Understanding chronic myeloid leukaemia

> “I had the bruising which was symptomatic of CML. It was absolutely a relief to be diagnosed in the end. I just thought at least there's a name for this, so there must be some sort of treatment.”

Andrea, diagnosed with chronic myeloid leukaemia

About this booklet

This booklet is about chronic myeloid leukaemia (CML). It is for anyone who has been diagnosed with CML. There is also information for carers, family members and friends.

The booklet explains how CML is treated. It also has information about looking after yourself and getting support. We hope it helps you deal with some of the questions or feelings you may have.

We cannot give advice about the best treatment for you. You should talk to your doctor, who knows your medical history.

How to use this booklet

This booklet is split into sections to help you find what you need. You do not have to read it from start to finish. You can use the contents list to help you.

It is fine to skip parts of the booklet. You can always come back to them when you feel ready.

On pages 84 to 95, there are details of other organisations that can help.

There is also space to write down notes and questions for your doctor or nurse.

Quotes

In this booklet, we have included quotes from people who have had CML, which you may find helpful. These are from people who have chosen to share their story with us. This includes Andrea, who is on the cover of this booklet. To share your experience, visit macmillan.org.uk/shareyourstory

For more information

If you have more questions or would like to talk to someone, call the Macmillan Support Line free on **0808 808 00 00**, 7 days a week, 8am to 8pm, or visit macmillan.org.uk

If you would prefer to speak to us in another language, interpreters are available. Please tell us, in English, the language you want to use.

If you are deaf or hard of hearing, call us using Relay UK on **18001 0808 808 0000**, or use the Relay UK app.

We have some information in different languages and formats, including audio, easy read, Braille, large print, interactive PDFs and translations. To order these, visit macmillan.org.uk/otherformats or call **0808 808 00 00**.

Contents

The blood and leukaemia

What is leukaemia?

Leukaemia is a cancer of the white blood cells. People with leukaemia usually have more or fewer white blood cells than normal. These leukaemia cells act differently from healthy white blood cells.

The 4 main types of leukaemia are:

- acute lymphoblastic leukaemia (ALL)
- acute myeloid leukaemia (AML)
- chronic myeloid leukaemia (CML)
- chronic lymphocytic leukaemia (CLL).

Each type of leukaemia is different. We have separate information about these types of leukaemia. Visit macmillan.org.uk/cancer-types

The blood and bone marrow

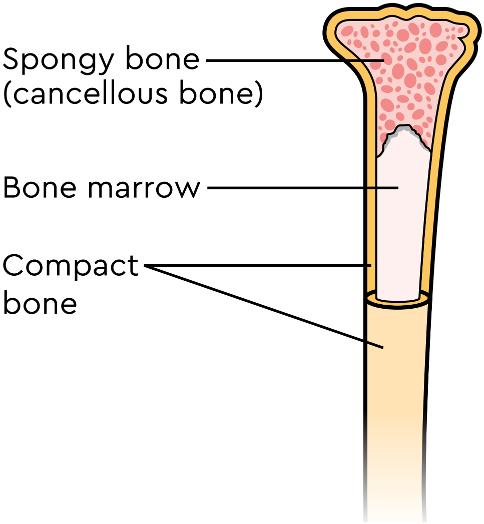
To understand chronic myeloid leukaemia (CML) and its treatment, it can help to know more about the blood, how it is made and what it does.

Blood is made up of blood cells, which move around in a liquid called plasma. Blood cells are made in the bone marrow. The bone marrow is the spongy material in the middle of our bones. Most blood cells are made in the:

- back of the hip bones (pelvis)
- backbone (spine)
- breastbone (sternum).

The bone marrow makes billions of new blood cells every day to replace old and aging blood cells.

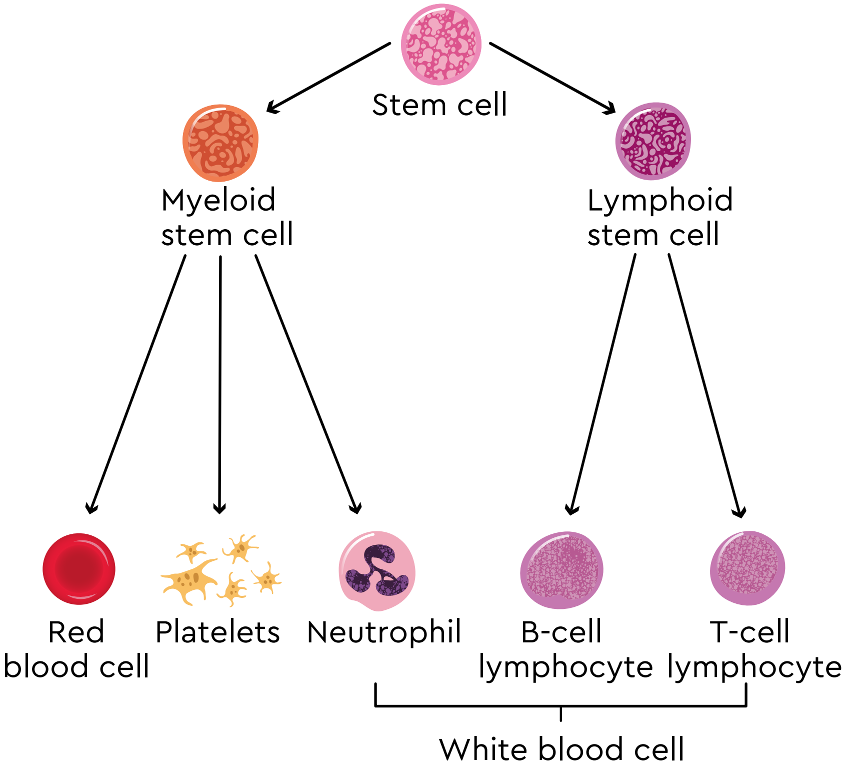
Bone marrow



All blood cells are made from blood stem cells. These are blood cells at the earliest stage of their development. Blood stem cells develop into the following 2 types:

- Lymphoid stem cells make white blood cells called lymphocytes.
- Myeloid stem cells make all the other types of blood cell. These include red blood cells, platelets and other white blood cells, such as neutrophils.

How blood stem cells divide



Blood cells go through different stages of development before they are ready to leave the bone marrow. All blood stem cells develop into immature cells. These are called blast cells. They then develop into mature red blood cells, platelets or white blood cells.

When blood cells are fully developed, they are released into the blood to carry out different functions:

- Red blood cells contain haemoglobin (Hb), which carries oxygen from the lungs to all parts of the body.
- Platelets help the blood to clot and prevent bleeding and bruising.
- White blood cells fight and prevent infection. There are different types of white blood cell. The most important are neutrophils and lymphocytes.

The levels of these cells in your blood are measured in a test called a full blood count (FBC). The table below gives an idea of the normal ranges for certain blood cells in a healthy adult.

Types of blood cell	**Levels found in a healthy person**
Red blood cells – measured in haemoglobin (Hb) levels	130 to 180g/L of Hb in men 115 to 165g/L of Hb in women
Platelets	150 to 400 × 10^9/L
White blood cells (WBC)	4.0 to 11.0 × 10^9/L
Neutrophils	2.0 to 7.5 × 10^9/L
Lymphocytes	1.5 to 4.5 × 10^9/L

These numbers can differ slightly between hospitals. Your doctor or nurse can tell you the normal ranges they use. The levels can also vary between people based on their age, ethnic background or biological sex (male or female).

The numbers might look complicated when written down, but doctors and nurses talk about them in a way that is easy to understand.

For example, you will hear them saying things such as, 'Your haemoglobin is 140' or 'Your neutrophils are 4'.

Most people with CML quickly get used to these numbers and what they mean. But if you do not understand, you can always ask your healthcare team to explain in more detail.

Your doctors will look at how your blood test results change over time. This helps them know if you need treatment, and what type you should have.

Chronic myeloid leukaemia (CML)

CML is a cancer of the white blood cells. It starts to develop in blood stem cells in the bone marrow. It causes early white blood cells to become abnormal. CML usually develops very slowly.

About 830 people in the UK are diagnosed with CML each year. It can affect people at any age, but it is more common as people get older. For many people, it can be well controlled and it will not shorten their life.

How CML develops

CML develops because of a genetic change in the stem cells. This change stops them developing into normal myeloid cells. Knowing how CML develops can help you understand the information about:

- having tests for CML
- treatment for CML.

