Bloodwise

For anyone affected by blood cancer

bloodwise.org.uk

Chronic myeloid leukaemia (CML)
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 people affected by blood cancer. 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.

The quotes included in this booklet are genuine comments that people living with blood cancer have shared with us.

This booklet is one of many we offer – you can find a list of our other booklets and fact sheets on pages 97–98. For the very latest information, visit our website: bloodwise.org.uk

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 because we’re suggesting other places to go for good information and support.

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

Bloodwise staff revised the text to make it easy to read, and a non-medical panel including people with blood cancer checked it for understanding. Professor Jane Apperley is responsible for the content overall.

Bloodwise is the UK’s leading blood cancer charity.

Since 1960, we’ve invested £500 million in research to improve treatments. We’re also here to offer information and support to anyone affected by blood cancer.

To find out more:
- Visit bloodwise.org.uk/info-support
- Get in touch with our Support Services Team on 0808 2080 888 (Mon, Tue, Thu, Fri: 10am–4pm, Wed: 10am–1pm) or email support@bloodwise.org.uk
- Join our online forum for people affected by blood cancer at forum.bloodwise.org.uk

If you find this booklet helpful, you can support our work:
- Visit bloodwise.org.uk/donate
- Call us on 0808 169 5155

A list of references used in this booklet is available on request. Please email us at information@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 2019).
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Introduction

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

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

There’s sure to be a lot of information to take in at first.

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

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

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

What is CML?
Leukaemia is a type of blood cancer that affects your blood cells – usually white blood cells. CML is a slow-developing form of leukaemia. There are three stages of CML and most people are diagnosed in the early (chronic) phase. In this phase your body makes too many mature (fully functioning) white blood cells known as granulocytes. Treatment can bring the number of blood cells under control, but if the disease is left untreated, it can progress to a more aggressive form of CML known as blast phase, where the white blood cells don’t develop as they should.

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

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

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

Slightly more men than women get CML.

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

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

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

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

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

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

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

Blood
The blood has many important functions:

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

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

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

Repair system
It contains cells and chemicals that can seal off damaged blood vessels and control blood loss.
**Bone marrow, blasts and blood cells**

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

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

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

**Blood cells**

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

**White blood cells (leukocytes)**

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

**Red blood cells (erythrocytes)**

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

**Platelets (thrombocytes)**

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

**Blood cell production**
How many of each type of blood cell should you have?
If you’re diagnosed with CML, your healthcare team will check the different number and type of blood cells in your bloodstream by taking blood samples/tests.

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

Everyone has slightly different numbers of each type of blood cell, and these numbers will go up and down a little from time to time, but they should generally stay within a normal range. The table below shows what you might expect to see in a healthy person:

<table>
<thead>
<tr>
<th></th>
<th>WHITE BLOOD CELLS</th>
<th>RED BLOOD CELLS</th>
<th>HAEMOGLOBIN</th>
<th>NEUTROPHILS</th>
<th>PLATELETS</th>
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<tbody>
<tr>
<td></td>
<td>(10^9/l)</td>
<td>(10^12/l)</td>
<td>(g/dl)</td>
<td>(10^9/l)</td>
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<tr>
<td>ADULT MALE</td>
<td>4 to 11</td>
<td>4.5 to 6.5</td>
<td>13 to 18</td>
<td>2 to 7.5</td>
<td>150 to 400</td>
</tr>
<tr>
<td>ADULT FEMALE</td>
<td>4 to 11</td>
<td>3.9 to 5.6</td>
<td>11.5 to 16</td>
<td>2 to 7.5</td>
<td>150 to 400</td>
</tr>
</tbody>
</table>

This range depends on a number of different things, including sex, age and ethnicity. Also, different laboratories will use different equipment and testing methods, so normal values can vary slightly from hospital to hospital. As a result, this table should only be used as a rough guide; your healthcare team can explain what your results mean for you.

Your immune system
Your immune system is a network of cells, tissues and organs that protect your body against infection. It’s able to react quickly to infections it’s seen before: white blood cells (lymphocytes in particular) play an important role in this. They circulate around your body in your blood and fight infections. Most people with CML don’t get more infections than usual.
CML is a slow-developing blood cancer that affects your stem cells. With treatment, you can usually manage the disease and keep it under control.

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

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

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

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

Your body needs new blood cells all the time, and it usually makes the right amount. But if you have CML, this process goes wrong and your body produces too many myeloid blasts and granulocytes. These cells overcrowd the bone marrow, meaning there isn’t enough room for other important blood cells to be made.
Some blasts also enter the bloodstream and, because they haven’t developed properly, aren’t able to fight infection properly. Both of these things cause many of the signs and symptoms of CML.

Phases of CML
The three phases of CML are defined according to the number of myeloid blasts and granulocytes in the blood and bone marrow. Your treatment and outlook will depend on which phase of the disease you have. These phases are explained briefly below, but your healthcare team will be able to tell you more about your individual diagnosis, and what it means for you.

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

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

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

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

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

CML is thought to begin when chromosomes nine and 22 get mixed up when a stem cell divides. This creates a new, shorter chromosome called the Philadelphia chromosome (it was named this because it was discovered in Philadelphia).

During this mix-up, a small part of chromosome nine (containing the ABL1 gene) gets stuck next to a small part of chromosome 22 (containing the BCR gene). This swapping of genetic material is called a translocation, or chromosomal translocation. This particular translocation is called t(9;22).

