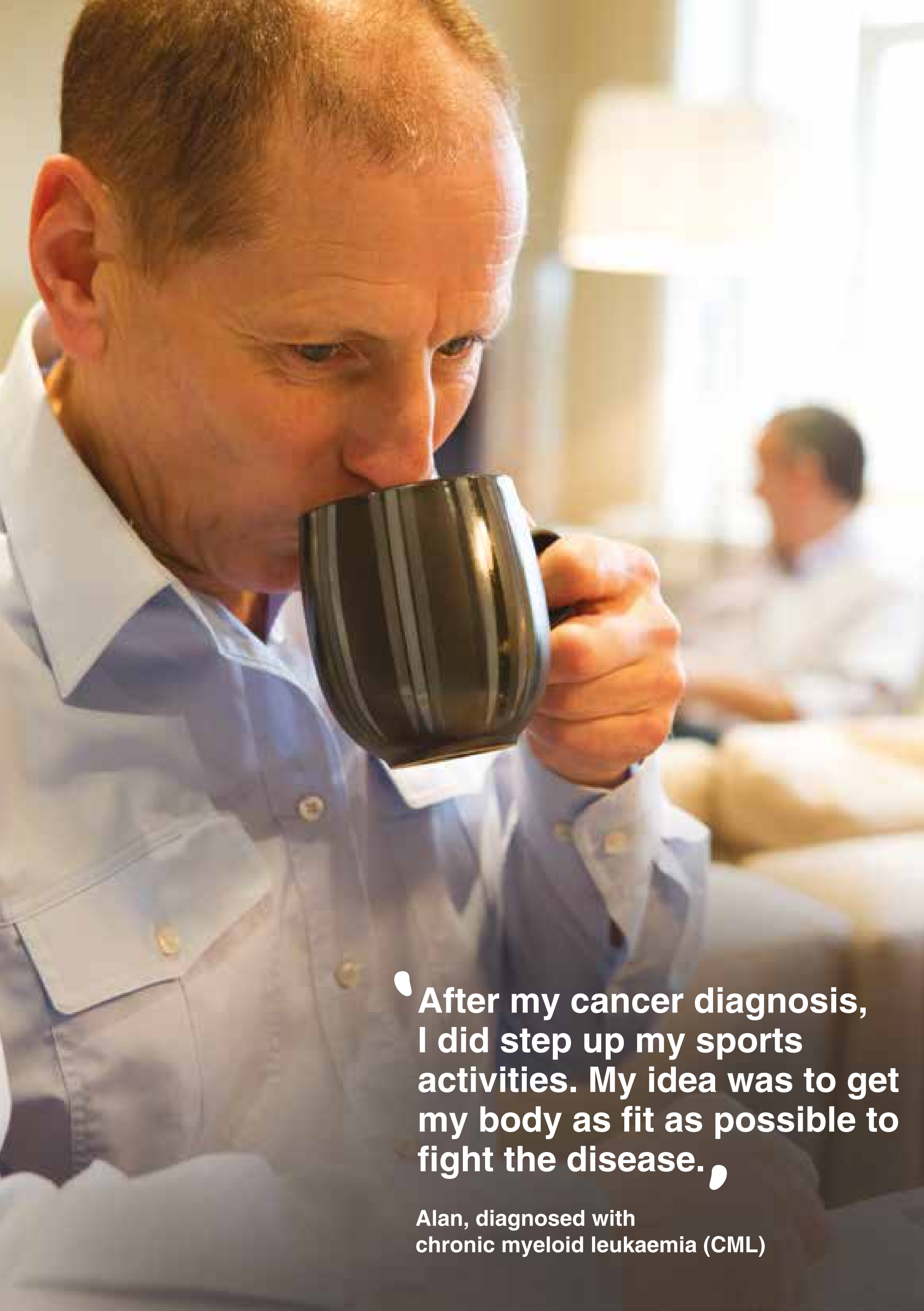
MACMILLAN
CANCER SUPPORT

UNDERSTANDING CHRONIC MYELOID LEUKAEMIA



> After my cancer diagnosis, I did step up my sports activities. My idea was to get my body as fit as possible to fight the disease.

Alan, diagnosed with
chronic myeloid leukaemia (CML)

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 diagnosed and 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 on page 3 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 88 to 92, there are details of other organisations that can help.

There is also space to write down questions and notes for your doctor or nurse (see page 93).

Quotes

In this booklet, we have included quotes from people who have had CML, which you may find helpful. Some are from **healthtalk.org** The others are from people who have chosen to share their story with us. This includes Alan, 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 NGT (Text Relay) on **18001 0808 808 00 00**, or use the NGT Lite app.

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

Contents

THE BLOOD AND CML

What is leukaemia?

Leukaemia is a cancer of the white blood cells. People with leukaemia have abnormal white blood cells in their bone marrow. This usually means their white blood cell count is high. But in a few people with leukaemia, their white blood cell count is low.

The abnormal white blood cells are called leukaemia cells. They act differently from healthy white blood cells.

There are four main types of leukaemia:

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

Each type of leukaemia is different. We have separate information for these types of leukaemia. We have more information on how to order these booklets (see page 84).

The blood and bone marrow

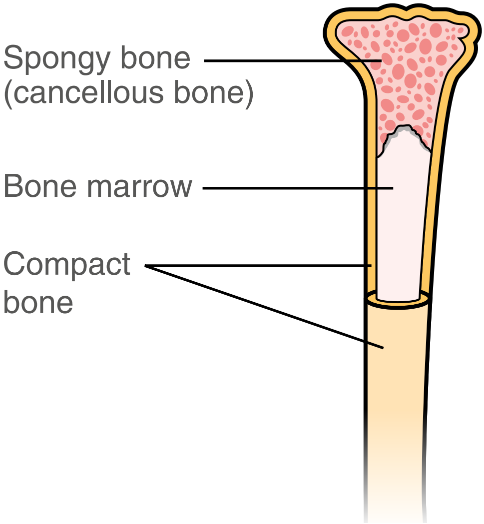
To help you understand CML and its treatment, it can help to know more about your blood and blood cells.

Blood is made up of blood cells which float in a liquid called plasma. Blood cells are made in the bone marrow. The bone marrow is the spongy material found inside our bones. Most blood cells are made in the:

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

The bone marrow usually makes billions of new blood cells every day to replace old and worn-out blood cells.