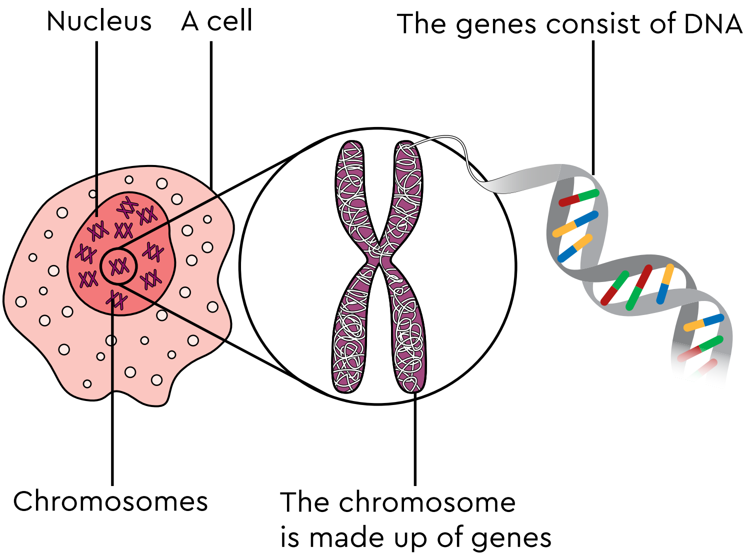
It might help to read this information more than once. Do not worry if it is too much to take in. It is fine to come back to it another time. You can ask your consultant or clinical nurse specialist to explain anything you do not understand.

You can also talk to one of our cancer information nurse specialists by calling our support line on **0808 808 00 00**.

Genes and chromosomes

All cells have a nucleus that contains structures called chromosomes. Most cells in the body contain 23 pairs of chromosomes. Chromosomes are made up of DNA, which has a set of instructions that tell them how to behave. These instructions are called genes.

Genes and chromosomes



The BCR-ABL1 gene

New cells are made when 1 cell divides into 2. Before a cell divides, it makes a copy of all the instructions stored in the genes on the chromosomes. CML develops when something goes wrong during this copying process.

A gene called ABL1, which is on chromosome 9, gets stuck to a gene called BCR on chromosome 22. They combine to make a new abnormal gene called BCR-ABL1. This is called a fusion gene.

This new BCR-ABL1 gene gives instructions to the CML cell to make too much of a substance called tyrosine kinase. Too much tyrosine kinase can cause the bone marrow to make too many white blood cells. It also stops these cells developing into normal white blood cells or dying when they should. These abnormal cells are the CML cells.

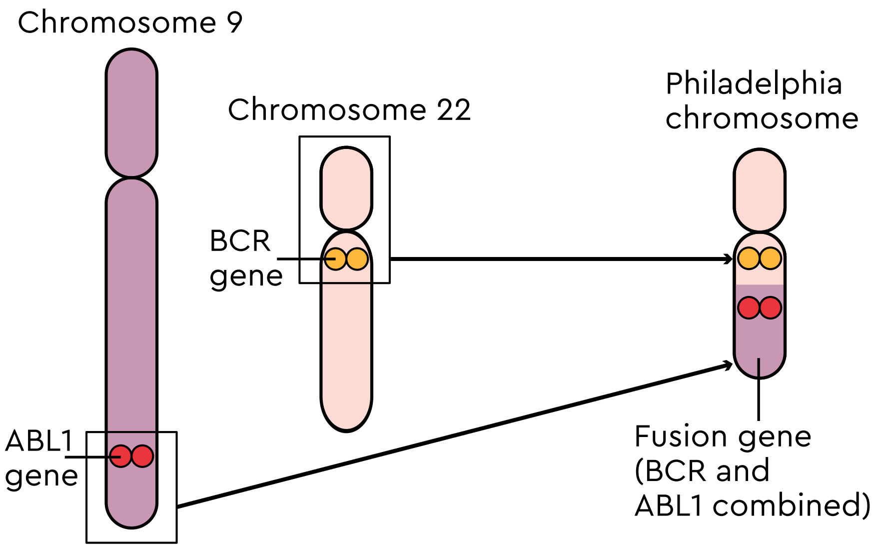
The Philadelphia (Ph) chromosome

When the BCR-ABL1 gene forms on chromosome 22, it changes how the chromosome looks. Scientists can see it when they look at the leukaemia cells under a special microscope. They call it the Philadelphia chromosome. You are not born with this. If you have children, it cannot be passed on to them.

Most people with CML have the Philadelphia chromosome in all the leukaemia cells. It is only in the leukaemia cells. In fewer than 5 in 100 people with CML , the Philadelphia chromosome cannot be seen in bone marrow samples. But tests on the leukaemia cells can be used to find the BCR-ABL1 fusion gene.

Rarely, some people develop a different type of leukaemia called atypical chronic myeloid leukaemia (aCML). It does not have the BCR-ABL1 gene and is treated differently to CML. Leukaemia Care has more information about aCML.

How the Philadelphia chromosome develops



> **I went back for the genetic test. The Philadelphia gene is not hereditary.**
>
> Andrea

Finding out you have CML

Being diagnosed with chronic myeloid leukaemia (CML) can cause many different emotions. There is no right or wrong way to feel. You may have been worrying about having cancer for a while. Or your diagnosis may have been unexpected. Having tests and waiting for test results can be a difficult time.

This information is written for people who have already been diagnosed with CML. We have more information about the possible causes, risk factors and symptoms of CML , and about how CML is diagnosed at macmillan.org.uk/cml

You may be worried about telling people or what treatment you will have. You might choose to spend some time reading about CML. Or you may prefer to wait until you meet with your cancer doctor. Do what feels right for you.

If you need support, you can contact our cancer support specialists on **0808 808 00 00**. They will be able to talk to you about what has happened and any worries you have.

Your data and the cancer registry

When you are diagnosed with cancer, some information about you, your diagnosis and your treatment is collected in a cancer registry.

The information is used to help understand cancer in the UK better. This is important for planning and improving health and care services. It can be used to ensure that people living with cancer get the best possible care and support.

Hospitals automatically send information to the cancer registry. There are strict rules about how the information is stored, accessed and used. Information about health is sensitive, so by law it has to be kept under the highest levels of security.

If you have any questions, talk to your doctor or nurse. If you do not want your information included in the registry, you can contact the cancer registry in your country to opt out.

Planning treatment for CML

Phases of CML

The treatment you have depends on the phase of chronic myeloid leukaemia (CML). CML usually develops slowly. The 3 phases of CML are the:

- chronic phase
- accelerated phase
- blast phase.

Doctors know the phase of CML from:

- the number of immature blood cells (blast cells) in your blood and bone marrow
- your symptoms.

Most people are diagnosed when CML is in the chronic phase.

Chronic phase

When CML is in the chronic phase, there may be no symptoms. Most people can live a normal life. Treatment is tablets you can take at home. You have regular blood tests to check how well the treatment is working.

For most people, the leukaemia can be well controlled for as long as treatment continues.

In the chronic phase, fewer than 15 in 100 blood cells in the blood or bone marrow (15%) are blast cells.

Accelerated phase

In a small number of people, the leukaemia may go from the chronic phase to the accelerated phase. This can happen if the CML does not respond well to treatment. Sometimes people are diagnosed with CML in the accelerated phase.

In the accelerated phase, fewer than 20 in 100 blood cells in the blood or bone marrow (10% to 19%) are blast cells.

In this phase, there are more blast cells in the blood or bone marrow. You may also develop some of the more common symptoms of CML. If you feel unwell or develop new symptoms, tell your doctor.

Blast phase

For some people, CML in the accelerated phase may go into the blast phase. Rarely, people are diagnosed with CML in the blast phase. Or the leukaemia may change straight from the chronic phase to the blast phase.

The blast phase is like an acute leukaemia. In this phase, more than 20 in 100 blood cells in the blood or bone marrow (20%) are blast cells. The blast phase is sometimes called blast crisis.

You will likely develop symptoms because the bone marrow is not making enough healthy blood cells.

We have more information about symptoms of CML on our website. Visit macmillan.org.uk/cml

Relapse

Relapse means the leukaemia cells have come back after a time in remission (where there are no signs of leukaemia cells). In CML, this is usually found using the PCR test. We have more information on our website. Visit macmillan.org.uk/cml

Risk score

As well as the phase of CML, your cancer doctor will calculate your risk score. This can help them to plan the best treatment for you.

Risk scores are based on:

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

Depending on the risk score, people with CML can be grouped into 3 risk groups:

- low
- intermediate
- high.

Knowing the risk group can give your haematologist an idea of how likely the CML is to respond well to treatment.

Most people with CML respond to tyrosine kinase inhibitor drugs (TKIs) regardless of their risk score.

Treatment overview

Chronic myeloid leukaemia (CML) usually develops very slowly, over several years.

The aim of treatment is to put CML into remission and keep it in remission. This means there are no signs of CML in your PCR blood test, and you feel well. There are different levels of remission.

Treatments for CML are very effective. Remission can usually be maintained for many years. For most people, CML can be well controlled and it will not shorten their life.

Types of treatment

Most people with CML are treated with targeted therapies called tyrosine kinase inhibitors (TKIs). You take them as tablets or capsules every day. There are several TKIs for CML. Your doctors can usually change the TKI you have if the first one:

- does not work
- causes side effects that are difficult to manage
- stops working.

