Chronic myeloid leukaemia (CML)
My details

This is a place to put important information about you, your condition and key contacts.

Name and hospital number

My NHS number

My condition

My contacts

My consultant

My key worker (usually your CNS)

Haematology ward

Haematology clinic

Out of hours

Notes
As the weeks passed and having gathered copious quantities of information from charities, books and my healthcare team, I slowly began to understand my condition and with understanding came acceptance.

Our patient information is for you and those close to you to use whenever, wherever and however you need it. You’ll probably have lots of questions; this booklet aims to help you answer as many of them as possible.

Our information is developed for and with patients. It’s written in line with national guidelines and created with health professionals from our dedicated Medical Advisory Panel, so you know it’s accurate and up to date.

This booklet is one of many we make – you can find a list of our other booklets on pages 90–91. For the very latest information, visit our website.

Our booklets contain general information. Always listen to the advice of your specialist about your individual treatment – because every person is different.

When you see the symbols below in the booklet, it’s a sign that we think the websites and other organisations mentioned will also give you good information and support.

A team of people helped produce this booklet. We’d like to thank a member of our Medical Advisory Panel, Professor Jane Apperley, for her help and support in developing the content and checking for clinical accuracy. The draft was also assessed at an early stage by Dr Dragana Milojkovic and clinical nurse specialist Irene Caballes.

Bloodwise staff revised the text to make it easy to read, and a panel of patients checked it for understanding. Professor Jane Apperley is responsible for the content overall.

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

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

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

The information in this booklet is correct at the time it was printed (January 2015).
Date of next review January 2017.
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Registered charity 216032 (England & Wales) SC037529 (Scotland)
Being told that you, or a loved one, have any type of cancer can be one of the hardest things you’ll ever have to hear. There’s sure to be a lot of information to take in right now. We hope this booklet will help you to understand your condition and feel in control throughout this time. We’ll try to answer as many of the questions you might have along the way – from symptoms through to tests, treatment and living with CML, and where you can get support.

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

We also produce a diary which you can order online. It’s yours to use however you like – for practical information or to record thoughts or sketches > bloodwise.org.uk/patient-diary

Introduction

This is a booklet for adults with CML, and for people who know someone with CML. Childhood CML is rare but is treated in a similar way – the patient’s healthcare team will be able to give you more information about it.

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

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

For most people, it’s possible to have CML and have a good quality of life, thanks to drugs you take on a daily basis.

What is CML?
Chronic myeloid leukaemia (CML) is a cancer of the blood. There are three stages of CML and most patients are diagnosed in the early (or chronic) phase. In this phase your body makes too many mature white blood cells, known as granulocytes. If the disease is left untreated it progresses through a period of instability known as the accelerated phase, to the blast phase. In this phase there are too many immature, or blast, cells.

Who gets CML?
You can get CML at any age, though it’s very rare in children below 15. It’s more common in older people: the average age at diagnosis is about 60 years.

Slightly more men than women get it. It’s quite rare, but there are still around 750 new cases each year in the UK.

What are the treatments for CML?
The most common treatment for CML are drugs called tyrosine kinase inhibitors (TKI). The very first TKI to be made, which is still the most commonly used, is called imatinib.

Doctors can usually tell which patients aren’t going to respond to imatinib within the first three months of treatment. If this is the case for you, you’ll be asked to try another TKI to try and get a better response. TKI don’t work well for 5–10% of people with CML. Stem cell transplantation is a good treatment for these patients.

What’s the outlook?
Before TKI were introduced, CML was considered a serious illness. Now, for most patients CML is considered a chronic condition that can be managed with TKI, with normal life expectancy and good quality of life.

For the vast majority of people with CML, their disease doesn’t progress past the first, chronic stage. It’s rare nowadays for people to progress to the accelerated or blast phases, but it can happen. If you do enter these phases, your healthcare team will talk to you about your individual outlook.

Thanks to imatinib and other TKI, we’ve seen great improvements in survival rates and quality of life for most people with CML.
Blood, bone marrow and your immune system

It’s a good idea to know a bit about blood, bone marrow and your immune system, as your healthcare team will talk to you about them.

Blood
The blood has four important functions:

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

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

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

Repair system
It contains cells and chemicals which can seal off damaged blood vessels and control blood loss.

Knowing the basics about blood, bone marrow and your immune system is useful.
Bone marrow, blasts and blood cells

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

When stem cells divide they create lymphoid stem cells and myeloid stem cells – these stem cells then go on to form immature blood cells called lymphoid blasts or myeloid blasts. These blasts then become fully formed lymphoid blood cells and myeloid blood cells.

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

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

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

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

Platelets (thrombocytes)
These stick together at the site of any tissue damage and stop bleeding.

Lymphocytes are lymphoid cells and red blood cells, platelets and all other white cells – so neutrophils, monocytes, eosinophils and basophils – are myeloid cells.
How many of each type of blood cell should you have?
Everyone has slightly different numbers of each type of blood cell. If you’re healthy, the amount you have of each normally stays the same.

The table on the opposite page shows how many of each type a healthy person has.

### Your immune system
Your immune system is a network of cells, tissues and organs which protect your body against infection. It is able to react quickly to infections it has seen before: white blood cells and lymphocytes in particular play an important role in this. They circulate around your body in your blood and fight infections. Most patients with CML don’t get more infections than usual.

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<th>WHITE BLOOD CELLS</th>
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(Some data unavailable for West Indian and African patients)

Adapted with permission from *A Beginners Guide to Blood Cells*  
Dr Barbara Bain; Blackwell Oxford, 1996
CML is a blood cancer which affects the myeloid cells. With treatment, you can usually manage it and keep it under control.

What is CML?

Chronic myeloid leukaemia (CML) is a cancer of the blood. There are three stages of CML and most patients are diagnosed in the early or chronic phase. In this phase your body makes too many mature white blood cells called granulocytes.

If the disease is left untreated it progresses through a period of instability known as the accelerated phase, to the blast phase. In this phase there are too many immature cells (blast cells). You have very few blast cells in your blood or bone marrow if you’re in the chronic phase.

The granulocytes can collect in the spleen, making it swell. The spleen is part of your lymphatic system. It’s an organ on your left side, under your ribs.

The blasts can overcrowd the bone marrow, meaning there isn’t enough room for other important blood cells to be made. This can cause many of the signs and symptoms of CML (see page 19).
What is CML?

You may hear your doctor talk about a 'Philadelphia chromosome' or refer to your 'Philadelphia status'. If you have this chromosome it almost always means you have CML, and it'll be inside all of your leukaemia cells.

You can’t inherit this chromosome, or pass it on to your children.

All cells in your body contain a set of instructions which tell the cell what to do and when to do it, stored inside the cells in structures called chromosomes. The chromosomes are made up of a chemical known as DNA.

The DNA is arranged in sections called genes. There are 23 pairs of chromosomes in each cell in your body.

When cells divide to form new cells, normally the chromosomes stay the same in each new cell.