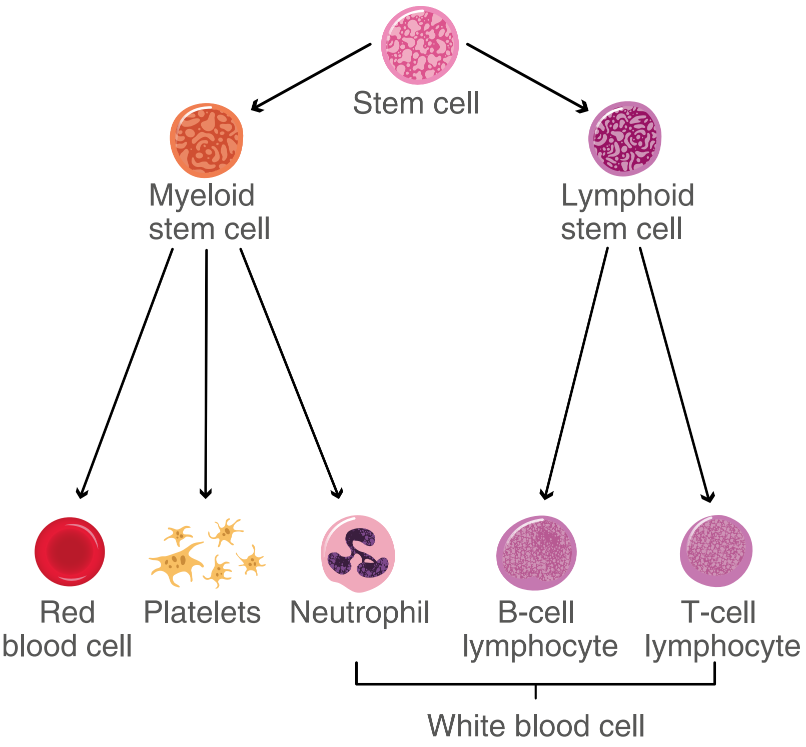
Bone marrow



All blood cells are made from blood stem cells. These are blood cells at the earliest stage of their development. There are two types of blood stem cell:

- lymphoid stem cells – which make a type of white blood cell called lymphocytes
- myeloid stem cells – which make the other white blood cells such as neutrophils, red blood cells and platelets.

How blood 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 (called blast cells). They then develop into mature, red blood cells, platelets or white blood cells.

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

- **Red blood cells** contain haemoglobin (Hb). This 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 ones 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 x 10^9/L
White blood cells (WBC)	4.0 to 11.0 x 10^9/L
Neutrophils	2.0 to 7.5 x 10^9/L
Lymphocytes	1.5 to 4.5 x 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 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 like, ‘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 is a cancer of the white blood cells. It develops when some white blood cells start behaving abnormally. It usually develops very slowly.

About 750 people in the UK are diagnosed with CML each year. CML can affect people at any age, but it is more common as people get older. For many people, CML can be well controlled, and it will not shorten their life.

How CML develops

The information here explains how CML develops. It will help you understand the information about:

- having tests for CML (see pages 20 to 23)
- treatment for CML (see pages 29 to 57).

The information is quite complicated, so you might need to read it more than once. Do not worry if it is too much to take in. It is fine to skip it and 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**.

> **‘I’d never heard of CML and thought it was a death sentence. Luckily my girlfriend helped me find some wonderful resources on the internet. My medical team also explained about the treatment, which was very easy to understand.’**
>
> **Alan, diagnosed with CML**

Genes and chromosomes

All cells contain a set of instructions that tell them how to behave. These instructions are stored as genes. The genes are organised into structures called chromosomes. Most cells in the body contain 23 pairs of chromosomes.

The BCR-ABL1 gene

New cells are made when a cell divides into two cells. 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, which is on chromosome 22. When the ABL1 gene sticks to BCR, it creates a completely new abnormal gene called BCR-ABL1 (see opposite).

This new BCR-ABL1 gene makes 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 leukaemia cells.

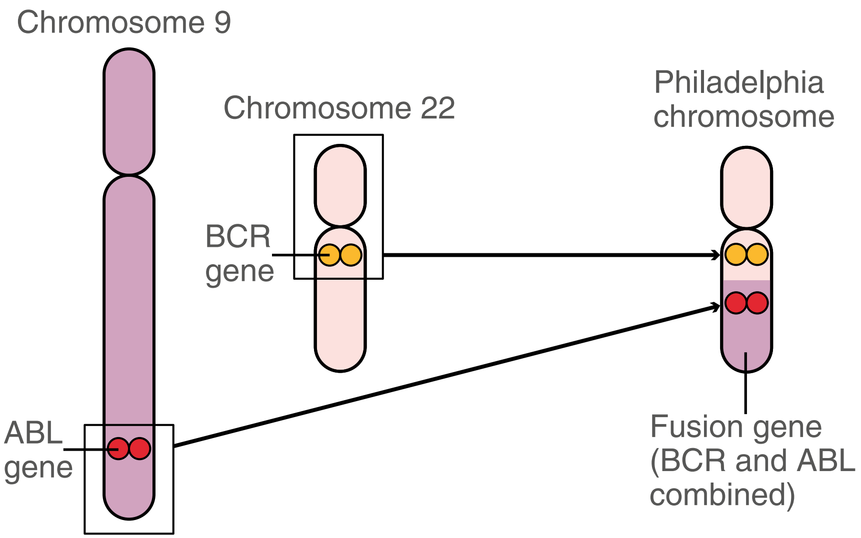
The Philadelphia (Ph) chromosome

When the new 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. Most people with CML have the Philadelphia chromosome in all the leukaemia cells. It is only in the leukaemia cells.

The Philadelphia chromosome is not inherited. You are not born with it, so you cannot pass it on to your children.

How the Philadelphia chromosome develops



Risk factors and causes

It is not clear why people get CML. It is not linked to smoking, diet, exposure to chemicals or infections. It also does not run in families. Like other cancers, CML is not infectious and cannot be passed on to other people.

There are some factors that might increase the risk of developing CML.

Age

CML can develop at any age. But it is more common as people get older. Over half of people diagnosed with CML in the UK are over the age of 60.

Sex

CML is slightly more common in men than women, but the reason for this is not known.

Radiation exposure

Exposure to very high radiation levels increases the risk of developing CML. For example, these might be high levels of radiation following a nuclear accident. Very few people in the UK will be exposed to radiation levels high enough to increase their risk of CML.

Research has found no link between the risk of developing CML and:

- living near nuclear power stations
- exposure to electro-magnetic fields
- living near high-voltage electricity cables
- household radon (naturally occurring gas).

Symptoms

CML develops slowly and many people do not have symptoms in the early stages. Sometimes CML is found by chance when you have a blood test before an operation, or as part of a routine health check.

