

# UNDERSTANDING CHRONIC MYELOID LEUKAEMIA





**I've been overwhelmed with kindness and information from the hospital staff and fellow CML sufferers.**

**Alan, diagnosed with CML.**

# About this booklet

This booklet is about chronic myeloid leukaemia (CML). CML is also known as chronic myelogenous leukaemia.

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

This booklet includes quotes from people who have had CML. Some are from Alan, who is on the cover of this booklet. The rest are from **healthtalk.org** and people who have shared their experiences with us. To share your experience, visit **macmillan.org.uk/shareyourstory**

## How to use this booklet

The booklet is split into sections to help you find what you need. You don't have to read it from start to finish. You can use the contents list opposite to help you. It is fine to skip parts of the booklet. You can always come back to them when you feel ready.

At the end of this booklet there are some useful organisations and websites (see pages 89 to 93).

If you find this booklet helpful, you could give it to your family and friends. They may also want information to help them support you.

## 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**.

### Your data and the cancer registry

When you are diagnosed with cancer in the UK, some information about you and your health 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.

Talk to your doctor or nurse if you have any questions. If you do not want your information included in the registry, you can contact the cancer registry in your country to opt out. You can find more information at **macmillan.org.uk/cancerregistry**

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# THE BLOOD AND CHRONIC MYELOID LEUKAEMIA

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# What is leukaemia?

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

The four main types of leukaemia are:

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

Each type of leukaemia is different. We have separate information about these different leukaemias.

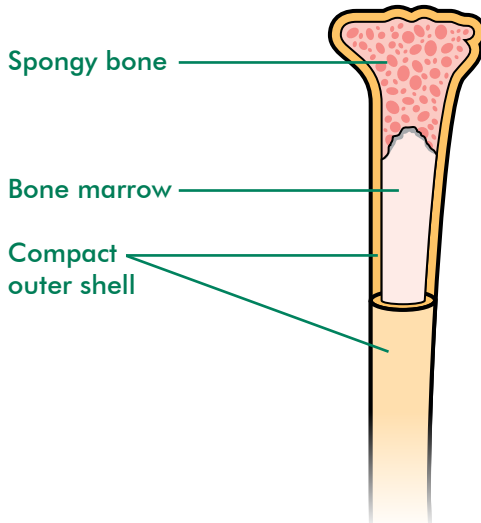


# The blood

To help you understand CML and its treatment, it is useful to know how your blood is made, and what it does.

Blood is made up of blood cells, which float in a liquid called plasma. Blood cells are made in the bone marrow. This is a spongy material that is found in the middle of our bones, particularly in our pelvis and backbone (spine). Normally, millions of new blood cells are made every day to keep the body healthy.

## Bone marrow



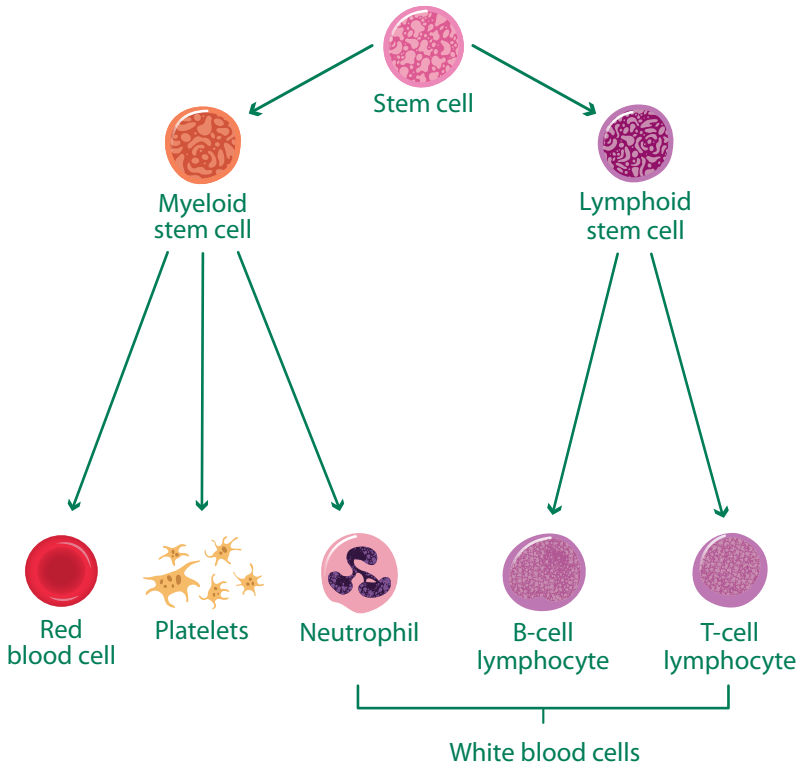
All blood cells are made from cells, in the bone marrow, called **blood stem cells**.

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 all the other types of blood cell: red blood cells, platelets, and other white blood cells.

Blood stem cells in the bone marrow divide to make new blood cells. The new blood cells begin as immature cells called blast cells. They do not look like mature cells and they cannot do the jobs that mature cells do. Usually, blast cells stay in the bone marrow until they mature to become red blood cells, platelets or white blood cells.

## How blood cells divide



The mature cells are then released into your blood to carry out different functions:

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

The levels of these cells in your blood are measured in a blood test called a full blood count (FBC). The figures below are a guide to the levels usually found in a healthy person.

Type of cell	Levels found in a healthy person
Red blood cells (Hb)	130–180g/l (men)
	115–165g/l (women)
Platelets	150–400 x 10 <sup>9</sup> /l
White blood cells (WBC)	4.0–11.0 x 10 <sup>9</sup> /l
Neutrophils	2.0–7.5 x 10 <sup>9</sup> /l
Lymphocytes	1.5–4.5 x 10 <sup>9</sup> /l

These figures vary from hospital to hospital. Your doctor or nurse will be able to tell you which levels they use. They can also vary slightly between people from different ethnic groups.

The figures might look difficult, but they're used in a straightforward way. For example, you will hear doctors or nurses saying things like: 'your platelets are 150,' or 'your neutrophils are 4'.

You will probably find you get used to these figures and what they mean. Remember, you can always ask your doctor or nurse if you are unsure.

# Chronic myeloid leukaemia

Chronic myeloid leukaemia (CML) is a rare type of cancer. It causes the body to make too many white blood cells.

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. It usually develops very slowly, which is why it is described as a **chronic** leukaemia. For most people, CML can be well controlled, and they will live a normal life-span.

## How CML develops

The information below and on the next two pages explains how CML develops. This information will help you understand the sections about:

- having tests for CML (see pages 22 to 27)
- treatment for CML (see pages 31 to 59).

The information is quite technical, so you might need to read it more than once. Don't worry if it is too much to take in. It is fine to skip it and come back to it another time.

## Genes and chromosomes

CML is a cancer of the white blood cells. It develops when some white blood cells start behaving abnormally.

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 the BCR gene, it creates a completely new abnormal gene called **BCR-ABL1** (see the diagram opposite).

