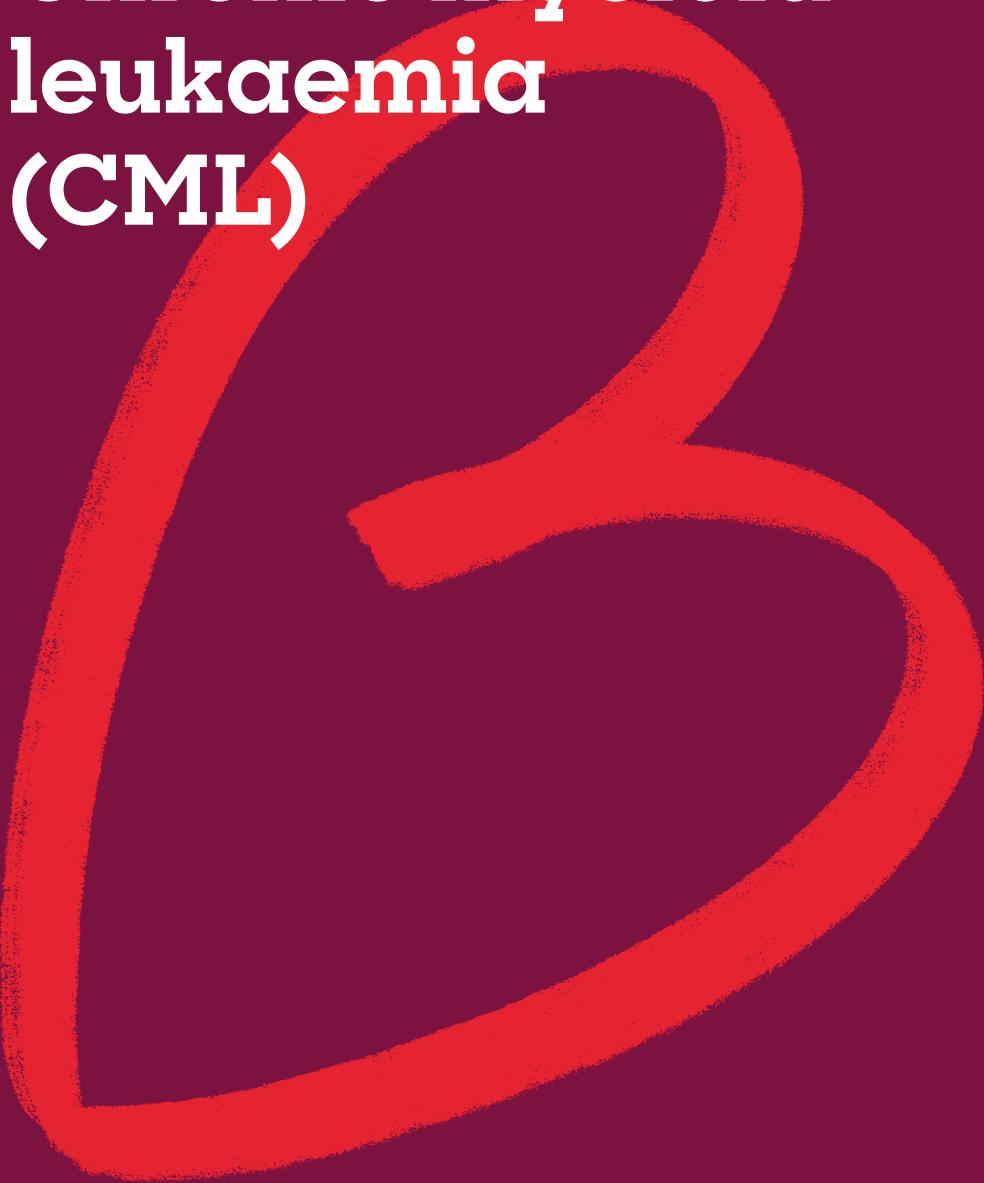


Chronic myeloid leukaemia (CML)



**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 Jane Apperley and Dr Dragana Milojkovic; and Clinical Nurse Specialist Irene Caballes 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 105.

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 (January 2019)

Date of next review: January 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 Chronic myeloid leukaemia (CML) at a glance
- 9 Blood, bone marrow and your immune system
- 15 What is CML?
- 23 Who gets CML?
- 27 Symptoms
- 33 Diagnosis
- 47 Treatment
- 67 The outlook
- 73 Living with CML
- 85 Places you can get help and support
- 92 Questions for your healthcare team
- 96 Glossary
- 102 Our health information
- 105 About us
- 113 My details

Introduction

This is a booklet for adults with chronic myeloid leukaemia (CML), and for people who know someone with CML. Childhood CML is rare but is treated in a similar way – if your child has been diagnosed with CML, their healthcare team will be able to give you more information about it.

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 first.

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

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



Our Support Services Team are here for anyone affected by blood cancer. Contact us on **0808 2080 888** or **support@bloodcancer.org.uk**

We have more information and personal stories about living with and beyond blood cancer on our website: **bloodcancer.org.uk/living-well**.

Chronic myeloid leukaemia (CML) at a glance

For most people, it's possible to have chronic myeloid leukaemia (CML) and have a normal life expectancy and a good quality of life, thanks to tablets that you take on a daily basis.

What is CML?

Leukaemia is a type of blood cancer that affects your blood cells – usually white blood cells. CML is a slow-developing form of leukaemia. There are three stages of CML and most people are diagnosed in the early (chronic) phase. In this phase your body makes too many mature (fully functioning) white

blood cells known as granulocytes. Treatment can bring the number of blood cells under control, but if the disease is left untreated, it can progress to a more aggressive form of CML known as blast phase, where the white blood cells don't develop as they should.

Between the chronic phase and blast phase there may be a period of time when your disease becomes more difficult to control and there are a small number of immature (not fully functioning) cells in your blood – this is known as the accelerated phase.

Who gets CML?

Around 750 people are diagnosed with CML each year in the UK.

You can get CML at any age, though it's very rare in children under 15. In the UK, the median age at diagnosis is 60. This means that half of everyone with CML is under the age of 60, while the other half is over 60.

Slightly more men than women get CML.

What are the treatments for CML?

The aim of treatment for CML is to reduce the number of leukaemia cells in your body to low enough levels for you to have a normal life expectancy.

The most common treatment for CML are drugs known as tyrosine kinase inhibitors (TKIs), which are taken daily in tablet form (orally). Most people on TKIs take these tablets for life, but recent research has shown that some people can eventually stop treatment (under the supervision of their healthcare team) and stay cancer free.

Imatinib, which was the first TKI to be made, is the most commonly used. Doctors will usually be able to tell if you're not going to respond to imatinib after the first three to six months of treatment. If this is the case, you'll be asked to try another TKI to see if that works better. Unfortunately, TKIs don't work well for around 5–10% of people with CML. If this is the case for you, a stem cell transplant may be a good alternative.

What's the outlook?

Before TKIs were introduced, survival rates for CML were much lower. Now, for most people, CML is considered a long-term (chronic) condition that can be managed with TKIs, with normal life expectancy and a good quality of life.