In the process, they form a new fusion gene called BCR-ABL1.

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

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

In 95% of people with CML, the Philadelphia chromosome can be detected with a cytogenetic test (where cells from a blood sample are studied under a microscope). If you’re one of the 5% of people for whom this test can’t pick up the Philadelphia chromosome, you will have a PCR test or a FISH test to confirm your diagnosis.

Treating CML

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

Find out more about PCR, FISH and other tests used to diagnose CML in the Diagnosis chapter.
Who gets CML?

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

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

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

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

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

Does CML run in families?
There’s no evidence that family members of people with CML are at a higher risk of developing the condition than anyone else.
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’ve been diagnosed with CML, you may have noticed some symptoms before your diagnosis.

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

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

Symptoms in the chronic phase

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

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

Symptoms in the accelerated phase

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

“I found it quite hard to tell which 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 blast phase

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

These may include:

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

We produce a diary for people affected by blood cancer, which you can order online.

It’s yours to use however you like – to note down practical information or to record thoughts or keep sketches. For information on how to order or download a copy, see page 100.
It’s important to know and understand your diagnosis. You could ask your team to write the details (including any test results) in the space provided at the back of this booklet, so you have it to hand.

Diagnosis

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

Tests to diagnose CML

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

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

Full blood count (FBC)

A full blood count (FBC) measures the number of each type of cell in your blood: red blood cells, white blood cells and platelets. A small sample of blood will be taken from a vein in your arm and a machine will measure the numbers of different types of blood cells in the sample. You might be sent for this test by your GP as part of a routine check-up. Or you might have one if you’re in hospital for something else.
When I was diagnosed I asked my consultant to write my diagnosis down and I’m really glad I did. I could then do my own research and also tell people accurate information about my condition.

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

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

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

**Polymerase chain reaction (PCR) test**

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

**Bone marrow sample**

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

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

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

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

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

The laboratory doctors will do a number of tests on your bone marrow, to look at how many mature (fully functioning) and immature (not fully functioning) cells you have. This helps to confirm the stage of your disease.
Cytogenetics
Almost everyone with CML will have cytogenetic tests (cytogenetics is the study of chromosomes). This is because in 95% of people with CML, these tests will detect a chromosome called the Philadelphia chromosome. So testing for this chromosome is a common way to diagnose CML.

If you’re one of the 5% of people for whom the Philadelphia chromosome isn’t detected, your doctors can use the results of your PCR test (described on page 28) or run a FISH test (described below) to confirm your diagnosis.

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

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

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

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

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

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

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

“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.”
Risk scores
As part of staging, your doctors will work out your ‘risk score’. Your doctor may use your risk score to help choose the most appropriate treatment for you.

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

The Sokal risk score looks at:
› your age,
› the size of your spleen,
› the number of blast cells in your blood, and
› your platelet count.

Risk scores are less important today than before the introduction of tyrosine kinase inhibitors (TKIs), because the great majority of people with CML respond to these drugs, regardless of their risk score. TKIs vary in strength, so it makes sense to use a stronger drug for those at high risk.

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

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

Your clinical nurse specialist (CNS)
People with cancer are normally given a key worker, usually a clinical nurse specialist (CNS). They’re your point of contact with the rest of your healthcare team. You may like to have a meeting with your CNS when you’re first diagnosed, to discuss your condition. Your CNS will be with you every step of the way, so do make use of their help and expertise if and when you need it. They can also be a useful link to reach out to your doctors between your appointments.

Your multidisciplinary team (MDT)
Your condition should be discussed at regular MDT meetings. An MDT brings together doctors, nurses and any other specialist staff who will be looking after you. They’ll discuss the best treatment for you and every aspect of your care, including any changes in your condition.
Talking to other people
You may want to ask your consultant or CNS if you can talk to someone who has had a similar diagnosis and treatment to you. If you do this, remember that someone else’s experience won’t always be the same as yours. For example, some people will experience side effects from a drug and others won’t.

Your other healthcare professionals
It’s definitely worth telling other healthcare professionals you see – like your dentist or optician – about your diagnosis and any medication you’re taking. They may need to check with your specialist or GP before giving you some types of treatment.

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

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

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

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

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

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

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

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

You can get in touch with other people who are going through (or have been through) similar things, and read about their experiences at bloodwise.org.uk/community

Our Support Services Team offer practical and emotional support for anyone affected by blood cancer. Contact us on 0808 2080 888 or support@bloodwise.org.uk

For a list of support organisations, please see pages 77–81.
If you have questions about your care

If you’re unhappy with any aspect of your care, speak to someone in your healthcare team. Or, ask your hospital or treatment centre who is best to speak to outside of the team.

Sometimes, asking your doctor or another member of the team to explain your diagnosis again can clear up any concerns you may have.

You can also ask for a second opinion from another doctor at any stage – before, during or after treatment. You could discuss this with your GP.

There are services that provide support and information for people who have concerns about their healthcare. In England this is the Patient Advice and Liaison Service (PALS), in Scotland it’s the Patient Advice and Support Service (PASS), and in Wales it’s the Community Health Councils (CHCs). In Northern Ireland, you need to ask your hospital for a copy of their complaints procedure.