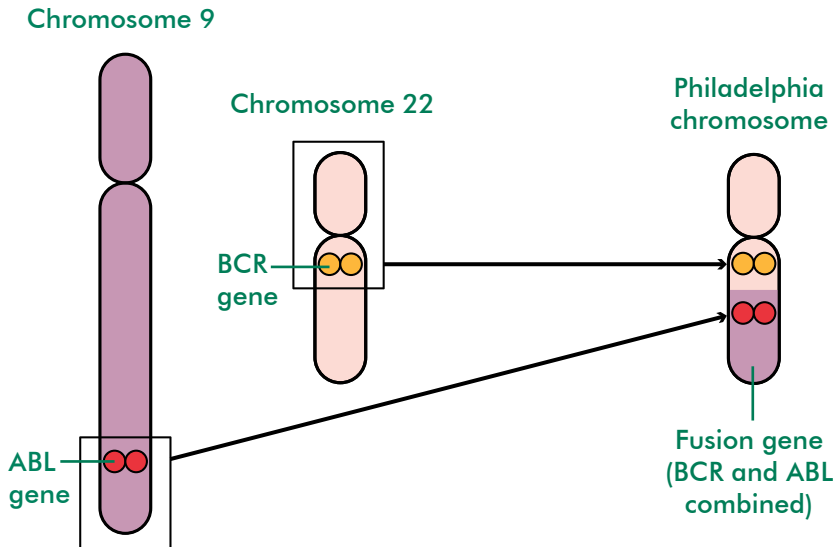
This new BCR-ABL1 gene makes a substance called **tyrosine kinase**. Too much tyrosine kinase causes the bone marrow to make too many white blood cells. It also stops these cells from developing into normal blood cells or dying when they should. These abnormal cells are the leukaemia cells.

### The Philadelphia (Ph) chromosome

When the new BCR-ABL1 gene forms on chromosome 22, it changes how the chromosome looks. Doctors can see it when they look at the leukaemia cells under a microscope. They call it the **Philadelphia chromosome** (see the diagram opposite). Most people with CML have the Philadelphia chromosome in all their 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



'I'd never heard of CML and didn't know anything about leukaemia. But my medical team explained what the cancer is, which made it easy to understand.'

Alan

# Risk factors and causes

It is not clear why people get CML. It is not linked to smoking, diet, exposure to chemicals or infections. And it does not run in families.

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

## Age

CML can happen at any age. But it is more common as people get older. Over half of the people diagnosed with CML in the UK are over 65.

## Gender

CML is slightly more common in men than women.

## Radiation exposure

Exposure to very high radiation levels increases the risk of developing CML. For example, these might be the 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.



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).

Like other cancers, CML is not infectious and it cannot be passed on to other people.



# Symptoms

CML develops slowly and many people don't have symptoms in the early stages. Sometimes CML is discovered by chance when a blood test is done before an operation or as part of a routine health check.

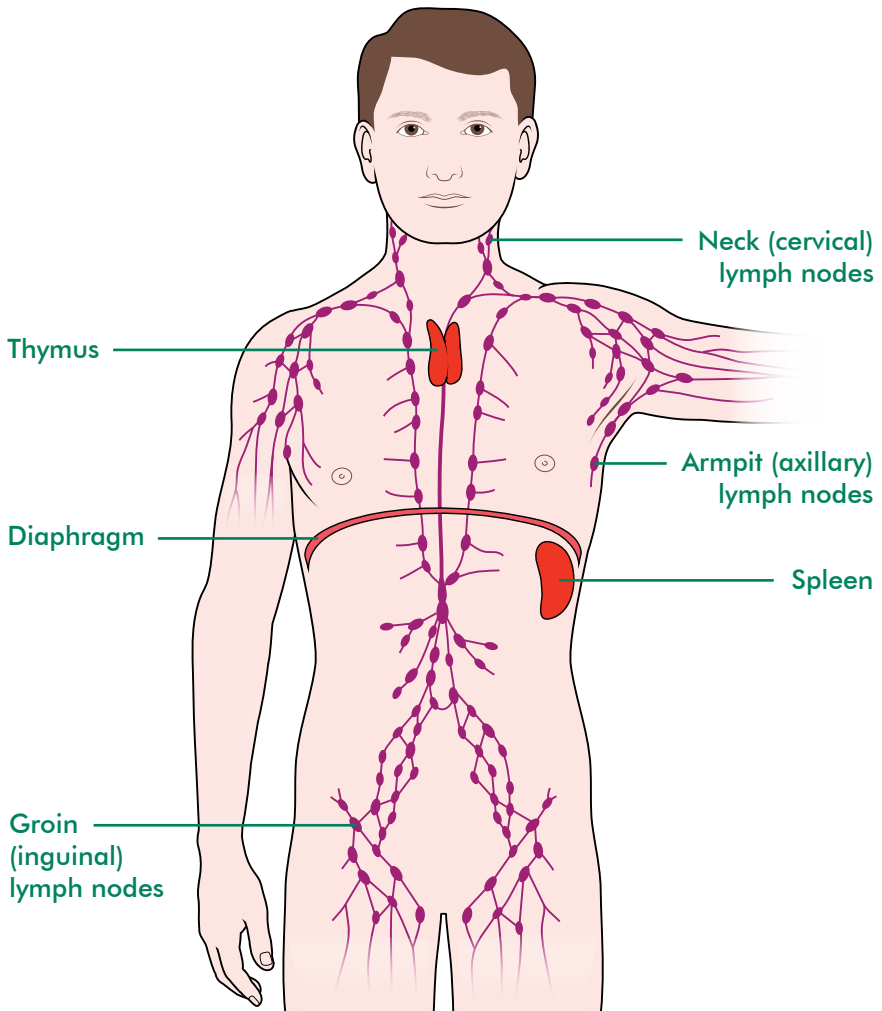
If there are symptoms in the early stages of CML, they are usually mild and develop gradually. The symptoms can be confused with the symptoms of more common illnesses, such as flu.

## Common symptoms

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

- Feeling generally tired.
- Having a poor appetite and losing weight.
- Heavy sweating or having a high temperature at night.
- Feeling full or tender on the left side of your tummy (abdomen). This is caused by abnormal blood cells (leukaemia cells) collecting in the spleen, making it bigger. The spleen is part of the lymphatic system – see the diagram opposite. The spleen stores blood cells and destroys old and damaged blood cells. The bone marrow and the lymph nodes (glands) are also part of the lymphatic system.

## The spleen in the lymphatic system





## Less common symptoms

Sometimes abnormal white blood cells (the leukaemia cells) build up in the blood and bone marrow. The bone marrow may not be able to make enough healthy red blood cells, white blood cells and platelets (see pages 7 to 10). This can cause the following symptoms:

- Bleeding or bruising, due to a lack of 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 are too many leukaemia cells in the bone marrow.
- Visual disturbances and headaches. This can happen if the blood becomes thick because it contains too many white blood cells.

If you have any of these symptoms, it is important to see your doctor. But remember that these can be symptoms of many illnesses other than CML.

