

# Bloodwise

For anyone  
affected by  
blood cancer

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

## Chronic lymphocytic leukaemia (CLL)

**PATIENT  
INFORMATION**

“

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

”

A team of people helped produce this booklet. We'd like to thank members of our Medical Advisory Panel, Dr Samir Agrawal and Dr Claire Dearden, 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 Lucy Whiteman.

Bloodwise staff revised the text to make it easy to read, and a non-medical panel, including patients and relevant societies, checked it for understanding. We'd like to acknowledge the help and support of the CLL Support Association in the development of this booklet.

A list of references used in this booklet is available on request. Please email us at [information@bloodwise.org.uk](mailto: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 (July 2017).

Date of next review: July 2020.

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

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 will help you answer as many of them as possible.

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

This booklet is one of many we offer – you can find a list of our other booklets on page 79. For the very latest information, visit our website, [bloodwise.org.uk](http://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 a sign that we think the websites and other organisations mentioned will also give you good information and support.



Our website



Another of our booklets



Another page of the booklet



Another website



Another organisation

# Contents

- 5 Introduction
- 6 CLL at a glance
- 9 Blood, bone marrow and your immune and lymphatic systems
- 17 What causes CLL?
- 21 Symptoms
- 25 Diagnosis
- 41 Treatment
- 53 The outlook
- 55 Everyday life and CLL
- 63 Research and new developments
- 67 Places you can get help and support
- 71 Questions to ask
- 74 Glossary
- 76 About us
- 77 Getting involved
- 78 Your feedback
- 79 Information booklets
- 80 Fact sheets
- 83 My details

## Introduction

This is a booklet for people with CLL, and for people who know someone with CLL.

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 this time.

We hope this booklet will help you to understand your condition and feel in control. We'll try to answer as many of the questions you might have along the way – from symptoms through to tests, treatment and living with CLL, and where you can get support.

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

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**Everyone is different, so listening to the advice of your specialist and your healthcare team is really important.**

# Chronic lymphocytic leukaemia at a glance

It's possible to have CLL and have a good quality of life – many people are able to manage their condition with the appropriate treatment.

## What is CLL?

If you've got CLL, your body produces too many of a certain type of white blood cell called lymphocytes which don't work properly. CLL is a chronic condition, which means it usually develops very slowly.

## Who gets CLL?

CLL is more common in older people (over 70). Children don't get CLL. It's rare in young adults, but becomes more common with age.

## What's the outlook?

CLL is a condition you can usually live with and keep under control with treatment. Because people with CLL often don't feel unwell at first, it's often found when you're having a routine blood test or a blood test for something else. You might hear your doctor call this an 'incidental finding' of CLL.

Although CLL isn't a curable condition in most cases, many people with the disease will have a good quality of life.

## What are the treatments for CLL?

You might not need treatment at first – especially if you don't have any symptoms. There's no evidence that being treated early on, when you have no symptoms, has any benefits.

If you feel well, your team might just see you for regular check-ups or, in certain situations, your condition can be monitored without you needing to come to hospital – this is known as 'watch and wait'. Your specialist will tell you when they think you might need to start treatment and discuss your options with you.

Active treatment for CLL can involve medication (either chemotherapy or non-chemotherapy tablets) and antibodies. Some people may have a stem cell transplant, but this is rare.

A very small number of people might need more intensive treatment earlier on if their CLL is progressing more quickly, or if they were diagnosed at a late stage.

## Can CLL lead to any other conditions?

In a small number of people (about 5-10%) CLL can transform into a faster growing disease, a type of non-Hodgkin lymphoma called Richter's syndrome. If this happens, your team will explain Richter's syndrome to you in more detail.

## Small lymphocytic lymphoma (SLL)

SLL is a type of blood cancer that affects the same type of blood cell (lymphocytes) that CLL affects. It's basically the same disease as CLL, but the difference is that it affects your body in a different way.

- › If most of the cancer cells are found in your blood and bone marrow this is CLL.
- › If the cancer cells are mostly found in your lymph nodes, this is SLL.

CLL and SLL are treated in the same way.

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Knowing the basics about blood, bone marrow, your immune system and lymphatic system is useful.

## Blood, bone marrow and your immune and lymphatic systems

It's a good idea to know a bit about blood, bone marrow, your immune system and your lymphatic system, as your healthcare team will probably 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. This is the function that's most affected by CLL.

#### Communication system

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

#### Repair system

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

## Blood cells

Blood contains three types of cells: red blood cells, white blood cells and platelets.

### 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 produce energy from your food.

### White blood cells (leukocytes)

These fight and prevent infection. There are five different types of white blood cell: lymphocytes, neutrophils, monocytes, eosinophils, and basophils.

### Platelets (thrombocytes)

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

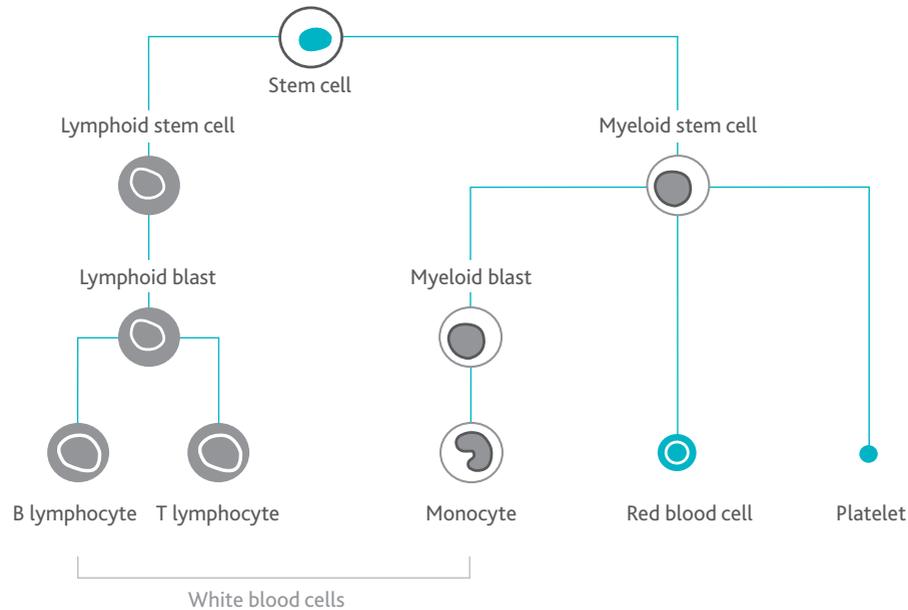
How many of each type of blood cell should you have?