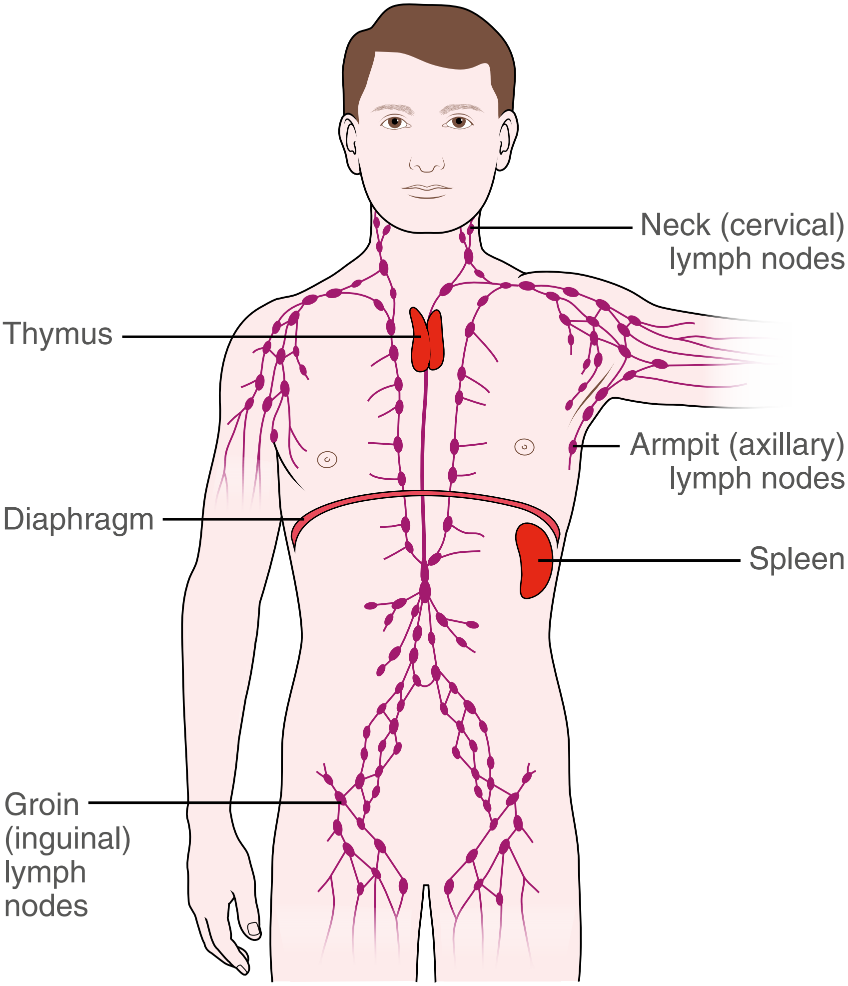
In the early stages of CML, any symptoms are usually mild and develop slowly. They can be confused with the symptoms of more common illnesses, such as flu.

Common symptoms

If you do have symptoms, they may include the following:

- Feeling tired (fatigue).
- Weight loss.
- Heavy sweating at night.
- Feeling tender or full on the left side of your tummy (abdomen). This is caused by abnormal blood cells (leukaemia cells) collecting in the spleen, making it bigger (see next page). The spleen stores blood cells and destroys old and damaged blood cells. It is part of the lymphatic system.

The spleen in the lymphatic system



Less common symptoms

Sometimes abnormal white blood cells (leukaemia cells) build up in the blood or bone marrow (see pages 6 to 10). This can make the blood thick, or mean the bone marrow cannot make enough healthy blood cells. These changes can cause the following symptoms:

- Bleeding or bruising if there are too few platelets in the blood. This may include bruising without any obvious cause, bleeding gums or nosebleeds. Women may bleed more heavily during their periods.
- Looking pale and feeling tired or breathless. This is caused by a lack of red blood cells in the blood (anaemia).
- Aching joints and bones. This can happen if there is a build-up of leukaemia cells in the bone marrow. You may also get gout in some joints, for example your big toes.
- Visual disturbances and headaches. Some men may have long-lasting, painful erections. These symptoms can happen if the blood is thick and does not flow as well as normal.

If you have any of these symptoms, it is important to see your GP. But remember that they can be caused by other illnesses as well as CML.

DIAGNOSING CML

How CML is diagnosed

If your GP thinks you may have CML, they will refer you to a haematologist for further tests. A haematologist is a doctor who specialises in diagnosing and treating blood problems.

At the hospital

The haematologist will ask you about any illnesses or health problems you have had. They will examine you to check if your spleen is enlarged (see page 16).

Blood tests

You will have blood tests at the hospital. These tests will:

- check the numbers of blood cells in your blood, called a full blood count (FBC)
- look for leukaemia cells.

If there are leukaemia cells in your blood, the haematologist will arrange more tests for you. These will find what type of leukaemia you have and what phase it is (see pages 24 to 25). This will help your doctors plan your treatment.

Bone marrow test

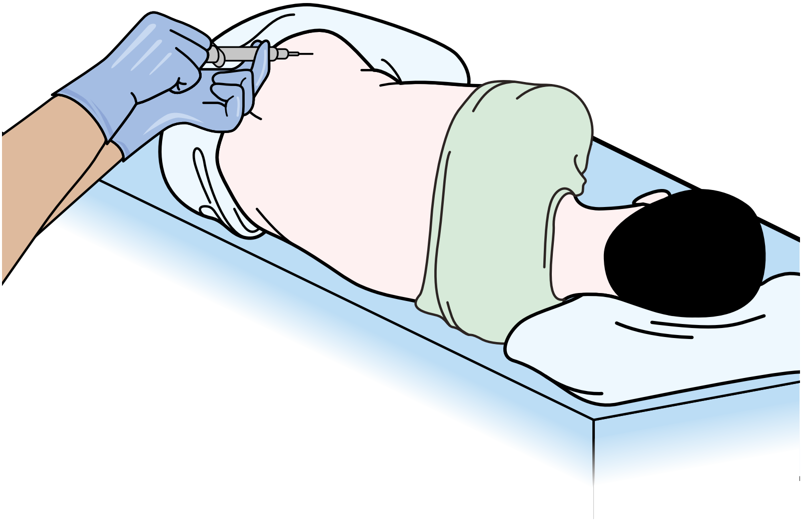
A bone marrow test is when a doctor or nurse takes a small sample of bone marrow to test for abnormal white blood cells. They usually take the bone marrow from the back of the hip bone (pelvis). Rarely, they may take it from the breast bone (sternum).

A bone marrow test may be done on a ward or in an outpatient department. It takes about 20 to 30 minutes in total. Removing the bone marrow sample only takes a few minutes.

First, the doctor or nurse gives you a local anaesthetic to numb the area. They may also offer you a sedative to reduce any pain or discomfort during the test.

The doctor or nurse passes a needle through the skin into the bone. They then draw a small sample of liquid from inside the bone marrow into a syringe. This is called a bone marrow aspirate. It can feel uncomfortable for a few seconds when the liquid marrow is drawn into the syringe.

A sample of bone marrow being taken from the back of the hip bone



The doctor or nurse may also take a small core of bone marrow. This is called a trephine biopsy. They pass a thicker needle through the skin into the bone marrow. When they take the needle out, it has a small core of bone marrow in it.