Go to citizensadvice.org.uk for more information about your local patient advice or complaints service.

“I didn’t know whether to tell people I had cancer and at first only told people on a need-to-know basis – after all, I looked well physically so didn’t think people would understand. But I’ve found since telling people that I’ve largely continued to be treated as ‘me’ rather than ‘me with cancer’.”

Telling people

Many people tell us that keeping in touch with loved ones throughout their illness keeps them going. However, some people may find it stressful having to discuss their condition lots of times with family, friends and colleagues.

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

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

You might not want to tell many people – or anyone at all – about your condition. This is ok too. It’s entirely up to you.
Talking to children and teenagers
Talking to children and teenagers about your cancer diagnosis can be difficult. There are lots of organisations that can support you and offer you advice about how to explain cancer to children of different ages.

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

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

Macmillan Cancer Support has some useful advice about cancer and work online; you can also order a booklet. Go to macmillan.org.uk then search for ‘work’.

Macmillan Cancer Support also has information on talking to children about cancer. Go to macmillan.org.uk then search for ‘talking to children and teenagers’

There’s more information about cancer and how it can affect your work or study on page 70.

Katie was diagnosed with CML when she was 22, during her third year of university. Her condition is now well controlled by daily medication and she’s embarked on a new career as a Naturopathic Physician.

“Don’t let cancer define you; let it shape who you are. A lot of my life is cancer – but it’s not all my life.”

Hear Katie’s story at bloodwise.org.uk/living-with-CML
If you’re taking TKIs, it’s really important that you take them exactly as directed by your doctor and are aware of advice around diet and getting pregnant.

Treatment

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

Starting treatment

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

The aim of treatment for CML is to achieve very low levels of leukaemia cells and keep the disease under control, so there is a very low chance of it progressing. There are several levels of response to treatment, which you normally achieve one by one, based on how long you’ve been having treatment. For more information see the ‘Follow up’ section on pages 51–53.

Our Treatment decisions fact sheet may help you understand the choices you might be asked to make. To download a copy, go to bloodwise.org.uk/information
Chemotherapy
If your white blood cell count is high and/or you have a lot of symptoms and feel unwell, your healthcare team may give you a mild chemotherapy tablet, known as hydroxycarbamide. This will lower the number of blood cells in your bloodstream and control your symptoms until your diagnosis is confirmed.

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

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

In this procedure, a plastic tube will be inserted into each arm. Your blood will drain from one tube into a machine (centrifuge) which will be spinning at high speed. The spinning separates the blood into white blood cells, red blood cells and plasma. The white blood cells are removed and either thrown away or, with your agreement, could be used for research. The red blood cells and plasma are then returned to your body through the tube in your other arm.

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

Tyrosine kinase inhibitors (TKIs)
Once your diagnosis is confirmed, your doctors will prescribe a TKI. This is a drug that comes in tablet form, which kills leukaemia cells.

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

First-line treatment
If you’re diagnosed in the chronic phase, your first treatment will usually be a regular standard dose of one of three types: imatinib, dasatinib or nilotinib. In general, people cope well with these drugs, and can return to a relatively normal lifestyle, such as continuing to work and study.

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

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

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

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

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

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

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

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

Stem cell transplant

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

For more information on fertility and pregnancy, see pages 49–50. Turn to page 53 to find out more about what it means to achieve a ‘deep molecular response’. There’s also important advice you should read about diet on pages 65–66.

If you’re diagnosed in the blast phase

Very few people will be in this phase when diagnosed. If you are, your CML will be treated with stronger treatments, in a similar way to an acute (fast-growing) leukaemia. This usually includes chemotherapy, and sometimes TKIs. If this treatment is successful and you return to the chronic phase, your doctor may recommend a stem cell transplant, which could offer the chance of a long-term cure. Your doctor will talk you through your treatment options, which will depend on what’s most suitable for you.

It’s likely that these stronger treatments will affect your fertility (ability to have children), so it’s important to speak to your healthcare team about the options available to you if you think you might want to have children in the future.
Side effects of treatment
For most people on TKIs, side effects are not severe. However, you may notice some changes to your body that could be linked to the drugs you’re taking. If you do, it’s important to let your healthcare team know, as there are lots of things they can do to help you manage these side effects. For example, anti-sickness medication can help if the TKIs make you feel sick. The following side effects are common to all TKIs:

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

Imatinib
Some other side effects of imatinib include:

- fluid build-up (retention) that causes puffiness around the eyes,
- dry, gritty eyes,
- haemorrhages into the white of the eye; these are not dangerous or harmful to your sight but can look unpleasant, and
- feeling sick (nausea) if you don’t take the drug on a full stomach.

Dasatinib
Some other side effects of dasatinib include:

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

Nilotinib
Some other side effects of nilotinib include:

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

There’s more information on stem cell transplants in our booklet The seven steps: blood stem cell and bone marrow transplants. For more information on how to order or download, go to page 100.
Bosutinib
Some other side effects of bosutinib include:
› diarrhoea (frequent watery poos), which can be particularly severe in the first few days.

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

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

While there’s no evidence that any TKI affects fertility (your ability to have a baby), doctors strongly recommend that you avoid becoming pregnant while you’re taking imatinib and other TKIs, and use reliable contraception. This is because there’s evidence to suggest that TKIs might be harmful to babies in the womb (uterus).