Everyone has slightly different numbers of each type of blood cell. If you're healthy, the amount you have of each normally stays the same, with slight changes up and down over time. Here's a table which shows how many of each type a healthy person has.

	WHITE BLOOD CELLS	RED BLOOD CELLS	HAEMO-GLOBIN	NEUTRO-PHIL	PLATELETS
	( $10^9/l$ )	( $10^{12}/l$ )	(g/dl)	( $10^9/l$ )	( $10^9/l$ )
ADULT MALE	4 to 11	4.5 to 6.5	13 to 18	2 to 7.5	150 to 440
ADULT FEMALE	4 to 11	3.8 to 5	11.5 to 16.5	2 to 7.5	150 to 440



You can find out more about normal blood and bone marrow on our website [bloodwise.org.uk](http://bloodwise.org.uk)



## Bone marrow and how blood cells are made

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. Lymphoid stem cells go on to form lymphocytes (a type of white blood cell) and myeloid stem cells go on to form red blood cells, platelets and other types of white blood cells.

A lot of blood cells are made in the bone marrow every second because your body needs them.

If everything's 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.

If you have CLL, your body produces too many lymphocytes that don't work properly. These cells won't fight infection as well as normal white blood cells do, and they multiply in an uncontrolled way and stop normal blood cells from working properly. This is what causes most of the symptoms that people with CLL get.

## Your immune system

Your immune system is a network of cells, tissues and organs which protect your body against infection. It's able to react quickly to infections it's seen before, and lymphocytes play an important role in this. There are lots of different kinds of lymphocyte, but the important ones to know are T cells and B cells.

CLL affects B cells, which normally produce antibodies to fight infections. Because of this, CLL often affects your body's defences. This means you might get:

### Infections

They could be more severe than usual and last longer. Your healthcare team can let you know ways to reduce your risk of infections.

### Auto-immune conditions

Normally your immune system knows your own cells and won't harm them. However, if you've got CLL, your immune system can get confused and damage some of your tissues. Anaemia, low platelet count and rheumatoid arthritis are all examples of auto-immune conditions.

### Shingles

Shingles is an infection of a nerve and the skin around it. It can affect you if you've had chickenpox, even if you had it a long time ago.

You're more likely to get shingles if your immune system isn't working well – for example, if you have CLL.

There is a vaccine available for shingles but if you have CLL you should not have this vaccine because it's a 'live vaccine' – see page 57 for more information.

For more information on how to spot and treat shingles see [page 58](#).

You can find more information about how to manage infections on our website [bloodwise.org.uk](http://bloodwise.org.uk)



## Your lymphatic system

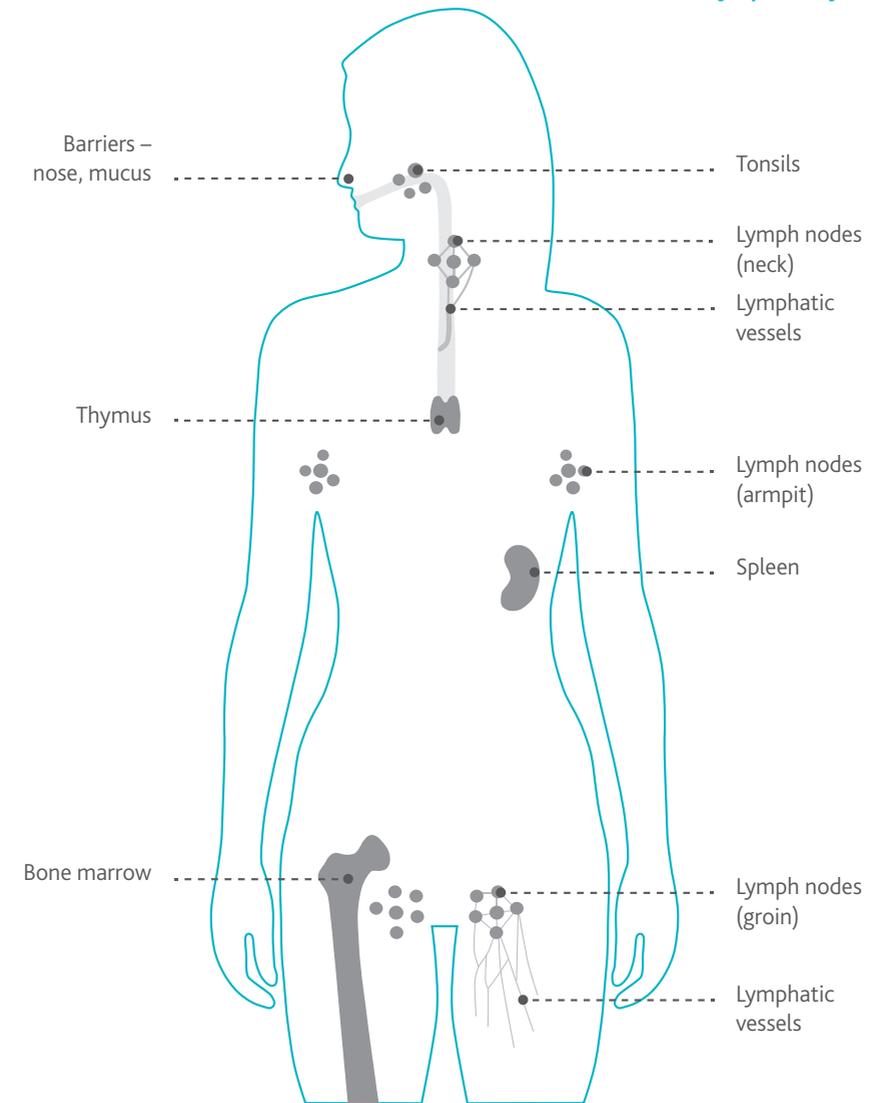
A network of thin tubes called lymph vessels runs around your body. This is your lymphatic system. The vessels collect fluid called lymph and return it to your blood.

Along the lymph vessels are small lumps of tissue called lymph nodes or lymph glands. There are many of these in your body. If you get an infection when you're healthy, these can swell and become tender – people usually call them 'swollen glands'.

Although CLL mainly affects the bone marrow, it often causes swelling in lymph nodes because abnormal lymphocytes build up in them. The ones in your neck, armpits and groin are often affected but, more rarely, those in your gut lining can be too. CLL can also cause swelling in your spleen, the most important organ in your immune system, meaning that it can't work properly.