When you are first diagnosed, you may have a very high level of white blood cells in your blood. If this happens, you may be given chemotherapy tablets for a few days or weeks before starting TKI treatment. Sometimes chemotherapy is given into a vein (intravenously) along with a TKI. Some people have a treatment called leukapheresis to remove some white blood cells from the blood.

Your doctors may suggest chemotherapy followed by a stem cell transplant. This is sometimes called a bone marrow transplant. This might be if TKI treatment does not work,
or if you are diagnosed in the blast phase. A stem cell transplant is an intensive treatment that is not suitable for everyone.
It is not often used to treat CML.

How your treatment is planned

There are national and international guidelines for treating CML. Your treatment is based on these guidelines but will be adjusted for your situation.

A team of specialists work with you to plan your treatment. This is called the multidisciplinary team (MDT).

The MDT may include a:

- haematologist – a doctor who diagnoses and treats blood disorders and cancers
- clinical nurse specialist (CNS) – a nurse who gives information about cancer and support during treatment
- pathologist – a doctor who advises haematologists about any chromosome or genetic changes in the leukaemia cells
- radiologist – a doctor who looks at scans and x-rays to diagnose problems
- pharmacist – someone who gives out medicines and gives advice about taking medicines.

It may also include other professionals, such as a:

- dietitian
- physiotherapist
- occupational therapist
- psychologist
- counsellor.

After the MDT meeting, your haematologist will talk to you about your treatment options.

The MDT will consider many factors when recommending which treatments are likely to be best for you. These may include the phase of the CML and your general health.

You may be invited to take part in a clinical trial of a new treatment for CML.

Making decisions about treatment

If treatment has a good chance of putting the leukaemia into remission, you may find it easy to make your decision about having treatment. But sometimes it is more difficult. You may find it harder to decide what to do if a treatment has a:

- smaller chance of working
- higher risk of serious side effects.

Talking through the benefits and risks with your doctor will help.

We have more information in our booklet Making treatment decisions.

Giving your permission (consent)

Doctors need your permission (consent) before you have any treatment. They will give you all the information you need to make your decision. We explain this in our section on talking about your treatment plan.

You can give consent in writing when you sign a form that your doctor gives you, agreeing to a treatment. Or it can be a spoken agreement with your doctor. Your doctor records your consent in your patient notes.

You may decide not to have treatment even when your doctor advises you to have it. If you refuse treatment, your decision must be respected. But your doctor needs to make sure you have all the information you need to make your decision. You need to understand all your treatment options and what will happen if you do not have the treatment. Always talk to your doctor about any concerns you have, so they can give you the best advice.

We have more information about cancer treatment consent on our website. Vist macmillan.org.uk/treatment-consent.

Second opinion

A second opinion is an opinion from a different doctor about your treatment. If you think you want a second opinion, talk to your cancer doctor or GP first. Tell them your concerns or ask them to explain anything you do not understand. This might help reassure you.

If you still want a second opinion, you can ask your cancer doctor or GP to arrange it. They are usually happy to do this. You may have to travel to another hospital to get a second opinion. Getting a second opinion could delay your treatment. Check with your doctor if this delay could be harmful to you.

If the doctor you meet with for the second opinion gives you the same advice, this can reassure you. Sometimes they give you other treatment options to think about.

We have more information about getting a second opinion on our website. Visit macmillan.org.uk/second-opinion

Clinical trials – research

Clinical trials are a type of medical research involving people. They are important because they show which treatments are most effective and safe. This helps healthcare teams plan the best treatment for the people they care for.

Trials may test how effective a new treatment is compared to the current treatment used. Or they may get information about the safety and side effects of treatments.

Some trials help answer questions about treatments we already use. They may test whether combining treatments is more effective. Or they may research different ways to give a treatment so it works better or causes fewer side effects.

Clinical trials also research other areas of cancer care. These include diagnosis and managing side effects or symptoms.

Taking part in a clinical trial

Your cancer doctor or specialist nurse may talk to you about taking part in a clinical trial. Or you could ask them if there are any trials suitable for you.

Joining a trial is always your decision. If you join and then change your mind, you can leave at any time. You do not have to give a reason. Your healthcare team will support you whatever you decide. You will always have the standard treatment for the type and stage of cancer you have.

Not all hospitals have the expertise or resources to take part in certain trials. This means for some trials you may have to travel to a different hospital.

A research nurse or doctor will give you information about the trial. You can ask them any questions you have. It is important to understand what is involved before you agree (consent) to take part. They will explain the possible benefits and any possible risks of the trial. Clinical trials are designed with safety measures to keep any risks to you as low as possible.

Some trials involve collecting blood samples, or tissue samples from a biopsy. This often happens as a standard part of your treatment. But your research nurse or doctor will explain if they need to take extra samples for the trial.

Your samples can only be stored and used for research if you give your permission. Your name is removed from the samples before they are used. This means you cannot be identified.

We have more information about clinical trials on our website. Visit macmillan.org.uk/clinical-trials

Treating CML

Tyrosine kinase inhibitors (TKIs)

The main treatment for chronic myeloid leukaemia (CML) is a type of drug called tyrosine kinase inhibitors (TKIs).

TKIs are a type of targeted therapy. They work by switching off (inhibiting) the tyrosine kinase that is made by the BCR-ABL1 gene in the leukaemia cells. This stops the bone marrow from making abnormal white blood cells, or from making so many. It also allows the leukaemia cells to mature and die.

The TKI drugs used to treat CML come as tablets or capsules. You usually take them every day for as long as they are working. The 3 main TKI drugs currently used in the UK for people newly diagnosed with CML are:

- imatinib
- nilotinib
- dasatinib.

Imatinib is the most commonly used TKI.

Other TKI drugs are available, but less commonly used. These may be given if the first TKI you were given:

- does not work as well as expected
- causes severe side effects.

These TKI drugs include:

- bosutinib
- ponatinib
- asciminib.

Different drugs are used for different situations. Your haematologist will discuss which is best for you.

Although the TKIs are similar, they can have different side effects. To make sure the TKI you have is right for you, your haematologist will think about:

- how likely the CML is to respond
- any other health problems you have
- the possible side effects.

If TKIs stop working for you, you may be referred to a specialist CML centre. Your haematologist will talk to you about this if needed.

Before starting TKI treatment, your haematologist will arrange blood tests and heart tests to make sure it is safe for you to have TKIs. We have more information about each of these TKIs at macmillan.org.uk/treatments-and-drugs

Testing for HIV, hepatitis B and hepatitis C

Before you begin treatment with a TKI, you will have blood tests to check for:

- HIV – a virus that attacks the immune system
- hepatitis B and C – these are liver infections.

TKI treatment can affect your immune system and make hepatitis infections active again. Your doctor or nurse will talk to you about this before your blood tests.

Heart tests

TKIs can affect how your heart works. Before you begin treatment, you have tests to check how well your heart is working. This usually includes an electrocardiogram (ECG) to record the rhythm and electrical activity of your heart.

If you already have heart problems, your haematologist may refer you to a heart specialist before starting treatment.

Types of TKIs

You may have one of the following types of TKIs.

Imatinib (Glivec®)

Imatinib is the most commonly used TKI for CML. It can be used in any phase.

Nilotinib (Tasigna®)

Nilotinib can be used as a first treatment in the chronic phase.

It can also be used in any other phase if other TKIs are causing severe side effects or are not working to control the CML.

Dasatinib (Sprycel®)

Dasatinib can be used as a first treatment in the chronic phase. It can also be used in any phase if other treatments are causing severe side effects or are not working to control the CML.

Bosutinib (Bosulif®)

You might have bosutinib if other TKIs are causing severe side effects or are not working for you.

Ponatinib (Iclusig®)

Your doctors may prescribe ponatinib if you have leukaemia cells with a gene change (mutation) called T3151. Only a few people with CML have this gene change in their leukaemia cells.

You may also be offered ponatinib if other TKIs have stopped working, or if you had to stop taking them because of side effects.

Asciminib (Scemblix®)

Your doctor may prescribe asciminib if all of the following apply to you:

- you have chronic phase CML
- 2 or more TKIs stopped working for you or caused severe side effects
- there is no change in the T3151 gene.


NHS
NHS

Side effects of TKIs

The side effects of TKIs are usually mild and treatable. Side effects are often more noticeable when you first start treatment and may get better over time.

If you have severe side effects, your doctor may ask you to stop taking the drug for a few days. After a short break, you may be able to start taking it again without having the same problems. Sometimes, people need to stop treatment with the TKI they are taking because their side effects are too severe. If this happens, you will usually be offered a different TKI drug.

Sometimes a new side effect can develop many months after starting treatment. Always tell your doctor if you notice any new symptoms or your side effects get worse. Your symptoms may not be related to CML or your treatment, but you should always check with your doctor.