You may feel bruised after having a sample of bone marrow taken. You may have an ache in the area for a few days. This can be helped with mild painkillers.

> **‘When I was first diagnosed, I had to do a bone marrow test. It’s uncomfortable but was over in a flash.’**
>
> **Alan, diagnosed with CML**

Cytogenetic and molecular tests

Cytogenetic and molecular tests look at chromosomes.

Philadelphia chromosome test

Doctors use the blood and bone marrow samples they have taken to look for the Philadelphia chromosome (see page 13).

Polymerase chain reaction (PCR) test

This blood test looks for the BCR-ABL1 gene in the leukaemia cells (see page 12). It is a very sensitive test, which can detect tiny amounts of leukaemia.

If you are diagnosed with CML, you will have regular PCR blood tests. Doctors use this test to check how well treatment is working.

Ultrasound scan

You might have an ultrasound scan to check the size of your spleen and liver. Ultrasound scans use sound waves to build up a picture of the inside of the body. This is a painless test that only takes around 10 to 15 minutes.

When you are lying comfortably on your back, the person doing the scan spreads a gel on the skin over the area they are scanning. They then pass a small device that makes sound waves over the area. A computer turns the sound waves into a picture.

Phases of CML

CML usually develops slowly. There are three phases of CML:

- chronic phase
- accelerated phase
- blast phase.

Most people are diagnosed when CML is in the chronic phase. Doctors know the phase of CML from:

- the number of immature blood cells (blast cells) in your blood and bone marrow (see pages 6 to 10)
- your symptoms.

Chronic phase

When CML is in the chronic phase, there may be no symptoms and most people can have a normal life. Treatment is with tablets you can take at home. You will 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 they continue to take treatment.

In the chronic phase, less 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 progress 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, less than 2 in 10 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 symptoms such as:

- tiredness
- weight loss
- bone pain
- sweating and a high temperature at night.

If you feel unwell or develop new symptoms, tell your doctor.

Blast phase

In some people, CML in the accelerated phase may transform into the blast phase. Rarely, people are diagnosed with CML in the blast phase. Or, the leukaemia progresses straight to the blast phase from the chronic phase.

The blast phase is like an acute leukaemia. In this phase, more than 2 in 10 blood cells in the blood or bone marrow (20%) are blast cells. The blast phase is sometimes called blast crisis.

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 (see page 23).

Your data and the cancer registry

When you are diagnosed with cancer in the UK, some information about you, your cancer diagnosis and your treatment is collected in a cancer registry. This is used to plan and improve health and care services. Your hospital will usually give this information to the registry automatically. There are strict rules to make sure the information is kept safely and securely. It will only be used for your direct care or for health and social care planning and research.

TREATING CML

Treatment overview

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 blood during a standard blood test, and you feel well. There are different levels of remission (see pages 46 to 50).

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

Most people with CML are treated with targeted therapies called tyrosine kinase inhibitors (TKIs) – see pages 36 to 45. You take them as tablets or capsules every day. There are several TKIs for CML. If one TKI does not work, or stops working, your doctors can usually give you a different one.

You may have a very high level of white blood cells in your blood when you are first diagnosed. If this happens, you may be given chemotherapy tablets for a few days before starting TKI treatment.

Sometimes, your doctors may suggest chemotherapy followed by a stem cell transplant (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 and it is not suitable for everyone.

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 CML. These cells can gather in the blood vessels and cause problems, such as headaches or blurred vision. Doctors can remove some white blood cells from the blood using a machine called a cell separator. This is called leukapheresis. It may also be used for women who are pregnant when they are diagnosed. You may also find our booklet **Cancer and pregnancy** helpful (see page 84).

During leukapheresis, you lie on a bed or reclining chair with a small plastic tube (cannula) in a vein in each arm. Each cannula is connected to the cell separator by a tube. Blood goes from one of your arms 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 your blood and blood cells are then returned to your body through the cannula in your other arm. This takes a few hours.

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

How your treatment is planned

There are guidelines for treating CML. Your treatment will be based on the guidelines but adapted to your situation.

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

The MDT may include:

- haematologists – doctors who specialise in diagnosing and treating blood cancers and disorders
- specialist nurses – who give information and support
- pathologists – who advise on the type of leukaemia you have, as well as any chromosome changes
- radiologists – who specialise in understanding scans and x-rays
- pharmacists – who specialise in 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 they talk to you about which treatments are likely to be best for you. These may include the phase of the leukaemia and your general health.

You may be invited to take part in a clinical trial of a new treatment for CML (see pages 56 to 57).

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, or a higher risk of serious side effects.

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

Giving your consent

Your doctor will explain the aims of your treatment before you have it. They will usually ask you to sign a form saying that you give permission (consent) for the hospital staff to give you the treatment. No medical treatment can be given without your consent. Before you are asked to sign the form, you should be given full information about:

- the type and extent of the treatment
- its advantages and disadvantages
- any significant risks or side effects
- any other treatments that may be available.

If you do not understand what you have been told, tell the staff straight away. They can explain it again. Some leukaemia treatments are complex, so it is not unusual to need things explaining to you again. It is a good idea to have a family member or friend with you when the treatment is explained. They can help you remember the discussion. You may also find it useful to write a list of questions before your appointment.

People sometimes feel hospital staff are too busy to answer their questions. But it is important for you to know how the treatment is likely to affect you. The staff should be willing to make time for your questions.

You can always ask for more time if you feel that you cannot make a decision when your treatment is first explained to you.

You may choose not to have the treatment. The staff can explain what may happen if you do not have it. You must tell a doctor or the nurse in charge, so they can record your decision in your medical notes. You do not have to give a reason for not wanting treatment, but it can help to tell the staff your concerns. This means they can give you the best advice.

If you choose not to have treatment, you can have supportive (palliative) care, with medicines to control any symptoms.

Second opinion

Your multidisciplinary team (MDT) uses national treatment guidelines to choose the most suitable treatment for you. But you may want another medical opinion. If you feel it will be helpful, you can ask your specialist or GP to refer you to another specialist for a second opinion.

Getting a second opinion may delay the start of your treatment, so you and your doctor need to be confident it will give you useful information. If you do see another specialist for a second opinion, it may be a good idea to take a family member or friend with you. Also try to have a list of questions ready so you can make sure your concerns are discussed during the appointment.

Tyrosine kinase inhibitors (TKIs)

The main treatment for CML is with drugs 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 – see page 12. This stops or slows, the bone marrow from making abnormal white blood cells. It also allows the leukaemia cells to mature and die.

The TKI drugs used to treat CML come as tablets or capsules. You take them every day for as long as they are working. The three main TKI drugs currently used are:

- imatinib
- nilotinib
- dasatinib.

Imatinib is the most commonly used TKI.