If CLL is affecting your lymphoid tissues a lot, it may be called small lymphocytic lymphoma (SLL), which is a type of CLL. Your treatment will still be the same though and your condition won't develop any differently.

## Your lymphatic system



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You're not alone:  
CLL is the most  
common type  
of leukaemia in  
adults.

## What causes CLL?

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

With CLL, there are no clear reasons other than things like age and gender. Here's what we do know:

- › CLL is the most common type of leukaemia in adults.
- › Of all people diagnosed with leukaemia, around a third are diagnosed with CLL.
- › About one person in 200 will develop CLL at some point in their life.

There have been some suggestions that exposure to radiation or certain chemicals may increase your risk of developing CLL, but this link hasn't been proven.



*When I was diagnosed, 'why me' was one of the first things that went through my head. Then I wanted to know what caused it, but with CLL it's not something you can point to.*



### Age

People who get CLL are usually in their 70s or older. It's very rare for people under 40 to get CLL, but about 10% are under 55 when diagnosed. Children don't get CLL.

### Gender

Men are about twice as likely as women to get it – we don't know why.

### Family history

A parent, child, brother or sister of someone with CLL has a slightly higher chance than others of developing the condition, but the risk for any individual is still very low.

Because of this, experts don't recommend testing family members unless they're being considered as donors for a stem cell transplant – which is rare for people with CLL.

### Ethnicity

CLL is more common in white people – we don't know why.

### Monoclonal B-cell lymphocytosis

There's a condition called monoclonal B-cell lymphocytosis (MBL) where people have very low levels of CLL-like cells in their blood but no symptoms.

Not all people with MBL go on to get CLL. However, we think that most people diagnosed with CLL previously had MBL, possibly for many years.

Experts don't recommend testing family members for MBL unless they're being considered as donors for a stem cell transplant.

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If you get any new symptoms after you've been diagnosed, or if you feel unwell, contact your hospital as soon as possible.

## Symptoms

There are some symptoms you might have before you're diagnosed and some symptoms you might have afterwards. Not everyone will have the same symptoms.

### Before you're diagnosed

It's likely that you won't have any symptoms at all before or when you're diagnosed. That's why so many people with CLL are diagnosed after routine blood tests or when a doctor finds swollen lymph glands at a check-up.

However, you may have noticed the following symptoms before you were diagnosed with CLL:

- › extreme tiredness (fatigue) and/or weakness
- › swollen lymph nodes (glands)
- › drenching night sweats
- › fast and significant weight loss without trying
- › high temperature (fever) without any other signs of infection
- › repeated infections (such as colds and flu).

Some people have one or two of the symptoms; others may have all of them.

## After you're diagnosed

If you get any new symptoms after you've been diagnosed, or if you feel unwell, contact your hospital straight away. Your hospital team will tell you whether you need to see them, or if you can see your GP instead.

Symptoms of CLL usually develop slowly and you might not be sure of what to look out for. Here are the main ones:

- › getting tired and breathless more quickly
- › drenching night sweats
- › losing weight quickly, when you've not been dieting
- › a high temperature (fever) without any other signs of infection
- › swollen lymph nodes (swellings in your neck, armpits, groin, or under your collarbone) – if you had swollen lymph nodes before you were diagnosed, see your doctor if they increase in size or you notice more of them
- › feeling full after only eating small amounts, or discomfort or pain under your ribs on your left side – this can mean your spleen is enlarged.

## Infections

Because of your CLL, you're more likely to get infections. The most common signs of infection are:

- › raised temperature
- › cough or sore throat
- › confusion or agitated behaviour, especially if it comes on suddenly – this is more likely in older people
- › rapidly feeling more poorly
- › fast heartbeat and breathing
- › difficulty in passing urine or producing little or no urine
- › pain which comes on quickly and gets worse.

If you're receiving treatment, your doctor will probably suggest that you contact your hospital team if you have signs of an infection. If you're not receiving treatment (for example if you're on 'watch and wait' – see page 46), you may be able to see your GP instead. Speak to your specialist about spotting infections and who to call.

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It's important to know and understand your diagnosis. You could ask your team to write it in this booklet, so you have it to hand.

## Diagnosis

You'll have a set of tests to confirm whether you have CLL or not. If you're diagnosed with CLL, your healthcare team at the hospital may then do further tests to 'stage' your cancer (see how much it's developed). At any time, you can ask your healthcare team to tell you why you're having a certain test and what the results mean.

### Tests to diagnose CLL

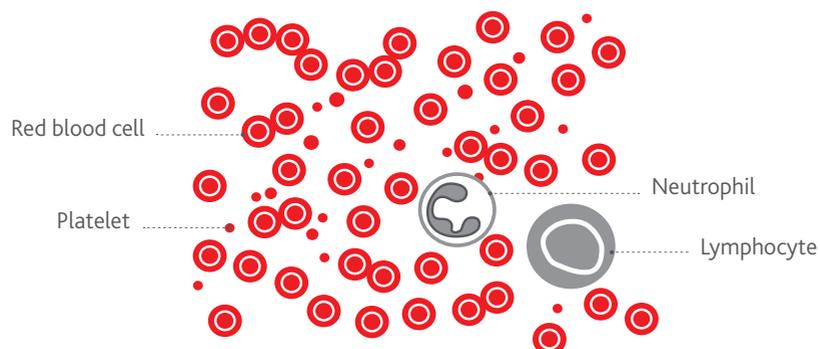
Here's an overview of the tests you'll have to confirm whether you have CLL.

#### Full blood count

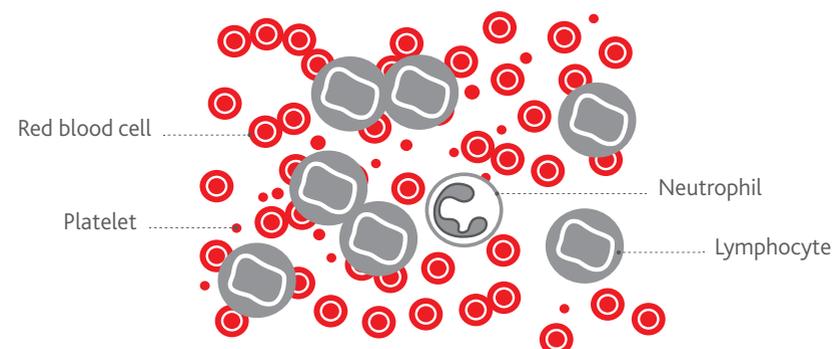
A full blood count (FBC) measures the number of each type of cell in the blood: red cells, white cells and platelets. You might be sent for this test by your GP as part of a routine check-up. Other people might have one when they're in hospital for something else.