Each TKI has slightly different side effects, so it is best to read specific information about the drug you are having. We have more detailed information about the different TKIs. We have listed some possible side effects of TKIs below.

Tiredness and feeling weak (fatigue)

This is a common side effect, but it is usually mild. Try to have rest periods with regular, gentle exercise. This can help reduce tiredness.

Feeling sick (nausea)

This is usually mild. Your doctor may give you anti-sickness drugs to prevent or reduce it. If you still feel sick, tell your doctor. They can give a different anti-sickness drug that may work better for you.

Diarrhoea

If you have diarrhoea, contact the hospital for advice. Try to drink at least 2 litres (3½ pints) of fluids every day. It can help to avoid:

- alcohol
- caffeine
- milk products
- high-fat foods
- high-fibre foods.

Your doctor or nurse may give you anti-diarrhoea drugs to take at home. The diarrhoea can usually be controlled with these medicines. But it is very important to tell your doctor if it is severe, or if it continues.

Your doctor may ask you to stop taking your treatment. When the diarrhoea is better, they will tell you whether you can start taking it again. Sometimes they reduce the dose.

Loss of appetite

A dietitian or specialist nurse can give you advice and tips on:

- improving your appetite
- coping with eating difficulties
- maintaining your weight.

Headaches

Tell your doctor if you have headaches. They can advise you on which painkillers to take.

Mood changes and problems sleeping

Treatment can affect your mood. It can also cause difficulty sleeping. Tell your doctor or nurse if you have any of these side effects.

Changes in the way your heart works

Some TKI drugs can affect the way your heart works. Your doctor or nurse may organise tests to check your heart before you start treatment. Tell your doctor straight away if you:

- have pain or tightness in your chest
- feel breathless or dizzy
- feel your heart is beating too fast or too slowly
- feel that your heartbeat is irregular.

Keeping to a healthy weight and not smoking can help keep your heart healthy.

Fluid retention

This can affect different parts of the body. Your ankles may swell, or you may get swelling around the eyes. This often gets better without needing treatment. If it does not get better, your doctor may give you a drug that makes you pass more urine (pee), called a diuretic. This can help get rid of some of the fluid.

Build-up of fluid in the lining of the lungs

Some TKIs, particularly dasatinib, can cause fluid to build up in the lining around the lungs. This is called a pleural effusion. If this happens, your doctor may ask you to stop taking it for a short time until the fluid goes away. Or they may prescribe medicine to help.

Tell your doctor if you:

- feel breathless
- have chest pain
- develop a cough.

Muscle, bone and joint pains

You may get some pain in your muscles, bones or joints. Your doctor can give you painkillers to help.

Skin changes

Your skin may become dry and itchy. Some people develop a skin rash. This is usually mild, but for some people it can be more severe.

Increasing the amount of fluids you drink can help with dryness and itching. Your doctor can also give you medicine or creams to help.

Constipation

If you are constipated, it usually helps to:

- drink plenty of fluids
- eat a high-fibre diet
- do regular, gentle exercise.

Sometimes you may need to take a medicine called a laxative. Your doctor can give you these.

Changes in the way your liver works

Some TKIs can affect the way your liver works. This is usually mild. Your doctor or nurse will take regular blood samples to check how well your liver is working.

Effect on blood cells

Sometimes TKIs can reduce the number of blood cells in your blood. Your blood count will be checked regularly while you are having treatment. If your blood cell numbers are too low, your doctor may stop your treatment for a few days to let them recover.

Risk of infection

TKIs can reduce the number of white blood cells in your blood. These cells fight infection. If the number of white blood cells is low, you are more likely to get an infection. A low white blood cell count is called neutropenia.

You will have regular blood tests. If your white blood cell count is low, your doctor may delay your treatment for a short time.

If you have an infection, it is important to treat it as soon as possible. If you have any of the following symptoms, contact the hospital straight away on the 24-hour number:

- a temperature above 37.5°C
- a temperature below 36°C
- you suddenly feel unwell, even with a normal temperature
- you have symptoms of an infection.

Symptoms of an infection include:

- feeling shivery and shaking
- a sore throat
- a cough
- breathlessness
- diarrhoea
- needing to pass urine (pee) often, or discomfort when you pass urine.

It is important to follow any specific advice your cancer treatment team gives you.

Rarely, some people are given injections of a growth factor called G-CSF. This can stimulate the bone marrow to make healthy white blood cells.

Bruising or bleeding

TKIs can reduce the number of platelets in your blood. Platelets are cells that help the blood to clot. Tell your doctor if you have any unexplained bruising or bleeding. This may include:

- nosebleeds
- bleeding gums
- blood spots or rashes on the skin.

They will tell you about this and explain any precautions you should take.

Anaemia (low number of red blood cells)

You may become anaemic. This can make you feel tired and breathless. Tell your doctor or nurse if you feel like this. If your red blood cell count is too low, you may need a drip to give you extra red blood cells. This is called a blood transfusion.

Rarely, people are given injections of a growth factor called erythropoietin. This can help increase the number of red blood cells made by the bone marrow.

Fertility and pregnancy

Because TKIs are a newer type of drug, there is limited information about becoming pregnant or getting someone pregnant while taking them. But TKIs are not thought to affect your ability to become pregnant or make someone pregnant. This is called your fertility.

If you might want children in the future, talk to your doctor about this as early as possible. If you can, talk about it before starting treatment. They may refer you to a specialist CML unit or fertility expert. They can talk to you about the possible options for planning your treatment.

Taking a TKI during pregnancy increases the risk of harm to a developing baby. Because of this, you are strongly advised to use contraception while being treated with a TKI.

If you think you may have become pregnant while taking a TKI, tell your doctor as soon as possible. This is because the highest risk to the baby is during the first few weeks of the pregnancy. Your doctor can talk to you about the possible options for planning your treatment and controlling the CML. They will aim to make things as safe as possible for you and the baby.

Monitoring response to TKI treatment

When you first start treatment with a tyrosine kinase inhibitor (TKI), you will be monitored by your healthcare team every 1 to 2 weeks.

At these check-ups, your doctor will:

- ask about your general health
- ask about any new symptoms or side effects of treatment
- do a blood test to check the numbers of blood cells – this is called a full blood count (FBC).

Your doctor will do a polymerase chain reaction (PCR) blood test to check for leukaemia cells every 3 months to start with. If you have a good response to TKI treatment, this may be done less often.

Sometimes they may take a bone marrow sample. Your doctor can tell you how often you might need this. If you were diagnosed in the chronic phase, you will not usually need another bone marrow sample taken. This is because PCR testing is very effective in checking how much leukaemia is present.

These test results help your doctors know how well the treatment is working. They will also check for any side effects and make any changes if needed.

As time goes on, you will not need to meet with your doctors as often. Eventually, you may only need a check-up every 3 to 6 months.

We have more information about these tests on our website.
Visit macmillan.org.uk/cml

Levels of response

The aim of treatment is to put the CML into remission. This means there are low levels or no signs of CML in your blood during a standard blood test. It does not mean the leukaemia has completely gone. You will need to keep taking treatment to keep the leukaemia in remission. Because there are still leukaemia cells, your doctors may use the word response instead of remission.

There are different levels of response. These are based on the results of different tests that look at how leukaemia cells respond to treatment.

Your doctors will regularly monitor your response to treatment. This is to check how well it is working for you. We explain the different levels of response below.

Haematological response

This is the first level of response to treatment. It is measured with a full blood count (FBC).

When you first develop CML, the number of white blood cells in your blood is usually high. If there is a complete haematological response, it means:

- your FBC has gone back to normal
- the doctors cannot see any leukaemia cells
- if your spleen was large before starting treatment, it has gone back to a normal size.

Most people get a complete haematological response within 3 months of starting a TKI. Although your blood counts are normal, there may still be leukaemia cells that cannot be detected by an FBC.

Cytogenetic response

This refers to the amount of Philadelphia chromosome in the bone marrow and blood. It involves having a bone marrow sample taken. As your treatment starts working, the number of Philadelphia chromosome-positive (Ph+) cells in your bone marrow reduces. A complete cytogenetic response means there are no Ph+ cells in the bone marrow sample. It takes longer to get a cytogenetic response than a haematological response.

Very few people need another bone marrow biopsy. You only have this done if your doctor thinks it would be useful in your situation.

> **"I'm lucky to be in full remission with zero blood count for the Philadelphia gene for nearly a year now."**
>
> Andrea, diagnosed with CML

Molecular response

Molecular response is the standard way of measuring your response to treatment. It uses the PCR test, which is very sensitive for finding leukaemia cells. This is important because there may only be 1 leukaemia cell among many thousands of normal blood cells.