CML is thought to begin when an event takes place which doesn’t usually happen. A small part (the ABL1 gene) of chromosome 9 gets stuck next to a small part (the BCR gene) of chromosome 22 by mistake when the cell divides. They form a new fusion gene called BCR-ABL1 and make chromosome 22 shorter than normal. This new, shorter chromosome is called the Philadelphia chromosome, because that’s where it was discovered.

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

The new BCR-ABL1 gene is important in the development of CML because it makes a new protein (also called BCR-ABL1). This protein is a type of enzyme known as tyrosine kinase, that causes the leukaemia stem cells to divide more often and to live longer than usual.

If doctors can detect the BCR-ABL1 fusion gene, it can help them to diagnose CML – and also monitor your response to treatment. The standard treatment for CML is to use drugs that inhibit the tyrosine kinase enzyme and block its effects.
You’re not alone. Although it’s quite rare, around 750 people are diagnosed with CML each year in the UK.

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

Although the Philadelphia chromosome is present in around 95% of cases of CML, for some people we can’t say what exactly has caused their illness. However, there are some things which mean you’re at higher risk of developing CML.

Age
CML is more common in older people. The average age at diagnosis is about 60 years.

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

Family history
There’s no evidence that family members of CML patients are at a higher risk of developing the condition than anyone else.

Radiation
The only clearly defined risk factor for CML is exposure to high levels of ionizing radiation. When we say ‘high’, it means similar to a level you’d see after an atomic bomb explosion. It’s extremely unlikely that anyone in the UK would be exposed to a level of radiation high enough to increase the risk of getting CML.
It's important to remember that not everyone will get all, or even any, of the symptoms listed – each person is different.

Symptoms

If you’re diagnosed with CML, there are some symptoms you might notice before your diagnosis. It’s important to remember that not everyone will get all, or even any, of these symptoms. Each person is different, and will have a different experience.

Some people won’t be aware of any symptoms at all and are diagnosed by chance after routine blood tests, or blood tests you were having for something else.

About 90% of people with CML are diagnosed during the chronic phase of the disease and most will be able to stay in this phase for life. This section talks about the symptoms associated with each of the three phases.
Symptoms in the chronic phase
Symptoms in this phase are usually quite vague, and appear and develop very slowly. Remember that many of these symptoms are very common, and are often caused by other things.

They include:

» Fatigue, or tiredness — this is sometimes caused by anaemia

» Loss of appetite

» Unexplained weight loss

» Increased sweating, particularly at night

» Abdominal bloating, swelling and occasionally pain (if your spleen is enlarged)

» Blurred vision

» Unusual or excessive bleeding — for example from your gums or nose.

Most patients with chronic phase CML will have an enlarged spleen, which may cause abdominal discomfort (tenderness around the stomach) and a feeling of fullness when you eat. Occasionally, the liver might be enlarged at the time of diagnosis.

I found it quite hard to tell what symptoms to be concerned about, because so many of them are quite common. I found the best thing to do was just to check out each and every one with my healthcare team.

Symptoms in the accelerated phase
If you’re in the accelerated stage, your symptoms don’t normally change much from the chronic stage. Progression to this stage is measured by looking at changes in your blood, bone marrow and blast count. This stage may sometimes indicate a progression to the more aggressive blast stage.

The change in symptoms you might notice from chronic stage is an increase in bone pain, which may be caused by leukaemia cells building up in your bone marrow.

Symptoms in the blast phase
It’s rare for people to be diagnosed at the blast phase, sometimes known as ‘blast crisis’. It’s also rare, with current treatments, for people to progress from the chronic to blast phase, but both of these things can happen. People in the blast phase often have noticeable extra symptoms.

These may include:

» Weight loss

» Fever

» Bone pain

» Tiredness or fatigue

» Bruising more easily than normal

» Unusual bleeding, for example from your gums or nose

» Repeated infections

» Painful haemorrhages

» Swollen lymph nodes

» Blast cells may be present in the fluid which surrounds the brain and spinal cord, and this can cause severe headaches.
It's important to know and understand your diagnosis. You could ask your team to write it in this booklet, so you have it to hand.

**Diagnosis**

You'll have a set of tests to confirm whether you have CML or not. If you're diagnosed with CML, you'll have some further tests to determine the right treatment for you. At any time, you can ask your healthcare team to tell you why you're having a certain test, what the results mean and for a copy of the test results.

**Tests to diagnose CML**

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

About 9 in 10 people with CML are diagnosed during the chronic (stable) phase of the disease. The remainder are diagnosed in either the accelerated or blast phase.
When I was diagnosed I asked my consultant to write it down and I'm really glad I did. I could then go away and do my own research and also tell people accurate information about my condition.

Full blood count (FBC)
A full blood count (FBC) measures the number of each type of cell in your blood: red cells, white cells and platelets. A small sample of blood will be taken from a vein in your arm and checked under a microscope in a laboratory (known as a blood film). You might be sent for this test by your GP as part of a routine check-up. Other patients might have one when they’re in hospital for something else.

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

The way the cells look under the microscope is also distinctive, so all of this information means that your doctors can be reasonably sure about the diagnosis of CML at this point.

If this is the case, you’ll need to have more tests to check the extent of the leukaemia. If you’re diagnosed with CML, you’ll have regular FBCs to monitor your condition.

Polymerase chain reaction (PCR) test
Your doctor will also do a PCR test when you first visit the hospital, using the blood sample taken for your FBC. This will measure the amount of the BCR-ABL1 fusion gene in your blood. The PCR is an important test that you’ll have throughout your treatment. It’s used to monitor how you’re responding to treatment and to look at whether you might need to change treatments.
Bone marrow aspirate and trephine
Most patients will have a bone marrow sample (biopsy) soon after diagnosis: this will allow your doctors to confirm the diagnosis and provide additional information about the disease.

A small amount of bone marrow is taken from the hip bone using a fine needle (an aspirate). Your doctors will then look at the bone marrow sample under a microscope. You don’t need to stay overnight in hospital for a bone marrow biopsy; you can have it as an outpatient using local anaesthetic, gas and air, or mild sedation. It’s usually quite quick but may be uncomfortable while the sample is being taken from the marrow; you can take painkillers if you need to after the procedure.

Some patients will also have a bone marrow trephine. This is similar to a bone marrow aspirate, but involves taking a piece of bone from the hip bone instead using a larger needle, under local anaesthetic or mild sedation.

The laboratory doctors will do a number of tests on your bone marrow, to look at how many mature and immature cells you have. This helps to confirm the stage of your disease.

Cytogenetics
Almost everyone with CML will have cytogenetic tests. Cytogenetics is the study of the chromosomes. This test is important as it identifies the Philadelphia (Ph) chromosome and confirms the diagnosis of CML. Ninety-five percent of patients with CML have a Ph chromosome, which contains the BCR-ABL1 fusion gene. In the remaining 5% of patients a Ph chromosome is not obvious, but the PCR test will identify the BCR-ABL1 gene.