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

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

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

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

To find out more about the possible side effects of TKIs, go to cancerresearchuk.org and search for ‘biological therapy drugs for CML’.
If you don’t respond to a TKI and are planning to have a stem cell transplant, it’s quite likely that the drugs used for the transplant will cause an early menopause (when a woman stops having periods and no longer releases an egg each month, so cannot become pregnant naturally).

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

**Fertility and CML – men**

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

Most hospitals and treatment centres will also recommend storing some of your sperm at the time when you’re diagnosed, but if this isn’t discussed with you, you can ask your healthcare team about it. If you don’t respond to a TKI and are considering a stem cell transplant, it’s important to have this conversation with your healthcare team.

**Late effects**

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

**TKIs and other drugs**

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

**Follow-up**

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

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

**Haematological response**

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

You can find out more about the impact that stem cell transplants can have on your fertility in our booklet: The seven steps: blood stem cell and bone marrow transplants. Find out how to download or order on page 100.
Although your blood count is normal, this doesn’t necessarily mean that it’s ok to stop treatment. If you were to stop treatment as soon as your blood count returns to normal, it’s likely that your white blood cell count would increase rapidly again.

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

Your healthcare team can explain what your test results mean for you.

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

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

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

Molecular response (PCR tests)
If you’re responding to treatment, you’ll usually have a polymerase chain reaction (PCR) test every three months using a blood sample. This will measure how you’re responding to treatment and let your doctor know if you need to change drugs or doses (the amount you’re receiving). This is a very reliable and sensitive test that can detect one leukaemia cell in up to 100,000 normal blood cells.

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

<table>
<thead>
<tr>
<th>PCR RESULT</th>
<th>KNOWN AS</th>
<th>WHAT IT MEANS</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt; 1%</td>
<td>Complete cytogenetic response (CCyR)</td>
<td>Less than 1 leukaemia cell in every 100 blood cells</td>
</tr>
<tr>
<td>&lt; 0.1%</td>
<td>Major molecular response (MMR)</td>
<td>Less than 1 leukaemia cell in every 1,000 blood cells</td>
</tr>
<tr>
<td>&lt; 0.01%</td>
<td>Deep molecular response (MR4)</td>
<td>Less than 1 leukaemia cell in every 10,000 blood cells</td>
</tr>
<tr>
<td>&lt; 0.0032%</td>
<td>MR4.5</td>
<td>Less than 1 leukaemia cell in every 32,500 blood cells</td>
</tr>
<tr>
<td>&lt; 0.001%</td>
<td>MR5</td>
<td>Less than 1 leukaemia cell in every 100,000 blood cells</td>
</tr>
</tbody>
</table>

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

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

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

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

Clinical trials are done for several reasons, including to look for new treatment options and to improve existing treatments. Taking part in a clinical trial has many advantages, such as the opportunity to have a new test or treatment, which may not be given outside of the trial.

Your safety and wellbeing will always be the first priority when taking part in a clinical trial – you’ll be very closely monitored and have detailed follow-up. You can choose to withdraw at any time.

Taking part in a clinical trial does come with uncertainties and risks, and there’s no guarantee that the new treatment will be better than the best current treatment. If you don’t want to be in a trial, or there isn’t a suitable trial available, you’ll be offered the best treatment available at that time that’s suitable for your individual condition.

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

For more information, read our booklet: Your guide to clinical trials. See page 100 for details of how to order or download a copy.

Kris was diagnosed with CML when he was 32. He now takes a daily dose of dasatanib to manage his condition.

“

I was on imatinib for about three years, but I experienced some side effects so I moved on to another drug called dasatinib – and that was just great. I now take two of those in the morning and don’t get any side effects.

“

Hear Kris’s story at bloodwise.org.uk/CML-treatment
Every person is different, so your healthcare team are the best people to ask about your likely outlook (prognosis).

The outlook

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

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

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

It’s also important to remember that statistics can only give an overall picture. Your own outlook is individual to you and will depend on your age, level of fitness and the stage of your disease, so it’s always best to speak to your healthcare team about this.
Talking about your outlook
You may find it hard to ask or talk about your outlook. Sometimes those close to you might want to know your outlook even if you don’t. However, your healthcare team aren’t allowed to give this or any other information to anyone – not even family members – without your permission.

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

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

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

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

For more information about stem cell transplants, turn to page 100 to find out how to order or download our booklet: The seven steps: blood stem cell and bone marrow transplants
If you’re in blast phase

Unfortunately, it’s harder to control blast-phase CML, as it doesn’t always respond to TKIs. If this is the case for you, your healthcare team will talk you through other treatment options and explain the impact they might have on your outlook. These options may include chemotherapy with or without TKIs, and/or a stem cell transplant.

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

Change in outlook

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

*It’s been nearly five years since my diagnosis and thankfully I’ve now achieved a major molecular response. 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.

Living with CML

If you've been diagnosed with CML you might experience a range of emotions at different times. There can be a physical impact on your day-to-day life too.

Looking after yourself emotionally

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

Your healthcare team should discuss your emotional spiritual, social, practical and physical needs with you and talk about how they can be met. This is called a holistic needs assessment. You should have one a few times throughout the course of your treatment and beyond, as your emotional needs might change.
Looking after yourself physically

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

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

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

While even the idea of doing something can be tiring if you’re fatigued, try to keep as active as you can, because evidence shows that this could help to reduce the symptoms of fatigue.