There are different levels of molecular response:

- **MR2** means there is fewer than 1 leukaemia cell in every 100 white blood cells (fewer than 1%). This response is usually equal to a complete cytogenetic response.
- **MR3** or major molecular response (MMR) means there is fewer than 1 leukaemia cell in every 1,000 white blood cells (fewer than 0.1%).
- **MR4** or deep molecular response (DMR) means there is fewer than 1 leukaemia cell in every 10,000 white blood cells (fewer than 0.01%).
- **MR4.5** means there is fewer than 1 leukaemia cell in every 32,500 white blood cells (fewer than 0.003%).
- **MR5** means there is fewer than 1 leukaemia cell in every 100,000 white blood cells (fewer than 0.001%).

Continuing with treatment

You will need to keep taking the TKI for as long as it is controlling the leukaemia. This is important, even if your PCR tests show very low levels of leukaemia.

Regularly missing a dose of TKI can affect how well the CML responds to treatment. Research has shown that missing as few as 3 doses a month lowers your chances of getting the best response to treatment.

The following tips may help you remember to take your treatment every day:

- Take your tablets or capsules at the same time each day.
- Set a daily reminder on your mobile phone.
- Put your tablets or capsules in a place where you will notice them every day – but keep them out of sight and reach of children.
- Mark off each dose you take on a calendar.
- Keep a supply of tablets or capsules with you when you travel and take your medicine in your carry-on luggage when you fly.

Your prescriptions will be organised through the hospital, so you may have to go there to collect the treatment each time you need more. If it is difficult for you to get to the hospital, tell your doctor, nurse or pharmacist.

Treatment-free remission

Clinical trials have shown that some people who have been taking TKI drugs for a few years and had a good response may be able to stop TKI treatment. This is called treatment-free remission. If your TKI treatment is stopped, you will be closely monitored so that treatment can be started again if needed. Your doctor can tell you more about this.

Chemotherapy for CML

Most people with chronic myeloid leukaemia (CML) are treated with targeted therapy drugs called tyrosine kinase inhibitors (TKIs). But sometimes, chemotherapy is also given. It can be given on its own or in combination with a TKI.

Chemotherapy uses anti-cancer (cytotoxic) drugs to destroy or damage leukaemia cells. It works by disrupting the way leukaemia cells grow and divide.

Chemotherapy may be given:

- while you are waiting for test results to confirm you have CML
- with a TKI to treat CML in the blast phase
- if the CML has not responded to TKI treatment
- before a stem cell transplant.

Low-dose chemotherapy capsules

Some people may be given low-dose chemotherapy if the number of white blood cells is very high when they are first diagnosed with CML.

The most commonly used chemotherapy drug for CML is hydroxycarbamide. We have more information about hydroxycarbamide at macmillan.org.uk/treatments-and-drugs This can help to reduce very high numbers of white cells in the blood when the CML is in the chronic or accelerated phase.

You take this as capsules that you swallow. Your doctor, nurse or pharmacist will talk to you about this treatment and its possible side effects before you agree (consent) to have treatment.

Combination chemotherapy

If the CML is in the blast phase, you may be given a combination of chemotherapy drugs. This usually involves a nurse giving you 3 or 4 chemotherapy drugs into a vein (intravenously).

The most common combination drug treatment is called FLAG-Ida. This name uses the initials of the drugs used:

- fludarabine (Fludara®)
- cytarabine (Ara C)
- G-CSF (granulocyte-colony stimulating factor)
- idarubicin (Zavedos®).

G-CSF is not a chemotherapy drug. It is a type of protein called a growth factor that increases the number of white blood cells in the blood.

FLAG-Ida is usually given with a TKI. We have more information about FLAG-Ida and all the chemotherapy drugs mentioned here at macmillan.org.uk/treatments-and-drugs

High-dose chemotherapy

People who are treated with a stem cell transplant will have intensive, high-dose chemotherapy for several days before the transplant. This process is called 'conditioning' of the bone marrow.

Side effects of chemotherapy

If you are taking a single chemotherapy tablet, the side effects are usually mild.

Treatment with a combination of 2 or more chemotherapy drugs may cause more severe side effects. Your doctor, nurse or pharmacist will tell you what to expect.

We have more information about each type of chemotherapy, its side effects and how to help manage these at macmillan.org.uk/treatments-and-drugs

The more common side effects of chemotherapy include:

- feeling sick
- risk of infection, because of a lower number of white blood cells
- bruising and bleeding, because of a low number of platelets
- anaemia (a low number of red blood cells)
- a sore mouth
- changes to your bowel function (constipation or diarrhoea)
- tiredness (fatigue)
- hair loss
- numb or tingling hands or feet
- changes to fertility.

Stem cell transplants

You may be offered a stem cell transplant if:

- the CML is in the blast phase
- treatment with TKIs is not controlling the CML.

If your doctor thinks a stem cell transplant may be appropriate for you, they will discuss it with you in more detail. Stem cell transplants are only done in specialist cancer treatment centres. A stem cell transplant may cure some people with CML or put the CML into remission.

A stem cell transplant allows you to have much higher doses of chemotherapy.

If you have a stem cell transplant for CML, you will usually have stem cells from someone else who is a match for you (a donor). This is called a donor stem cell transplant or an allogeneic stem cell transplant.

A donor stem cell transplant aims to replace bone marrow that is no longer working properly with healthy stem cells from another person.

You have chemotherapy and sometimes other treatments, such as targeted therapy. You may also be given radiotherapy to your whole body. This is also called total body irradiation. These treatments:

- get your body ready to accept the donor stem cells
- weaken your immune system to try and stop it attacking the donor stem cells
- remove any remaining leukaemia cells from your body.

You are then given the donor's stem cells through a drip (infusion).

A donor stem cell transplant is a complex treatment. We have some information on this our website. Visit macmillan.org.uk/stem-cell
You can find out more on the Anthony Nolan website.
This includes information about side effects, such as graft versus host disease.

Removing white blood cells from the blood (leukapheresis)

Some people have a very high number of white blood cells in their blood when they are diagnosed with chronic myeloid leukaemia (CML). These cells can gather in the blood vessels and cause symptoms such as:

- breathlessness
- headaches
- blurred vision.

Doctors can remove some white blood cells from the blood using a machine called a cell separator. This process is called leukapheresis.

During leukapheresis, you lie on a bed or reclining chair. A small plastic tube (cannula) is put in a vein in each arm. Each cannula is connected to the cell separator by a tube. Blood goes from the arm through the tube into the cell separator.

As the blood travels through the cell separator, the machine removes the white blood cells. The rest of the blood and blood cells are then returned to the body through the cannula in the other arm. This takes a few hours.

Leukapheresis is painless, but some people may find it uncomfortable having the cannula put in.

If you are pregnant and have a high number of white cells in your blood, your haematologist might talk to you about having leukapheresis. This can be done to improve your symptoms and is safe to use during pregnancy.

Targeted therapy drugs called tyrosine kinase inhibitors (TKIs) are usually used to treat CML, but these should be avoided during pregnancy. This is because they can increase the risk of harm to a developing baby. After the baby is born, you can start treatment with a TKI. Your haematology team can give you more information about this.

Interferon alpha

Interferon alpha is a protein that the immune system normally makes to help fight infection. Scientists can make this protein in the laboratory and use it as a treatment. In people with CML, it may help stop the bone marrow from producing too many white blood cells.

If other treatments have not worked, some people may be given interferon alpha in the chronic phase of CML.

Interferon alpha and pregnancy

Doctors may also use interferon alpha for people who need CML treatment and are planning to get pregnant, or are already pregnant. Your doctor will talk to you about the possible benefits of this treatment and any possible risks to the developing baby.

Some doctors may recommend switching from interferon alpha to a TKI in the last 3 months of pregnancy. But this will depend on your situation. Your doctor will talk to you about what treatment may be right for you.

If you are planning to become pregnant, you should discuss this with your doctor. If you are pregnant, you should tell your doctor straight away.

How interferon alpha is given

You have interferon alpha as an injection under the skin using a very fine needle. You or a family member or friend can be taught how to give these injections, so you can have them at home.

Side effects

Interferon alpha can cause different side effects. Some are like the symptoms of flu. They include:

- chills
- fever
- depression
- weight loss
- feeling sick
- headaches
- aching in the back, joints and muscles
- tiredness.

Some of these side effects can be reduced by taking a mild painkiller, such as paracetamol, before the injection. Your doctor can give you more advice.

The side effects are most noticeable with the first and second injections. They usually improve after that, but the tiredness may continue.

Life with CML

Living with CML

Most people with chronic myeloid leukaemia (CML) have a normal life expectancy. To help you stay as well as possible, you may want to make changes to your lifestyle. Even if you had a healthy lifestyle before your diagnosis, you may want to make the most of your health.

A healthy lifestyle does not have to be difficult or expensive. It is about making small changes to the way you live. This will improve your health and sense of well-being. It will also lower your risk of getting other illnesses and some other cancers.

A healthy lifestyle includes:

- having a well-balanced diet
- being physically active
- reducing stress
- being involved in your healthcare.

When planning changes to your life, think about any side effects of your treatment. Try to avoid doing too much, too soon.