I did feel from time to time that I couldn’t keep track of all the tests and what they were for. I often wrote down basic details, and just kept checking in with my key worker on the specifics for each one.
Diagnosis 28

In most forms of cancer, doctors will do tests to 'stage' the disease and help to plan treatment. With solid tumours, staging usually refers to how far the cancer has spread from its original site. This isn't the case for CML, because it's always in the blood and bone marrow.

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

The main difference between the three stages is the number of immature cells or blasts in your bone marrow. When the disease progresses you have more blasts in your bone marrow and more symptoms.

It's important to know that most people with CML stay in the chronic phase. If the disease does progress, it doesn't always do it in a linear manner. So you might move from chronic phase straight to the blast phase. If you do move into the accelerated (second) stage, it doesn't necessarily mean you'll progress to the blast phase.

Treatment at the accelerated stage can move you back to the chronic phase. The FBC, cytogenetics and the bone marrow aspirate all help doctors stage the disease.

Risk scores
As part of staging, your doctors will look at your risk score. There are three risk scores for CML that you might hear mentioned: Sokal, Hasford and EUTOS. All of these are less important today than before the introduction of TKI, because the great majority of patients respond to these drugs, regardless of their risk score.

Your doctor may use your risk score to help choose the most appropriate drug for you. TKI vary in strength, so it makes sense to use a more potent drug for those at high risk.

These risk scores look at various factors including:
- your age
- the size of your spleen
- the number of blast cells, platelets, basophils and eosinophils in your blood.

You can read about the experiences of other people who are going through, or have been through, the same thing on our website > bloodwise.org.uk/patient-support

Staging

Risk scores

You can read about the experiences of other people who are going through, or have been through, the same thing on our website > bloodwise.org.uk/patient-support
Your healthcare team

If you’re diagnosed with CML, your hospital will give you the names and contact details of your consultant, clinical nurse specialist and other members of your healthcare team – there’s space to write them at the back of this booklet if you want to. You can then use these details to contact your team if you have any questions you want to ask when you’re not in the hospital.

Your consultant
Most patients with a blood cancer are treated by a haematologist – a doctor who specialises in treating patients with blood diseases.

Your clinical nurse specialist
All cancer patients are normally given a key worker, usually a clinical nurse specialist. They are your point of contact with the rest of your healthcare team. You may like to have a meeting with your clinical nurse specialist when you’re first diagnosed, to discuss your condition. Really make use of your clinical nurse specialist, as they’ll be with you all the way through.

Your multidisciplinary team
When you’re diagnosed with something like CML, your condition is discussed at a multidisciplinary team (MDT) meeting. An MDT brings together doctors, nurses and any other specialist staff who will be looking after you. A senior consultant usually leads the meetings, which are held regularly. They’ll discuss the best treatment for you and every aspect of your care, including any changes in your condition.

Talking to other patients
You may want to ask your key worker or consultant if you can talk to someone who has had the same diagnosis and treatment as you. If you do this, remember that someone else’s experience won’t always be the same as yours. For example, some patients have side effects from a drug and other patients don’t.

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

Your other healthcare professionals
It’s important to tell other healthcare professionals you see – like your dentist or optician – about your diagnosis and any medication you’re taking.

For a list of support organisations > see page 69

We also produce a diary which you can order online. It’s yours to use however you like – for practical information or to record thoughts or sketches > bloodwise.org.uk/patient-diary
Finding out more

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

› Let your consultant and clinical nurse specialist know how much information you’d like, and in what form. You can always ask for more information later.

› Write down any questions you have and keep them handy for when you see your consultant or key worker. If they can’t answer your questions, they’ll be able to tell you who to speak to.

› You might prefer to ask your clinical nurse specialist questions rather than your consultant, but do whatever works for you.

› Most patients say they find it useful taking someone with them to consultations. If you’d find it helpful, you could ask them to take notes while you listen. You can choose who to take; it doesn’t have to be a family member.

› If you’re staying in hospital it might be harder to have someone with you when you speak to your consultant. It might be useful to ask in advance what time the consultant is likely to speak to you, so you can try to arrange for someone to be with you at that time.

› When you’re in the clinic or staying in the hospital you may be looked after by a more junior doctor, a senior house officer or a registrar. These doctors have left medical school but are still training to be consultants. They’ll be able to answer many of your questions, but if they can’t then they’ll ask the consultant. All doctors in training are supervised closely by more senior colleagues.

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

You can find a list of questions you might want to ask on page 75 and room to write more questions on page 79
Your questions
Many patients tell us that keeping in touch with loved ones throughout their illness keeps them going. However, some people may find it stressful having to discuss their condition lots of times with family, friends and colleagues.

You might find it easier to ask a trusted family member or friend to be your ‘information person’ and ask them to keep people updated on your behalf.

Another idea is setting up a blog or Facebook page, so you or different people can post information on it that everyone can read.

You might not want to tell many people – or anyone at all – about your condition. This is ok too, whatever works for you.

Telling children and teenagers
Talking to children and teenagers about your cancer diagnosis can be difficult. There are lots of organisations that are able to support you and offer you advice about how to explain cancer to children of different ages.

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

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

Macmillan have some useful advice about cancer and work online; you can also order a booklet > go to macmillan.org.uk then search for ‘work’

Macmillan make a booklet about talking to children about cancer > go to macmillan.org.uk then search for ‘talking to children and teenagers when an adult has cancer’

There’s more information about cancer and how it can affect your work or study on page 62
If you’re taking TKI, it’s really important that you take them exactly as directed by your doctor and are aware of advice around diet and getting pregnant.

**Treatment**

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

**Starting treatment**

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

The aim of treatment is to achieve remission. Remission is when leukaemia cells can’t be detected and you’re clinically well. There are several levels of remission with CML which you normally achieve one by one, based on how long you’ve been having treatment. For more information see the ‘Follow up’ section on page 49.

The treatment guidelines used most in the UK are available to view online > leukemia-net.org/content/home
When will I start treatment?

When you first have a blood count that shows you have too many white blood cells and may have CML, your doctors will have to do a number of the other tests (described on pages 23–29) to confirm the diagnosis.

Allopurinol

Almost all patients will be given a drug called allopurinol 24 hours before starting any chemotherapy. This is to prevent gout you may get, because of the rapid death and breakdown of the leukaemia cells at the start of your treatment.

Chemotherapy

If your white blood cell count is high and/or you have a lot of symptoms and feel unwell, they may give you a mild chemotherapy tablet, known as hydroxycarbamide. This will reduce your blood count and control your symptoms until the diagnosis is absolutely confirmed.

Pheresis

If your white cell count is very high (and it can be over 100 at diagnosis) and particularly if you have certain symptoms such as blurred vision, your doctors might advise removing some white blood cells in a mechanical process called pheresis.

In this procedure, a plastic tube will be inserted into your arm. Your blood will drain slowly into a machine (centrifuge) which will be spinning at high speed. The spinning separates the blood into white blood cells, red blood cells and plasma. The white blood cells are removed and discarded and the red cells and plasma are returned to your body.

At any one time no more than a cupful of blood will be in the centrifuge and the procedure is very safe. You might be a bit bored as it can take 2–3 hours to reduce your white cell count in this way. The pheresis will be done by a specially trained nurse, who will talk you through the procedure as they do it.