'I was having all sorts of different symptoms – aching limbs, tiredness, night sweats, headaches. As it went on, it didn't seem quite right.'

**Mark**



# DIAGNOSING CHRONIC MYELOID LEUKAEMIA

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# How CML is diagnosed

If your GP suspects you have CML, they will refer you to a haematologist. This 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.

### Blood tests

You will have blood tests at the hospital.

These tests are to:

- check the number of blood cells in your blood (a full blood count – see pages 7 to 10)
- look for leukaemia cells.

If the tests show there are leukaemia cells in your blood, the haematologist will arrange more tests. This is to find out the type of leukaemia you have and its extent. The results of these tests will help them plan your treatment. You can read about these tests over the next few pages.





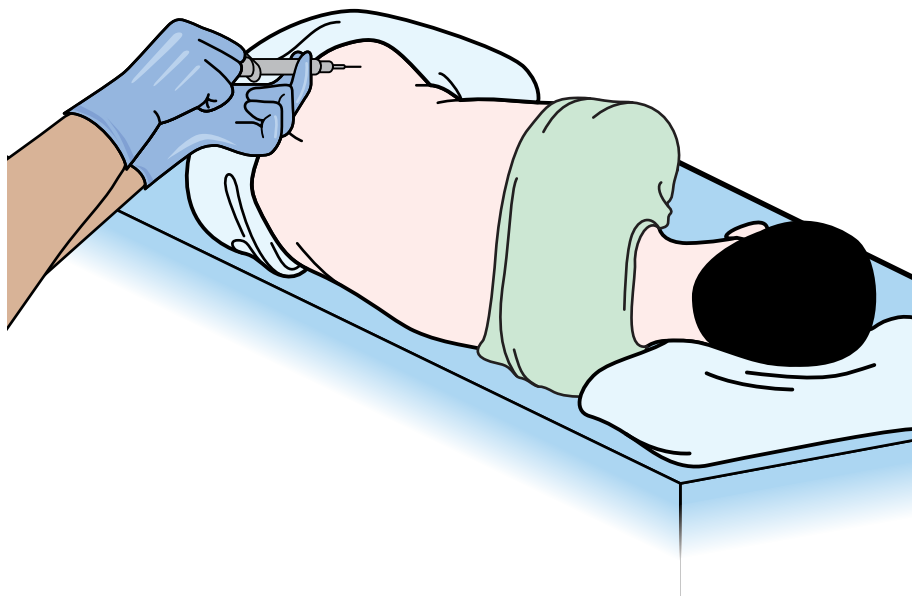
Having a blood test

## Tests

### Bone marrow sample

A doctor or nurse takes a small sample of bone marrow. They usually take it from the back of the hip bone (pelvis). Rarely, it is taken from the breast bone (sternum). The sample is sent to a laboratory to be checked for abnormal white blood cells.

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



The procedure can be done on the ward or in the outpatient department. It takes about 20 to 30 minutes in total but removing the bone marrow sample only takes a few minutes.

Before the bone marrow sample is taken, you'll be given a local anaesthetic injection to numb the area. You may also be offered 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.

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

You may feel bruised after having a sample of bone marrow taken, and have an ache for a few days. This can be eased with mild painkillers.

'I had to do a bone marrow test. It's uncomfortable, but over in a flash.'

**Alan**



## Cytogenetic and molecular tests

Cytogenetic and molecular tests look at chromosomes. They might include the following two tests.

### Philadelphia chromosome test

Doctors use the blood and bone marrow samples they have taken to look for the Philadelphia chromosome (see pages 11 to 13).

### Polymerase chain reaction (PCR) test

This blood test looks for the BCR-ABL1 gene in the leukaemia cells (see pages 11 to 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 (see pages 16 to 17). Ultrasound scans use sound-waves to build up a picture of the inside of the body. This is a painless test that only takes a few minutes.

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

# Phases of CML

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

- The chronic phase.
- The accelerated phase.
- The blast phase.

Doctors know the phase of CML you are in from:

- the number of immature blood cells (blast cells) in your blood and bone marrow (see pages 7 to 8)
- 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 and most people lead a normal life. People usually have treatment by taking tablets at home. They have regular blood tests to check how well 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 1 in 10 (10%) of the blood cells in the blood or bone marrow are blast cells.

## Accelerated phase

Sometimes CML does not respond very well to treatment. In a small number of people, the leukaemia may progress from the chronic phase to the accelerated phase. Occasionally people may be diagnosed with CML in the accelerated phase.

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, let your doctor know.

## Blast phase

In some people who have CML in the accelerated phase, the leukaemia may transform into the blast phase. Occasionally people may be diagnosed with CML in the blast phase or progress straight to it from the chronic phase.

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





# TREATING CHRONIC MYELOID LEUKAEMIA

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# Treatment overview


The aim of treatment is to put CML into **remission** and to maintain the remission. Remission means there are no signs of leukaemia cells in your blood or bone marrow, and you feel well. There are different levels of remission (see pages 48 to 50).

Treatments for CML are very effective. And remission can usually be maintained for many years – people with CML usually live a normal life-span.

Most people with CML are treated with tablets called **tyrosine kinase inhibitors (TKIs)**. These block the action of the tyrosine kinase made by the leukaemia cells (see page 12). You take the tablets every day. There are many different TKIs for CML. If a TKI does not work, or stops working, you can usually be switched to a different one.

If you have a very high level of white blood cells in your blood when you are first diagnosed, you may be given chemotherapy tablets for a few days (see pages 52 to 53). This is usually only until the doctors check that a TKI will work for you.

If TKI treatment does not work, or if you are diagnosed in the blast phase, your doctors may suggest chemotherapy and a stem cell transplant (sometimes called a bone marrow transplant – see page 54). A stem cell transplant is an intensive treatment and it is not suitable for everyone. Doctors take into account someone's general health and fitness when they decide if it might be suitable.

A middle-aged man with thinning brown hair, wearing a light blue button-down shirt, is seated at a table. He is looking down at a newspaper in front of him. A dark mug is on the table to his left. In the background, a large window lets in bright light, and another person is visible sitting on a sofa. A green text box is overlaid on the lower half of the image.

**'I take an interest in my cancer and the treatment, so I understand what's happening to me. If you don't understand something, just ask.'**

**Alan**

## Reducing a high level of white blood cells in the blood

Some people have a very high number of white blood cells in their blood when they are diagnosed with CML. The cells can clog up blood vessels and cause problems. Doctors can remove the extra cells from the blood using a machine called a cell separator. This process is called **leukapheresis**. This treatment may also be used for women who are pregnant when they are diagnosed.

You lie on a bed or reclining chair with a small plastic tube (cannula) 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

Specialist leukaemia doctors are called haematologists. They follow guidelines for treating CML. Your treatment will be based on the guidelines, but tailored to your situation.

A team of specialists plan your treatment. They will meet to discuss your treatment plan. After this, your haematologist will talk to you about your treatment options.

This **multi-disciplinary team** (MDT) of specialists may include:

- one or more **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, 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 or counsellor.

The MDT will take a number of factors into account when they advise you on which treatments are likely to be best for you. These factors include the phase of your leukaemia and your general health.