Eat well and keep to a healthy weight

A well-balanced diet should include:

- plenty of fresh fruit and vegetables – aim to eat at least 5 portions a day
- foods high in fibre, such as beans and cereals
- plenty of water or other non-alcoholic drinks.

You should also try to reduce your intake of:

- red meat and animal fats
- alcohol
- salted, pickled and smoked foods.

We have more information in our booklet Healthy eating and cancer.

Stop smoking

If you smoke, speak to your cancer doctor, nurse or GP for advice. Or you can contact your local stop smoking service for further advice. We have more information about stopping smoking at macmillan.org.uk/stop-smoking

Reduce stress

There are different ways of reducing stress. Try to take some time for yourself to do something you find relaxing. You might decide to start doing a new hobby or type of exercise. You could try learning relaxation techniques or a complementary therapy such as massage. We have more information in our booklet Cancer and complementary therapies.

Some people find it helpful to talk about their feelings, or have contact with other people who have been through a similar experience. Others find it helpful to write a journal or blog. We have more information in our booklet How are you feeling? The emotional effects of cancer.

Get physically active

Physical activity can improve your sense of well-being and help build up your energy levels. It reduces the risk of heart disease, strokes, diabetes and bone thinning (osteoporosis). Physical activity does not have to be difficult. You can start gently and increase the amount you do. We have more information in our booklet Physical acitivty and cancer.

Get involved in your healthcare

This includes taking your medicines as prescribed and always going to your hospital appointments. If you have any problems or notice any new symptoms between your appointments, tell your doctor as soon as possible.

Understanding more about CML and its treatment can also help you. This means you can discuss treatment, tests and check-ups with your doctors and nurses. It also means you can be involved in making decisions. This can make you feel more confident and more in control.

“I have made sure I exercise and I continued to walk my dog. I danced and had a little time off my teaching job. I believe exercise can help everyone. At best it prevents more drugs being prescribed which have their own side effects. It also keeps the anxiety and depression at bay. „

Andrea

Self-help and support groups

Talking about your feelings can help reduce stress, anxiety and isolation. There are lots of different ways to communicate, and they can all help people feel less alone.

Self-help or support groups can help you talk to other people who may be in a similar situation and facing the same challenges as you. Joining a group can be helpful if you live alone, or if you find it difficult to talk about your feelings with friends or family.

Not everyone finds it easy to talk in a group, so it might not be for you. You could try going to a support group to discover what it is like before you decide.

For information about leukaemia support groups across the UK, visit macmillan.org.uk/supportgroups or call us on **0808 808 00 00**.

Online support

Many people now get support on the internet. For people affected by leukaemia there are:

- online support groups
- social networking sites
- forums
- chat rooms
- blogs.

You can use these to ask questions and share your experience.

Our Online Community is a social networking site where you can talk to people in our chat rooms, blog about your journey, make friends and join support groups. We have a forum for people affected by CML in our Online Community that you may find helpful. For more information visit macmillan.org.uk/community

Your feelings

It is common to have many different feelings when you are told you have leukaemia. You may feel shocked, scared, depressed, guilty or angry. This can be difficult to cope with. Partners, family and friends may also have some of the same feelings.

We have more information about emotions on our website and in our booklet How are you feeling? The emotional effects of cancer.

Your healthcare team will usually give you support. But you may feel you need more help. Talk to your cancer doctor, GP or specialist nurse. They can refer you to a specialist doctor, psychologist or counsellor who can help.

You can also call the Macmillan Support Line on **0808 808 00 00** and talk to one of our cancer support specialists.

Talking to family, friends or other people affected by cancer may help. For more information or for help finding local support groups, visit macmillan.org.uk/supportgroups Or talk to other people on our Online Community at macmillan.org.uk/community

There is more information about other ways we can help you.

> “I also went with my emotions and listened to my body and head. If I needed to cry I did, If I needed to be upset and angry at the world I was. Whatever emotion I had, I went with it.„

Kiwi, diagnosed with CML

Relationships

Leukaemia and its treatment are stressful and may affect your relationships. Your experience of leukaemia may strengthen your relationships with people close to you. Or it may put a strain on relationships. Any problems usually improve over time, especially if you talk openly with each other.

We have more information about relationships online and in our booklets:

- Talking about cancer
- Cancer and relationships: support for partners, families and friends.

If you are a family member or friend

If you know someone with leukaemia, you might find it hard to talk about the leukaemia, or your feelings. You can support the person with leukaemia by listening and talking with them.

We have more information about supporting someone on our website and in our booklet Talking with someone who has cancer.

If you are looking after a family member or friend with leukaemia, you may be a carer. We have more information and practical tips for carers on our website and in our booklet Looking after someone with cancer.

Talking to children and teenagers

Deciding what to tell children or teenagers about leukaemia is difficult. It can be hard to know what to tell them, and you may be worried about upsetting them. It may be best to start by giving them small amounts of information, and then tell them more when they are ready. Use simple, straightforward language to explain what is happening. You can encourage them to talk to someone they trust, who can support them. They may also find support online.

We have more information in our booklet Talking to children and teenagers when an adult has cancer.

You can order our booklets and leaflets for free.
Visit orders.macmillan.org.uk or call **0808 808 00 00**.

Money and work

Help with money and benefits

When you are affected by leukaemia, you may need help with extra costs. Or you may need support with money if you have to stop working. We have more information online about Statutory Sick Pay and benefits you may be entitled to. We also have information for carers in our booklet Working while caring for someone with cancer.

Benefits are payments from the government to people who need help with money. You can find out more about benefits and apply for them online. Go to:

- gov.uk if you live in England or Wales
- socialsecurity.gov.scot if you live in Scotland
- nidirect.gov.uk if you live in Northern Ireland.

The benefits system and other types of financial support can be hard to understand. Our money advisers can give you more information about benefits. Call the Macmillan Support Line on **0808 808 00 00**.

You can get information about benefits and other types of financial help from Citizens Advice if you live in England, Scotland or Wales, or Advice NI if you live in Northern Ireland.

Our booklet Help with the cost of cancer has lots more information.

Grants

You may be able to get some financial help from other charities, for example one-off grants. For further information, contact the Macmillan Support Line on **0808 808 00 00**.

Insurance

If you have, or have had, leukaemia, you may find it hard to get certain types of insurance. We have information about insurance on our website. Visit macmillan.org.uk/insurance-cancer

We have more information about travel insurance in our booklet Travel and cancer. Our Online Community forum on **Travel insurance** may also be helpful. Visit macmillan.org.uk/community

Work

You may not know how leukaemia will affect your work, now or in the future.

It is a good idea to talk to your manager or human resources (HR) department soon after you are diagnosed. This will help them to support you better.

Some people stop working during leukaemia treatment and for a while after, until they feel ready to go back. Others carry on working, sometimes with reduced hours or other changes to their job.

Your haematologist, GP or specialist nurse can help you decide whether you should stop working, and when and if you should go back to work.

Our booklets Work and cancer, Working while caring for someone with cancer and Self-employment and cancer have more information that may be helpful. You can also find out more about your employment rights in our booklet Your rights at work when you are affected by cancer.

There is also lots more information online at macmillan.org.uk/work

Further information

About our information

We provide expert, up-to-date information about cancer. And all our information is free for everyone.

Our information has the PIF Tick quality mark for trusted health information. This means our information has been through a professional and strong production process.

Order what you need

You may want to order more booklets or leaflets like this one. Visit orders.macmillan.org.uk or call us on **0808 808 00 00**.

We have booklets about different cancer types, treatments and side effects. We also have information about work, financial issues, diet, life after cancer treatment and information for carers, family and friends.

Online information

All our information is also available online at macmillan.org.uk/information-and-support You can also find videos featuring stories from people affected by cancer, and information from health and social care professionals.

Other formats

We also provide information in different languages and formats, including:

- audiobooks
- Braille
- British Sign Language
- easy read booklets
- interactive PDFs
- large print
- translations.

Find out more at macmillan.org.uk/otherformats

If you would like us to produce information in a different format for you, email us at **informationproductionteam@macmillan.org.uk** or call us on **0808 808 00 00**.

The language we use

We want everyone affected by cancer to feel our information is written for them.

We want our information to be as clear as possible. To do this, we try to:

- use plain English
- explain medical words
- use short sentences
- use illustrations to explain text
- structure the information clearly
- make sure important points are clear.

We use gender-inclusive language and talk to our readers as 'you' so that everyone feels included. Where clinically necessary we use the terms 'men' and 'women' or 'male' and 'female'. For example, we do so when talking about parts of the body or mentioning statistics or research about who is affected.

To find out more about how we produce our information, visit macmillan.org.uk/ourinfo

Other ways we can help you

At Macmillan, we know how a cancer diagnosis can affect everything, and we are here to support you.

Talk to us

If you or someone you know is affected by cancer, talking about how you feel and sharing your concerns can really help.