There are also some newer TKI drugs:

- bosutinib
- ponatinib.

Different drugs are used for different situations. Your haematologist will discuss which one 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:

- any other health problems you have
- the possible side effects of the TKI.

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

For more information about each of these targeted therapy drugs, visit **macmillan.org.uk**

Hepatitis B and C

Before you begin treatment with a TKI, you will have a blood test to check for hepatitis B and C (liver infections). This is because TKI treatment can make these infections active again. Your doctor or nurse will talk to you about this before the blood test.

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 the chronic or accelerated phase if you cannot have imatinib. This might be because of side effects or if imatinib is not working.

Dasatinib (Sprycel®)

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

Bosutinib (Bosulif®)

You might have bosutinib if other TKIs have stopped working or are not suitable 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.

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 you started treatment. Always tell your doctor if you notice any new side effects, or if your side effects get worse.

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 at **macmillan.org.uk** We have listed some possible side effects of TKIs on pages 39 to 42.

Tiredness and feeling weak (fatigue)

This is a common side effect, but it is usually mild. Try to balance 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 food.

Your nurse or doctor 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 if 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 settles without needing treatment. If it does not settle, your doctor may give you a drug that makes you pass more urine (pee) – a diuretic. This can help get rid of some of the fluid.

Dasatinib can sometimes 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 fluid 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 numbers of blood cells in your blood. Your blood count will be checked regularly while you are having treatment (see page 20). 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. Contact the hospital straight away if:

- your temperature goes over 37.5°C (99.5°F)
- you suddenly feel unwell, even with a normal temperature
- you have symptoms of an infection.

Symptoms of an infection include:

- feeling shivery
- a sore throat
- a cough
- diarrhoea
- needing to pass urine often.

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 (blood-clotting cells) in your blood. 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 to have a blood transfusion. Rarely, some people are given injections of a growth factor called erythropoietin. This can help increase the numbers of red blood cells made by the bone marrow.

Fertility and pregnancy

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

If you may want to have children in the future, talk to your doctor about this as early as possible – before starting treatment if you can. 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.

Women

Taking a TKI during pregnancy increases the risk of harm to a developing baby. Because of this, women 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.

Men

Research has shown it may be safe for men to continue to take imatinib if they are trying to start a pregnancy. But there is less information about the newer TKI treatments. You should talk to your doctor before planning to have a baby. Their advice may be different depending on which TKI you are taking.

> ‘I am not allowed to conceive on this treatment. This was big as I always wanted a family. My consultant has said once I have been in remission for 2 years, they may be willing to stop the medication so I can try to get pregnant. I would then start the pills again after the birth. This is still a hope for the future and something I am working towards.’
>
> **Chloe, diagnosed with CML**

Monitoring response to treatment

When you first start treatment with a 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 blood tests to check the numbers of blood cells (FBC) – see page 20, and leukaemia cells (PCR test) – see page 23.

Sometimes they may take a bone marrow sample (see pages 20 to 22). Your doctor can tell you how often you might need this.

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

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

Levels of response

The aim of treatment is to put the CML into remission. This means there are 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 for leukaemia cells as the leukaemia responds to treatment.

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

Haematological response

This is the first level of response to treatment. It is measured with a full blood count (FBC) – see page 20.

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 full blood count 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 (CHR) within 3 months of starting a TKI.

Although your blood counts are normal, there may still be leukaemia cells that cannot be detected by a full blood count.

Cytogenetic response

This is the next level of response. It refers to the amount of Philadelphia chromosome (see page 13) in the blood and bone marrow (see pages 6 to 10). As treatment starts working, the number of Philadelphia chromosome-positive (Ph+) cells in the blood and bone marrow goes down.

It takes longer to get a cytogenetic response than a haematological response. It can take many months.

A complete cytogenetic response (CCyR) means there are no Ph+ cells detected in the bone marrow sample.

Molecular response

Even after you have a cytogenetic response, there can still be leukaemia cells in your blood and bone marrow. Because there may only be 1 leukaemia cell among 1000s of normal blood cells, a very sensitive test is needed to find the leukaemia cells. This test is called a polymerase chain reaction (PCR) test.

There are different levels of molecular response:

- **MR3**, or major molecular response (MMR) – this means there is less than 1 leukaemia cell in every 1000 white blood cells.
- **MR4**, or deep molecular response (DMR) – this means there is less than 1 leukaemia cell in every 10,000 white blood cells.
- **MR4.5** – this means there is less than 1 leukaemia cell in every 32,500 white blood cells.
- **MR5** – this means there is less than 1 leukaemia cell in every 100,000 white blood cells.

We have more information about levels of response at **macmillan.org.uk**

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 to 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 see 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. Tell your doctor, nurse or pharmacist if it is difficult for you to get to the hospital.

Treatment free remission

Trials are being done to see whether it may be safe to stop TKI treatment if someone has had a deep molecular remission (MR4) for a long time (see pages 49). This is called treatment free remission.

Your doctor can tell you more about this. We have more detailed information about treatment free remission at **macmillan.org.uk**

Chemotherapy for CML

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

Chemotherapy tablets

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. This may be while their doctors are waiting for test results to confirm whether the CML is likely to respond to a TKI (see pages 36 to 45).

The most commonly used chemotherapy drug for CML is hydroxycarbamide. You take this as tablets. Your doctor, nurse or pharmacist will tell you how many tablets to take. Your doctors will usually change your treatment to a TKI when they have your test results.

Combination chemotherapy

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

People who are treated with a stem cell transplant usually have intensive chemotherapy as preparation for the transplant (see page 53).

Your doctor or specialist nurse will tell you about the chemotherapy drugs and their possible side effects.

Side effects of chemotherapy

If you are taking a single chemotherapy tablet, the side effects are usually mild. Treatment with a combination of two or more chemotherapy drugs may cause more severe side effects.

People with CML rarely have chemotherapy, so we have not given much detail on the side effects in this booklet. Your doctor or nurse will tell you what to expect. We have more information about each type of chemotherapy, its side effects and how to help manage these. To order our information, call us on **0808 808 00 00**.

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 (see pages 24 to 25)
- treatment with TKIs is not controlling the CML (see pages 46 to 50).

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 leukaemia, or put the leukaemia into remission.

A stem cell transplant allows you to have much higher doses of chemotherapy. You may also have radiotherapy (high-energy rays) to the whole body.

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.

Interferon alpha

Interferon alpha is a protein that the body normally makes during viral infections, such as flu. Scientists can make this protein in the laboratory, so it can be used as a treatment.

If other treatments have not worked, some people may be given interferon alpha in the chronic phase of CML. Doctors may also use it for women who need treatment and are pregnant or want to become pregnant (see pages 44 to 45).

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.