You may be invited to take part in a clinical trial of a new treatment for CML (see pages 58 to 59).

## 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

Before you have any treatment, your doctor will explain its aims. 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, and 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 don't understand what you've been told, let the staff know straight away, so they can explain it again. Some leukaemia treatments are complex, so it's not unusual to need repeated explanations. It's a good idea to have a relative or friend with you when the treatment is explained, to help you remember the discussion. You may also find it useful to write a list of questions before your appointment.

People sometimes feel that hospital staff are too busy to answer their questions, but it's 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 can't make a decision when your treatment is first explained to you.

You are also free to choose not to have the treatment. The staff can explain what may happen if you don't have it. It's essential to tell a doctor or the nurse in charge, so they can record your decision in your medical notes. You don't have to give a reason

for not wanting treatment, but it can help to let the staff know your concerns so 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 decide the most suitable treatment for you. Even so, you may want another medical opinion. If you feel it will be helpful, you can ask either 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 that it will give you useful information.

If you do go for a second opinion, it may be a good idea to take a relative or friend with you, and have a list of questions ready, so that you can make sure your concerns are covered during the discussion.

# Tyrosine kinase inhibitors (TKIs)

The main treatment for CML uses drugs called tyrosine kinase inhibitors (TKIs).

TKIs are a type of targeted therapy. They work by switching off (inhibiting) the tyrosine kinase made by the BCR-ABL1 gene in leukaemia cells (see page 12). This slows or stops 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. You keep taking them for as long as they are working. The three main TKI drugs currently used for CML are:

- imatinib
- nilotinib
- dasatinib.

Imatinib is the most commonly used TKI.

There are also some newer TKI drugs, such as ponatinib and bosutinib. Different drugs are used for different situations. Your haematologist will discuss which one is appropriate for you.

Although the TKIs are similar, they work in slightly different ways. This means they can have different side effects. To make sure the TKI you have is right for you, your doctor will think about:

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



If a drug is not available on the NHS, there may be different ways you can still have it. Some people may be given it as part of a clinical trial (see pages 58 to 59). Your doctor can give you advice. We also have information on what to do if a drug is not available – call us on **0808 808 00 00** or visit **macmillan.org.uk**

## 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 can't have imatinib because of side effects or if it is 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 the chronic, accelerated or blast phase if imatinib is causing severe side effects or isn't working to control the CML.

## Bosutinib (Bosulif®)

Bosutinib is a newer TKI. You might have bosutinib if other TKIs have stopped working or are not suitable for you.

**We can send you more information about imatinib, dasatinib, nilotinib and bosutinib.**

## Ponatinib (Iclusig®)

Ponatinib is a newer TKI. It may be used for people who have leukaemia cells with a particular gene change (mutation) called T3151. Only a few people with CML have this gene change in their leukaemia cells.

You may be offered ponatinib if you have tried other TKI treatments but:

- they have stopped working
- 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 they may improve with 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. Occasionally people need to stop treatment with the TKI they are taking because their side effects are too severe. If this happens, they will usually be offered a different TKI drug.

Sometimes a new side effect can develop many months after you started treatment. Always let your doctor know if you notice any new side effects or if your side effects get worse.

Each TKI can have 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 on our website – visit **macmillan.org.uk** We have listed some possible side effects of TKIs over the next few pages.

## **Tiredness and feeling weak**

This is a common side effect, but it's 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 prescribe anti-sickness drugs to prevent or reduce it. If you still feel sick, tell your doctor. They can prescribe another anti-sickness drug that may work better for you.

## **Diarrhoea**

This can usually be controlled with anti-diarrhoea medicine, but tell your doctor if it is severe or continues. It is important to drink plenty of fluids if you have diarrhoea.

## **Loss of appetite**

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

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

## **Headaches**

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

## **Changes in the way your heart works**

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

- you feel breathless
- you have chest pain
- your heartbeat becomes fast or irregular.

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

## Build-up of fluid

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 doesn't settle, your doctor may prescribe a drug that makes you pass more urine (diuretic) to 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 the dasatinib 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 or joint pain

You may get some pain in your muscles, bones or joints. Your doctor can prescribe 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 prescribe 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 prescribe 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 monitored regularly while you are having treatment. If your blood cell numbers fall too low, your doctor may stop your treatment for a few days to let them recover.

## Risk of infection

TKIs can sometimes temporarily reduce the number of healthy white blood cells made in the bone marrow. This is most common in the first few weeks of treatment, but it can also happen later. Having a low number of white blood cells can make you more likely to get an infection. Your doctors and nurses will monitor your blood count more regularly at the start of your treatment.

Contact your doctor straight away if:

- your temperature goes over 37.5°C (99.5F)
- you suddenly feel unwell, even with a normal temperature
- you feel shivery and shaky
- you have any symptoms of an infection, such as a cold, sore throat, cough, passing urine frequently (urine infection), or diarrhoea.

**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. We can send you more information about G-CSF – call us on **0808 808 00 00**.

## Bruising or bleeding

TKIs can reduce the number of platelets (blood-clotting cells – see pages 9 to 10) 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 advise 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 number of red blood cells becomes 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.

We can send you more information about erythropoietin. Call us on **0808 808 00 00**.

## Contraception and fertility

Below is information for women and men about TKIs and fertility. But because TKIs are a newer type of drug, there is not a lot of information available yet about women becoming pregnant or men fathering children while taking TKIs.

### 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 want to have children in the future, talk to your doctor about this as soon as possible. They can talk to you about the possible options for planning your treatment. They will aim to make things as safe as possible for you and any future pregnancy. If you think you may have become pregnant while taking a TKI, discuss this with your doctor as soon as possible. This is because the highest risk to the baby is during the first few weeks of the pregnancy.

### Men

There is less evidence about men fathering children while taking a TKI. But you should still talk to your doctor if you are planning to have a baby. The advice may be different depending on which type of TKI you are having.





# Monitoring response to treatment

When you first start treatment with a TKI, you will need to go to the clinic every 1 to 2 weeks. This is so your doctors can closely monitor how well treatment is working, and to check for any side effects. As time goes on, you won't need to go as often. Eventually, you may only need a check-up every 3 to 6 months.

At these check-ups, your doctor will:

- ask about your general health
- ask about any new symptoms or side effects from treatment
- do blood tests to check the numbers of blood cells (FBC) and leukaemia cells (PCR test) – see page 27.

Sometimes they may also take a bone marrow sample (see pages 24 to 25). Your doctor can tell you how often you might need this.

The results of these tests help your doctors know how well the treatment is working to control the leukaemia. This means they can make any changes if needed.

## Levels of remission (response)

The aim of treatment is to put CML into remission. In CML, remission means there are no signs of CML in your blood during a standard blood test. But this 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, doctors may use the word **response** instead of remission.

There are different levels of remission (response). These are based on the results of different tests that look for leukaemia cells as the leukaemia responds to treatment.

We explain the different levels of remission (response) below and on the next page.