Once the diagnosis is confirmed, your doctors will prescribe a TKI. The aim of treatment is to get you into remission. The usual drugs you’ll have for your first treatment, if you’re diagnosed in the chronic phase, are standard doses of one of the TKI licensed for first-line use, such as imatinib, dasatinib or nilotinib. These drugs allow most people with CML to return to a virtually normal lifestyle, including continuing to work and study.

Taking TKI

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

Unlike most anti-cancer drugs, you’ll probably be taking your TKI for life. These drugs work by slowly destroying the leukaemia cells in your body and if you stop taking your TKI without being advised to do so by your doctor, your leukaemia will come back.

There are a few reports of patients stopping imatinib and remaining well, but this is in special circumstances where they’ve been on treatment for several years and have responded exceptionally well. So it’s very strongly advised that you don’t stop taking your TKI unless your doctor tells you to.

Imatinib

Most people start on imatinib. Imatinib (Glivec™ in the UK or Gleevec™ in the US) was introduced for treatment of CML in 1998. It was the first of a new class of drug called tyrosine kinase inhibitors (or TKI) which work by counteracting the effect of the protein that causes the leukaemia. Imatinib is taken as a pill once a day after food.
Nilotinib and other TKI
Newer TKI include nilotinib, bosutinib, dasatinib (called ‘second generation’ drugs) and ponatinib (a ‘third generation’ drug). Your doctor will decide, with you, whether you should take imatinib or nilotinib. The decision will be based on your disease phase, the potential risk of side effects, your risk score and any other conditions you may have. Nilotinib is a stronger drug than imatinib, so if your risk scores are higher they may suggest you start on this drug.

Nilotinib can cause your blood sugar to rise, which can cause problems for some patients, such as people with diabetes. If this is the case for you, you might start on imatinib and only move to nilotinib if imatinib isn’t effective.

The other TKI – bosutinib, dasatinib and ponatinib – are all currently available in the UK through the Cancer Drug Fund. You may take one of these drugs if neither imatinib nor nilotinib work for you.

All of these drugs are taken as a pill. Nilotinib is taken twice a day with a ‘fasting regimen’, meaning no food two hours before or one hour after taking the pill. Dasatinib and ponatinib are taken once a day (with or without food), and bosutinib is taken after a meal.

If you’re diagnosed in the blast phase
Very few patients will be in this phase when diagnosed. If you are, your CML will be treated more aggressively, like an acute leukaemia. Your doctor will discuss your treatment options with you.

What happens if initial treatment doesn’t work?
If you don’t respond well to your first TKI, your doctor will normally recommend that you try an alternative TKI. Most patients will respond to the second or third TKI.

Sometimes your doctor can identify a specific reason why you’re not responding to a TKI. Your leukaemia cells might have developed a genetic fault (mutation) that changes the shape of the BCR-ABL1 protein in a way that means that imatinib can’t attach (bind) and stop it working. The newer TKI were designed to be able to inhibit BCR-ABL1 proteins with mutations, so you ought to be able to find a drug that suits you. There is one particular mutation (T315I) that responds only to ponatinib.

If CML progresses while you’re taking imatinib it shows that the drug isn’t working for you, so you’ll stop taking it.

However, it may be possible to achieve a remission with another TKI such as dasatinib or nilotinib, as these have been shown to be effective against most types of imatinib resistance.

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

There’s more information on stem cell transplants in two of our other booklets > Stem cell and bone marrow transplantation and Seven steps: blood and bone marrow transplantation
**Side effects of treatment**

Side effects from imatinib and other TKI are rarely severe, because unlike other anti-cancer drugs they target the specific cause of the cancer – in this case the tyrosine kinase protein produced because of the fusion BCR-ABL1 gene.

However, you may notice some things which could be connected to the drugs you’re taking. Your healthcare team will be able to help you manage any side effects you have. The following side effects are common to all TKI:

- fatigue
- fluid retention (this may cause swelling)
- abnormal liver function (this will be monitored using blood tests)
- skin rash
- muscle cramps
- joint pains
- headaches
- nausea
- diarrhoea
- low blood counts.

**Bosutinib**

Some common side effects of bosutinib include:

- diarrhoea, which can be particularly severe in the first few days.

**Dasatinib**

Some common side effects of dasatinib include:

- headaches
- abdominal cramps
- very rarely, blood in the stool
- fluid retention, particularly in between the linings of the lung (this can be managed easily by stopping taking the drug either temporarily or permanently – make sure you tell your doctor if you notice new fevers, a cough or pain in the chest when you take a deep breath).

**Imatinib**

Some common side effects of imatinib include:

- weight gain
- fluid retention, particularly around the eyes
- dry gritty eyes
- haemorrhages into the white of the eye; these are not dangerous or harmful to your sight but can look unpleasant
- nausea, if you don’t take the drug on a full stomach.

**Nilotinib**

Some common side effects of nilotinib include:

- rash (more common than with bosutinib, dasatinib and imatinib)
- changes in the chemicals made by the liver
- increase in blood glucose (sugar levels)
- increases in cholesterol levels
- rarely, clots in the arteries of the heart, brain and lower legs (this usually happens in patients who already have a higher risk of clots, such as heavy smokers, patients with high blood pressure and previous history of clots).

**Ponatinib**

Some common side effects of ponatinib include:

- dry skin
- high blood pressure
- inflammation of the pancreas, an organ in the abdomen (stomach area); if this happens you’d notice severe pain
- clots in the arteries of the heart, brain and lower legs (this is slightly more common than with nilotinib, see page 42, but again this usually happens in patients who already have a higher risk of clots).

You can find more about the possible side effects of TKI online > leuka.org.uk/cml-alliance/about-cml/side-effects

Or you can go to > cancer.org and search for ‘targeted therapies for chronic myeloid leukaemia’
Fertility and CML – women
If you’re considering having children at the time when you’re diagnosed or in the future, you should consider talking to your doctor, who’ll be able to refer you to a specialist. There is no evidence that any TKI affects fertility (your ability to have a baby).

However, you should avoid becoming pregnant while you’re taking imatinib and other TKI, and use reliable contraception.

This is because a number of babies born to mothers who were taking imatinib while they were pregnant have suffered from abnormalities. Although some mothers taking imatinib have had healthy babies, doctors strongly recommend that you don’t become pregnant, because the risk is too high.

Because it’s currently thought that people with CML will have to take TKI for the rest of their life, this may impact your plans to have children. There are options available in terms of egg storage and coming off treatment for a period of time. It’s best to discuss your individual circumstances with your doctor, who might make certain recommendations based on how you’re responding to treatment.

There isn’t much information about whether other TKI are also harmful. They are more potent than imatinib however, so it’s likely that they will be. Doctors recommend that you follow the same advice, and take care not to become pregnant.