In some cases, when people have consistently responded really well to their TKI, and have been taking it for a number of years, they may be able to reduce their dose or even stop taking it without their CML coming back. If your doctor thinks this is possible for you, they will discuss this with you – but it's very important that you continue to take your TKI every day unless your specialist doctor (consultant) tells you otherwise.

For many people with CML, their disease doesn't progress past the first, chronic phase – for example, fewer than 10% of people taking imatinib go on to develop accelerated or blast- phase CML within five years of their diagnosis. If you do enter these phases, your healthcare team will talk to you about your treatment options and your individual outlook (prognosis).

**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 will talk to you about them.

Blood

The blood has many important functions:

Transport system

It 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

Organs in your body release hormones into the blood, which send messages to other organs.

Repair system

It contains cells and chemicals that can seal off damaged blood vessels and control blood loss.

Bone marrow, blasts and blood cells

Blood cells all start off in the soft material inside your bones (bone marrow), as a type of cell called a stem cell.

When stem cells divide they create lymphoid stem cells and myeloid stem cells – these stem cells then go on to form immature (not fully functioning) blood cells called lymphoid blasts or myeloid blasts. These blasts then become mature (fully functioning) white blood cells, red blood cells and platelets – see the diagram opposite.

A lot of blood cells are made in the bone marrow every second, because your body needs them. If everything is working normally, your body makes the right number of each type of cell to keep you healthy. If there are too many or too few of any type of blood cell, this can make you unwell.

Blood cells

Blood contains three types of cells: white blood cells, red blood cells and platelets. Red blood cells, platelets and some white blood cells are made from myeloid stem cells. Other white blood cells, known as lymphocytes, come from lymphoid stem cells.

White blood cells (leukocytes)

These fight and prevent infection. There are five different types of white blood cell: lymphocytes, monocytes, eosinophils, neutrophils, and basophils. These last three types are also called granulocytes, because they have granules (tiny, grain-like particles) in them.

Red blood cells (erythrocytes)

These contain a chemical called haemoglobin, which carries oxygen to all the tissues of your body. Muscles and other tissues need oxygen to use the energy from your food.

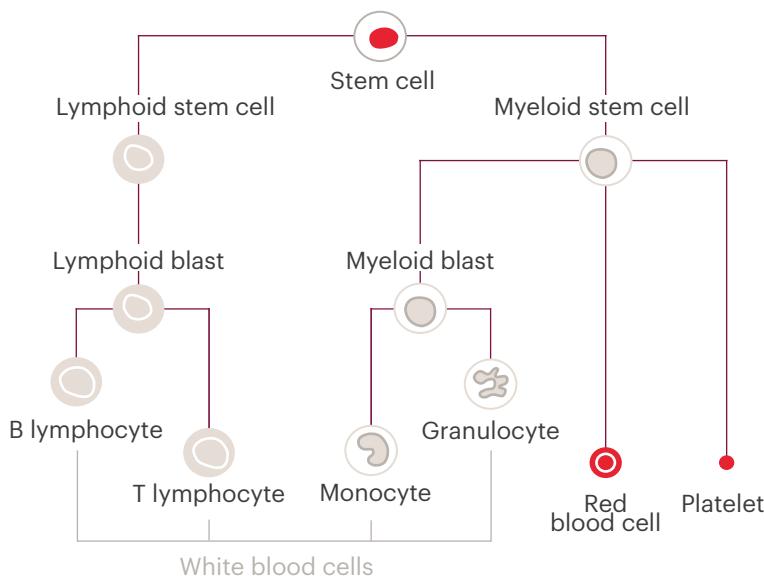
Platelets (thrombocytes)

These stick together at the site of any tissue damage and stop bleeding.

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

If you're diagnosed with CML, your healthcare team will check the different number and type of blood cells in your bloodstream by taking blood samples/tests.

Blood cell production



You might hear the number of blood cells in a blood sample called a blood 'level', 'count' or 'value'. Each of your results will come with a range of normal (healthy) values next to it, so your healthcare team can check to see whether your results are higher or lower than they should be.

Everyone has slightly different numbers of each type of blood cell, and these numbers will go up and down a little from time to time, but they should generally stay within a normal range. The table opposite shows what you might expect to see in 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	$150\text{--}400 \times 10^9/\text{l}$
White blood cells (WBC)	$4.0\text{--}11.0 \times 10^9/\text{l}$
Neutrophils	$2.0\text{--}7.5 \times 10^9/\text{l}$
Lymphocytes	$1.5\text{--}4.5 \times 10^9/\text{l}$

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 that protect your body against infection. It's able to react quickly to infections it's seen before: white blood cells (lymphocytes in particular) play an important role in this. They circulate around your body in your blood and fight infections. Most people with CML don't get more infections than usual.

CML is a slow-developing blood cancer that affects your stem cells. With treatment, you can usually manage the disease and keep it under control.

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

What is CML?

Leukaemia is a type of blood cancer that affects your blood cells – usually white blood cells. Chronic myeloid leukaemia (CML) is a slow-developing form of leukaemia, which has three phases. Most people are diagnosed in the first (chronic) phase.

Leukaemia

People with leukaemia have large numbers of abnormal white blood cells, which take over the bone marrow and spill out into the bloodstream. There are many different types of leukaemia – some that develop faster (acute) and others that develop more slowly (chronic).

Chronic myeloid leukaemia (CML)

CML is a slow-developing form of leukaemia that mainly affects a group of blood cells collectively known as myeloid cells.

In a healthy person, your myeloid stem cells (the ‘starter cells’ in your bone marrow) develop into myeloid blasts, before eventually turning into mature (fully functioning) red blood cells, platelets and specific white blood cells known as granulocytes and monocytes.

Your body needs new blood cells all the time, and it usually makes the right amount. But if you have CML, this process goes wrong and your body produces too many myeloid blasts and granulocytes. These cells overcrowd the bone marrow, meaning there isn’t enough room for other important blood cells to be made.

Some blasts also enter the bloodstream and, because they haven’t developed properly, aren’t able to fight infection properly. Both of these things cause many of the signs and symptoms of CML.

Phases of CML

The three phases of CML are defined according to the number of myeloid blasts and granulocytes in the blood and bone marrow. Your treatment and outlook will depend on which phase of the disease you have. These phases are explained briefly below,

but your healthcare team will be able to tell you more about your individual diagnosis, and what it means for you.

Chronic-phase CML

Most people (nine in 10) are diagnosed with CML in the early (chronic) phase. In this phase your body makes too many granulocytes, but the disease is developing slowly.

These granulocytes can collect in the spleen, making it swell. The spleen is an organ that's part of your lymphatic system – the network of tissues and organs that make up the body's drainage system and help it fight infection. The spleen sits on your left side, under your ribs. A swollen spleen is most common during the chronic phase, but can also happen during the accelerated and blast phases.

You have very few myeloid blasts in your blood or bone marrow (less than 15%) in this phase.

Accelerated-phase CML

If CML is left untreated, it begins to develop more quickly and reaches the accelerated phase. In this phase, you have more myeloid blasts in your blood or bone marrow than in the chronic phase, but this number is still relatively small.