## **Haematological response**

When you first develop CML, your number of white blood cells is usually high. If there's a haematological response, it means your full blood count has returned to normal and no leukaemia cells can be seen. If your spleen was enlarged, it's gone back to its normal size.

Most people get a haematological response within three months of starting a TKI.

## **Cytogenetic response**

This is the next level of response. It refers to the amount of Philadelphia chromosome in the blood and bone marrow (see pages 11 to 13). As treatment starts working, the number of Philadelphia chromosome-positive (Ph+) cells in the blood and bone marrow goes down.

To check for a cytogenetic response, you have a bone marrow sample taken (see pages 24 to 25). Your doctors will usually examine at least 20 cells from the sample to see if there has been a cytogenetic response. There are different levels of cytogenetic response, depending on the amount of Ph+ cells in the bone marrow.

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

About 8 out of 10 people taking imatinib for CML in the chronic phase (80%) get a complete cytogenetic response. This 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 one leukaemia cell among thousands of normal blood cells, a very sensitive test is needed to find the leukaemia cells.

The PCR test can detect 1 leukaemia cell in 10,000 normal blood cells. It does this by measuring a substance made by the BCR-ABL1 gene in the leukaemia cells (see pages 11 to 12).

When you are first diagnosed with CML, you will have blood taken for a PCR test (see page 27). After diagnosis, you will have this done every three months. Because it is so sensitive, the PCR test may keep showing signs of leukaemia for many months after your treatment starts, even though you are feeling well.

There are two different levels of molecular response:

- If you have a **major molecular response**, it means there are tiny amounts of the BCR-ABL1 gene in the blood.
- If you have **molecularly undetectable leukaemia**, the PCR test cannot detect any of the BCR-ABL1 gene in your blood.

‘There’s a possibility that my tablets could give a lifetime’s control. But I do try to keep in mind that there might come a day when I have to seek other options.’

**Chanelle**

## Continuing to take 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 do not show any signs of leukaemia.

If you find it difficult to remember to take your tablets every day, you may find the following ideas helpful:

- Take your tablets at the same time each day.
- Put your tablets 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 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 tablets each time you need more. Tell your doctor, nurse or pharmacist if it is difficult for you to get to the hospital. There are trials currently looking at whether it may be safe to stop TKI treatment if someone has had molecularly undetectable leukaemia for a long time. This is not recommended at the moment, but if someone is finding side effects too difficult, it may occasionally be done. In the future, it may become more common practice, depending on the results of the trials.

If you have questions about this, you can talk to your doctor.

# 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 very occasionally used for CML.

## Chemotherapy tablets

Some people may be given a type of gentle chemotherapy if their 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 that the CML is likely to respond to a TKI.

The most commonly used chemotherapy drug for CML is **hydroxycarbamide**. It is given as a tablet. The doctor, nurse or pharmacist will tell you how many tablets to take. You need to be sure you are taking the right dose. You will usually be changed to a TKI once the test results are available. We can send you more information about hydroxycarbamide.

## Combination chemotherapy

Combination chemotherapy is occasionally used if CML is in the blast phase. This usually involves a combination of three or four drugs given into a vein (intravenously).

People who are treated with a stem cell transplant usually have intensive chemotherapy as preparation for the transplant (see page 54).

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 troublesome 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 about what to expect. We have more information about each different type of chemotherapy, its side effects and how to manage them. 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
- a sore mouth
- changes to your bowel habits (constipation or diarrhoea)
- tiredness (fatigue)
- hair loss
- changes to fertility.

# Stem cell transplants

A stem cell transplant may be used if:

- the CML is in the blast phase (see pages 28 to 29)
- treatment with TKIs is not controlling the CML (see pages 48 to 51).

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 allows you to have much higher doses of chemotherapy than usual. You may also have radiotherapy (high-energy rays) to the whole body. This may cure some people with leukaemia, or put the leukaemia into remission.

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**. We can send you more information about donor stem cells transplants – call us on **0808 808 00 00**.





# 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.

If other treatments haven't worked, occasionally some people are given interferon alpha in the chronic phase. Doctors may also use it for women who need treatment and are pregnant or want to become pregnant (see page 46).

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

'I learned to inject myself properly without hurting myself. It did take me a little while to get the knack of it.'

**Chanelle**

## Side effects

Interferon alpha can cause various side effects. Some are similar to the symptoms of flu. They include:

- chills
- fever
- depression
- weight loss
- 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 one or two injections, and they usually wear off after that. But the tiredness may continue.

We can send you more information about interferon alpha – call us on **0808 808 00 00**.

## Research – clinical trials

Leukaemia research trials are carried out to try to find new and better treatments for leukaemia. Trials that are carried out on patients are known as clinical trials. These may be carried out 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 reduce side effects
- compare the effectiveness of drugs used to control symptoms
- find out how leukaemia 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 surgery, chemotherapy, hormone therapy, radiotherapy, or other 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 in doing 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. It's important to bear in mind that some treatments that look promising at first are often later found not to be as good as existing treatments or to have side effects that outweigh the benefits.

If you decide not to take part in a trial, your decision will be respected and you don't have to give a reason. However, it can help to let the staff know your concerns so that they can give you the best advice. There will be no change in the way that you're treated by the hospital staff, and you'll be offered the standard treatment for your situation.

Our booklet **Understanding cancer research trials (clinical trials)** describes clinical trials in more detail. We can send you a free copy.

## Blood samples

Blood samples may be taken to help make the right diagnosis. You may be asked for your permission to use some of your samples for research into leukaemia. If you take part in a trial you may also give other samples, which may be frozen and stored for future use when new research techniques become available. Your name will be removed from the samples so you can't 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 CHRONIC MYELOID LEUKAEMIA

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# Living with CML

Most people with CML live a normal life-span. 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 focus more on making the most of your health.

A healthy lifestyle doesn't 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.

We've listed some tips over the next few pages. When planning changes, you need to take any side effects of treatment into account. Try not to do too much, too soon.

'One of the things I did when I was diagnosed was do more exercise. I wanted my body to be fit so that I could fight the cancer.'

**Alan**



## 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 five 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.

Our booklet **Healthy eating and cancer** has more information.

'I've always been sporty. And I eat lots of fruit, veg and fresh food.'

**Aude**

## 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.

Our booklet **Giving up smoking** has more information and tips to help you succeed.

## Reduce stress

There are different ways of reducing stress, and they will vary from person to person. Try to take some time for yourself to do something you find relaxing. You might decide to take up a new hobby or exercise. You could try learning relaxation techniques or try a complementary therapy like massage.

We can send you more information about cancer and complementary therapies – call us on **0808 808 00 00**.

Some people find it helpful to talk about their feelings or have contact with other people who have been through a similar experience (see page 65 to 66). Others find it helpful to write a journal or blog.

‘I have tried aromatherapy, reflexology and hypnotherapy. I found them all to be of some benefit in different ways. And the consultant asked a patient who had CML if they would give me a call. That was the biggest benefit of all – actually talking to somebody who knew exactly how you felt. It was a great comfort talking to somebody who knew what I was going through. And in turn, I’ve now done that for quite a lot of other people.’