Research – clinical trials

Leukaemia research trials are done to try to find new and better treatments for leukaemia. Trials done on patients are called clinical trials. These may be done to:

- test new treatments, such as new chemotherapy drugs or targeted therapies
- look at new combinations of existing treatments, or change the way they are given to make them more effective or to reduce side effects
- compare the effectiveness of drugs used to control symptoms
- find out how cancer treatments work
- find out which treatments are the most cost-effective.

Trials are the only reliable way to find out if a different type of treatment is better than what is already available.

Taking part in a trial

You may be asked to take part in a treatment research trial. There can be many benefits to this. Trials help to improve knowledge about leukaemia and develop new treatments. You will be carefully monitored during and after the study.

Usually, several hospitals around the country take part in these trials. Some treatments that look promising at first are later found not to be as good as existing treatments. Or they have side effects that outweigh the benefits. This is something for you to keep in mind.

If you decide not to take part in a trial, your decision will be respected. You do not have to give a reason. But it can help to tell the staff your concerns so they can give you the best advice. There will be no change in the way you are treated by the hospital staff. You will still be offered the standard treatment for your situation.

Blood samples

You may be asked for your permission to use samples of your blood for research into leukaemia. Your name will be removed from the samples so you cannot be identified.

The research may be carried out at the hospital where you are treated, or at another one. This type of research takes a long time, and results may not be available for many years. The samples will be used to increase knowledge about the causes of leukaemia and its treatment, which will hopefully improve the outlook for future patients.

LIVING WITH CML

THE NEW SKINNY
ANKLE-ZIP JEAN

Living with CML

Most people with CML live a normal lifespan. 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, you need to 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** (see page 84).

Stop smoking

If you smoke, speak to your doctor or call a stop-smoking helpline for further advice. They can tell you where your local stop-smoking service is.

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 like massage. We have more information about this in our booklet **Cancer and complementary therapies** (see page 84).

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. You may find our booklet **Talking about cancer** helpful (see page 84).

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 build up the amount you do.

Our booklet **Physical activity and cancer** has more information that you may find useful (see page 84).

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 cope. 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.

> ‘Meeting someone who had been through the same thing was so helpful. CML is very treatable and you should take an interest in your cancer and treatment. If you don’t understand something, just ask.’

Alan, diagnosed CML

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. We have suggested some of them in this information.

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 the people close to you. 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 see 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. Visit **macmillan.org.uk/community** Or you could use the CML Support Group’s forum. Visit **cmlsupport.org.uk/forum**

Your feelings

It is common to have many different feelings when you are told that you have leukaemia. We talk about some of these here. Partners, family and friends may also have some of the same feelings.

You might have different reactions to the ones we describe here. There is no right or wrong way to feel. You will cope with things in your own way. Talking to people close to you or other people affected by leukaemia can often help.

Shock and denial

You may find it hard to believe when your doctor tells you that you have leukaemia. It is common to feel shocked and numb. You may not be able to understand all the information you are given. You may find that you keep asking the same questions. At first, it can be hard to talk about the leukaemia. Or you might find it hard to think or talk about anything else. Both reactions are normal. Your mind is trying to process what is happening. These feelings usually get easier over time.

Fear and anxiety

You may be anxious or frightened about whether treatments will work and what will happen in the future. This can be one of the hardest things to cope with. It can help to try and focus on things you can control. You may want to find out more about the leukaemia, your treatment options, and how to manage any side effects. It can also help to talk about your feelings. Try to keep doing the things that are important to you and that you enjoy. You can also talk to your doctor about your concerns.

Avoidance

You may cope by trying not to find out much about the leukaemia. Or by not talking about it. If you feel like this, tell people that you do not want to talk about it right now. You can also tell your doctor if there are things you do not want to know or talk about yet.

Sometimes, it may be hard to accept that you have leukaemia. This can stop you making decisions about treatment. If this happens, it is very important to get help from your healthcare team.

You may feel that your family or friends are avoiding you or avoiding talking about the leukaemia. This is usually because they are also finding it difficult to cope. They may need support too. Try to tell them how this makes you feel. It may help you, and your family and friends, to talk openly about how you are feeling.

Anger

You may feel angry about your diagnosis. You may also resent other people for being well. These are normal reactions. They are more likely when you feel frightened, stressed or unwell. You may get angry with your family, friends or partner. Tell them you are angry at your illness and not at them. Finding ways to relax can help with anger. This can include talking about or writing down how you feel, doing gentle exercise, having relaxation therapy or meditating.

Guilt and blame

You may feel guilty or blame yourself for the leukaemia. You may want to find reasons for why it has happened to you. Most of the time, it is impossible to know exactly what causes leukaemia. Over time, a combination of different risk factors may cause leukaemia. Doctors do not fully understand all these factors yet. Try to focus on looking after yourself and getting the help and support you need.

Feeling alone

You may feel alone or isolated. This could be because you do not think you have support. Family and friends may live far away, be busy, or feel uncomfortable talking about the leukaemia. Try to tell your family and friends how you feel. This can help them find ways to support you.

You may have times when you want to be alone for a while. But if you find you are avoiding people a lot of the time, try to talk to your doctor or nurse.

If you need more support, you can call the Macmillan Support Line on **0808 808 00 00** and talk to one of our cancer support specialists. Our website can help you find local support groups. Visit **macmillan.org.uk/supportgroups** You can also talk to other people affected by leukaemia on our Online Community. Visit **macmillan.org.uk/community**

> **‘With the help and support of Macmillan, I was understood as person as well as a patient. It has helped give me the strength to take my life back and put the control into my hands.’**

Hannah, diagnosed with CML

If you need more help

You may find it very difficult to cope with your emotions and may need more help. This does not mean you are failing in any way.

Talk to your doctor or nurse if:

- you feel anxious or worried a lot of the time
- you think you may be depressed.

They can refer you to a specialist doctor, psychologist or counsellor who can help. They may also prescribe medicines to help.

We have more information about coping in our booklet **How are you feeling? The emotional effects of cancer** (see page 84).

Talking to children about CML

Deciding what to tell children about leukaemia is difficult. It can be hard to know what to tell them, and you may be worried about upsetting them. Children do not always show their feelings, but their behaviour may change at home or at school.

Talking to children about the leukaemia can:

- help them understand what is going on
- help them feel supported
- prepare them for any changes.

It may also help with some of your own anxiety too. For example, not telling them about hospital appointments may cause extra stress.

How much you tell children will depend on their age and how mature they are. It may be best to start by giving them small amounts of information, and then tell them more when they are ready. Teenagers usually understand what leukaemia is. Some will want to know more.

Whether they are teenagers or young children, talking about the leukaemia helps them cope.

Teenagers

It can help to encourage teenagers to ask questions, ask them their opinion and try to give them time to think about what is happening. They may have to, or want to, take on more responsibilities to help – perhaps cooking meals or looking after younger children. This can be hard at a time when they may want more freedom and independence.