Blast-phase CML

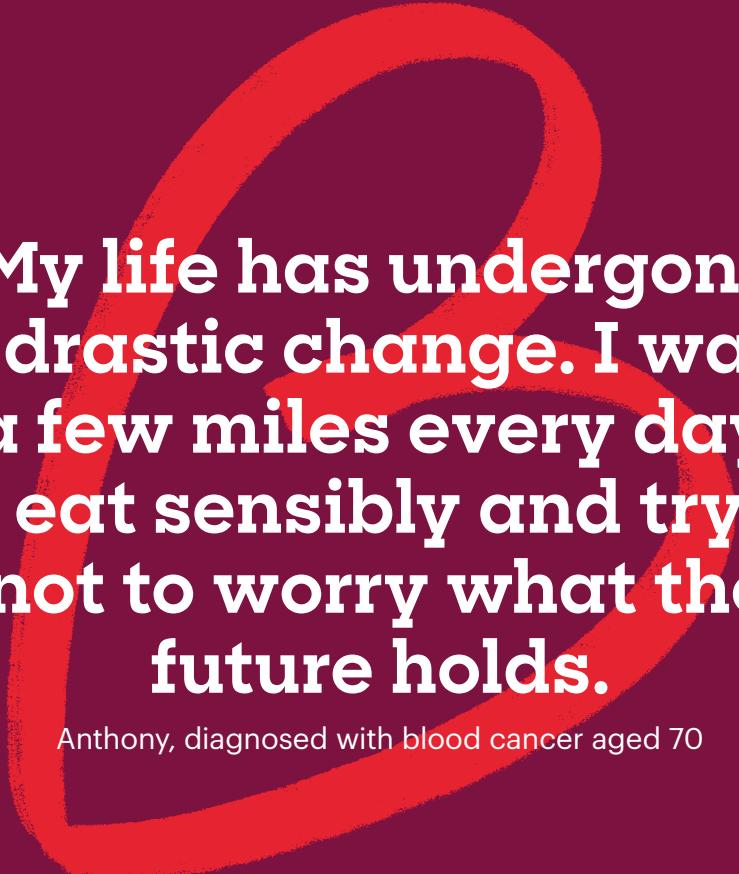
If the leukaemia continues to develop, it will eventually reach the blast phase. This is where the disease transforms into an acute form of leukaemia (one that develops more quickly) – usually a form of acute myeloid leukaemia. In this phase you have too many myeloid blasts in your blood and bone marrow.

The Philadelphia chromosome

All cells in your body contain a set of instructions that tell the cell what to do and when to do it, stored inside the cells in structures called chromosomes. There are 23 pairs of chromosomes in each cell in your body.

Your chromosomes are made up of a chemical called DNA, which is arranged in sections called genes. Each gene is a code that helps the body make different proteins.

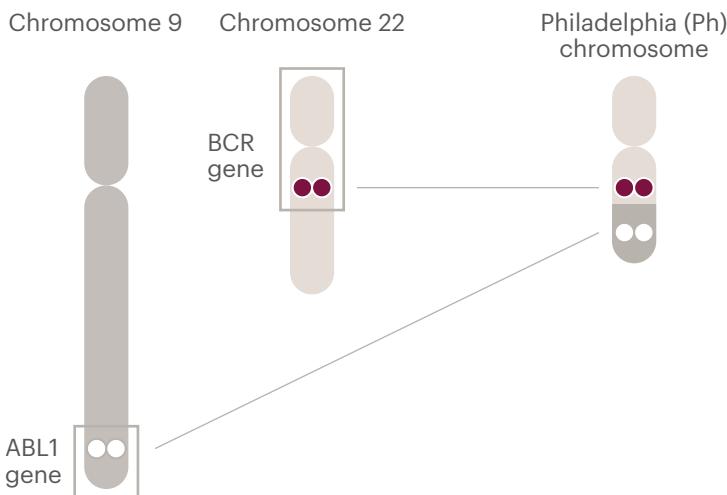
When cells divide to form new cells, normally the chromosomes stay the same in each new cell. But if you have CML, something goes wrong with this process.



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

Anthony, diagnosed with blood cancer aged 70

Philadelphia chromosome



CML is thought to begin when chromosomes nine and 22 get mixed up when a stem cell divides.

- This creates a new, shorter chromosome called the Philadelphia chromosome (it was named this because it was discovered in Philadelphia).
- During this mix-up, a small part of chromosome nine (containing the ABL1 gene) gets stuck next to a small part of chromosome 22 (containing the BCR gene). This swapping of genetic material is called a translocation, or chromosomal translocation. This particular translocation is called t(9;22).

- In the process, they form a new fusion gene called BCR-ABL1.
- The new BCR-ABL1 fusion gene makes a new protein (also called BCR-ABL1). This protein is a type of enzyme (the part of the cell that speeds up chemical reactions) known as tyrosine kinase, which causes leukaemia stem cells to divide more often and to live longer than normal blood cells.

We don't know why this translocation happens, but we do know that you aren't born with this chromosome and can't pass it on to your children.

In 95% of people with CML, the Philadelphia chromosome can be detected with a cytogenetic test (where cells from a blood sample are studied under a microscope). For the other 5% of people, a PCR test or a FISH test will be used to confirm a CML diagnosis.

Treating CML

The standard treatment for CML is to use drugs that block (inhibit) the tyrosine kinase enzyme and stop its effects.



Find out more about PCR, FISH and other tests used to diagnose CML in the Diagnosis chapter on **page 33**.

You're not alone. Although it's quite rare, around 750 people are diagnosed with CML each year in the UK.

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

Who gets CML?

When you're diagnosed with any cancer, one of the first things you might think is: why me?

Although the Philadelphia chromosome is found in around 95% of cases of CML, we can't say what exactly causes the illness. However, there are some things that affect how likely you are to develop CML. Here's what we do know:

Age

CML is more common in older people. The median age at diagnosis is 60 years, which means that half of people with CML are under 60 and the rest are over 60.

Sex

CML is slightly more common in men than women, but we don't know why.

Radiation

The only clearly defined risk factor for CML is exposure to a large amount of high-energy (ionizing) radiation. By this, we mean similar to a level you'd see after an atomic bomb explosion. It's extremely unlikely that anyone in the UK would be exposed to a level of radiation high enough to increase the risk of getting CML.

Does CML run in families?

There's no evidence that family members of people with CML are at a higher risk of developing the condition than anyone else.



Don't let cancer define you
or let it shape who you are.
A lot of my life is cancer,
but it's not all my life.

Katie, diagnosed with CML aged 22

**It's important to remember
that not everyone will
get all, or even any, of the
symptoms listed - each
person is different.**

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

Symptoms

If you've been diagnosed with CML, you may have noticed some symptoms before your diagnosis.

Other people won't have been aware of any symptoms at all and will have been diagnosed by chance after blood tests they were having for other reasons.

This section talks about the symptoms associated with each phase of CML. It's important to remember that not everyone will get all, or even any, of these symptoms. Each person is different, and will have a different experience.

Symptoms in the chronic phase

Symptoms in this phase usually develop very slowly. Remember that many of these symptoms are very common, and are often caused by other things.