**Mark**

## 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 doesn't have to be very strenuous. You can start gently and build up the amount you do.

You can read more about exercise and its benefits in our booklet **Physical activity and cancer treatment**.

## 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, let your doctor know as soon as possible.

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

## 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've suggested some of them over the next few pages.

Self-help or support groups offer a chance to 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 don't feel able to talk about your feelings with the people around you. Not everyone finds it easy to talk in a group, so it might not be for you. Try going along to see what the group is like before you decide.

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

## Online support

Many people now get support on the internet. There are online support groups, social networking sites, forums, chat rooms and blogs for people affected by leukaemia. 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](https://macmillan.org.uk/community)** You could also use the CML Support Group's forum – see page 89.

'I got lots of support from fellow patients – it was a life-saver. They really showed me how to live with cancer and helped me through tough moments. It was wonderful to hear from people who were going through, or who had gone through, the same things I had.'

**Alan**



# Your feelings

It's common to feel overwhelmed by different feelings when you're 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'll cope with things in your own way. Talking to people close to you or other people affected by leukaemia can often help.

## Shock and disbelief

You may find it hard to believe it when your doctor tells you that you have leukaemia. It's common to feel shocked and numb. You may not be able to take in much information and find that you keep asking the same questions again and again. At first, you might find it hard to talk to family and friends about the leukaemia. This usually gets easier as the shock wears off and it becomes more real to you. You may find you can't think or talk about anything but the leukaemia. This is because your mind is trying to process what you're going through.

## Fear and anxiety

People can be worried about whether treatment will work and what will happen in the future. This can be hard to cope with. It can help to try to focus on what you can control. You may want to find out more about the leukaemia, its treatment and how to manage side effects. It can also help to talk about your feelings and to take time to do things that are important to you and that you enjoy. You can also talk to your doctor about your concerns.

## Avoidance

Some people cope by not wanting to know very much about the leukaemia and by not talking about it. If you feel like this, let your family and friends know that you don't want to talk about it right now. You can also tell your doctor if there are things you don't want to know or talk about yet.

Occasionally, this avoidance can be extreme. Some people may not believe that they have leukaemia. This is sometimes called being in denial. It may stop them making decisions about treatment. If this happens, it's very important for them to get help from their doctor.

Sometimes, avoidance is the other way around. Family and friends may seem to avoid you and the fact that you have leukaemia. They may not want to talk about it or they might change the subject. This is usually because they are also finding the leukaemia difficult to cope with, and they may need support too. Try to let them know how this makes you feel and that talking openly with them about your illness will help you.

## Anger

You may feel angry about your illness and sometimes resent other people for being well. These are normal reactions, especially when you feel frightened, stressed, out of control or unwell. You may get angry with the people close to you. Let them know that you are angry at your illness and not at them. Finding ways to help you relax and reduce stress can help with anger. This can include talking about or writing down how you feel, gentle exercise, breathing or relaxation therapy, yoga or meditation.

## Guilt and blame

Some people feel guilty or blame themselves or others for the leukaemia. You may try to find reasons for why it has happened to you. Most of the time, it's impossible to know exactly what has caused a person's leukaemia. Over time, several different factors may act together to cause a leukaemia. Doctors don't fully understand all of these factors yet. Instead, try to focus on looking after yourself and getting the help and support you need.

## Feeling alone

Some people feel alone because they don't have enough support. Family and friends may live far away, have other commitments or feel uncomfortable because of their own fears about leukaemia. Try to let your family and friends know how you feel and how they could support you more.

If you need more support, you can call the Macmillan Support Line free on **0808 808 00 00** and talk to one of our cancer support specialists. Our website can help you find out about local support groups – visit **[macmillan.org.uk/supportgroups](https://macmillan.org.uk/supportgroups)** You can also talk to other people going through the same thing on our Online Community at **[macmillan.org.uk/community](https://macmillan.org.uk/community)**

It's normal to have times when you want to be left alone to sort out your feelings. But if you find you're avoiding people a lot of the time, then try to talk to your doctor or nurse.



## If you need more help

These feelings can be very difficult to cope with and sometimes people need more help. This happens to lots of people and doesn't mean you're not coping.

If you feel anxious, panicky or sad a lot of the time, or think you may be depressed, talk to your doctor or nurse. They can refer you to a doctor or counsellor who can help. They may also prescribe medicine to help with anxiety or an antidepressant drug.

Our booklet **How are you feeling? The emotional effects of cancer** discusses the feelings you may have in more detail, and has suggestions for coping with them.

'My mind went berserk when I first found out I had cancer – I started to get my affairs in order. But then I met a woman who had been diagnosed with CML eight years ago. She was a star – she completely changed my mind about it. Meeting someone who had been through the same thing was so helpful.'

**Alan**



# Talking to children

Deciding what to tell your children or grandchildren about your cancer is difficult. An open, honest approach is usually best.

Even very young children can sense when something is wrong, and their fears can sometimes be worse than the reality.

How much you tell your children will depend on their age and how mature they are. It may be best to start by giving only small amounts of information and slowly tell them more to build up a picture of your illness.

Our booklet **Talking to children and teenagers when an adult has cancer** gives more information about talking to children and teenagers. There is also a video that may help at [macmillan.org.uk/talkingtochildren](https://www.macmillan.org.uk/talkingtochildren)

## 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, such as meals on wheels, a home helper or 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's 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 doctor or counsellor who specialises in supporting people with leukaemia and their families. Our cancer support specialists on **0808 808 00 00** can tell you more about counselling and can let you know about services in your area.

# If you are a relative or friend

Some people find it hard to talk about leukaemia or share their feelings.

Partners, relatives and friends can help by listening carefully to what the person with leukaemia wants to say. It may be best not to rush into talking about the illness. Often it is enough just to listen and let the person with leukaemia 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, to help friends and family support their loved ones affected by cancer. Visit **[macmillan.org.uk/learnzone](https://macmillan.org.uk/learnzone)** to find out more.

Our booklet **Talking with someone who has cancer** has more suggestions if you have a friend or relative with leukaemia.

If you're looking after a family member or friend with leukaemia, you may find our booklet **Looking after someone with cancer** helpful. It's based on carers' experiences and has lots of practical tips and information.

We have more information about supporting someone with leukaemia at **[macmillan.org.uk/carers](https://macmillan.org.uk/carers)**





# WORK AND FINANCIAL SUPPORT

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Work

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# Financial help and benefits

If you are struggling to cope with the financial effects of leukaemia, help is available.

If you cannot work because you are ill, you may be able to get Statutory Sick Pay. Your employer will pay this for up to 28 weeks of sickness. If you qualify for it, they cannot pay you less.

Before your Statutory Sick Pay ends, or if you do not qualify for it, check whether you can get Employment and Support Allowance (ESA). This benefit is for people who cannot work because they are ill or disabled.

There are two different types of ESA:

- contributory – you can get this if you have made enough national insurance contributions
- income-related – you can get this if your income and savings are below a certain level.