Sometimes teenagers may find it hard to talk about a leukaemia diagnosis. You can encourage them to talk to someone they trust, who can support and listen to them. This might be a grandparent, family friend, teacher or counsellor. They may also find support online. The website **riprap.org.uk** offers information and support for teenagers who have a parent with cancer.

We have more information in our booklet **Talking to children and teenagers when an adult has cancer**. We also have a video on our website about talking to children (see page 84).

Who can help?

Many people with CML manage well and will not need much extra help. But if you do, there is help available.

District nurses work closely with GPs and visit people and their families at home if needed.

The hospital social worker can give you information about social services and benefits you may be able to claim. This includes:

- meals on wheels
- a home helper
- hospital fares.

If you need help with childcare, they may also be able to arrange this.

Specialist nurses called palliative care nurses are experienced in treating symptoms of advanced leukaemia. Your GP or hospital specialist nurse can usually arrange a visit.

There is also specialist help available to help you cope with the emotional impact of leukaemia and its treatment. You can ask your hospital doctor or GP to refer you to a counsellor. Our cancer support specialists on **0808 808 00 00** can tell you more about counselling and about services in your area.

If you are a relative or friend

If you know someone with leukaemia, you might find it hard to talk about the leukaemia or your feelings. You might think it is best to pretend everything is fine. You might not want to worry them. Or you might feel you are letting them down if you admit you are worried or scared.

But not talking to them about how you feel may make them feel alone.

You can support your relative or friend by listening and talking with them. Do not feel you have to talk about leukaemia. Often it is enough just to listen and let them talk when they are ready.

You may find some of the courses on our Learn Zone website helpful. There are courses to help with listening and talking. Visit **macmillan.org.uk/learnzone** to find out more.

We have more information about this in our booklet **Talking to someone with cancer** (see page 84).

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 in the booklet **Looking after someone with cancer** (see page 84).

WORK AND FINANCIAL SUPPORT

Financial help and benefits

When you are affected by leukaemia, you might need help with extra costs. Or you might need financial support if you have to stop working.

Statutory Sick Pay

If you work for an employer and take time off sick, you may be able to get Statutory Sick Pay. Your employer will pay this for up to 28 weeks.

Benefits

Benefits are payments from the government to people who need financial help. You can find out more about benefits and apply for them online. Go to **gov.uk** if you live in England, Wales or Scotland, or **nidirect.gov.uk** if you live in Northern Ireland.

Here are some benefits that you might be able to get if you are affected by leukaemia.

Employment and Support Allowance (ESA)

This benefit is for people under State Pension age who have an illness or disability that affects how much they can work. There are different types of ESA, so it is a good idea to speak to a welfare rights adviser to see if you can make a claim.

Universal Credit

Universal Credit (UC) is a benefit for people under State Pension age who are either:

- out of work – for example, because of an illness or because they are caring for someone
- on a low income.

UC can include money for basic living costs, looking after children and housing.

Personal Independence Payment

This benefit is for people aged 16 to State Pension age who have problems moving around or looking after themselves. You must have had these problems for 3 months and expect them to last for at least 9 months, unless you are terminally ill.

Attendance Allowance

This benefit is for people at or over State Pension age who have problems looking after themselves because of an illness or disability. This could mean problems getting out of bed, having a bath or getting dressed. You must have had these problems for at least 6 months, unless you are terminally ill.

Special rules

If you are terminally ill, you can apply for some benefits using a fast-track process called special rules. You can apply if your doctor thinks you may be reasonably expected to live for less than 6 months. Your claim will be dealt with quickly and you will get the benefit you applied for at the highest rate. It does not matter if you live longer than 6 months. Your doctor or specialist nurse will need to fill out a form for you.

Help for carers

Carer’s Allowance is a weekly benefit to help people who look after someone with a lot of care needs. If you do not qualify for it, you may still be able to apply for Carer’s Credit.

Carer’s Credit helps prevent gaps in your National Insurance record if you have to stop working while you are caring for someone else. You do not get money, but it protects your right to a State Pension later in life.

Macmillan Grants

Macmillan Grants are small, mostly one-off payments to help people with the extra costs leukaemia can cause. They are for people who have a low level of income and savings.

If you need things like extra clothing, help paying heating bills or even a relaxing holiday, you may be able to get a Macmillan Grant.

How much you get will depend on your situation and needs. A grant from Macmillan does not normally affect the benefits you are entitled to. It is an extra bit of help, not a replacement for other support.

Insurance

If you have, or have had, cancer (including leukaemia), you may find it hard to get certain types of insurance. This includes life and travel insurance. A leukaemia diagnosis might also mean that you can get a payout from an insurance scheme that you already have.

If you are thinking about buying insurance or making a claim, one of our financial guides can help. You can call them on **0808 808 00 00**.

We have more information in our booklets **Insurance** and **Travel and cancer** (see page 84). Our Online Community forum on **Travel insurance** may also be helpful. Visit **macmillan.org.uk/travelinsurancegroup**

More information

The benefits system and other types of financial support can be hard to understand. Macmillan has experienced welfare rights advisers and financial guides. You can speak to one by calling the Macmillan Support Line on **0808 808 00 00**.

You can also get information about benefits and other types of financial help from Citizens Advice (see pages 90 to 91).

Our booklet **Help with the cost of cancer** has lots more information (see page 84).

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 soon after you are diagnosed. If your workplace has a human resources (HR) or personnel department, contact them as soon as you can. If they know how the leukaemia or treatment may affect your ability to work, they can support you better.

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

Some people may decide not to go back to work. Or they may choose to do something different. Others may not be able to go back to work because of the effects of leukaemia on their health. Going back to work may depend on the type of work you do or how much your income is affected.

It is important not to do too much, too soon. Your specialist doctor, GP or specialist nurse can help you decide 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 (see page 84). There is also lots more information at **macmillan.org.uk/work**

Employment rights

If you have, or have ever had, cancer (including leukaemia), the law considers this as a disability. This means you cannot be treated less favourably than people who do not have leukaemia because you have leukaemia, or for reasons connected to the leukaemia. That would be discrimination.

The law also says your employer must make reasonable adjustments (changes) to your workplace and their work practices to help you stay at work or return to work.

If you live in England, Scotland or Wales, you are protected by the Equality Act 2010. If you live in Northern Ireland, you are protected by the Disability Discrimination Act 1995.

Our booklet **Your rights at work when you are affected by cancer** has more information (see page 84).

FURTHER INFORMATION

About our information

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

Order what you need

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

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 free, confidential phone line is open 7 days a week, 8am to 8pm. Our cancer support specialists can:

- help with any medical questions you have about cancer or your treatment
- help you access benefits and give you financial guidance
- be there to listen if you need someone to talk to
- tell you about services that can help you in your area.