Although there’s no evidence that any particular exercise programme can improve your condition or how you respond to treatment, we do know that staying active is good for your general wellbeing and your mood.

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

Things to think about if you’re taking TKIs
If you’re taking TKIs, it’s important to:

› take your tablets according to the instructions of your doctor or pharmacist,

› only take half the recommended maximum dose of paracetamol, as TKIs can stop your body from processing this properly,

› avoid eating or drinking grapefruit, grapefruit juice, pomegranate, Seville oranges or any Seville orange juice (other types of orange and orange juice are still fine to eat/drink), since chemicals in these fruits can stop TKIs from working properly.

You can get in touch with other people who are going through (or have been through) similar things, and read about their experiences at bloodwise.org.uk/community

You might like to get in touch with an organisation that can offer support for you and people close to you. See page 77 for suggestions.
At the moment, there’s not much evidence about the impact that drinking alcohol can have on TKIs. But if your liver is working normally, it’s generally thought to be ok for you to drink alcohol – as long as you follow the UK’s guidelines and drink sensibly. If your treatment starts to affect your liver, your healthcare team may advise you to drink less alcohol, or to stop drinking completely.

Things to think about if you need stronger treatment
If you don’t respond well to at least two TKIs and need stronger treatment involving chemotherapy or a stem cell transplant, your immune system may not be working as normal, so you’ll need to take extra care to avoid infections that you might get from food. Your body won’t be able to destroy germs and resist infection as easily, so be careful about food use-by dates and take particular care to keep raw meat separate from ready-to-eat foods in the fridge. You may also be advised to be extra careful about takeaway food and eating out while you’re having this treatment. You won’t need to take these precautions if you’re in the chronic phase and are taking TKIs, however.

A diet for people with a weakened immune system is known as a neutropenic diet. Your healthcare team will advise you on any changes you need to make to your eating habits.

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

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

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

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

If you don’t respond well to TKIs and need stronger treatment, our booklet Eating well with neutropenia has advice on how to avoid infections from food. For details of how to order or download, see page 100.
Complementary therapies
Complementary therapies are treatments like massage, meditation or acupuncture that are used alongside standard medical treatments with the aim of making you feel better.

There’s no evidence to suggest that these therapies can treat or cure blood cancer, but there’s some that suggests some of them may help you manage your symptoms or the side effects of your treatment. Other therapies may just help you relax or improve your general sense of wellbeing.

I had good days and bad days during treatment. I found it helpful to record these ups and downs in a journal, to spot patterns and remind myself of the good days when I wasn’t feeling so well.

Alternative therapies
There’s an important difference between complementary therapies, which are used alongside standard medical treatments (like chemotherapy and radiotherapy), and alternative therapies, which are offered instead of these treatments. We don’t recommend that you use any alternative therapy in place of proven medical care, but you may be interested in using complementary therapies alongside your treatment.

Keeping yourself safe
If you’re thinking about using complementary therapies, you should let your healthcare team know, so you can discuss what’s safe for you. They may advise you to avoid certain therapies because of specific risks to do with your condition or the treatments you’re receiving.

In other cases, they may say a therapy is ok as long as you take specific precautions, like visiting a complementary therapist who’s a member of the relevant professional association or register. Your healthcare team can explain how to check this.

Some hospitals will have a complementary therapies team that offers sessions free of charge, while others might have a specialist who visits once or twice a week. Sometimes these therapies are there for your partner or close relatives, too. Your healthcare team will be able to tell you what’s on offer.

If your hospital doesn’t offer complementary therapies, there may be a local cancer centre or charity that you could visit instead. Speak to your healthcare team to see if they can recommend anywhere nearby.

Some people choose to see an independent complementary therapist. If you do this, it’s important to make sure they will keep you safe. Speak to your healthcare team about what you need to keep in mind when finding a therapist.
**Practical support**

**Work, education and home life**
If you work or are studying you might want to contact your employer or college, or ask someone to do it for you.

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

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

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

**Cancer and the law**
People with a disability are protected by the Equality Act 2010 in England, Scotland and Wales, and the Disability Discrimination Act 1995 in Northern Ireland. For the purposes of these Acts, cancer is considered a disability. This means that employers and places of study are required by law to make reasonable adjustments for people with cancer and can’t discriminate against them. An example of a reasonable adjustment would be allowing you time off to go to hospital for treatment.

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

If this isn’t possible and transport is a problem, you can ask about hospital transport. You might also be able to apply for support with travel costs. If you’d like to find out more about this support, speak to your team at the hospital or a benefits advisor. The organisations signposted below can also advise you.

**Financial support**
There are lots of places you can get help and advice if you’re worried about money.

Your hospital will normally have social workers or welfare rights (benefits) advisors who can advise on which benefits you might be able to receive. These might be especially useful if you’re on a low income or are unemployed. If you’re worried ask to speak with an advisor as soon as possible after your diagnosis. Alternatively, your hospital may be able to arrange for an advisor from somewhere else to visit you.

If you normally pay for your prescriptions, you can apply for a medical exemption certificate. This means you won’t have to pay for prescriptions for anything you need because of your cancer or the effects of your cancer treatment. Application forms are available from your GP surgery or hospital clinic.