Macmillan Support Line

Our support line is made up of specialist teams who can help you with:

- emotional and practical support if you or someone you know has been diagnosed with cancer
- clinical information from our nurses about things like diagnosis and treatments from our nurse specialists
- welfare rights advice, for information about benefits and general money worries.

To contact any of our teams, call the Macmillan Support Line for free on **0808 808 00 00**. Or visit macmillan.org.uk/support-line to chat online and see the options and opening times.

Our trained cancer information advisers can listen and signpost you to further support.

Our cancer information nurse specialists can talk you through information about your diagnosis and treatment. They can help you understand what to expect from your diagnosis and provide information to help you manage symptoms and side effects.

If you are deaf or hard of hearing, call us using Relay UK on **18001 0808 808 00 00**, or use the Relay UK app.

You can also email us, or use the Macmillan Chat Service via our website. You can use the chat service to ask our advisers about anything that is worrying you. Tell them what you would like to talk about so they can direct your chat to the right person. Click on the 'Chat to us' button, which appears on pages across the website. Or go to macmillan.org.uk/talktous

If you would like to talk to someone in a language other than English, we also offer an interpreter service for our Macmillan Support Line. Call **0808 808 00 00** and say, in English, the language you want to use. Or send us a web chat message saying you would like an interpreter. Let us know the language you need and we'll arrange for an interpreter to contact you.

Macmillan Information and Support Centres

Our Information and Support Centres are based in hospitals, libraries and mobile centres. Visit one to get the information you need and speak with someone face to face. If you would like a private chat, most centres have a room where you can speak with someone confidentially.

Find your nearest centre at macmillan.org.uk/informationcentres or call us on **0808 808 00 00**.

Help with money worries

Having cancer can bring extra costs such as hospital parking, travel fares and higher heating bills. If you have been affected in this way, we can help. Please note the opening times may vary by service.

Financial advice

Our expert money advisers on the Macmillan Support Line can help you deal with money worries and recommend other useful organisations that can help.

Help accessing benefits

You can speak to our money advisers for more information. Call us free on **0808 808 00 00**. Visit macmillan.org.uk/financialsupport for more information about benefits.

Help with work and cancer

Whether you are an employee, a carer, an employer or are self-employed, we can provide support and information to help you manage cancer at work. Visit macmillan.org.uk/work

Talk to others

No one knows more about the impact cancer can have on your life than those who have been through it themselves. That is why we help bring people together in their communities and online.

Support groups

Whether you are someone living with cancer or a carer, family member or friend, we can help you find support in your local area, so you can speak face to face with people who understand. Find out about support groups in your area by calling us or by visiting macmillan.org.uk/selfhelpandsupport

Online Community

Thousands of people use our Online Community to make friends, blog about their experiences and join groups to meet other people going through the same things. You can access it any time of day or night. Share your experiences, ask questions, or just read through people's posts at macmillan.org.uk/community

You can also use our Ask an Expert service on the Online Community. You can ask a money adviser, cancer information nurse or an information and support adviser any questions you have.

Macmillan healthcare professionals

Our nurses, doctors and other health and social care professionals give expert care and support to individuals and their families. Call us or ask your GP, consultant, district nurse or hospital ward sister if there are any Macmillan professionals near you.

Other useful organisations

There are lots of other organisations that can give you information or support. Details correct at time of printing.

Leukaemia support organisations

African Caribbean Leukaemia Trust (ACLT)

www.aclt.org
The ACLT aims to raise awareness on stem cell, blood and organ donation in the UK, with a particular focus on Black and mixed-heritage communities.

Anthony Nolan

Tel **0303 303 0303**
www.anthonynolan.org
Information and support for people with blood cancer or a blood disorder who need a stem cell transplant. Runs a stem cell register of potential donors. Offers telephone support, grants, online community and support days.

Blood Cancer UK

Tel **0808 208 0888**
www.bloodcancer.org.uk
Information and support for people with leukaemia, lymphoma, myeloma and all types of blood cancer. Offers information and support online, by phone, by email, and through support groups and buddy systems. Also has a clinical trials support service.

CML Support

www.cmlsupport.org.uk
Has an online support community for CML patients, their families and supporters.

Leukaemia Care

Helpline **0808 801 0444**
www.leukaemiacare.org.uk
Provides care and support for people affected by blood cancer. Provides information, support from clinical nurse specialists and the opportunity to meet others diagnosed with leukaemia.

NHS Stem Cell Donor Registry

Tel **0300 123 2323**
www.blood.co.uk/stem-cell-donor-registry
Helps people find stem cell matches from its own registry and others. Provides information about transplants and donating blood and stem cells.

Welsh Bone Marrow Donor Registry

Tel **0800 371 502**
www.welsh-blood.org.uk/donating-bone-marrow
Helps people find stem cell matches from its own registry and others. Provides information about transplants and donating blood and stem cells.

General cancer support organisations

Black Women Rising

www.blackwomenrisinguk.org
Aims to educate, inspire and bring opportunities for women from the BAME community. Shares stories and supports Black cancer patients and survivors through treatment and remission.

Cancer Black Care

Tel **0734 047 1970**
www.cancerblackcare.org.uk
Provides support for all those living with and affected by cancer, with an emphasis on Black people and people of colour.

Cancer Focus Northern Ireland

Helpline **0800 783 3339**
www.cancerfocusni.org
Offers a variety of services to people affected by cancer in Northern Ireland.

Cancer Research UK

Helpline **0808 800 4040**
www.cancerresearchuk.org
A UK-wide organisation that has patient information on all types of cancer. Also has a clinical trials database.

Macmillan Cancer Voices

www.macmillan.org.uk/cancervoices
A UK-wide network that enables people who have or have had cancer, and those close to them such as family and carers, to speak out about their experience of cancer.

Maggie's

Tel **0300 123 1801**
www.maggies.org
Has a network of centres in many locations throughout the UK. Provides free information about cancer and financial benefits. Also offers emotional and social support to people with cancer, their family, and friends.

Penny Brohn UK

Helpline **0303 300 0118**
www.pennybrohn.org.uk
Offers physical, emotional and spiritual support across the UK, using complementary therapies and self-help techniques.

Tenovus

Helpline **0808 808 1010**
www.tenovuscancercare.org.uk
Aims to help everyone in the UK get equal access to cancer treatment and support. Funds research and provides support such as mobile cancer support units, a free helpline, benefits advice and an online 'Ask the nurse' service.

General health information

Health and Social Care in Northern Ireland

www.northerntrust.hscni.net
Provides information about health and social care services in Northern Ireland.

NHS.UK

www.nhs.uk
The UK's biggest health information website. Has service information for England.

NHS 111 Wales

111.wales.nhs.uk
NHS health information site for Wales.

NHS Inform

Helpline **0800 22 44 88**
www.nhsinform.scot
NHS health information site for Scotland.

Patient UK

www.patient.info
Provides people in the UK with information about health and disease. Includes evidence-based information leaflets on a wide variety of medical and health topics. Also reviews and links to many health-related and illness-related websites.

Counselling

British Association for Counselling and Psychotherapy (BACP)

Tel **0145 588 3300**
www.bacp.co.uk
Promotes awareness of counselling and signposts people to appropriate services across the UK. You can also search for a qualified counsellor on the 'Therapist directory' page.

UK Council for Psychotherapy (UKCP)

Tel **0207 014 9955**
www.psychotherapy.org.uk
Holds the national register of psychotherapists and psychotherapeutic counsellors, listing practitioners who meet exacting standards and training requirements.

Emotional and mental health support

Mind

Helpline **0300 123 3393**
www.mind.org.uk
Provides information, advice and support to anyone with a mental health problem through its helpline and website.

Samaritans

Helpline **116 123**
Email **jo@samaritans.org**
www.samaritans.org
Provides confidential and non-judgemental emotional support, 24 hours a day, 365 days a year, for people experiencing feelings of distress or despair.

Financial support or legal advice and information

Advice NI

Helpline **0800 915 4604**
www.adviceni.net
Provides advice on a variety of issues including financial, legal, housing and employment issues.

Benefit Enquiry Line Northern Ireland

Helpline **0800 232 1271**
Textphone **0289 031 1092**
www.nidirect.gov.uk/money-tax-and-benefits
Provides information and advice about disability benefits and carers' benefits in Northern Ireland.

Carer's Allowance Unit

Tel **0800 731 0297**
Textphone **0800 731 0317**
www.gov.uk/carers-allowance
Manages state benefits in England, Scotland and Wales. You can apply for benefits and find information online or through its helplines.