If you’re diagnosed with CML while you’re pregnant, or if you become pregnant after being diagnosed, your doctors will be able to discuss your options with you. This might – if appropriate for you – include delaying or adapting your treatment until the baby is born. This is something you’ll need to think very carefully about and discuss with your healthcare team. Imatinib is present in breast milk, so women taking imatinib shouldn’t breastfeed.

If you don’t respond to a TKI and are planning to have a transplant, it is quite likely that the drugs used for the transplant will cause an early menopause. Discuss options for preserving your fertility after the transplant with your doctor, and consider starting hormone replacement therapy soon after your transplant.

There’s more information about CML and fertility online > leuka.org.uk/cml-alliance/about-cml/fertility-and-pregnancy
Follow-up
Your doctor will measure your response to treatment, and whether you’re in remission, at your follow-up appointments. It’s really important that you attend these.

Remission is when leukaemia cells can’t be detected and you’re clinically well. There are several levels of remission with CML which you normally achieve one by one, based on how long you’ve been having treatment.

Haematological remission
When your blood counts return to normal, you’re said to be in complete haematological remission (CHR). This normally happens around three months after you start treatment.

Although your blood count is normal, the disease isn’t necessarily well controlled. If you were to stop treatment as soon as your blood count returns to normal, it’s likely that your white cell count would increase rapidly again.

This is because a blood test is a relatively insensitive test, which can’t detect a small number of residual leukaemia cells. This means that there may still be large numbers of leukaemia cells remaining.

Cytogenetic remission
A more sensitive test is when doctors look for the amount of Philadelphia chromosome in your bone marrow. If the Philadelphia chromosome can’t be detected, this is called a complete cytogenetic response (CCyR). This is performed on a sample of your bone marrow.

Today, this follow-up test is often replaced by the molecular test described on page 50. It differs from hospital to hospital. There’s thought to be some benefit in having the bone marrow test at least annually, as it can detect other genetic changes that may develop. However, the benefit hasn’t been proven yet.

Fertility and CML – men
There’s no evidence at the moment about any harmful impact if the father was taking imatinib at the time of conception. However, some TKI are relatively new and there isn’t much evidence so your doctor might suggest coming off treatment – if appropriate for you – while you conceive. Again, this is something you’d need to think very carefully about and discuss with your healthcare team.

Most CML centres will recommend storing some of your sperm at the time when you’re diagnosed.

Late effects
Because TKI are relatively new drugs, the effects of taking them for life aren’t yet known. There may late effects, but we’ll only find out about these after many years of follow up on patients who’ve been taking TKI for a long time. Current evidence suggests that TKI are likely to bring a good quality of life for a long time, with no known late effects so far.

Imatinib and other drugs
There’s some evidence that taking imatinib or other TKI in combination with other treatments may cause more side effects than if you take it on its own. Clinical trials are currently being carried out, to find out if the benefits of adding other drugs outweigh the side effects.
Molecular remission (PCR negativity)
A PCR test (a polymerase chain reaction test) is the recommended test for monitoring patients who are responding to treatment for CML. It’s carried out every three months, using a blood sample, to measure how you’re responding and let your doctor know if you need to change drugs or dosages. This is a very reliable and sensitive test which can detect one leukaemia cell in up to one million normal blood cells.

It’s used to detect tiny amounts of a product (called a transcript) made by the abnormal BCR-ABL1 fusion gene.

If the level of the BCR-ABL1 transcripts is reduced at least 1,000-fold, then it’s called a major molecular response (MMR). If no BCR-ABL1 transcripts can be detected you might hear your result referred to as ‘undetectable transcripts’, because there may be leukaemia cells present somewhere in your body, even when the test is negative.

You can find out more about clinical trials in the UK Clinical Trials Gateway > www.ukctg.nihr.ac.uk

For more information, read our booklet > Clinical trials

For more information on the PCR tests, go to > cmlsupport.org.uk/node/8525

Clinical trials
If there’s a clinical trial (study) available that’s suitable for you, your consultant may recommend that you consider this.

Clinical trials are done for several reasons, including to look for new treatment options and to improve existing treatments. Taking part in a clinical trial has many advantages, such as the opportunity to have the newest available treatment which may not be given outside of the trial. You’ll also be very closely monitored and have detailed follow up.

In a clinical trial, the best current treatment is compared to one that could be better. You’ll still get normal treatment while you’re taking part in the trial, and your safety and well-being is always the first priority.

Taking part in a clinical trial does come with uncertainties, and you may prefer not to take part in one. If you don’t want to be in a trial, or there isn’t a suitable trial available, you’ll be offered the best treatment available at that time which is suitable for your individual condition.
Every person is different, so your consultant and healthcare team are the best people to ask about your likely outlook (your prognosis).

The outlook

Thanks to imatinib and other TKI, the outlook for the majority of people with CML is generally positive. The drugs usually stop CML from progressing; survival rates have improved; and you can have a good quality of life. While we haven’t seen the same improvements for people who don’t respond well to TKI, there are still treatment options available.

Talking about your prognosis

You may find it hard to ask or talk about your prognosis. Sometimes those close to you might want to know your prognosis even if you don’t. However, your healthcare team aren’t allowed to give this or any other information to anyone – not even family members – without your permission. Try to decide early on who you want to know about your condition, then tell your healthcare team – you can change your mind at any time.

Remember that your outlook might change, for example if you respond well to treatment. If there’s a change in your condition, or if you’ve finished all or part of your treatment, you might want to consider asking if your prognosis is still the same.
The outlook

Imatinib and other TKI have been used to treat CML for 16 years. If – like most patients – you’re diagnosed in the early chronic phase, these drugs will usually stop the disease progressing and you’ll stay in a prolonged chronic phase.

It’s currently thought that patients treated with TKI will need to take them for the rest of their lives, although this may change in the future as more data becomes available.

If you’re in blast phase

Imatinib and other TKI haven’t brought the same benefits for the small number of patients diagnosed in the blast phase, or patients who enter the blast phase. If this is the case for you, you may be invited to take part in a clinical trial.

Sometimes patients will respond to intensive therapy and enter a second chronic phase, so have an improved outlook. If this isn’t the case for you, you should discuss your likely prognosis with your specialist.

If you don’t work for you

If you don’t achieve a good response to TKI, your outlook will depend on how you respond to alternative treatments such as a stem cell transplant. If this is the case for you, you should discuss treatment options and your likely prognosis with your specialist.

It’s been nearly five years since my diagnosis and thankfully I’m in major molecular remission now. I take my tablets every day, follow my consultant’s advice and get on with my life.
Your healthcare team should look after your emotional needs, as well as your physical ones.

Everyday life and CML

If you’ve been diagnosed with CML you might experience a range of emotions at different times. There can be a physical impact on your day-to-day life too. This section will guide you through both aspects.

Looking after yourself emotionally

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

Your healthcare team should consider your emotional, as well as physical, needs – this is called a holistic needs assessment. You’ll have one a few times throughout the course of your treatment and beyond, as your emotional needs might change.

