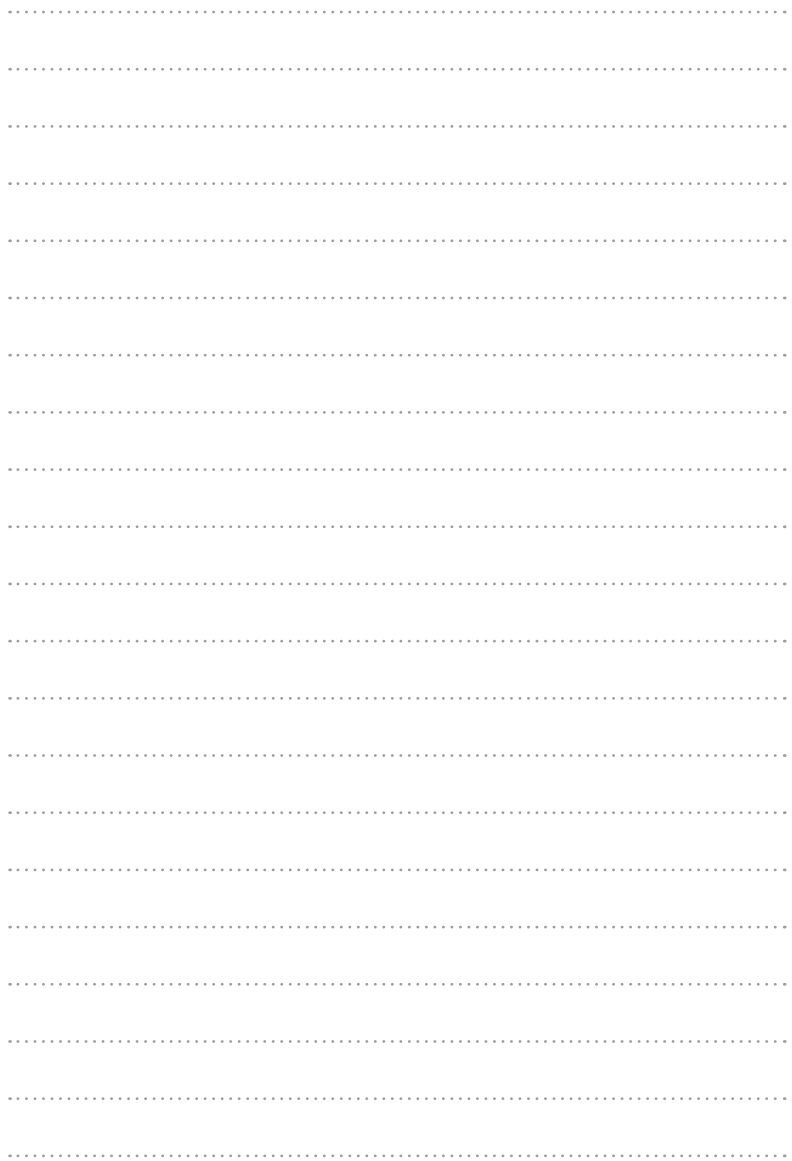
bloodcancer.org.uk/corporate-partnerships

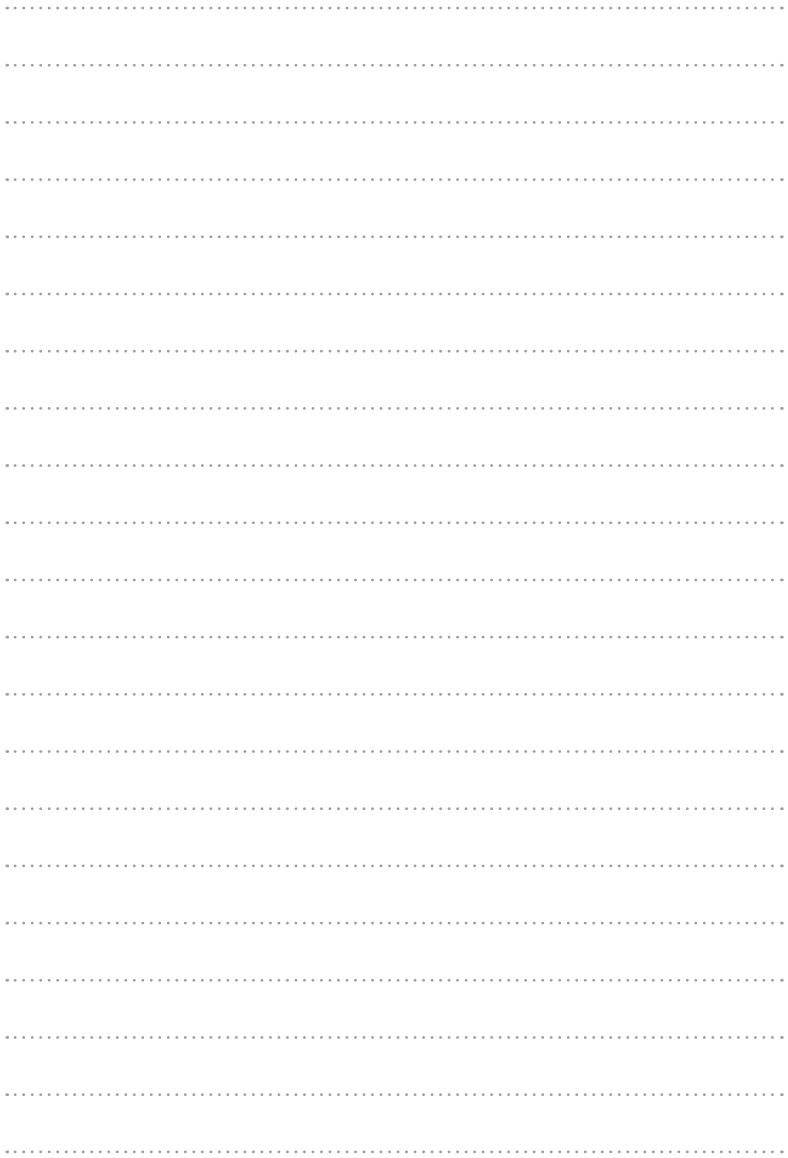
Or call us on **0808 169 5155**



**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 aged 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 112)

.....

.....

.....

.....

.....

Keep in touch

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**



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

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

Because we face it together

We're a community dedicated to beating blood cancer by funding research and supporting those affected.

Get in touch for:

- Free and confidential support by phone or email
- Information about blood cancer and life after diagnosis
- An online forum for people affected by blood cancer

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

0808 2080 888

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

support@bloodcancer.org.uk

forum.bloodcancer.org.uk

Your feedback on this booklet can help us improve – please send any comments to **information@bloodcancer.org.uk**



**Blood
cancer
UK**

Blood Cancer UK is a trading name of Bloodwise, 39-40 Eagle Street, London, WC1R 4TH. A company limited by guarantee 738089 (registered in England and Wales). Registered charity 216032 (England and Wales) SCO37529 (Scotland) © 2020 ALL/0219.2