Citizens Advice

Provides advice on a variety of issues including financial, legal, housing and employment issues. Use its online webchat or find details for your local office by contacting:

England

Helpline **0800 144 8848**
www.citizensadvice.org.uk

Scotland

Helpline **0800 028 1456**
www.cas.org.uk

Wales

Helpline **0800 702 2020**
www.citizensadvice.org.uk/wales

Disability and Carers Service

Tel **0800 587 0912**
Textphone **0800 012 1574**
nidirect.gov.uk/contacts/disability-and-carers-service
Manages Disability Living Allowance, Attendance Allowance, Carer's Allowance and Carer's Credit in Northern Ireland. You can apply for these benefits and find information online or through its helplines.

GOV.UK

www.gov.uk
Has information about social security benefits and public services in England, Scotland and Wales.

Jobs and Benefits Office Enquiry Line Northern Ireland

Helpline **0800 022 4250**
Textphone **0800 587 1297**
www.nidirect.gov.uk/money-tax-and-benefits
Provides information and advice about disability benefits and carers' benefits in Northern Ireland.

Law Centres Network

www.lawcentres.org.uk
Local law centres provide advice and legal assistance. They specialise in social welfare issues including disability and discrimination.

Local councils (England, Scotland and Wales)

Your local council may have a welfare rights unit that can help you with benefits. You can also contact your local council to claim Housing Benefit and Council Tax Reduction, education benefits, and for help from social services (the Social Work department in Scotland).

You should be able to find your local council's contact details online by visiting:

England

www.gov.uk/find-local-council

Scotland

www.cosla.gov.uk/councils

Wales

www.gov.wales/find-your-local-authority

Macmillan Benefits Advice Service (Northern Ireland)

Tel **0300 1233 233**

Money Advice Scotland

www.moneyadvicescotland.org.uk
Use the website to find qualified financial advisers in Scotland.

NI Direct

www.nidirect.gov.uk
Has information about benefits and public services in Northern Ireland.

Northern Ireland Housing Executive

Tel **0344 892 0902**
www.nihe.gov.uk
Offers help to people living in socially rented, privately rented and owner-occupied accommodation.

StepChange Debt Charity

Tel **0800 138 1111**
www.stepchange.org
Provides free debt advice through phone, email, the website and online through live chats with advisers.

Unbiased.co.uk

Helpline **0800 023 6868**
www.unbiased.co.uk
You can search the website for qualified advisers in the UK who can give expert advice about finances, mortgages, accounting or legal issues.

LGBT-specific support

LGBT Foundation

Tel **0345 330 3030**
lgbt.foundation
Provides a range of services to the LGBT community, including a helpline, email advice and counselling. The website has information on various topics including sexual health, relationships, mental health, community groups and events.

OUTpatients

www.outpatients.org.uk
A safe space for anybody who identifies as part of the queer spectrum and has had an experience with any kind of cancer at any stage. Also produces resources about LGBT cancer experiences. OUTpatients runs a peer support group with Maggie's Barts.

Cancer registries

The cancer registry is a national database that collects information on cancer diagnoses and treatment. This information helps the NHS and other organisations plan and improve health and care services. There is a cancer registry in each country in the UK. They are run by the following organisations:

England – National Disease Registration Service (NDRS)

www.digital.nhs.uk/ndrs/patients

Scotland – Public Health Scotland (PHS)

www.publichealthscotland.scot/our-areas-of-work/conditions-and-diseases/cancer/scottish-cancer-registry-and-intelligence-service-scris/overview

Wales – Welsh Cancer Intelligence and Surveillance Unit (WCISU)

Tel **0292 010 4278**
www.phw.nhs.wales/wcisu

Northern Ireland – Northern Ireland Cancer Registry (NICR)

Tel **0289 097 6028**
www.qub.ac.uk/research-centres/nicr/AboutUs/Registry

Your notes and questions

Disclaimer

We make every effort to ensure that the information we provide is accurate and up to date but it should not be relied upon as a substitute for specialist professional advice tailored to your situation. So far as is permitted by law, Macmillan does not accept liability in relation to the use of any information contained in this publication, or third-party information or websites included or referred to in it. Some photos are of models.

Thanks

This booklet has been written, revised and edited by Macmillan Cancer Support's Cancer Information Development team. It has been approved by our Senior Medical Editor, Dr Anne Parker, Consultant Haematologist.

With thanks to: Dr Guy Hannah, Consultant Haematologist; Dr Jonathan Kell, Consultant Haematologist; Caroline Kerr, Clinical Nurse Specialist; and Joanna Large, Clinical Nurse Specialist.

Thanks also to the people affected by cancer who reviewed this edition, and those who shared their stories.

We welcome feedback on our information. If you have any, please contact **informationproductionteam@macmillan.org.uk**

Sources

Below is a sample of the sources used in our CML information. If you would like more information about the sources we use, please contact us at **informationproductionteam@macmillan.org.uk**

National Institute for Health and Care Excellence (NICE). Asciminib for treating chronic myeloid leukaemia after 2 or more tyrosine kinase inhibitors (Published 03 August 2022). Available from: https://www.nice.org.uk/guidance/ta813 [accessed July 2023].

Qayed, M. et al. Leukapheresis guidance and best practices for optimal chimeric antigen receptor T-cell manufacturing. Cryotherapy. 2022; 24, 9: 869–878. Available from: https://www.isct-cytotherapy.org/article/S1465-3249(22)00641-7/fulltext [accessed August 2023].

Smith, G., Apperley, J., et al. A British Society for Haematology Guideline on the diagnosis and management of chronic myeloid leukaemia. British Journal of Haematology. 2022; 191: 171–193. Available from: https://onlinelibrary.wiley.com/doi/10.1111/bjh.16971 [accessed July 2023].

Yeung D.T, Shanmuganathan N, et al. Asciminib: a new therapeutic option in chronic-phase CML with treatment failure. Blood. 2022: Jun 16; 139(24): 3474–3479. Available from: https://pubmed.ncbi.nlm.nih.gov/35468180/ [accessed August 2023].

Can you do something to help?

We hope this booklet has been useful to you. It is just one of our many publications that are available free to anyone affected by cancer. They are produced by our cancer information specialists who, along with our nurses, benefits advisers, campaigners and volunteers, are part of the Macmillan team. When people are facing the toughest fight of their lives, we are here to support them every step of the way.

We want to make sure no one has to go through cancer alone, so we need more people to help us. When the time is right for you, here are some ways in which you can become a part of our team.

5 ways you can help someone with cancer

1. **Share your cancer experience**
   Support people living with cancer by telling your story, online, in the media or face to face.

2. **Campaign for change**
   We need your help to make sure everyone gets the right support. Take an action, big or small, for better cancer care.

3. **Help someone in your community**
   A lift to an appointment. Help with the shopping. Or just a cup of tea and a chat. Could you lend a hand?

4. **Raise money**
   Whatever you like doing you can raise money to help. Take part in one of our events or create your own.

5. **Give money**
   Big or small, every penny helps. To make a one-off donation see over.

Please fill in your personal details

Mr/Mrs/Miss/Other

Name

Surname

Address

Postcode

Phone

Email

Please accept my gift of £
(Please delete as appropriate)

I enclose a cheque / postal order / Charity Voucher made payable to Macmillan Cancer Support
OR debit my:
Visa / MasterCard / CAF Charity Card / Switch / Maestro

Card number

Valid from

Expiry date

Issue no

Security number

Signature

Date / /

Do not let the taxman keep your money

Do you pay tax? If so, your gift will be worth 25% more to us – at no extra cost to you. All you have to do is tick the box below, and the tax office will give 25p for every pound you give.

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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 is my responsibility to pay any difference. I understand Macmillan Cancer Support will reclaim 25p of tax on every £1 that I give.

Macmillan Cancer Support and our trading companies would like to hold your details in order to contact you about our fundraising, campaigning and services for people affected by cancer. If you would prefer us not to use your details in this way please tick this box. ☐

In order to carry out our work we may need to pass your details to agents or partners who act on our behalf.

If you would rather donate online go to macmillan.org.uk/donate

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Please cut out this form and return it in an envelope (no stamp required) to: Supporter Donations, Freepost RUCY-XGCA-XTHU, Macmillan Cancer Support, PO Box 791, York House, York YO1 0NJ

MACMILLAN
CANCER SUPPORT

This booklet is about chronic myeloid leukaemia (CML). It is for anyone who has been diagnosed with CML. There is also information for carers, family members and friends.

The booklet explains how CML may be treated. It also has information about feelings, practical issues and money.

At Macmillan we know cancer can disrupt your whole life. We'll do whatever it takes to help everyone living with cancer in the UK get the support they need right now, and transform cancer care for the future.

For information, support or just someone to talk to, call **0808 808 00 00** or visit macmillan.org.uk

Would you prefer to speak to us in another language? Interpreters are available. Please tell us in English the language you would like to use. Are you deaf or hard of hearing? Call us using Relay UK on **18001 0808 808 00 00**, or use the Relay UK app.

Need information in different languages or formats? We produce information in audio, interactive PDFs, easy read, Braille, large print and translations. To order these, visit macmillan.org.uk/otherformats or call our support line.

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