Macmillan Cancer Support has some useful advice about cancer and work online. Go to [macmillan.org.uk](http://macmillan.org.uk) and then search for ‘work’.

Consider seeking legal advice about your rights from [acas.org.uk](http://acas.org.uk) or [citizensadvice.org.uk](http://citizensadvice.org.uk)

For information about help with travel and other costs relating to your treatment, go to [citizensadvice.org.uk](http://citizensadvice.org.uk) or [macmillan.org.uk](http://macmillan.org.uk) and search ‘help with health costs’.
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 that is helping us find cures, better tests and kinder treatments for everyone living with blood cancer.

Survival rates for people diagnosed with CML have been transformed with the development of tyrosine kinase inhibitors (TKIs) — drugs that block the faulty protein at the heart of CML and stop the disease getting worse. But TKIs currently don’t provide a cure, and some people struggle with the side effects of their treatment, become resistant to it, or find that their CML has come back.

Our research is looking at new ways to wipe out CML completely, offering the chance of a real cure. We also want to find ways to improve the quality of life of people with CML who are taking these drugs and reduce the possible side effects.
Improving the lives of people living with CML

Until recently, TKI treatment for CML was life-long, with some people experiencing side effects that seriously affected their quality of life.

The DESTINY trial, led by our researchers in Liverpool, is testing whether people who are responding really well to TKIs and have been taking the drugs for a number of years can remain well either on a lower dose or without treatment altogether. The results of this study so far are really encouraging, and suggest that under careful monitoring, many people who are doing well on their TKI may be able to reduce or even stop taking this medication.

But this study is not complete and reducing or stopping treatment will not be right for everyone, so it’s really important that people with CML talk to their doctor before considering any change to their medication.

We’ve also been looking at ways to improve treatments for people with more advanced (blast-phase) CML. People who progress to this phase have often already tried several TKIs in the chronic or accelerated phases that haven’t controlled their CML, so have fewer treatment options at this point.

MATCHPOINT, a clinical trial that’s based in Glasgow, but is part of our pioneering Trials Acceleration Programme so is open to people with CML across the UK, is testing whether it’s safe to combine ponatinib (a relatively new TKI for people who become resistant to other forms of these drugs), with chemotherapy. If the treatment combination is found to be safe, researchers hope this approach could be used in future trials to improve the outlook for people with CML who are in the blast phase.

Finding a cure for CML

Despite their success, TKIs aren’t effective at wiping out all CML cells, which is why many people still have to take these drugs for life. Our work in Glasgow is focusing on the ‘master’ CML cells – so-called ‘cancer stem cells’ – which are usually left behind following TKI treatment.

The team is studying two key proteins that these CML stem cells need to survive. The project aims to understand how these proteins work together, so researchers can design better ways to treat and eventually wipe out CML.

Meanwhile, another team in Glasgow is looking at ways to predict which people with CML will do well on TKIs, and which will require different treatments. The team is also focusing on networks of proteins in CML stem cells that work together to help cancer cells survive, and how we might be able to target them with new drugs. This research has the potential to cure more people with CML and create new treatments for those who are resistant to TKIs or have the advanced or blast phase disease.

For more information about Bloodwise-funded research and clinical trials, go to bloodwise.org.uk/research
There are lots of organisations out there that offer information and support to people affected by CML.

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

- 0808 2080 888  
- support@bloodwise.org.uk  
- bloodwise.org.uk

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

- 0808 808 0000  
- macmillan.org.uk

**Cancer Research UK**
Offers information about different conditions, current research and practical support.

- 0808 800 4040  
- cancerresearchuk.org

**Leukaemia Care**
Offers patient information, a 24-hour care line and support groups for people affected by leukaemia and other types of blood cancer.

- 08088 010 444  
- care@leukaemiacare.org.uk  
- leukaemiacare.org.uk
CML Support
An online patient support community for people with CML, their families and supporters.
› cmlsupport.org.uk

African Caribbean Leukaemia Trust (ACLT)
Aims to increase the number of black, mixed race and ethnic minority people on UK stem cell registries by raising awareness and running donor recruitment drives.
› 020 3757 7700  › info@aclt.org  › aclt.org

Anthony Nolan
Runs the UK’s largest blood stem cell and bone marrow register, matching donors to patients with leukaemia and other blood-related disorders who need a stem cell transplant.
› 0303 303 0303  › anthonynolan.org

Maggie’s
Has 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
Runs nine hospices throughout the UK and offers end-of-life support to terminally-ill patients in their own homes, free of charge.
› 0800 090 2309  › mariecurie.org.uk

MedicAlert
Offers personalised jewellery that provides vital medical information to emergency professionals.
› 01908 95104  › info@medicalert.org.uk  › medicalert.org.uk

Cancer on Board
Supplies ‘cancer on board’ badges to people with cancer, to help make journeys via public transport a little more bearable.
› canceronboard.org

Shine Cancer Support
Provides support to adults in their 20s, 30s and 40s who have experience of a cancer diagnosis.
› shinecancersupport.org  › hi@shinecancersupport.org

Teenage Cancer Trust
Offers a range of information, advice and practical support for young people who have been diagnosed with cancer.
› 020 7612 0370  › hello@teenagecancertrust.org  › teenagecancertrust.org