Symptoms include:

- tiredness or fatigue (extreme tiredness)
- loss of appetite
- unexplained weight loss
- increased sweating, particularly at night
- bloating, swelling, general discomfort and sometimes pain around the stomach area (this can happen if your spleen is enlarged, which is common in people with chronic-phase CML)
- blurred vision
- unusual or excessive bleeding – for example from your gums or nose
- in men, long-lasting, painful erections (priapism).

Symptoms in the accelerated phase

If you're in the accelerated phase, your symptoms won't normally change much from the chronic phase, but you may notice an increase in bone pain, which happens when leukaemia cells build up in your bone marrow. Your healthcare team will run tests to look for changes in your blood, bone marrow and blast count to check for signs of development to this phase. This stage sometimes suggests CML is changing to the blast phase, so your healthcare team will monitor you closely to check for any signs of this.

Symptoms in the blast phase

It's rare for people to be diagnosed at the blast phase, sometimes known as 'blast crisis'. It's also rare, with current treatments, for people to progress from the chronic to blast phase, but there is a chance that these things can happen. In addition to the fatigue, tiredness and unexpected weight loss mentioned on the previous pages, people in the blast phase often notice extra symptoms.

These may include:

- fever
- bone pain
- bruising more easily than normal
- painful or unusual bleeding, for example from your gums or nose
- repeated infections
- swollen lymph nodes
- headaches (this can happen if blast cells are present in the fluid that surrounds the brain and spinal cord).



We produce a diary for people affected by blood cancer where you can note down practical information or record your thoughts. See **page 102**.

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

You'll have a set of tests to confirm whether you have CML. If you're diagnosed with CML, you'll have some more tests to help your healthcare team decide which is the best treatment for you. At any time, you can ask your healthcare team to tell you why you're having a certain test, what the results mean and – if you would like – for a copy of the test results.

Tests to diagnose CML

It's increasingly common for people to be diagnosed with CML by chance, when they have no specific symptoms but are having a routine check-up with their GP, or having blood tests for another reason.

About nine in 10 people with CML are diagnosed during the slow-growing (chronic) phase of the disease and, with treatment, most will be able to stay in this phase for life. The rest are diagnosed in either the accelerated or blast phase.

Full blood count (FBC)

A full blood count (FBC) measures the number of each type of cell in your blood: red blood cells, white blood cells and platelets. A small sample of blood will be taken from a vein in your arm and a machine will measure the numbers of different types of blood cells in the sample. You might be sent for this test by your GP as part of a routine check-up. Or you might have one if you're in hospital for something else.

If you have CML, your FBC will normally show that you have more white blood cells than normal. In particular, you may have higher numbers of some rarer types of white blood cells (basophils and sometimes eosinophils). The number of platelets may be slightly higher too and you might have low levels of haemoglobin (which can make you anaemic).

If, after these tests, your doctor thinks you have CML, you'll need to have more tests to check how far the leukaemia has developed. This will usually involve a bone marrow biopsy, which is explained on the next page.

If you're diagnosed with CML, you'll then have regular FBCs (to begin with, every few weeks – and then usually every few months) to monitor your condition.

Polymerase chain reaction (PCR) test

Your doctor will also do a PCR test when you first visit the hospital, using the blood sample taken for your FBC. This will measure the amount of the BCR-ABL1 fusion gene in your blood. The PCR is an important test that you'll have throughout your treatment. It's used to monitor how you're responding to treatment and to look at whether you might need to change treatments.

Bone marrow sample

Most people will also have a bone marrow sample (biopsy) soon after diagnosis. This is a procedure that will allow your doctors to confirm the diagnosis and will provide more information about the disease.

A small amount of bone marrow is taken from the hip bone using a fine needle (an aspirate). Your doctors will then look at the bone marrow sample under a microscope. You don't need to stay overnight in hospital for a bone marrow biopsy; you can have it as an outpatient (which means you can leave the hospital after your appointment). The procedure is done using local anaesthetic (which numbs the area to stop you feeling pain).

If you feel discomfort, your healthcare team can use gas and air (which will reduce any pain or discomfort), or mild sedation (which will make you feel relaxed). It's usually quite quick but may be uncomfortable while the sample is being taken from the bone marrow; you can take painkillers if you need to after the procedure.

You may also have a bone marrow trephine. This is similar to a bone marrow aspirate, but involves taking a piece of bone from the hip instead, using a larger needle. Other than this, the procedure is done in the same way.

The laboratory doctors will do a number of tests on your bone marrow, to look at how many mature (fully functioning) and immature (not fully functioning) cells you have. This helps to confirm the stage of your disease.

Cytogenetics

Almost everyone with CML will have cytogenetic tests (cytogenetics is the study of chromosomes). This is because in 95% of people with CML, these tests will detect a chromosome called the Philadelphia chromosome. So testing for this chromosome is a common way to diagnose CML.

If you're one of the 5% of people for whom the Philadelphia chromosome isn't detected, your doctors can use the results of your PCR test

(described on page 35) or run a FISH test (described below) to confirm your diagnosis.

Cytogenetic tests are usually done on cells from your blood or from your bone marrow before you start treatment. These cells can come from a sample from a blood test or bone marrow biopsy.

Your cells will be sent to a laboratory where they will be grown over a number of days and then viewed under a microscope. The cells may be treated to make the chromosomes show up and help identify any unusual changes. The results of the test will be sent back to your specialist doctor (consultant).

FISH (fluorescence in situ hybridization) tests

This is a test that looks for changes in your genes. If you have cytogenetic tests and they don't pick up the Philadelphia chromosome, your doctors may also run a FISH test to check for the BCR-ABL1 fusion gene. This will help them confirm your diagnosis.

Staging

In most forms of cancer, doctors will do tests to 'stage' the disease and help to plan treatment.

When doctors 'stage' CML, they are trying to find out what phase the disease is in – chronic, accelerated or blast – and through this, give your likely outlook (prognosis).

It's important to know that most people with CML stay in the chronic phase – which is the easiest phase to treat. If the disease does develop, it doesn't always do it phase by phase. Rarely, people might move from chronic phase straight to the blast phase.

Likewise, treatment at the accelerated phase or blast phase can move you back to the chronic phase. The full blood count, cytogenetics and bone marrow sample tests all help doctors to stage the disease.

Risk scores

As part of staging, your doctors will work out your 'risk score'. Your doctor may use your risk score to help choose the most appropriate treatment for you.

There are four risk scores for CML that you might hear mentioned: Sokal, Hasford, ELTS and EUTOS – but Sokal is most commonly used.

The Sokal risk score looks at:

- your age,
- the size of your spleen,
- the number of blast cells in your blood, and
- your platelet count.

Risk scores are less important today than before the introduction of tyrosine kinase inhibitors (TKIs),

because the great majority of people with CML respond to these drugs, regardless of their risk score. TKIs vary in strength, so it makes sense to use a stronger drug for those at high risk.

Your healthcare team

If you're diagnosed with CML, 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 haematologist – a doctor who specialises in treating people with blood diseases. Some people are treated by an oncologist (a cancer specialist). Either way, your consultant at the hospital will be an expert in treating your specific disease.

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 your CNS 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. They can also be a useful link to reach out to your doctors between your appointments.