It’s important to remember that there is an excellent chance of response with tablet therapy.
Looking after yourself physically

Changes in your condition
During and after your treatment it’s important to contact your healthcare team at the hospital straight away if you notice any new symptoms – don’t wait for your next check up. Symptoms to watch out for are bone pain and other signs of progressive disease, as well as potential side effects from your treatment.

Keeping active
Do exercise in moderation, but if you’re suffering from a lot of pain – like particularly bad cramps and stiffness – after exercise then make sure you talk to your doctor about this.

Although staying active may help, there’s no evidence that any particular exercise programme can improve your condition or how you respond to treatment.

You might feel tired a lot (fatigue). This might be caused by your treatment and isn’t the same as normal tiredness, which improves with rest and sleep.

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

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

If you’re taking TKI it’s important to:

- keep well hydrated
- only take 50% of the recommended maximum dose of paracetamol
- increase your intake of calcium, magnesium and potassium to help with cramps caused by TKI – for calcium eat dairy products or take calcium supplements; potassium is found in orange juice, plain chocolate and bananas
- not eat or drink grapefruit, grapefruit juice, pomegranate, Seville orange or any Seville orange juice – make sure if you’re taking orange juice for potassium it’s not made from Seville oranges. Chemicals in these fruits interfere with the action of the TKI.

You can drink a small amount of alcohol with TKI, in a similar quantity to if you were planning on driving.

You can read about the experiences of other people who are going through, or have been through, the same thing on our website > bloodwise.org.uk/patient-support

You might like to get in touch with an organisation which can offer support for you and people close to you > see page 69
Alternative and complementary therapies

There’s an important difference between alternative therapies, which are offered in place of medical treatment, and complementary therapies, which are used alongside standard treatment.

Extensive research has shown no evidence that any alternative therapy has any benefit in treating of any form of cancer. We don’t recommend that you use any alternative therapy in place of proven medical care.

Always let your healthcare team know about any complementary treatments you’re using or thinking of using. They may advise you to avoid certain therapies, for example St John’s wort, because of specific risks to do with your CML or the treatments you’re receiving. In other cases they may say a therapy is OK as long as you take specific precautions.

Herbal medicines
Herbal preparations may be safe for a healthy person but they could be dangerous when combined with your chemotherapy. Make sure you talk to your doctor before you consider taking herbal medicines.

Acupuncture
If you’re considering acupuncture, you should look for a medically qualified acupuncturist who’s likely to follow safe practices to avoid infection.

We have a booklet on complementary and alternative therapies > Complementary and alternative therapies (CAM)
Practical support

Your work, education and domestic arrangements
If you work or are studying you might want to contact your employer or college, or ask someone to do it for you. Most will do everything they can to help.

You might need to make a short term arrangement with your employer or college at the time when you’re diagnosed so you can have time off when you need to be at the hospital. If you have to stay in hospital for your treatment, or you’re not well enough to go to work or college, you’ll probably need to make a more formal agreement.

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

You might want to consider taking time out from work during your treatment. Advice you’re given on this might vary but it’s entirely your decision, so consider discussing it with your healthcare team and thinking about the demands of the specific work you do. If you’re studying at college or university, you might similarly want to think about whether you want to continue with your course or delay it for a short time.

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

Cancer and the law
People with cancer, or any other serious disease, are covered by a law called the Equality Act – for the purposes of the act, cancer is considered a disability. This means that employers and places of study are required by law to make reasonable arrangements for ‘people with disabilities’ and can’t discriminate against you.

An example of a reasonable arrangement would be if you need time off to go to hospital for treatment. Your employer or college has to allow this and isn’t allowed to reduce your pay or make you take the time as unpaid leave.

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

Financial support
Your finances might be the last thing on your mind if you’ve just been diagnosed with cancer, but there are lots of places you can get help and advice.

Your hospital will normally have medical social workers or welfare rights (benefits) advisors who can advise on which benefits you might be able to receive. These might be especially useful if you’re on a low income or are unemployed. If you’re worried you can ask to speak with an advisor as soon as possible after your diagnosis.
Our researchers are making discoveries that will have a positive impact for people with CML.

Research and new developments

Each year, we invest a large part of the money we raise in research which aims to stop people dying from blood cancer; make patients' lives better; and stop people getting blood cancer in the first place.

Survival rates for people diagnosed with chronic myeloid leukaemia have been transformed with the development of tyrosine kinase inhibitors (TKI) – drugs that block the faulty protein at the heart of cancer and keep the leukaemia in check.

However, patients currently have to take these drugs for the rest of their lives and many suffer some side effects of the treatment. A trial, called DESTINY, led by our researchers in Liverpool but open in centres across the country, is testing whether it’s safe for some patients to reduce their dose or even stop their treatment altogether.
You can find more information about the latest CML research on the Cancer Research UK website > go to cancerresearchuk.org and search for 'CML research'

It'll also help reveal the reasons why certain patients relapse. An associated study is designing an incredibly sensitive test to better monitor how patients respond if they stop taking the drugs and quickly pick up those who are at risk of relapse.

Although TKI have improved the lives of many CML patients, for patients with more advanced disease – known as 'blast phase' – these drugs don't work or have stopped working and there are few remaining treatment options. A clinical trial in our pioneering Trials Acceleration Programme is testing whether it’s safe to combine a new drug, called ponatinib, with chemotherapy. If it is, our researchers hope to take the next step and test whether it’s effective at treating advanced disease.

Despite their success, TKI may not be effective at hitting all CML cells, which may be responsible for the drugs failing or the cancer coming back. Our work in Glasgow is focussing on the 'master' CML cells, so-called 'cancer stem cells', which may make up only a tiny proportion of the total population of cancer cells. A collaborative team is looking at how to target the faulty proteins specific to these master cells, which may be essential to truly wipe out the cancer. The team is also using high-powered computational analyses to identify abnormal molecular fingerprints in CML. Knowledge of faulty molecules can allow researchers to detect 'markers' of disease progression or response to drugs.
Places you can get help and support

Many people affected by blood cancer find it useful to call on the expert information, advice and support offered by a variety of organisations, including ourselves. Here are some we recommend.

Bloodwise
We offer patient information online and in free printed booklets, and have an online community you may like to join.

› 020 7504 2200  patientinformation@bloodwise.org.uk
› bloodwise.org.uk

We can help with practical and emotional support and signpost you to other available services.

› 0808 2080 888  patientservices@bloodwise.org.uk

Macmillan Cancer Support
Offers practical, medical, financial and emotional support.

› 0808 808 0000  macmillan.org.uk

CancerHelp UK
(Cancer Research UK’s patient support service)
Offers information about different conditions, current research and practical support.

› 0808 800 4040  cancerresearchuk.org/cancer-help
Leukaemia Care
Offers patient information, a 24 hour care line and support groups for people affected by leukaemia, lymphoma, myeloma, myelodysplastic syndromes, myeloproliferative neoplasms and aplastic anaemia.

› 01905 755 977 (general enquiries) or 08088 010 444 (Care Line)
› care@leukaemiacare.org.uk › leukaemiacare.org.uk

African Caribbean Leukaemia Trust (ACLT)
The ACLT aims to increase the number of black, mixed race and ethnic minority people on the UK Bone Marrow Register by raising awareness and running donor recruitment drives.