Since October 2013, a new benefit called Universal Credit has started replacing income-related ESA in England, Scotland and Wales. This benefit is for people who are looking for work or on a low income. Personal Independence Payment (PIP) is a new benefit for people under 65 who find it difficult to walk or look after themselves (or both). You must have had these difficulties for at least three months, and they should be expected to last for the next nine months. Since April 2013, PIP has started to replace a similar older benefit called Disability Living Allowance in England, Scotland and Wales. Attendance Allowance (AA) is for people aged 65 or over who find it difficult to look after themselves. You may qualify if you need help with things like getting out of bed, having a bath or dressing yourself. You don't need to have a carer, but you must have needed care for at least six months.



If you are terminally ill, you can apply for PIP, DLA or AA under the 'special rules'. This means your claim will be dealt with quickly and you will get the benefit you applied for at the highest rate.

## Help for carers

Carers Allowance is a weekly benefit that helps people who look after someone with a lot of care needs. If you don't qualify for it, you can apply for Carer's Credit. This helps you to build up qualifying years for a State Pension.

## More information

The benefits system can be hard to understand, so it's a good idea to talk to an experienced welfare rights adviser. You can speak to one by calling the Macmillan Support Line on **0808 808 00 00**. We've just listed some benefits here, but there may be others you can get.

You can find out about state benefits and apply for them online at **gov.uk** (England, Wales and Scotland) and **nidirect.gov.uk** (Northern Ireland). These websites have information about financial support, your rights, employment and independent living. You can also get information about these issues from the relevant Department for Work and Pensions helplines (see page 92) or Citizens Advice (see page 91). In Northern Ireland, you can call the Benefit Enquiry Line Northern Ireland on **0800 220 674**.

Our booklet **Help with the cost of cancer** has more detailed information. You might also find our video at **macmillan.org.uk/gettingfinancialhelp** useful.

## Insurance

People who have, or have had, leukaemia may find it hard to get certain types of insurance, including life and travel insurance. A financial adviser can help you look at your needs and find the best deal for you. You can find a financial adviser by contacting one of the organisations on page 91 to 92.

You may find our booklets **Insurance** and **Travel and cancer** helpful. To order them, call us on **0808 808 00 00**.



# Work

Most people with CML can continue working whilst taking TKI treatment. This may depend on how you feel and what work you do. If you are having more intensive chemotherapy or a stem cell transplant you will need time off work.

It can be helpful to talk to your employer about your situation and discuss getting time off for your regular hospital appointments. There is support for people around work and cancer.

## Employment rights

The Equality Act 2010 protects anyone who has, or has had, leukaemia. Even if a person who had leukaemia in the past has been successfully treated and is now cured, they are still covered by the act. This means their employer must not discriminate against them for any reason, including their past leukaemia. The Disability Discrimination Act protects people in Northern Ireland.

Our booklets **Work and cancer**, **Self-employment and cancer** and **Working while caring for someone with cancer** have more information that may be helpful. There's also lots more information at [macmillan.org.uk/work](https://macmillan.org.uk/work)

'The CML has had some impact on work and family, but overall I would say I've been lucky with the way things have turned out for me.'

**Saffiyah**



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# 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 leaflets or booklets like this one. Visit **be.macmillan.org.uk** or call us on **0808 808 00 00**.

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

All of our information is also available at **macmillan.org.uk/information-and-support**. There you'll also find videos featuring real-life 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'd 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**.



## Help us improve our information

We know that the people who use our information are the real experts. That's why we always involve them in our work. If you've been affected by cancer, you can help us improve our information.

We give you the chance to comment on a variety of information including booklets, leaflets and fact sheets.

If you'd like to hear more about becoming a reviewer, email **[reviewing@macmillan.org.uk](mailto:reviewing@macmillan.org.uk)** You can get involved from home whenever you like, and we don't ask for any special skills – just an interest in our cancer information.



# Other ways we can help you

At Macmillan, we know how a cancer diagnosis can affect everything, and we're 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](https://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'd 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](https://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's 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.

'Everyone is so supportive on the Online Community, they know exactly what you're going through. It can be fun too. It's not all just chats about cancer.'

Mal

## Help with money worries

Having cancer can bring extra costs such as hospital parking, travel fares and higher heating bills. If you've 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](https://www.macmillan.org.uk/financialsupport)** to find out more about how we can help you with your finances.

## Help with work and cancer

Whether you're 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](https://www.macmillan.org.uk/work)**



### Macmillan's My Organiser app

This free mobile app can help you manage your treatment, from appointment times and contact details, to reminders for when to take your medication. Search 'My Organiser' on the Apple App Store or Google Play on your phone.

# Other useful organisations

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

## **Anthony Nolan Bone Marrow Trust**

**Tel** 0303 303 0303

**[www.anthonynolan.org](http://www.anthonynolan.org)**

Runs the UK's largest register of fully tissue-typed volunteer donors. Accepts new bone marrow donors.

## **Bloodwise (Formerly Leukaemia & Lymphoma Research)**

**Tel** 020 7504 2200

**Email** [hello@bloodwise.org.uk](mailto:hello@bloodwise.org.uk)

**[www.bloodwise.org.uk](http://www.bloodwise.org.uk)**

Supports research into the causes, treatment and cure of leukaemia, lymphoma and myeloma. Provides information and booklets about the diseases and their treatments.

## **British Bone Marrow Donor Registry**

**Tel** 0300 123 23 23

**[www.nhsbt.nhs.uk/  
bonemarrow](http://www.nhsbt.nhs.uk/bonemarrow)**

A national register of donors. Also provides information about transplants and donating blood and stem cells.

## **Leukaemia CARE**

**Tel** 0808 8010 444

**[www.leukaemiacare.org.uk](http://www.leukaemiacare.org.uk)**

Provides care and support to people affected by leukaemia, lymphoma and the allied blood disorders. Offers a holiday programme, financial help, friendship and support, and regional support groups.

## **The CML Support Group**

**[www.cmlsupport.org.uk](http://www.cmlsupport.org.uk)**

Online support group for CML patients, their families and carers. Has a forum and information about current CML therapies.

## General cancer support organisations

### Cancer Focus

#### Northern Ireland

**Helpline** 0800 783 3339

(Mon to Fri, 9am to 1pm)

#### Email

[nurseline@cancerfocusni.org](mailto:nurseline@cancerfocusni.org)

**[www.cancerfocusni.org](http://www.cancerfocusni.org)**

Offers a variety of services to people affected by cancer in Northern Ireland, including a free helpline, counselling and links to local support groups.

### Cancer Support Scotland

**Tel** 0800 652 4531

(Mon to Fri, 9am to 5pm)

#### Email

[info@cancersupportscotland.org](mailto:info@cancersupportscotland.org)

**[www.cancersupportscotland.org](http://www.cancersupportscotland.org)**

Runs cancer support groups throughout Scotland. Also offers free complementary therapies and counselling to anyone affected by cancer.

### Maggie's Centres

**Tel** 0300 123 1801

#### Email

[enquiries@maggiescentres.org](mailto:enquiries@maggiescentres.org)

**[www.maggiescentres.org](http://www.maggiescentres.org)**

Has a network of centres in various 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.