Your multidisciplinary team (MDT)

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

Talking to other people

You may want to ask your consultant or CNS if you can talk to someone who has had a similar diagnosis and treatment to 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.

Your other healthcare professionals

It's definitely worth telling other healthcare professionals you see (like your dentist or optician)

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



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.

Finding out more

After you've been diagnosed, it's worth taking some 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'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 speak to you, so you can try to arrange for someone to be with you at that time.
- When you're in the clinic or staying in the hospital you may 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.
- 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.

Go to **[citizensadvice.org.uk](https://www.citizensadvice.org.uk)** for more information about your local patient advice or complaints service.

See **page 92** for a list of questions you may want to ask your healthcare team at different times.



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. You could discuss this with your GP.

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.

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 different 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. It's entirely up to you.

For support with telling other people about your diagnosis, contact our Support Services Team on **0808 2080 888** or support@bloodcancer.org.uk



We have more information and personal stories about cancer and work on our website: bloodcancer.org.uk/living-well

Talking to children and teenagers

Talking to children and teenagers about your cancer diagnosis can be difficult. There are lots of organisations that can support you and offer you 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 that 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

You may want to 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.

**If you're taking TKIs, it's
really important that
you take them exactly as
directed by your doctor and
are aware of advice around
diet and getting pregnant.**

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

Treatment

Throughout your treatment, your medical team will discuss your treatment options with you. You'll be able to give your opinions and preferences and ask questions at any point.

Starting treatment

Once your diagnosis is confirmed, your team will discuss your treatment options with you. The decision about what type of treatment any person with cancer has is based on guidelines produced by experts, which look at the very latest evidence.

The aim of treatment for CML is to achieve very low levels of leukaemia cells and keep the disease under control, so there is a very low chance of it progressing.

There are several levels of response to treatment, which you normally achieve one by one, based on how long you've been having treatment. For more information see the 'Follow up' section on page 60.

Chemotherapy

If your white blood cell count is high and/or you have a lot of symptoms and feel unwell, your healthcare team may give you a mild chemotherapy tablet, known as hydroxycarbamide. This will lower the number of blood cells in your bloodstream and control your symptoms until your diagnosis is confirmed.

Allopurinol

If you're given hydroxycarbamide, you'll usually also be given a drug (in tablet form) called allopurinol. This is to prevent gout (which happens when uric acid builds up in the blood), which can be a side effect of hydroxycarbamide.

Leukapheresis

If your white blood cell count is very high, and particularly if you have certain symptoms such as blurred vision, your doctors might advise removing some white blood cells in a process called leukapheresis.

In this procedure, a plastic tube will be inserted into each arm. Your blood will drain from one tube into a machine (centrifuge) which will be spinning at high

speed. The spinning separates the blood into white blood cells, red blood cells and plasma. The white blood cells are removed and either thrown away or, with your agreement, could be used for research. The red blood cells and plasma are then returned to your body through the tube in your other arm.

At any one time no more than a cupful of blood will be in the centrifuge and the procedure is very safe. As the procedure can take two to three hours to lower your white blood cell count in this way, you may want to bring something to keep you entertained, like a book or tablet. The leukapheresis will be done by a specially trained nurse, who will talk you through the procedure.

Tyrosine kinase inhibitors (TKIs)

Once your diagnosis is confirmed, your doctors will prescribe a TKI. This is a drug that comes in tablet form, which kills leukaemia cells.

There are now several different types of licensed TKIs available in the UK. The TKI that you're prescribed when you're first diagnosed will depend on your disease phase, the potential risk of side effects, your risk score and any other conditions you have.

First-line treatment

If you're diagnosed in the chronic phase, your first treatment will usually be a regular standard dose of one of three types: imatinib, dasatinib or nilotinib.

In general, people cope well with these drugs, and can return to a relatively normal lifestyle, such as continuing to work and study.

Of these three TKIs, most people start on imatinib, which was the first TKI to be developed. It's taken once a day, after food. Others will have dasatinib or nilotinib (described in the next section) as their first treatment after diagnosis. If one of these other TKIs is more appropriate for you, your doctor will discuss this with you.

Second-line treatment

If the first TKI that you try stops working for you or you struggle to cope with its side effects, your doctor may suggest you try another TKI. This will be either imatinib, nilotinib, dasatinib, bosutinib or ponatinib, depending on which TKI you tried first.

Nilotinib is taken twice a day with a 'fasting regimen', meaning no food two hours before or one hour after taking the tablet. Dasatinib and ponatinib are taken once a day (with or without food). Bosutinib is taken once a day after food.

Sometimes your doctor can identify a specific reason why you're not responding to a TKI. For example, sometimes leukaemia cells develop genetic faults (mutations) that stop a specific TKI from working, but still respond to other TKIs. There is one particular mutation (T315I) that responds only to ponatinib, for instance.

Taking your TKI

It's really important that you take your TKI exactly as directed by your doctor (this is known as your regimen). Evidence shows that if you do, you'll have a better response to the treatment. Your healthcare team will be able to help you find ways to stick to your regimen.

At the moment, most people with chronic-phase CML are advised to take their TKI for life. However, growing research suggests that it's safe for some people who are doing really well on TKIs (and who have been taking them for five years or more with a deep molecular response for at least two years) to reduce their dose or potentially stop taking them altogether, as long as they continue to be closely monitored by their doctor.

This won't be suitable for everyone, so it's very important that you don't stop taking your TKI unless your doctor tells you to. Otherwise, the number of leukaemia cells in your blood could increase and you'll be at greater risk of progressing to the accelerated or blast phases.

If you have any questions about your treatment plan, your healthcare team will be able to talk you through it.

Stem cell transplant

Stem cell transplants are now only recommended for people whose CML hasn't responded to at least two TKIs. Even if your risk score is higher, you're likely to try TKIs first. The only exception normally would be if you're diagnosed at an advanced stage, are otherwise fit and healthy, and a donor is available.

If you're diagnosed in the blast phase

Very few people will be in this phase when diagnosed. If you are, your CML will be treated with stronger treatments, in a similar way to an acute (fast-growing) leukaemia. This usually

There's more information on stem cell transplants in our booklet **Blood stem cell and bone marrow transplants: The seven steps**. See **page 102** for how to order.



includes chemotherapy, and sometimes TKIs. If this treatment is successful and you return to the chronic phase, your doctor may recommend a stem cell transplant, which could offer the chance of a long-term cure. Your doctor will talk you through your treatment options, which will depend on what's most suitable for you.

It's likely that these stronger treatments will affect your fertility (ability to have children), so it's important to speak to your healthcare team about the options available to you if you think you might want to have children in the future.

Side effects of treatment

For most people on TKIs, side effects are not severe. However, you may notice some changes to your body that could be linked to the drugs you're taking. If you do, it's important to let your healthcare team know, as there are lots of things they can do to help you manage these side effects. For example, anti-sickness medication can help if the TKIs make you feel sick.

The following side effects are common to all TKIs:

- extreme tiredness (fatigue)
- fluid build-up (retention)

- problems with your liver (picked up using blood tests)
- skin rash
- muscle cramps
- joint pains
- headaches
- feeling sick (nausea)
- diarrhoea (frequent watery poos)
- symptoms caused by low blood counts; you'll experience different symptoms depending on the type of blood cell that's low. For example, you might experience extreme tiredness (fatigue) if you have a low red blood cell count, frequent infections if you don't have enough healthy white blood cells, or bruising or bleeding if your platelet count is low.