Tenovus (Wales)
Provides an information service on all aspects of cancer, plus practical and emotional support for people with cancer and their families living in Wales.
› 0808 808 1010  › tenovuscancercare.org.uk
Financial advice

Citizens Advice Bureau (CAB)
Offers advice on benefits and help with filling out benefits forms.
› 03444 111 444 (England), 0344 477 2020 (Wales), 0808 800 9060 (Scotland)
› in Northern Ireland, contact your local Citizens Advice
› citizensadvice.org.uk

Department for Work & Pensions (DWP)
Responsible for social security benefits. Provides information and advice about financial support, rights and employment.
› gov.uk/government/organisations/department-for-work-pensions

Travel insurance

Macmillan Cancer Support
Provides information about what to consider when looking for travel insurance, along with recommendations from the Macmillan online community.
› 0808 808 0000 › macmillan.org.uk

British Insurance Broker's Association (BIBA)
Offers advice on finding an appropriate BIBA-registered insurance broker.
› 0370 950 1790 › enquiries@biba.org.uk › biba.org.uk
Questions to ask

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 people 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 they show?
› Where will I have them done?
› Are there any risks associated with the tests?
› Will any of the tests be painful?
› Do I need to know anything about preparing for them – for example, not eating beforehand?
› How long will it take to get the results?
› Who will explain them?
› What is my exact diagnosis and what stage is the CML?
Treatment
› Will I need to have treatment? If so, when?
› What does the treatment do?
› Is there a choice of treatments?
› Is there a clinical trial that I could join?
› What’s likely to happen if I decide not to have the treatment my healthcare team has recommended?
› Who do I contact if I feel unwell?
› Who can I contact if I have any questions?

My main treatment
› What type of treatment will I have?
› Will I have to stay in hospital?
› If not, how often will I need to go to hospital as an outpatient?
› What course of drugs (regimen) will I be given? Will I be given it by mouth, injection or drip (into a vein)?
› Will my treatment be continuous or in blocks of treatment (with breaks in between)?
› How long will my treatment last?
› What side effects could I get from my treatment?
› Can side effects be treated or prevented?
› Will they affect me all the time or only while I’m taking certain drugs?
› What are the fertility risks with treatments and what options are available to address the risks?
› What effect is the treatment likely to have on my daily life?
› Will I be able to carry on working or studying?
› Will I need to take special precautions – for example, against infection?
› Will I need to change my meal times or plan my drugs around these?
Stem cell transplant

- 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?
Cancer can sometimes feel like it has its own language. Here are some of the most common words you might hear:

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

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

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

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

**Bone marrow**
The spongy material inside your long bones that produces blood cells.

**Chemotherapy**
Treatment using anti-cancer drugs; it can be a single drug or a combination of drugs. Chemotherapy is used to kill cancer cells or stop them growing and dividing. Although it’s aimed at the cancer cells, the treatment also affects normal cells that divide quickly, like those in the hair and gut. This is why some people lose their hair when they have high-dose chemotherapy.

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

**Clinical trial**
A planned medical research study involving patients. They can be small trials involving only a few patients or large national trials. Clinical trials are always aimed at improving treatments and reducing any side effects they cause. You need to sign a consent form to take part in a clinical trial, so you’ll always be aware if your treatment is part of a trial.

**Cytogenetics**
The study of the structure of chromosomes. Cytogenetic tests are carried out on samples of blood and bone marrow taken from people with leukaemia. They aim to find any changes that could be linked to the disease. They can also help doctors to decide on the best treatment to recommend.

**Fatigue**
Fatigue is a feeling of extreme tiredness, which doesn’t go away after rest or sleep. It may be caused by the CML itself in the beginning, but once you’ve achieved a haematological, cytogenetic or molecular response, it’s likely to be a side effect of treatment. It’s one of the most common problems that people with cancer have. If you experience fatigue, your healthcare team should be able to offer guidance on helpful ways to manage it.
Granulocyte
A general term for white blood cells that contain granules (tiny, grain-like particles). Neutrophils, eosinophils and basophils are all types of granulocyte. It’s these cells that don’t develop properly in people with CML.

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

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

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

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

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

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

Spleen
A fist-sized organ that filters the blood. It sits under your ribs on the left-hand side of your body, next to your stomach and behind your ribs. The spleen has three main jobs: to control the level of blood cells in your body, to remove old red blood cells and to help protect your body from infection.

Stem cells
Cells that develop into other cell types. Stem cells act as a repair system for your body and create a new supply of cells to replace the ones that die. Blood stem cells are found in the bone marrow.

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

We’re Bloodwise, the UK’s specialist blood cancer charity.

We’re here to make things clear
We send our patient information for free to anyone who needs it. Whether you have blood cancer yourself or care for someone with blood cancer, we have a range of booklets, fact sheets and online information to support you and help you make sense of it all.

We’re here to listen, support and connect
Our Support Services Team are just a call or email away. Call us on 0808 2080 888 (Mon, Tue, Thu, Fri: 10am–4pm, Wed: 10am–1pm) email support@bloodwise.org.uk or visit us at bloodwise.org.uk to join our online community.

We’re here to beat blood cancer
We fund the research that gets results: research that tells us more about blood cancer and improves the lives of those with blood cancer. We’ve invested over £500 million in world-class research since 1960 – but we won’t stop until every single person with blood cancer can live their life to the full.