› 020 8240 4480 › info@aclt.org › aclt.org

Anthony Nolan
Runs the UK’s largest stem cell register, matching donors to patients with leukaemia and other blood related disorders who need a stem cell transplant.

› 0303 303 0303 › anthonyanolan.org

Maggie’s Cancer Caring Centres
Centres across the UK, run by specialist staff who provide information, benefits advice and psychological support.

› 0300 123 1801 › enquiries@maggiescentres.org › maggiescentres.org

Marie Curie Cancer Care
Nine hospices throughout the UK and offers end of life support to patients in their own homes, free of charge.

› 0800 716 146 › supporter.services@mariecurie.org.uk
› mariecurie.org.uk

MedicAlert Foundation
Provides an identification system for individuals with hidden medical conditions and allergies, in the form of emblems you wear on your body and necklaces or wrist bands.

› 0800 581 420 › info@medicalert.org.uk
› medicalert.org.uk

CML Support Group
An online patient support group for CML patients, their families and carers.

› cmlsupport.org.uk

Leuka CML Alliance
The Leuka CML Alliance is an innovative model of shared-care for patients with chronic myeloid leukaemia.

› 020 7487 3401 › info@leuka.org.uk
› leuka.org.uk/cml-alliance
Teenage Cancer Trust
Offers a range of information, advice and practical support to younger patients.
› 020 7612 0370  hello@teenagecancertrust.org
› teenagecancertrust.org

Financial advice
Citizens Advice Bureau (CAB)
Offers advice on benefits and help with filling out benefits forms.
› 08444 111 444 (England) or 0844 477 2020 (Wales)
› adviceguide.org.uk

Department for Work & Pensions (DWP)
Responsible for social security benefits. Provides information and advice about financial support, rights and employment.
› gov.uk

Travel insurance
Macmillan Cancer Support
Provides information about what to consider when looking for travel insurance. It also has a list of insurance companies recommended by people affected by cancer.
› 0808 808 0000  macmillan.org.uk

Association of British Insurers (ABI)
Provides information about getting travel insurance and contact details for specialist travel companies.
› 020 7600 3333  abi.org.uk

British Insurance Broker’s Association (BIBA)
Offers advice on finding an appropriate BIBA-registered insurance broker.
› 0870 950 1790  enquiries@biba.org.uk  biba.org.uk
It can be a good idea to write down the questions you want to ask before each appointment.

Questions to ask

It's easy to forget the questions you wanted to ask when you're sitting with your healthcare team and trying to take in lots of new information. Some patients find it useful to write down the questions they want to ask before they get there. Here are some questions you might like to ask at different times.

Tests

- What tests will I have?
- What will these tests show?
- Where will I have the tests done?
- Are there any risks associated with the tests?
- Will any of the tests be painful?
- Do I need to know anything about preparing for the tests, for example not eating beforehand?
- How long will it take to get the results?
- Who will explain the results?
- What is my exact diagnosis and what stage is the CML at?
Treatment

› Will I need to have treatment? If so, when?
› What does the treatment do?
› Is there a choice of treatments?
› Is there a clinical trial that I could join?
› What’s likely to happen if I decide not to have the treatment my healthcare team recommended?
› If I don’t need to start treatment straight away, how will I know when I need to start it?
› Who do I contact if I take a turn for the worse?
› Who can I contact if I have any questions?
› Is there any written information available or any recommended websites?

My main treatment

› What type of treatment will I have?
› Will I have to stay in hospital?
› If not, how often will I need to go to hospital as an outpatient?
› What drug regimen will I be given? Will I be given it by mouth, injection or drip (into a vein)?
› Will my treatment be continuous or in blocks of treatment with a break in between?

› How long will my treatment last?
› What side effects could I get from my treatment?
› Can side effects be treated or prevented?
› Will they affect me all the time or only while I’m taking certain drugs?
› What are the fertility risks with treatment and what options are available to me to address the risks?
› What effect is the treatment likely to have on my daily life?
› Will I be able to carry on working or studying?
› Will I need to take special precautions, for example against infection?
› Will I need to change my meal times or work my drugs around these?

Stem cell transplant

› Is a transplant an option for me?

If I’m having a transplant:

› How long will I be in hospital for?
› Do I have to be in isolation?
› How long will it be before I get back to normal?
Choosing the right treatment for you

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

› What’s the best outcome I can hope for?
› How might the treatment affect my quality of life?

Follow-up

› How will the cancer be monitored after my treatment?
› How often will I need to have follow-up appointments?
› Is there anything I need to watch out for after my treatment?
› Who can I contact if I have any questions or worries?

Relapse

› How will doctors know if the cancer is progressing?
› What are the options for more treatment?
› What will the treatment involve? Will it be different from my initial treatment?
› Will there be any side effects from more treatment?
› Is my prognosis likely to change with more treatment?
If you’re diagnosed with blood cancer you need to know that there are people who can help. You want to know what it means, what’s going to happen, what the treatment is like and what your chances of living a normal life are. You need to know someone is there for you.

Blood cancers represent one in 10 of all new cancer diagnoses – this means that each year 38,000 people are diagnosed with blood cancers and closely related conditions.

We play a vital role, working in collaboration with the NHS, health professionals, government, pharmaceutical companies and other charities to ensure that the needs of blood cancer patients are addressed. We take a leading role in research into blood cancers; we ensure patients have access to innovative clinical trials where possible; we provide information; and we’re a voice of influence when it really counts.

This means no blood cancer patient ever needs to feel alone. We have more than 1,000 researchers, clinicians and nurses making sure that our research has a clear line of sight to improving patients’ lives.

We ensure that when our expert knowledge counts, we speak to the people in the right places to influence decisions.

We support a community of thousands of individuals, families and friends who have their own experience of blood cancer and we create a safe space for patients to share their worries and also see that there can be light at the end of the tunnel.

As one of the UK’s leading blood cancer charities, we feel both the responsibility and the opportunity that we have to make patients’ lives better.
Our patient services

We put the patient at the heart of everything we do. We strive to help everyone affected by a blood cancer to live the best possible quality of life, for life. Alongside our ongoing commitment to support vital medical research into the cause and cure of blood cancers, we’re developing and delivering quality support and services for patients, their family, friends and carers to help with the emotional and practical impact of blood cancer.

Through our dedicated Patient Support area on our website, people can share their experiences of blood cancer, connect with each other and access our wide range of patient information. We provide support, information and advice over the phone and online, and we’re constantly developing new ways to support our patients based on what they tell us they want and need.

How we raise money

We don’t get any government funding: it’s the money raised by our incredible supporters that lets us continue our life-saving work.

It’s because of them that we can offer our patient information free of charge to blood cancer patients, so we’d like to say a big thank you to everyone who gives so generously to us.

If you – or anyone close to you – ever feels able to make any kind of donation, large or small, it will help us continue our life-saving work > bloodwise.org.uk/give

Our patient information is available to download, order or read online. You can also blog about your journey there and read about other people’s blood cancer experiences > bloodwise.org.uk/patient-support
How you can get involved

There's lots of other ways you can get involved that will help us achieve our vision of beating blood cancer.