Imatinib

Some other side effects of imatinib include:

- fluid build-up (retention) causing puffiness around the eyes
- dry, gritty eyes

- haemorrhages into the white of the eye; these are not dangerous or harmful to your sight but can look unpleasant
- feeling sick (nausea) if you don't take the drug on a full stomach.

Dasatinib

Some other side effects of dasatinib include:

- fluid build-up (retention) between the lining of the lungs (your consultant may suggest you stop taking the drug either temporarily or permanently to help manage this – make sure you tell your doctor if you notice new fevers, a cough or pain in the chest when you take a deep breath)
- tummy (abdominal) pain
- shortness of breath
- sickness (vomiting)
- infections
- very rarely, blood in your stool (poo).

Nilotinib

Some other side effects of nilotinib include:

- an itchy rash (more common than with other TKIs)
- high blood pressure
- higher blood glucose (sugar) levels
- higher cholesterol levels
- rarely, clots in the arteries of the heart, brain and lower legs. This might happen if you already have a higher risk of cardiovascular problems (problems affecting the heart or blood vessels). For example, if you smoke, have high blood pressure or a previous history of clots. You'll be monitored closely for these side effects if you're at greater risk.

Bosutinib

Some other side effects of bosutinib include:

- diarrhoea (frequent watery poos), which can be particularly severe in the first few days.

Ponatinib

Some other side effects of ponatinib include:

- dry skin
- high blood pressure
- inflammation of the pancreas, an organ in the abdomen (stomach area); if this happens you'd notice severe pain
- clots in the arteries of the heart, brain and lower legs. This is slightly more common than with nilotinib but again this usually happens in people who already have a higher risk of cardiovascular problems (problems affecting the heart or blood vessels), so you'll be monitored for these side effects if this is the case.

Fertility and CML - women

If you're thinking about having children at the time you're diagnosed, or think you might like to have children in the future, your doctor will be able to refer you to a specialist who'll explain all the options available to you.

While there's no evidence that any TKI affects fertility (your ability to have a baby), doctors strongly recommend that you avoid becoming pregnant while you're taking imatinib and other TKIs, and use reliable contraception.

This is because there's evidence to suggest that TKIs might be harmful to babies in the womb (uterus).

Because it's currently thought that most people with CML will have to take TKIs for the rest of their lives, this may affect your plans to have children. However, there are options available.

For example, you may want to think about storing your eggs or embryos (eggs that have been fertilised with your partner's or a donor's sperm), or coming off treatment for a period of time to become pregnant. It's best to discuss your individual circumstances with your specialist, as they can make recommendations based on how you're responding to treatment.

If you're diagnosed with CML while you're pregnant, or if you become pregnant after being diagnosed, your doctors will be able to discuss your options with you. This might – if appropriate for you – include delaying or adapting your treatment until the baby is born. This is something you'll need to think very carefully about and discuss with your healthcare team.

There's evidence to suggest that TKIs are present in the breast milk of women taking them, so doctors recommend that you don't breastfeed while taking them.

If you don't respond to a TKI and are planning to have a stem cell transplant, it's quite likely that the drugs used for the transplant will cause an early menopause (when a woman stops having periods and no longer releases an egg each month, so cannot become pregnant naturally).

If this happens to you, you may want to discuss ways to keep your fertility after the transplant with your doctor, and consider starting hormone replacement therapy (a treatment that takes away some of the symptoms of menopause) soon after your transplant.

Fertility and CML – men

For men, there's currently no convincing evidence to suggest taking TKIs at the time of conception could have a harmful impact on an unborn child. However, there is less information about the newer TKIs (bosutinib and ponatinib) so your doctor may suggest coming off treatment – if appropriate for you – if you decide to try for a baby. Again, this is something you'd need to think very carefully about and discuss with your healthcare team.

Most hospitals and treatment centres will also recommend storing some of your sperm at the time when you're diagnosed, but if this isn't discussed with you, you can ask your healthcare team about it.

If you don't respond to a TKI and are considering a stem cell transplant, it's important to have this conversation with your healthcare team.

Late effects

Because TKIs were only first introduced in the UK in 2003, we don't fully understand the effects of taking them for life. During your treatment, your healthcare team may run tests to monitor you for long-term side effects. If you experience any new side effects while you're taking TKIs, it's important to let your nurse or doctor know.

TKIs and other drugs

There's some evidence to suggest that taking TKIs in combination with other treatments may cause more side effects than if you take them on their own. Your healthcare team can explain how this might affect any other medication you're taking.

Follow-up

Your doctor will measure your response to treatment at your follow-up appointments, so it's really important that you attend these.



You can find out more about the impact that stem cell transplants can have on your fertility in our booklet: **Blood stem cell and bone marrow transplants: The seven steps**. See **page 102** for how to order.

There are several levels of response with CML, which you normally achieve one by one, based on how long you've been having treatment.

Haematological response

When your blood counts return to normal, you're said to have achieved a complete haematological response (CHR). This normally happens around three months after you start treatment.

Although your blood count is normal, this doesn't necessarily mean that it's ok to stop treatment. If you were to stop treatment as soon as your blood count returns to normal, it's likely that your white blood cell count would increase rapidly again.

This is because a full blood count (the test that measures the number of different types of cells in your blood) can't pick up a small number of left-over leukaemia cells. This means that there may still be leukaemia cells in your body, so you will need to continue having treatment to keep these levels under control. Your healthcare team can explain what your test results mean for you.

Cytogenetic response

This is another way of describing how you've responded to treatment. It involves a test that's more sensitive than a full blood count, which allows doctors to check the number of cells containing the abnormal Philadelphia chromosome in your bone marrow. To run this test, your doctor will need to take a sample (biopsy) of your bone marrow using a fine needle (an aspirate).

If the test can't detect the Philadelphia chromosome, this is called a complete cytogenetic response (CCyR).

This follow-up test is sometimes replaced by a polymerase chain reaction (PCR) test, which requires a simple blood sample rather than a bone marrow biopsy. A PCR test can be used instead at this stage because doctors consider a PCR level of less than 1% to be the same as a CCyR.

Molecular response (PCR tests)

If you're responding to treatment, you'll usually have a polymerase chain reaction (PCR) test every three months using a blood sample. This will measure how you're responding to treatment and let your

You can find out more about bone marrow biopsies on **page 35**.



PCR Result	Known as	What it means
< 1%	Complete cytogenetic response (CCyR)	Less than 1 leukaemia cell in every 100 blood cells
< 0.1%	Major molecular response (MMR)	Less than 1 leukaemia cell in every 1,000 blood cells
< 0.01%	Deep molecular response (MR4)	Less than 1 leukaemia cell in every 10,000 blood cells
< 0.0032%	MR4.5	Less than 1 leukaemia cell in every 32,500 blood cells
< 0.001%	MR5	Less than 1 leukaemia cell in every 100,000 blood cells

doctor know if you need to change drugs or doses (the amount you're receiving). This is a very reliable and sensitive test that can detect one leukaemia cell in up to 100,000 normal blood cells.