If your FBC shows that you might have CLL, you'll need to go to hospital for more tests. If you're diagnosed with CLL, you'll have regular FBCs to monitor your condition.

Normal blood film



Abnormal blood film



### Immunophenotyping

On its own, an FBC doesn't confirm a CLL diagnosis. You'll need to have more specialist tests such as immunophenotyping to do this. Immunophenotyping is a technique used to find out if you have abnormal CLL cells in your blood and if so, how many there are. It's very sensitive – even if there's only a small number of CLL cells there, it can still see them.

### Peripheral blood film

You might also have a peripheral blood film test, where your blood cells are looked at under a microscope. Because CLL cells look different to normal white blood cells, this test can help to identify any of these abnormal cells in your blood.

If you have CLL, there will be more lymphocytes in the blood film than there should be.

### Lymph node biopsy

Most people with CLL won't need a lymph node biopsy to have a diagnosis, because the condition is usually diagnosed in the blood. You might need a lymph node biopsy to make a diagnosis if you've got swollen lymph nodes and your FBC is normal. This could mean you have what's sometimes referred to as small lymphocytic lymphoma or SLL. See page 7 for more information on SLL.

Or much more rarely it might be due to another condition called Richter's syndrome (a different type of lymphoma). A small number of people with CLL go on to develop this condition, where there's usually a more rapid growth of lymph nodes in a single site.

Another reason you might have a lymph node biopsy is to rule out other lymphoid diseases such as mantle cell lymphoma (MCL).

A lymph node biopsy is a minor surgical procedure where a small sample is taken from a lymph node then studied under a microscope to check for signs of disease. You'll need a small number of stitches but you can normally go home on the same day and have them removed around a week later. If the node is easy to reach, the biopsy can be done under local anaesthetic.

Sometimes the whole lymph node is removed – this is called an excision biopsy. This procedure may be helpful to improve the accuracy of a diagnosis.



For more information about Richter's syndrome, go to [bloodwise.org.uk/patient-information](http://bloodwise.org.uk/patient-information)

## What is staging?

Staging describes the extent or severity of a person's cancer. Staging for solid cancers, like breast or lung cancer, is based on the size of the original tumour and on how much it spreads from the original site of the tumour. For conditions like leukaemia this isn't the case, because the leukaemia cells are spread throughout the blood and bone marrow.

There are two different ways of staging CLL. They both look at the number of CLL cells in your blood, the number of affected sites of lymphoid tissue and how much your condition has affected the production of normal blood cells.

The system most used in Europe is called the Binet system (in America there is a different system called the Rai system). The Binet system has three stages (A, B and C) with C being the most advanced stage. The Rai system has five stages (0 to IV) with IV being the most advanced stage. Rai stage 0 patients have just a raised lymphocyte count – this is similar to people with MBL.



19

See [page 19](#) for more information about MBL.



*When I was diagnosed I asked my consultant to write it down and I'm really glad I did. I could then go away and do my own research and also tell people accurate information about my condition.*



## Tests after diagnosis

It's important that you know and understand your diagnosis. It might be a good idea to get your consultant to write it down so you can use it if you're looking for more information or support, or if you need to tell other people about it.

Here's an overview of further tests you might have to help your healthcare team stage your cancer and decide, with you, what type of treatment would be best and when.

### Bone marrow aspirate (biopsy)

This is a procedure to check for any abnormalities in the bone marrow. A small amount of bone marrow is taken from the hip bone using a needle. You don't need to stay overnight in hospital for this; you can have it as an

outpatient using local anaesthetic or mild sedation. It's usually quite quick but will be uncomfortable while the sample is being taken from the marrow – you can take painkillers if you need to. Your doctors will then look at the bone marrow sample under a microscope to look for any disease which might be in it.

You may not need to have a bone marrow sample taken if you're not starting treatment in the near future. You'll usually have a sample taken before you start treatment, as this will be helpful later to show how well you've responded to it. You may also need a bone marrow biopsy if you have very low levels of normal blood cells (cytopenia) when you're diagnosed.



#### Bone marrow trephine

You'll usually have a trephine biopsy at the same time. This is where a 'core' of bone marrow from the hip bone is taken, under local anaesthetic or mild sedation. This provides information about the structure of your bone marrow and the number and distribution of the different blood cell types – and cancer cells, if present.

#### Lymphocyte doubling time

This tests the length of time taken for the number of lymphocytes in your blood to double. It's looked at with every full blood count and helps to show how quickly your CLL is progressing.

#### X-ray

X-rays provide good images of dense tissues, such as bone. For people with CLL they're mainly used to check for chest infections.

#### CT or CAT scan

You won't usually have a CT scan if you're not going to start treatment straight away. A CT scan is a type of X-ray that can be used to check if any lymph nodes are affected and if any lymphatic organs, like the spleen, are swollen.

The procedure won't cause any pain. You'll lie on a table that moves into a cylindrical tunnel while the pictures are taken. Your body is never completely enclosed and you'll be able to talk to the person who takes and assesses the images (the radiographer) all the time. You may need to have a dye injected into one of your veins, to help get a better image.

#### Magnetic resonance imaging (MRI) scan

People with CLL won't normally have an MRI scan. If you do have one, it's usually to look at certain parts of the body such as the central nervous system.

This scan shows up soft tissues (non-bony parts) and uses radio waves rather than X-rays. You'll be asked to lie on a table which will move you through the scanner. It isn't painful but it can take up to an hour to complete and some people find it claustrophobic. As with a CT scan, you might need to have a dye injected into one of your veins to get a better image.



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



**Fluorodeoxyglucose positron emission tomography (FDG PET or CT-PET scan)**  
CLL patients rarely have this scan, unless your doctors are assessing whether your CLL might have developed into Richter's syndrome.

It's similar to a CT scan, but you're injected with a radioactive tracer. The levels of radiation used are very small and won't harm you or anyone nearby.

**Liver function tests**  
This is a blood test to check if your liver is working normally. It's very important to test this if you need chemotherapy, as many of the drugs are broken down in the liver. If your liver isn't working normally, it may be necessary to adjust your doses.