Getting involved

Help us beat blood cancer.

We have lots of exciting opportunities for you to get involved and help us to beat blood cancer.

Give a gift
Whether it’s a regular or one off donation, every gift – big or small – will make a difference.

Take on a challenge
Every stride, stroke and pedal gets us closer to beating blood cancer. Whatever the event, make every mile matter.

Beat blood cancer locally
Join one of our regional branches and fundraising groups to discover how you can make a difference.

Join us online
Every like, share, tweet and mention could mean someone finds out about our services and raises awareness of blood cancer.
facebook.com/bloodwise.uk
twitter.com/bloodwise.uk

Partner with us
We’re always looking for companies who share our vision and energy.

Go to bloodwise.org.uk for more information.
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 produce better information for other people with blood cancer and those close to them.

Email us at information@bloodwise.org.uk with your feedback.

More information

We offer patient information on many blood cancer types and topics, online and in free printed booklets.

They cover everything from symptoms and diagnosis through to treatment and living with your condition.

Information booklets

Booklets which are available free of charge:

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<tr>
<th>Reference</th>
<th>Description</th>
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<tr>
<td>Leukaemia</td>
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<td>BWSEVEN</td>
<td>The seven steps: blood stem cell and bone marrow transplants</td>
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<tr>
<td>BWCT</td>
<td>Your guide to clinical trials</td>
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<tr>
<td>BWDAPN</td>
<td>Eating well with neutropenia</td>
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<tr>
<td>BWMYDIARY</td>
<td>Diary for anyone affected by blood cancer</td>
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For our patient information, go to bloodwise.org.uk/info-support
Fact sheets

We have the following fact sheets available online at bloodwise.org.uk/information

- Blood transfusions
- Chronic myelomonocytic leukaemia (CMML)
- Hairy cell leukaemia (HCL)
- Large granular lymphocytic leukaemia (LGLL)
- Managing sickness and vomiting
- Monoclonal gammopathy of undetermined significance (MGUS)
- Mucositis
- Treatment decisions
- Understanding infection
- Waldenström macroglobulinaemia (WM)
- Watch and wait – various fact sheets
- What to expect from your appointments

Please donate today to help Bloodwise beat blood cancer

- Go to bloodwise.org/donate
- Call us on 0808 169 5155
- Or complete and send this form to us freepost using the address:
  FREEPOST PLUS RTSU-XAYE-X2YK, Bloodwise, 111 George St, Edinburgh, EH2 4JN

First name __________________________________________ Surname __________________________________________

Address __________________________________________

Postcode ______________________________ Email ______________________________ Phone ______________________________

As a supporter, you’re at the heart of everything we do. We’d love to keep you updated about our exciting work and the ways you can help, including campaigns and events that you might be interested in. We promise to respect your privacy and we will never sell or swap your details.

I am happy for Bloodwise to contact me by: ☐ Email ☐ Phone ☐ SMS
☐ Please don’t contact me by post

You can change how we communicate with you at any time.
Contact us on 0808 169 5155 or email hello@bloodwise.org.uk

I’d like to donate ☐ £10 ☐ £25 ☐ £50 ☐ Other
☐ I enclose a cheque/CAF voucher made payable to Bloodwise

OR please debit my ☐ Visa ☐ Maestro ☐ MasterCard ☐ CAF card

Cardholder’s name __________________________________________ (Maestro only)

Card number __________________________________________ Expiry date _______ Issue no _______

Start date _______ Expiry date _______ Issue no _______

Make your donation worth an extra 25p for every £1 at no extra cost to you!
I’d like Bloodwise to claim Gift Aid on this donation, any donations I make in the future and any donations I’ve made in the past four years.

☐ *By ticking this box I confirm that I’m a UK taxpayer and understand that if I pay less Income Tax and / or Capital Gains Tax than the amount of Gift Aid claimed on all my donations in that tax year, it’s my responsibility to pay any difference.

*Today’s date __________________________ If you stop paying tax, change your name or address, or if you have any further questions about Gift Aid, please contact our Supporter Care team on 0808 169 5155.

*Information required for Gift Aid declaration to be valid.
More information from Bloodwise

You can order more information by:

› visiting bloodwise.org.uk/information
› emailing information@bloodwise.org.uk
› calling 020 7504 2200
› or completing and sending this form to us freepost using the address:
   FREEPOST PLUS RTSU-XAYE-X2YK, Bloodwise, 111 George St, Edinburgh, EH2 4JN

All of our information is free to people affected by blood cancer, but if you would like to include a donation with your order, please fill in the donation form over the page.

Please send me some information

Title ................................ First name ......................................... Surname ...........................................................
Address ..............................................................................................................................................................
Postcode ........................................... Email ........................................... Phone ........................................................

Please write the reference codes of the booklets that you would like to be sent to you (free of charge) in the spaces provided below:

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Keep in touch

We'd love to keep you updated about our exciting work and the ways you can help, including campaigns and events that you might be interested in. We promise to respect your privacy and we will never sell or swap your details.

I am happy for Bloodwise to contact me by:    Email    Phone    SMS

☐ Please don't contact me by post

You can change how we communicate with you at any time.
Contact us on 0808 169 5155 or email hello@bloodwise.org.uk

Bloodwise. Registered charity 216032 (England & Wales) SC037529 (Scotland) Ref PINFO