PCR results are expressed as percentages. The results tell you what proportion of your blood cells are leukemia cells. The table above shows the different PCR results you can get, and what they mean. The symbol '<' means 'less than'.

Once you've achieved MMR, you'll still have regular PCR tests – usually every three to six months – to make sure you're continuing to respond to treatment.

If no leukaemia cells can be detected you might hear your result referred to as 'undetectable transcripts'. This means there may be an incredibly small number of leukaemia cells present somewhere in your body, but the test can't pick these up. This is also called a complete molecular response (CMR) – where your tests can't detect any signs of CML and you no longer have disease symptoms.

Clinical trials

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

If you'd like to find out more about clinical trials for CML, speak to your healthcare team.

You can find out more about clinical trials in the UK at
bepartofresearch.nihr.ac.uk



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 will always be 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.

Taking part in a clinical trial does come with uncertainties and risks, and there's no guarantee that 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 at that time that's suitable for your individual condition.

**Every person is different,
so your 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

Thanks to imatinib and other TKIs, survival rates have improved dramatically over the last 20 years and the outlook for most people with CML is generally positive – particularly for those diagnosed in the chronic phase. Although we haven't seen the same improvements for people who don't respond well to TKIs, there are still treatment options available, as described in the previous chapter.

Most people with CML will have a very good outlook, with about 90% surviving five years after diagnosis.

These statistics do not mean that you'll only live for five years; because TKIs are still relatively new treatments, scientists have only been able to measure their impact for a short period. What we do know is that you are very unlikely to die from CML after five years on TKIs – in fact, recent evidence suggests that if you respond well to treatment, you could have a similar life expectancy to someone who doesn't have blood cancer.

It's also important to remember that statistics can only give an overall picture. Your own outlook is individual to you and will depend on your age, level of fitness and the stage of your disease, so it's always best to speak to your healthcare team about this.

Talking about your outlook

You may find it hard to ask or talk about your outlook. Sometimes those close to you might want to know your outlook even if you don't. However, your healthcare team aren't allowed to give this or any other information to anyone – not even family members – without your permission.

Try to decide early on who you want to know about your condition, then tell your healthcare team – you can change your mind at any time.

If you're taking TKIs

If you're diagnosed in the early chronic phase, TKIs will usually stop the disease progressing and you'll stay in this phase.

Until recently, it was thought that people treated with TKIs would need to take them for the rest of their lives. But recent research suggests that it's safe for some people (who have been taking TKIs for five years or more and who have had a deep molecular response for at least two years) to reduce their dose or potentially stop taking them altogether, as long as they continue to be closely monitored by their doctor.

If TKIs don't work for you

If you don't respond well to TKIs, your outlook will depend on how you respond to other treatments – like intensive (strong) chemotherapy and/or a stem cell transplant. If this is the case for you, you should talk to your healthcare team about your options and how they might affect your outlook.



For more information about stem cell transplants, order or download our booklet: **Blood stem cell and bone marrow transplants: The seven steps**. See page 102 for how to order.

If you're in blast phase

Unfortunately, it's harder to control blast-phase CML, as it doesn't always respond to TKIs. If this is the case for you, your healthcare team will talk you through other treatment options and explain the impact they might have on your outlook.

These options may include chemotherapy with or without TKIs, and/or a stem cell transplant.

If one's available, you may be invited to take part in a clinical trial, which could offer you promising new treatments that aren't currently available on the NHS.

Change in outlook

Remember that your outlook might change. If there's a change in your condition, or if you've finished all or part of your treatment, you might want to ask your healthcare team if your outlook is still the same.

Talk to us

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

Turn to **page 64** to find out more about clinical trials.





**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 CML

If you've been diagnosed with CML 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 emotional needs might change.

Looking after yourself physically

Changes in your condition

During and after your treatment, it's important to contact your healthcare team at the hospital straight away if you notice any new symptoms or side effects from your treatment – don't wait for your next check-up.

Keeping active

Do exercise in moderation, but if you experience any side effects from your treatment that make exercise more difficult, you should discuss this with your doctor.



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

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

You might feel tired a lot (fatigued). This might be caused by your 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're fatigued, 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 wellbeing and your mood.

Diet and infection risk

There's no evidence that any special diet will improve your condition or how you respond to treatment. However, you're likely to feel fitter and healthier if you follow general advice on good diet from your healthcare team or GP.

Things to think about if you're taking TKIs

If you're taking TKIs, it's important to:

- take your tablets according to the instructions of your doctor or pharmacist,
- only take half the recommended maximum dose of paracetamol, as TKIs can stop your body from processing this properly,
- avoid eating or drinking grapefruit, grapefruit juice, pomegranate, Seville oranges or any Seville orange juice (other types of orange and orange juice are still fine to eat/drink), since chemicals in these fruits can stop TKIs from working properly.

At the moment, there's not much evidence about the impact that drinking alcohol can have on TKIs. But if your liver is working normally, it's generally thought to be ok for you to drink alcohol – as long as you follow the UK's guidelines and drink sensibly. If your treatment starts to affect your liver, your healthcare team may advise you to drink less alcohol, or to stop drinking completely.

Things to think about if you need stronger treatment

If you don't respond well to at least two TKIs and need stronger treatment involving chemotherapy or a stem cell transplant, your immune system may not be working as normal, so you'll need to take extra care to avoid infections that you might get from food. Your body won't be able to destroy germs and resist infection as easily, so be careful about food use-by dates and take particular care to keep raw meat separate from ready-to-eat foods in the fridge.

You may also be advised to be extra careful about takeaway food and eating out while you're having this treatment. You won't need to take these precautions if you're in the chronic phase and are taking TKIs, however.

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 eating habits.



If you don't respond well to TKIs and need stronger treatment, our booklet **Eating well with neutropenia** has advice on how to avoid infections from food. For details of how to order or download, see **page 102**.

If you're having stronger treatment, you should also speak to your healthcare team about whether it's ok for you to do gardening and housework. Avoid fresh cut flowers and vases with old water in, as these carry germs that might cause infection.

Smoking

To reduce some of the risk of long-term side effects caused by treatment, it's essential that you give up smoking. Smoking is especially harmful to those who've previously had chemotherapy and it'll increase your risk of developing a new, second cancer or lung problems in the future.

Vaccination while taking TKIs

If you're taking TKIs, it's safe for you to have all killed (inactivated) vaccines, but you should discuss live vaccines with your specialist doctor (consultant).

Your doctor will recommend that you have a yearly flu vaccine to protect you from potential serious complications of flu; they may also advise you to have the pneumococcal vaccine. If that's the case, your healthcare team will be able to give you more information about this.

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

Work, education and home life

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 at the time when you're diagnosed so you can have time off when

you need to be at the hospital. If you have to stay in hospital for your treatment, or you're not well enough to go to work or college, you'll probably need to make a more formal agreement.

You might need to bring in written proof of your diagnosis from your healthcare team, which makes clear the effect your diagnosis and treatment could have on your ability to work or study.