**Urea and electrolytes**  
This is a blood test to check how well your kidneys are working. The results will help your doctors calculate the doses of drugs you'll need. It'll also show any damage that may have been caused either by the cancer or your treatment and can show if you're dehydrated. You'll usually have your kidneys checked every time you have an appointment at the hospital.

### Further tests

There are several further tests which some people might have, known as prognostic markers or prognostic tests. They might not be done at all hospitals, and in some cases you might only have them if you're taking part in a clinical trial. They will help your doctors find out more about your prognosis (outlook) but aren't used to decide whether you need treatment or not. These tests include:

#### Cytogenetics

All kinds of cancer, including blood cancer, involve changes in genes in the affected cells. This isn't the same thing as a faulty gene that you inherit from a family member which causes cancer.

Information about these gene changes may help doctors to decide which treatment you'll have. The study of these changes is called cytogenetics or molecular genetics. Cytogenetic tests (sometimes called FISH tests) are usually done on cells from the blood or from the bone marrow before you start any treatment.

This is because there's one particular abnormal change (called 17p deletion, TP53 deletion or mutation) which means you'll be less likely to respond

to the chemotherapy drugs used to treat CLL. Less than 10% of people will have this abnormality at the time when they need treatment. However if your CLL cells do have 17p deletion, your consultant will talk to you about different treatment options.

Sometimes your cytogenetic results might look normal. This doesn't mean there aren't any abnormalities – if you have CLL there will usually be some there – it just means they're too small to detect, or scientists simply haven't discovered certain abnormalities yet.

One particular type of cytogenetics test is for IgHV gene status. If you have CLL cells with unmutated IgHV genes your condition may progress more quickly. This test is only done once, as the result won't change.

#### Beta-2 microglobulin (B2M) test

This measures the level of a particular protein called Beta-2 microglobulin or B2M in your body. Your healthcare team may use it to find out more about the stage of your condition and your prognosis (outlook), or to monitor the progress of your treatment.



For more information about Richter's syndrome, go to our website [bloodwise.org.uk/patient-information](http://bloodwise.org.uk/patient-information)

### Immunophenotyping (flow cytometry)

This is a way of looking at the pattern of proteins on your cells.

Samples from your bone marrow or blood cells are taken from a biopsy or blood test. In the lab, these are combined with a particular type of antibody (a protein made by your white blood cells to fight infection), which will stick to the surface of abnormal cells, but not to a normal cell.

As the cells pass through a machine, the results are plotted on a graph.

Your samples may be checked for the following markers:

- › Zeta-associated protein 70 (ZAP-70)
- › CD38 antigen

These tests can help give a clearer idea of your outlook.

### Virology

Although this isn't a prognostic test, it's important if you're about to have treatment, as treatment can reactivate the hepatitis B virus. This is only the case if you've had it in the past but it's now not active (dormant) in your body. Your consultant will explain more about this before you start your treatment.

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You can find more information on tests and scans for CLL on our website [bloodwise.org.uk](http://bloodwise.org.uk)



A website supported by the Department of Health has more information on tests. Go to [labtestsonline.org.uk](http://labtestsonline.org.uk)

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### Your healthcare team

If you're diagnosed with CLL, your hospital should give you the names and contact details of your 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 in the hospital.

#### Your consultant

Most people with a blood cancer are treated by a haematologist – a doctor who specialises in treating patients 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

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

### Your multidisciplinary team

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

### Talking to other people

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

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

### Your other healthcare professionals

It's 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 clinical nurse specialist know how much information you'd like, and in what form. You can always ask for more information later.
- › Write down any questions you have and keep them handy for when you see your consultant or key worker. If they can't answer your questions, they'll be able to tell you who to speak to.
- › You might prefer to ask your clinical nurse specialist questions rather than your consultant, but do whatever works for you.
- › Most people say they find it useful taking someone with them to consultations. If you'd find it helpful, you could ask them to take notes while you listen. You can choose who to take – it doesn't have to be a family member.
- › If you're staying in hospital it might be harder to have someone with you when you speak to your consultant. It might be useful to ask in advance what time the consultant is likely to speak to you, so you can try to arrange for someone to be with you at that time.
- › Some people find that joining a patient support group is helpful. It may be easier to talk to someone outside of your family about your situation and being able to share similar experiences might also help you.



You can read about the experiences of other people who are going through – or have been through – the same thing on our website [bloodwise.org.uk](http://bloodwise.org.uk)



You can find a list of questions you might want to ask on [page 71](#)

## Telling people

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

You might find it easier to ask a trusted family member or friend to be your 'information person' and ask them to keep people updated on your behalf. Another idea is setting up a blog or Facebook page, so you or different people can post information on it that everyone can read.

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



*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'.*



You'll find more advice and support on telling people about blood cancer on our website [bloodwise.org.uk](http://bloodwise.org.uk)

## Telling your GP

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

## Cancer and work

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

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There's more information about cancer and how it can affect your work or study on [page 60](#).



Macmillan have some useful advice about cancer and work online; you can also order a booklet. Go to [macmillan.org.uk](http://macmillan.org.uk) then search for 'work'.

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The treatment you decide on with your healthcare team will depend on your health, your individual condition and your wishes.

## Treatment

Many people with CLL don't need to start treatment straight after they're diagnosed, and some won't ever need treatment. If you do need to start treatment, the type you have will depend on your health, your individual condition and your wishes. Although at the moment CLL can't be cured in most cases, treatment can help you manage the disease effectively.

### Chemo-immunotherapy

If you need to start treatment and your general health is good your healthcare team will probably suggest you are given anti-leukaemia drugs (chemotherapy). Drugs called monoclonal antibodies are usually given as well; these are artificial antibodies which can bind to and kill specific cells. Treatment using a combination of chemotherapy drugs and antibodies is called chemo-immunotherapy.

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*I'm on watch and wait – although I call it 'watch and worry'! Not knowing when you'll start treatment can be difficult to deal with at times.*

”

**FCR: Fludarabine, cyclophosphamide, and rituximab**  
If you're fit and have no other medical problems, you're most likely to be treated with FCR – a combination of chemotherapy (cell-killing) drugs and monoclonal antibodies.

FCR is given in treatment 'cycles'. Each cycle is 28 days long, and you'll normally have treatment each day for five days and then have a break of 23 days with no treatment. This is repeated up to six times – each period of treatment and rest is called a cycle.