Call us on **0808 808 00 00** or email us via our website, **macmillan.org.uk/talktous**

Information centres

Our information and support centres are based in hospitals, libraries and mobile centres. There, you can speak with someone face to face. Visit one to get the information you need, or if you would like a private chat, most centres have a room where you can speak with someone alone and in confidence.

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

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 to bring people together in their communities and online.

Support groups

Whether you are someone living with cancer or a carer, 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**

The Macmillan healthcare team

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.

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.

Financial guidance

Our financial team can give you guidance on mortgages, pensions, insurance, borrowing and savings.

Help accessing benefits

Our benefits advisers can offer advice and information on benefits, tax credits, grants and loans. They can help you work out what financial help you could be entitled to. They can also help you complete your forms and apply for benefits.

Macmillan Grants

Macmillan offers one-off payments to people with cancer. A grant can be for anything from heating bills or extra clothing to a much-needed break.

Call us on **0808 808 00 00** to speak to a financial guide or benefits adviser, or to find out more about Macmillan Grants.

We can also tell you about benefits advisers in your area. Visit **macmillan.org.uk/financialsupport** to find out more about how we can help you with your finances.

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**

Work support

Our dedicated team of work support advisers can help you understand your rights at work. Call us on **0808 808 00 00** to speak to a work support adviser (Monday to Friday, 8am to 6pm).

Other useful organisations

There are lots of other organisations that can give you information or support.

Leukaemia support organisations

Anthony Nolan

Tel **0303 303 0303**
www.anthonynolan.org
Matches people willing to donate their bone marrow (or stem cells) to patients in need of a transplant.

Blood Cancer UK

Support line **0808 208 0888**
Email **hello@bloodcancer.org.uk**
www.bloodcancer.org.uk
Provides information and support for anyone affected by blood cancer on their website, by phone or by email.

British Bone Marrow Registry

Tel **0300 123 23 23**
www.bbmr.co.uk
Helps people find stem cell matches from their own and other registries. Provides information about transplants and donating blood and stem cells.

CML Support

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

Leukaemia CARE

Helpline **0808 8010 444**
Email **support@leukaemiacare.org.uk**
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.

General cancer support organisations

Cancer Black Care

Tel **020 8961 4151**
www.cancerblackcare.org.uk
Offers UK-wide information and support for people from black and ethnic minority communities who have cancer. Also supports their friends, carers and families.

Cancer Research UK

Helpline **0808 800 4040** (Mon to Fri, 9am to 5pm)
www.cancerresearchuk.org
A UK-wide organisation that has patient information on all types of cancer. Also has a clinical trials database.

Maggie's

Tel **0300 123 1801**
Email **enquiries@maggies.org**
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** (Mon to Fri, 10am to 1pm)
Email **helpline@pennybrohn.org.uk**
www.pennybrohn.org.uk
Offers physical, emotional and spiritual support across the UK, using complementary therapies and self-help techniques.

Financial support or legal advice and information

Advice NI

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

Benefit Enquiry Line Northern Ireland

Helpline **0800 232 1271** (Mon, Tue, Wed and Fri, 9am to 5pm, and Thu, 10am to 5pm)
Textphone **028 9031 1092**
www.nidirect.gov.uk/money-tax-and-benefits
Provides information and advice about disability benefits and carers’ benefits in Northern Ireland.

Citizens Advice

Provides advice on a variety of issues including financial, legal, housing and employment issues. Use their online webchat or find details for your local office in the phone book or 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

Equipment and advice on living with a disability

Disability Rights UK

Tel **0330 995 0400**
Email **enquiries@disabilityrightsuk.org**
www.disabilityrightsuk.org
Provides information on social security benefits and disability rights in the UK. Has a number of helplines for specific support, including information on going back to work, direct payments, human rights issues, and advice for disabled students.

Disabled Living Foundation (DLF)

Helpline **0300 999 0004** (Mon to Fri, 10am to 4pm)
Email **info@dlf.org.uk**
www.dlf.org.uk
Provides free, impartial advice about all types of disability equipment and mobility products.

LGBT-specific support

LGBT Foundation

Tel **0345 330 3030** (Mon to Fri, 9am to 9pm, and Sat and Sun, 10am to 6pm)
Email **helpline@lgbt.foundation**
www.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.

Cancer registries

The cancer registry

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 one in each country in the UK:

National Cancer Registration and Analysis Service

Tel **020 7654 8000**
Email **enquiries@phe.gov.uk**
www.ncras.nhs.uk
Tel (Ireland) **021 4318 014**
www.ncri.ie

Scottish Cancer Registry

Tel **0131 275 7050**
Email **nss.csd@nhs.net**
www.isdscotland.org/health-topics/cancerscottishcancer-registry

Welsh Cancer Intelligence and Surveillance Unit (WCISU)

Tel **029 2037 3500**
Email **general.enquiries@wales.nhs.uk**
www.wcisu.wales.nhs.uk

Northern Ireland Cancer Registry

Tel **028 9097 6028**
Email **nicr@qub.ac.uk**
www.qub.ac.uk/nicr

Your notes and questions

Disclaimer

Thanks

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

With thanks to: Dr Mark Drummond, Consultant Haematologist; Dr Jonathan Kell, Consultant Haematologist; and Caroline Kerr, Haematology Clinical Nurse Specialist (CNS); and. 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 **cancerinformationteam@macmillan.org.uk**

Sources

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

Smith G, Apperley J, Milojkovic D, et al. A British Society for Haematology Guideline on the diagnosis and management of chronic myeloid leukaemia. British Journal of Haematology, 2020; 191, 2, Available from https://b-s-h.org.uk/ [accessed on October 2020].
Hochhaus A, Saussele S, Rosti G, et al. Chronic Myeloid Leukaemia: ESMO Clinical Practice Guidelines. Annals of Oncology, 2017; 28 (suppl 4), iv41-iv51. Available from https://www.esmo.org/ [accessed on October 2020].

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

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

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.

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?

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

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

Call us to find out more 0300 1000 200
macmillan.org.uk/getinvolved

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

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Valid from ☐☐ ☐☐

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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.

☐ I am a UK tax payer and I would like Macmillan Cancer Support to treat all donations I make or have made to Macmillan Cancer Support in the last 4 years as Gift Aid donations, until I notify you otherwise.

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, Macmillan Cancer Support, FREEPOST LON15851, 89 Albert Embankment, London SE1 7UQ

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 talks about the signs and symptoms of CML. It explains how it is diagnosed and how it may be treated. It also has information about emotional, practical and financial issues.

We're here to help everyone with cancer live life as fully as they can, providing physical, financial and emotional support. So whatever cancer throws your way, we're right there with you. For information, support or just someone to talk to, call **0808 808 00 00** (7 days a week, 8am to 8pm) 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 NGT (Text Relay) on **18001 0808 808 00 00**, or use the NGT Lite app.

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

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