### Tenovus

**Helpline** 0808 808 1010

(Daily, 8am to 8pm)

#### Email

[info@tenovuscancercare.org.uk](mailto:info@tenovuscancercare.org.uk)

**[www.tenovus](http://www.tenovuscancercare.org.uk)**

**[cancercare.org.uk](http://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.

## Counselling

### **British Association for Counselling and Psychotherapy (BACP)**

**Tel** 01455 883 300

**Email** [bacp@bacp.co.uk](mailto:bacp@bacp.co.uk)

Promotes awareness of counselling and signposts people to appropriate services across the UK. You can search for a qualified counsellor at [itsgoodtotalk.org.uk](http://itsgoodtotalk.org.uk)

### **Financial or legal advice and information**

#### **Benefit Enquiry Line Northern Ireland**

**Helpline** 0800 220 674

(Mon, Tue, Wed and Fri,  
9am to 5pm,

Thu, 10am to 5pm)

**Textphone** 028 9031 1092

**[www.nidirect.gov.uk/  
money-tax-and-benefits](http://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** 03444 111 444

**[www.citizensadvice.org.uk](http://www.citizensadvice.org.uk)**

### **Wales**

**Helpline** 03444 77 2020

**[www.citizensadvice.org.uk/  
wales](http://www.citizensadvice.org.uk/wales)**

### **Scotland**

**Helpline** 0808 800 9060

**[www.citizensadvice.org.uk/  
scotland](http://www.citizensadvice.org.uk/scotland)**

### **Northern Ireland**

**Helpline** 0800 028 1181

**[www.citizensadvice.co.uk](http://www.citizensadvice.co.uk)**

**Department for Work  
and Pensions (DWP)  
Disability Benefits Helpline**

08457 123 456

**Textphone** 0845 722 4433

**Personal Independence  
Payment Helpline**

0845 850 3322

**Textphone** 0845 601 6677

**Carer's Allowance Unit**

0845 608 4321

**Textphone** 0845 604 5312

**[www.gov.uk/browse/  
benefits](http://www.gov.uk/browse/benefits)**

Manages state benefits in  
England, Scotland and Wales.

You can apply for benefits  
and find information online  
or through its helplines.

**National Debtline  
(England, Wales  
and Scotland)**

**Tel** 0808 808 4000

(Mon to Fri, 9am to 8pm,  
Sat, 9.30am to 1pm)

**[www.nationaldebtline.org](http://www.nationaldebtline.org)**

A national helpline for people  
with debt problems. The service  
is free, confidential and  
independent. Has an online  
chat service with an expert  
debt adviser.

**Personal Finance Society –  
'Find an Adviser' service  
[www.thepfs.org/yourmoney/  
find-an-adviser](http://www.thepfs.org/yourmoney/find-an-adviser)**

Use the website to find qualified  
financial advisers in your area  
of the UK.

**The Money Advice Service  
Helpline (English)**

0800 138 7777

**Helpline (Welsh)**

0800 138 0555

(Mon to Fri, 8am to 8pm,  
Sat, 9am to 1pm)

**Typetalk**

18001 0300 500 5000

**Email** [enquiries@  
moneyadvice.service.org.uk](mailto:enquiries@moneyadvice.service.org.uk)

**[www.moneyadvice  
service.org.uk](http://www.moneyadvice<br/>service.org.uk)**

Runs a free financial health  
check service and gives advice  
about all types of financial  
matters across the UK. Has an  
online chat service for instant  
money advice.

## Support for carers

### **Carer's Allowance Unit**

**Tel** 0345 608 4321

**Textphone** 0345 604 5312

(Mon to Thu, 8.30am to 5pm,  
Fri, 8.30am to 4.30pm)

**[www.gov.uk/browse/benefits](http://www.gov.uk/browse/benefits)**

Manages state benefits in  
England, Scotland and Wales.

You can apply for benefits  
and find information online  
or through its helplines.

### **Carers UK**

#### **Helpline**

**(England, Scotland, Wales)**

0808 808 7777

(Mon to Fri, 10am to 4pm)

**Helpline (Northern Ireland)**

028 9043 9843

**Email** [advice@carersuk.org](mailto:advice@carersuk.org)

**[www.carersuk.org](http://www.carersuk.org)**

Offers information and  
support to carers across  
the UK. Has an online forum  
and can put people in contact  
with support groups for  
carers in their area.

## Support for older people

### **Age UK**

#### **Helpline (England)**

0800 055 6112 (8am to 7pm)

#### **Helpline (Scotland)**

0800 124 4222

#### **Helpline (Wales)**

0800 022 3444

#### **Helpline (Northern Ireland)**

0808 808 7575

**[www.ageuk.org.uk](http://www.ageuk.org.uk)**

Provides information and advice  
for older people across the UK  
via the website and advice line.  
Also publishes impartial and  
informative fact sheets and  
advice guides.



You can search for more organisations on our  
website at [macmillan.org.uk/organisations](http://macmillan.org.uk/organisations)  
or call us on 0808 808 00 00.

## 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.

## 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.

With thanks to: Dr Mark Drummond, Consultant Haematologist & Honorary Senior Clinical Lecturer, Beatson West of Scotland Cancer Centre; Joanna Large, Myeloid Clinical Nurse Specialist; and Professor Mary Frances McMullin, Clinical Professor of Haematology, Queen's University, Belfast. Thanks also to the people affected by cancer who reviewed this edition, and to those who shared their stories.

We welcome feedback on our information. If you have any, please contact **[cancerinformationteam@macmillan.org.uk](mailto:cancerinformationteam@macmillan.org.uk)**

## Sources

We've listed a sample of the sources used in the publication below. If you'd like further information about the sources we use, please contact us at **[cancerinformationteam@macmillan.org.uk](mailto:cancerinformationteam@macmillan.org.uk)**

European Leukemia Net. Recommendations for the management of chronic myeloid leukemia. 2013.

DeVita, Lawrence and Rosenberg. 2016. Lymphomas and leukemias.

Cancer: principles and practice of oncology.

Hoffbrand and Moss. Hoffbrand's essential haematology. 7<sup>th</sup> edition. 2016.



# Can you do something to help?

We hope this booklet has been useful to you. It's just one of our many publications that are available free to anyone affected by cancer. They're 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're there 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.



## **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](http://macmillan.org.uk/getinvolved)**

**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 the signs and symptoms  
of CML, and how it is diagnosed and 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** 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.

**MACMILLAN  
CANCER SUPPORT  
RIGHT THERE WITH YOU**

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What's this logo? Visit **macmillan.org.uk/ourinformation**

## Please fill in your personal details

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Surname

Address

Postcode

Phone

Email

Please accept my gift of £

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I enclose a cheque / postal order /  
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Macmillan Cancer Support

OR debit my:

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Card / Switch / Maestro

Card number

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Issue no

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Security number

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Signature

Date / /

## Don't 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.

- ☐ 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'd rather donate online go to [macmillan.org.uk/donate](https://macmillan.org.uk/donate)

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