Fludarabine and cyclophosphamide are tablets that you take by mouth (orally). Rituximab is given as a drip or injection into a vein in one of a number of areas – you might hear the terms 'infusion', 'intravenously', or 'IV'.

#### **Bendamustine**

FCR is not suitable for everyone. If you're older or have other medical conditions, and have CLL requiring treatment, you may be treated with the chemotherapy drug bendamustine.

Bendamustine is given as an infusion on the first two days of a four week cycle, for up to six cycles.

**Chlorambucil (usually given with obinutuzumab or ofatumumab)**  
If other treatments aren't suitable for you, you might be offered chemotherapy with a drug called chlorambucil, combined with the monoclonal antibodies obinutuzumab or ofatumumab.

Chlorambucil is given as tablets you take by mouth (orally). Obinutuzumab and ofatumumab are given as infusions and your healthcare team will tell you how many courses you'll have, and when.

#### **Rituximab**

In some cases (such as if you're taking part in a research study) you may be offered treatment with the monoclonal antibody rituximab alongside chemotherapy drugs. Rituximab is usually given as an infusion.

#### **Ibrutinib**

Ibrutinib is a targeted drug that blocks signals within cells that are important for their survival. You may be offered ibrutinib as a first treatment if other treatments aren't suitable for you and you have certain genetic characteristics known as 17p deletion or TP53 mutation (see Cytogenetics on page 33).

Ibrutinib can also be used as a second treatment if your first treatment hasn't worked as well as hoped and/or the CLL has returned after a previous response. You take ibrutinib as capsules once a day.

#### **Idelalisib and rituximab**

Idelalisib blocks some of the proteins inside cancerous blood cells that encourage the cancer to grow. It is usually used with rituximab. You may be offered idelalisib and rituximab as a first treatment if other treatments aren't suitable for you and you have certain genetic characteristics known as 17p deletion or TP53 mutation (see Cytogenetics on page 33).

It can also be used to treat some people whose leukaemia has not responded to other treatments.

Recent research has shown that you may be at greater risk of serious and fatal infections if you're treated with idelalisib. To manage these risks, you will be given antibiotics throughout your treatment as protection (which is referred to as prophylaxis). All drug treatments carry some risk. Your healthcare team will weigh the risks carefully against the benefits when deciding which treatment to offer you.

#### **Venetoclax**

Venetoclax is new targeted drug which blocks the growth of CLL cells and promotes cell death. This can be used if ibrutinib or idelalisib have stopped working or there is some other reason why you should not receive these. At the time that this booklet was published (July 2017) venetoclax was going through the approval process for use by the National Health Service (NHS). Speak to your healthcare team about which treatments are available to you.




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There are currently a number of new treatments for CLL in development. We'll update our online patient information with details about these new treatments as they become available at [bloodwise.org.uk/patient-information](http://bloodwise.org.uk/patient-information)

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## Radiotherapy

Most people with CLL don't have radiotherapy, but if your spleen is swollen and uncomfortable, local radiation treatment to shrink it might be helpful.

On very rare occasions you might have an operation to remove your spleen (a splenectomy). You might then get more infections, but your healthcare team will give you advice on how to decrease the chances of this happening. This might include long-term antibiotic treatment.

## Stem cell transplant

A stem cell transplant is what used to be called a bone marrow transplant. It aims to give patients healthy stem cells, which then produce normal blood cells.

It isn't a suitable treatment for most people with CLL. This is because the risks of a transplant aren't justified for patients with a slowly developing disease like CLL. For some people – especially those whose disease is progressing more quickly – a transplant may provide a cure, but the risks of a transplant need to be carefully weighed against the potential of a cure.

People with CLL who need a stem cell transplant will be offered one that uses stem cells from a healthy donor (an allogeneic/ allograft transplant).

Stem cell transplants using your own cells (autologous/autograft) are no longer used to treat people with CLL as they do not successfully stop the CLL from coming back.

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You can find out more about stem cell transplants in our booklet **The seven steps: blood stem cell and bone marrow transplants**. Find out how to order on **page 82**.

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## Side effects from your treatment

You may experience some side effects from your treatment, especially if you've had chemo-immunotherapy. They include:

- › achy feeling
- › constipation
- › diarrhoea
- › extreme tiredness
- › infections
- › low blood pressure
- › low platelet count (thrombocytopenia)
- › low red cell count (anaemia)
- › mouth sores
- › nausea and vomiting
- › low neutrophil count (neutropenia), which means your body will find it harder to fight infection.

You're unlikely to have all of these. Some side effects are linked to specific drugs – for example, fludarabine treatment can increase the risk of infections.

For most people with CLL, side effects aren't severe and they usually go away when you stop treatment. If you have side effects, do tell your healthcare team as they might be able to help with them – there are medicines you can take to help with nausea and vomiting, for instance.

Infections can become serious while you're on treatment. Your medical team should tell you who to contact if you are unwell and/or have signs/symptoms of infection. See page 23 for more information.

## When will I start treatment?

You'll only be given active treatment for CLL if and when you need it. If you don't need to start treatment straight away, your healthcare team may recommend 'watch and wait' (sometimes called 'active monitoring'). This means you won't start treatment straight away, but you'll have regular appointments where you'll be monitored closely for any changes.

It might be surprising to hear that you have cancer but you don't need treatment straight away, but research has shown that for people with few or no symptoms, starting treatment straight away is not any better than delaying treatment until tests show you need it. Watching and waiting won't affect your outlook (prognosis) and it means that you won't have to go through any of the side effects of chemotherapy unless you need to.

The decision about whether to watch and wait before starting treatment will be based on how you're doing and not on the cost to the NHS, or any other reason.

You'll have regular appointments at your GP surgery, in hospital, or using 'remote monitoring', which is like a phone or video clinic, and offers a good way to be followed up without affecting your life too much. Your doctor should speak to you about which type of monitoring is suitable for you.

Wherever your monitoring takes place, it's really important for you to take part, as this is when you and your medical team can talk about how you're feeling and whether you might need to start treatment.

## Starting treatment

You can't start treatment if your consultant doesn't think you need to. If you don't agree with them, you can ask for a second opinion.

You might need to start treatment if:

- › your blood counts are changing – so if your red cell count or platelet count is going down or the number of CLL cells in your blood is going up quickly
- › you have a very swollen spleen or lymph nodes, especially if these are uncomfortable
- › you have symptoms like increasing extreme fatigue, fever without any other signs of infection, drenching night sweats, or marked weight loss.