Another thing you might want to consider is taking time out from work during your treatment. You may receive varying advice on this but it's entirely your decision, so consider discussing it with your healthcare team and thinking about the demands of the specific work you do. Similarly, if you're studying at college or university, you might want to think about whether you want to continue with your course or delay it for a short time.

If you're a parent or a carer, you might need support during your treatment. You might have unplanned stays in hospital, for example – it's helpful to have plans in place just in case.

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 in overnight) you might need to go to 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, speak to your team at the hospital or a benefits advisor. The organisations signposted on the next page can also advise you.

Financial support

There are lots of places you can get help and advice if you're 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. These might be especially useful if you're on a low income or are unemployed. If you're worried ask to speak with 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, you can apply for a medical exemption certificate. This means you won't have to pay for prescriptions for anything you need because of your cancer or the effects of your cancer treatment. Application forms are available from your GP surgery or hospital clinic.



For information about help with travel and other costs relating to your treatment, go to **citizensadvice.org.uk** or **macmillan.org.uk** and search 'help with health costs'.

We have more information and practical tips about dealing with work and money when you have blood cancer at **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 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 and other types of blood cancer.

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

CML Support

An online patient support community for people with CML, their families and supporters.

- cmlsupport.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 blood stem cell and bone marrow register, matching donors to patients with leukaemia and other blood-related disorders who need a stem cell transplant.

- 0303 303 0303
- anthonymolan.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 terminally-ill patients in their own homes, free of charge.

- 0800 090 2309
- mariecurie.org.uk

MedicAlert

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

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

Cancer on Board

Supplies 'cancer on board' badges to people with cancer, to help make journeys via public transport a little more bearable.

- 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

Teenage Cancer Trust

Offers a range of information, advice and practical support for young people who have been diagnosed with cancer.

- 020 7612 0370
- hello@teenagecancertrust.org
- teenagecancertrust.org

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)
- 0344 477 2020 (Wales)
- in Scotland and 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

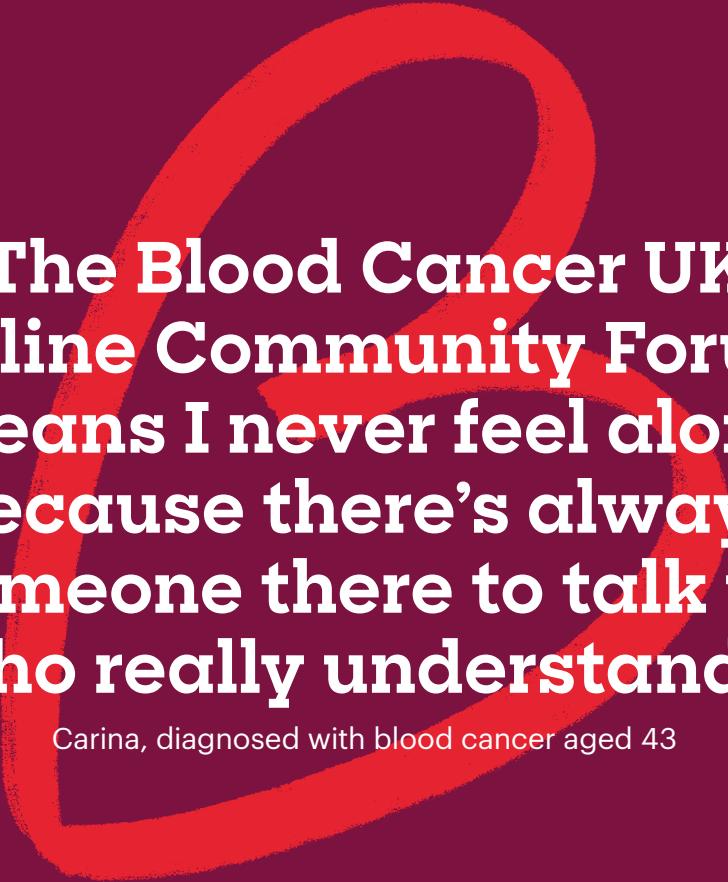
Provides information about what to consider when looking for travel insurance, along with recommendations from the Macmillan online community.

- 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



**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

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 them – for example, not eating beforehand?

How long will it take to get the results?

Who will explain them?

What is my exact diagnosis and what stage is the CML?

Treatment

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 has recommended?

Who do I contact if I feel unwell?

Who can I contact if I have any questions?

My main treatment

What type of treatment 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 course of drugs (regimen) will I be given? Will I be given it by mouth, injection or drip (into a vein)?

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

How long will my treatment last?

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 treatments and what options are available to address the risks?

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

Will I be able to carry on working or studying?

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

Will I need to change my meal times or plan my drugs around these?

Stem cell transplant

If I'm having a transplant, is a transplant an option for me?

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?

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 prognosis likely to change with more treatment?

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.

BCR-ABL1 fusion gene

The gene that forms when the BCR and ABL1 genes stick together because the body's cells haven't divided properly. It leads to the creation of a protein called tyrosine kinase, which is what stops the abnormal leukaemia cells from developing into healthy cells.

Blasts

Blood cells that haven't developed properly (immature blood cells). You'll have more blasts if the disease is more advanced.

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 that divide quickly, like those in the hair and gut. This is why some people lose their hair when they have high-dose chemotherapy.

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, myeloma, lymphoma 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.

Cytogenetic tests are carried out on samples of blood and bone marrow taken from people with leukaemia. They aim to find any 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 CML itself in the beginning, but once you've achieved a haematological, cytogenetic or molecular response, it's likely to be a side effect of treatment. It's one of the most common problems that people with cancer have. If you experience fatigue, your healthcare team should be able to offer guidance on helpful ways to manage it.

Granulocyte

A general term for white blood cells that contain granules (tiny, grain-like particles). Neutrophils, eosinophils and basophils are all types of granulocyte. It's these cells that don't develop properly in people with CML.

Immune system

The network of cells, tissues and organs that protect your body against infection.

Leukaemia

A type of blood cancer that's divided into many different subtypes: some that develop faster (acute), and others that develop more slowly (chronic). People with leukaemia have large numbers of abnormal white blood cells, which take over the bone marrow and often spill out into the bloodstream. Other areas that may be affected are lymph nodes, spleen, liver, testicles, the membranes surrounding the brain and spinal cord (meninges), gums and skin.

Lymph node or lymph gland

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

Genetic fault (mutation)

A small genetic change in the DNA of a cell. Mutations can happen following exposure to hazardous chemicals, or by copying mistakes when a cell divides. If the mutation affects the way cells normally work, it can lead to diseases like cancer.

Myeloid blood cells

A term for a group of cells including red blood cells, platelets and some types of white blood cells. Myeloid cells are affected in CML.

Philadelphia chromosome

An abnormal chromosome that forms when the BCR and ABL1 genes fuse together. Almost all CML patients have the Philadelphia chromosome.

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.

TKIs

Tyrosine kinase inhibitors (TKIs) are drugs used to treat CML. They act against the tyrosine kinase protein and stop CML cells from developing. Bosutinib, dasatinib, imatinib, nilotinib, and ponatinib are all examples of TKIs.

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

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 112**



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**

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

Notes



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!**

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.

gift aid it

*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**.

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 102)

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

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 CML/0119.1