Patient Support
Patient Support is your space to find information, share knowledge and experiences and connect with others affected by blood cancer.

bloodwise.org.uk/patient-support

Patient focus groups
Patients are at the heart of everything we do. That's why we consult patients at every opportunity to get their views about the services we provide. Check our website for upcoming events.

bloodwise.org.uk/focus-groups

Cycling
We like to think we're the UK's premier cycling charity! From short family rides through to our flagship London and Birmingham Bikeathons and epic London | Paris challenge, if you've got a bike you can cycle with us to beat blood cancer.

bloodwise.org.uk/cycling

Running
All around the country, right throughout the year, our unstoppable runners take to the streets to help us beat blood cancer. Whether it’s at the London Marathon, one of the Great Run series or a junior run, it's a case of every step counts.

bloodwise.org.uk/running

Triathlons
You won't know what you can do until you tri! Triathlons are ever popular with sporty types who want to conquer swimming, cycling and running, all on the same day! We're the proud title sponsor of the wonderful Blenheim Palace Triathlon but there are so many more on offer.

bloodwise.org.uk/triathlon

Challenges
And then there are some who want to climb mountains, trek through jungles and canoe rivers for us! Get in touch to tell us about your challenge and we'll support you all the way.

bloodwise.org.uk/challenges
How you can get involved

We're always looking for companies who share our vision of a future without blood cancer and we recognise the benefits that partnering with us can bring your business. We know we can achieve more together than we ever could alone and our dedicated corporate team will work with you to build an innovative, mutually beneficial partnership.

bloodwise.org.uk/corporate

We were formed back in 1960 by some brave parents in Middlesbrough whose daughter sadly died from leukaemia. Fast forward all these years and our local fundraisers are still right at the heart of our organisation. Our friendly regional teams can support you in every aspect of your fundraising and are always on hand for a chat.

bloodwise.org.uk/localfundraising

Corporate fundraising

Local fundraising

Special events

Meet the likes of Billy Connolly and Miranda Hart at our annual ‘Audience with’ events or frock up for our star-studded ‘Christmas with the Stars’ concert at the Royal Albert Hall. To see our very latest events check out our website.

bloodwise.org.uk/special-events

Being part of our online community

Short on time? Join our Facebook and Twitter communities. Every quick share could mean a new supporter, a new donation or a new patient finding out about our support services.

facebook.com/bloodwise.uk
twitter.com/bloodwise_uk

Shop with us

To give gifts that give back, visit our online shop. We have a great range of ethically sourced products and 100% of profits go towards beating blood cancer.

bloodwise.org.uk/shop

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bloodwise.org.uk/shop
## Your feedback

We’re always looking for ways to improve the information we provide for people with blood cancer.

We welcome your feedback on this booklet and our other patient information. Any improvements you suggest mean we can make better information for other blood cancer patients and people close to them.

To fill in a short survey about our patient information online, please go to [bloodwise.org.uk/bookletsurvey](http://bloodwise.org.uk/bookletsurvey)

## Other booklets

### Leukaemia
- Acute lymphoblastic leukaemia (ALL in children up to 16 years)
- Adult acute lymphoblastic leukaemia (ALL in children and young adults up to 16 years)
- Acute myeloid leukaemia (AML) in children and young adults up to 16 years
- Acute promyelocytic leukaemia (APL)
- Adult acute myeloid leukaemia (AML)
- Childhood acute myeloid leukaemia (AML)
- Chronic lymphocytic leukaemia (CLL)
- Chronic myeloid leukaemia (CML)

### Lymphoma
- Hodgkin lymphoma (HL)
- Low-grade non-Hodgkin lymphoma (NHL)
- High-grade non-Hodgkin lymphoma (NHL)

### Myeloma
- Myeloma

### Related conditions
- Myelodysplastic syndromes (MDS)
- Myeloproliferative neoplasms (MPN)

### Treatment
- Bone marrow and stem cell transplantation – for children and adults
- Chemotherapy
- Clinical trials
- Donating stem cells
- Donor lymphocyte infusion
- The seven steps – blood & bone marrow transplantation
- Treatment decisions
- Undergoing high dose therapy and autologous stem cell transplant

### General
- Complementary and alternative medicine
- Dietary advice for patients with neutropenia
- Newly diagnosed with a blood cancer
- Supportive care
- Watch and wait

### For children and young adults
- Jack’s diary
- Wiggly’s world
- Young adults with a blood cancer – what do I need to know?
Cancer can sometimes feel like it has its own language. Here are some of the most common words you might hear:

**Glossary**

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

**Blood count, full blood count or FBC**
A blood test that counts the different types of cells in your blood.

**BCR-ABL1 gene**
A fusion gene that’s created when cells don’t divide properly. It leads to a protein called tyrosine kinase being made, which is what stops the abnormal leukaemia cells from developing properly.

**Blasts**
Blood cells that are immature, or haven’t developed properly. You have more blasts if the disease is more advanced.

**Bone marrow**
A spongy material inside long bones, which produces your blood cells.

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

**Clinical trial**
A planned medical research study involving patients. They can be small trials involving only a few patients or large national trials. Clinical trials are always aimed at improving treatments and reducing any side effects they cause. You’ll always be told if your treatment is part of a trial.

**Cytogenetics**
The study of chromosomes in the affected cells.

**Fatigue**
Fatigue is a feeling of extreme tiredness which doesn’t go away after rest or sleep. It may be caused by the CML itself in the beginning, but following remission it’s likely to be a side effect of treatment. It’s one of the most common problems that patients with cancer have.
Granulocyte
A type of white blood cell which includes eosinophils, neutrophils and basophils. It’s granulocyte cells which are abnormal in CML.

Lymph node or lymph gland
A bean-shaped organ that acts as a filter to catch viruses, bacteria and other foreign materials. It contains white blood cells that fight infection.

Myeloid blood cells
Red blood cells, platelets and white cells other than lymphocytes – so neutrophils, monocytes, eosinophils and basophils – are myeloid cells. Myeloid cells are affected in CML.

Philadelphia chromosome
An abnormal chromosome which almost all CML patients have.

Spleen
An organ that filters the blood. It sits under your ribs on the left hand side of your body. The spleen has two main jobs: to remove old red blood cells and to help protect your body from infections.

Stem cells
Cells that are able to develop into other cell types. Stem cells act as a repair system for your body and replenish other cells. They’re found in embryos and some organs in adults.

TKI
Tyrosine kinase inhibitors (TKI) are drugs used to treat CML. They act against the tyrosine kinase protein and prevent the abnormal white cells from developing. Bosutinib, dasatinib, imatinib, nilotinib, and ponatinib are all examples of TKI.
Bloodwise
For adults and children with blood cancer

39–40 Eagle Street, London WC1R 4TH
bloodwise.org.uk
020 7504 2200 (Reception); 0808 2080 888 (Helpline)