None of these are an automatic 'trigger' for starting treatment. If your consultant thinks it's important to start treatment they'll tell you and explain the options open to you, to help you make a decision.

If you decide you don't want to start treatment, or you want to delay your treatment, it's important that you understand the risks involved.

### Initial or first-line treatment

The first treatment you have after being diagnosed is called initial or first-line treatment. The aim of initial treatment is to reduce the number of CLL cells, to get control of the disease.

If there is a clinical trial (study) available, your consultant might recommend that you consider this. Clinical trials are done for several reasons, including to look for new treatment options and to improve existing treatments. Taking part in a clinical trial has many advantages, such as the opportunity to have the newest available treatment which will only rarely be available outside of the trial. You'll also be very closely monitored and have detailed follow up.

Taking part in a clinical trial does come with uncertainties, and you may prefer not to take part in one. If you don't want to be in a trial, or there isn't a suitable trial available, you'll be offered the best treatment available at that time which is suitable for your individual condition.

### Second-line treatment

Most patients respond well to treatment, but it's unlikely to cure you. Unfortunately, even if you respond well to the first treatment, there's a strong chance that your disease will come back (recur), although this might not be for several years. If you've been in remission for a long time after having FCR or other chemo-immunotherapy, it's likely that the same treatment will work again, so repeating FCR is a potential option.

If your CLL comes back soon after your first FCR treatment or other chemo-immunotherapy, there are a number of options. Your team might recommend that you take part in a clinical trial or offer you different treatments. These include ibrutinib, or idelalisib with rituximab.

Rarely, younger patients with high-risk disease may be offered a stem cell transplant.

A small number of people don't respond well to initial treatment. This is called refractory CLL. If this happens to you and your lymph nodes or spleen are swollen, then you might be given high doses of steroids. This will usually cause them to shrink and then other treatments can be considered.

## Follow-up

Your follow-up will depend on what type of treatment, if any, you're having.

If you're treated with chemo-immunotherapy such as FCR and your illness responds well, it might be years before you need any more treatment. If you're treated with a targeted therapy such as ibrutinib you'll stay on treatment for the long term.

Your consultant will explain how often you'll have your follow-up appointments. This varies between people and will depend on your condition. Your doctor should talk to you about what to do between your appointments if your condition changes and if you can switch to remote monitoring after a certain amount of time.

### Protecting yourself against infections

You're likely to have an increased risk of infection during your treatment and for several months after. It's worth asking for advice on what precautions you may need to take. Do contact your healthcare team if you think you have an infection, or if you're poorly and you're not sure why.

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See **page 82** for information on how to order our booklet **Your guide to clinical trials**

You can find details of current CLL trials on a website provided by Leeds Teaching Hospitals [haematologyclinicaltrials.co.uk/diseases/8](http://haematologyclinicaltrials.co.uk/diseases/8)



You can find a list of UK trials on the UK Clinical Trials Gateway [ukctg.nihr.ac.uk](http://ukctg.nihr.ac.uk)

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### Prophylactic treatment (prophylaxis)

Your doctors may also advise that you take some tablets to reduce the risk of getting infections during and after your treatment for CLL. These can include medicines for bacterial, viral or fungal infections as needed – this is known as prophylactic (preventative) treatment or prophylaxis.

### Blood transfusions

If you've been treated with fludarabine or bendamustine and you then need a blood transfusion, you'll need to receive blood that has been treated with radiation (irradiated blood). This kills any white cells in the blood going into you and protects you against a very rare type of transfusion reaction.

You should be given a card to keep with you, explaining that you need irradiated blood. You may also want to wear a special bracelet to give this information to doctors caring for you if you're unconscious or unable to explain.

In an emergency, if you need a blood transfusion as a life-saving intervention non-irradiated blood can be used so the transfusion isn't delayed.

### CLL and skin cancer

People with CLL have a slightly higher risk of developing skin cancer, whether they have had treatment or not. You should take extra care to protect your skin from sunburn.

### Supportive care

It's sometimes necessary to give treatment to help with the recovery of your normal neutrophils (a type of white blood cell) if these have fallen to very low levels during or after your CLL treatment and/or you've had an infection. This is called G-CSF (granulocyte-colony stimulating factor) and is a small injection given under the skin (subcutaneously) for three to five days. The injection doesn't hurt but may sometimes cause some aching in your back or other bones.

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You can get a bracelet or 'dog tag' from a charity called MedicAlert. Go to [medicalalert.org.uk](http://medicalalert.org.uk) or call **01908 951 045**.

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Every person is individual, so your consultant and healthcare team are the best people to ask about your likely outlook (your prognosis).

## The outlook

New treatments for CLL which have been introduced in recent years mean that, generally speaking, people with CLL have a better prognosis than previously.

CLL generally progresses very slowly and survival can be measured in decades. It might progress more quickly in some people and they may need treating earlier or more aggressively.

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

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

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Your healthcare team should look after your emotional needs, as well as your physical ones.

## Everyday life and CLL

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

### Looking after yourself emotionally

Being told that you have cancer can be very upsetting and will almost certainly bring many different emotions. If you were diagnosed by chance, it can come as even more of a shock. Friends and family often offer a great deal of support, but it can be harder for them to understand the long-term emotional impact that you might experience.

Most people with CLL have a good general quality of life, but if you're on 'watch and wait' you might feel anxious.

If you do, then your healthcare team can offer support and reassurance – or you might like to try talking to other people who have, or have had, CLL.

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

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*Everyone is different, but I found it useful to talk to someone about my feelings and experiences.*

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## Looking after yourself physically

### Changes in your condition

You might need to live with symptoms for a long time – your healthcare team will be able to give you advice on how to cope with them. If your symptoms are really troubling you, you might want to see your consultant to talk about whether you need to start treatment.

### Keeping active

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

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

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

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You can read about the experiences of people who are going through – or have been through – the same thing on our website [bloodwise.org.uk](http://bloodwise.org.uk)

You might like to get in touch with an organisation which can offer support for you and people close to you. See [page 67](#) for a list of useful organisations.

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### Diet

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

Because your immune system may not be working as normal, 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 things like keeping cooked and raw meat separate in the fridge.

A diet for people with a weakened immune system is known as a neutropenic diet.

### Vaccination

If you have CLL, even if you are not on treatment, you should avoid having any live vaccines. Fortunately only a few vaccines used in the UK are live. The most commonly used ones are MMR (measles, mumps and rubella) and shingles. The yellow fever vaccine, occasionally needed for travel to certain areas, is also a live vaccine.

Babies who have received the oral (by mouth) polio vaccine will pass live virus in their poo (faeces). Because of this, avoid contact with their nappies and the contents – as well as the risk of infection from their stools (poo), there's a risk of getting polio.

You'll be advised to have a seasonal flu vaccine, pneumococcal vaccine and Hib vaccine to protect you against some serious infections. Your healthcare team will be able to give you more information about this.

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We have a booklet on dietary advice called [Eating well with neutropenia](#). See [page 82](#) for details of how to order it.

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### Shingles

Shingles is an infection of a nerve and the skin around it.

It's caused by the same virus as chickenpox. If you've had chickenpox, the virus can lie dormant (stay inactive) in your body for years. If the virus then reactivates, you'll develop shingles.

You're more likely to get shingles if your immune system isn't working well – for example, if you have CLL.

Shingles has some quite obvious symptoms. If you think you have it, let your GP or specialist know as quickly as possible (within 24 hours of the rash appearing is best). If it's treated early, the symptoms won't be as bad. Symptoms include:

- › a rash, normally on one side of your body
- › an itching, tingling or burning feeling
- › pain where the rash is
- › blisters filled with fluid which burst and form sores.

You can't catch shingles from someone who has it, but you can catch chickenpox from someone with an open shingles or chickenpox sore, if you haven't had chickenpox already.

Try and avoid people with shingles, chickenpox and other viruses.

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Always keep your healthcare team updated about any new or changed symptoms you have after you're diagnosed. See [page 22](#) for a list of what to watch out for.

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### Alternative and complementary therapies

There's an important difference between alternative therapies, which are offered in place of medical treatment, and complementary therapies, which are used alongside standard treatment. **We don't recommend that you use any alternative therapy in place of proven medical care.**

Many people with chronic conditions use complementary therapies. However, many complementary therapies are said to stimulate the immune system. As CLL is a disease where immune system cells have become abnormal, there's at least a possibility that it could make your condition worse. This is something you might want to consider.

Always let your healthcare team know about any complementary treatments you're using or thinking of using. They might advise you to avoid certain therapies because of specific risks to do with your CLL or the treatments you're receiving. In other cases they might say a therapy is OK as long as you take specific precautions.

#### Herbal medicines

Herbal preparations might be safe for a healthy person but they could be dangerous when combined with your chemotherapy. If you are on treatment for your CLL, discuss any herbal preparations you are taking, or thinking of taking, with your medical team.

#### Acupuncture

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

## Practical support

Your work, education and domestic arrangements

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

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

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

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

### Cancer and the law

People with cancer, or any other serious disease, are covered by a law called the Equality Act – for the purposes of the act, cancer is considered a disability. This means that employers and places of study are required by law to make reasonable adjustments for people with disabilities and cannot discriminate against you. An example of a reasonable adjustment would be giving you time off to go to hospital appointments.



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

“

*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.*

”

### Getting to hospital

If you're being treated as an outpatient (not staying in overnight) you might need to be at 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 claim a refund from the hospital for what it costs you to travel to your appointments. If you'd like to find out more about this support, you can speak to your team at the hospital or a benefits advisor.

### Financial support

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

Your hospital will normally have medical social workers or welfare rights (benefits) advisors who can advise on which benefits you might be able to receive. These might be especially useful if you're on a low income or unemployed. If you're worried you can 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 but are being treated for cancer (including any side effects) you can apply for a medical exemption certificate for any drugs you need to support your care. Application forms are available from your GP surgery or hospital clinic.

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Our researchers are making discoveries that will have a positive impact for people with CLL.

## Research and new developments

Each year, we invest a large part of the money we raise in research which aims to stop people dying from blood cancer; make patients' lives better; and stop people getting blood cancer in the first place. We have a number of CLL research projects going on. Here's an overview of some of the things our researchers are looking into.

### B cell receptor

CLL affects certain white blood cells called B cells. B cells have a protein on their surface called a B cell receptor. When the receptor isn't working properly it can cause uncontrolled production of abnormal B cells – leading to chronic lymphocytic leukaemia.

There are many signals that the B cell receptor uses to communicate in a cell, and current research is looking at all the molecular players that can be affected. For example, one of our projects in Southampton is looking at how the genetic messenger that translates a DNA sequence into a protein is changed when the B cell receptor is activated. This study may provide new opportunities to develop targeted therapies.

## The microenvironment

Most CLL cells multiply in the lymph nodes and bone marrow, where their survival and growth is sustained by the surrounding tissue. The latest research shows that this supporting 'microenvironment' can protect many CLL cells from being killed by drugs or recognised by the immune system.

Researchers have now recognised that a new way to treat CLL might be to target this 'support network', as well the cancer itself.

Some of our research at King's College London is investigating whether an immunosuppressant drug – which affects one type of cell in the leukaemia microenvironment – reduces the growth of the cancer.

“

*The research that's going on is truly amazing. It really gives me and my family hope to know that so much time, energy and wisdom is being devoted to finding new and better treatments.*

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## New tests

We know that every person's disease is different. For some people, their cancer doesn't develop much after diagnosis and they might not need treatment straight away, but in others the disease is aggressive and treatment is needed quickly.

New research is studying the genetics and cell biology of CLL in different people to find out why this is. For example, our research in Cardiff has shown that the length of telomeres – the protective caps at the end of chromosomes – in CLL cells is a good predictor of whether the disease is likely to be aggressive or not.

Researchers are now hoping to turn these findings into a quick and cheap diagnostic test, which would help doctors decide when and how best to treat a newly diagnosed patient.




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You can find more information about the latest CLL research on the Cancer Research UK website. Go to [cancerresearchuk.org](http://cancerresearchuk.org) and search for 'CLL research'.

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There are lots of organisations out there who offer information and support to people affected by CLL.

## Places you can get help and support

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

### General support

Bloodwise

We offer patient information online and in free printed booklets.

› 020 7504 2200 › [information@bloodwise.org.uk](mailto:information@bloodwise.org.uk) › [bloodwise.org.uk](http://bloodwise.org.uk)

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

› 0808 2080 888 › [support@bloodwise.org.uk](mailto:support@bloodwise.org.uk)

Macmillan Cancer Support

Offers practical, medical, financial and emotional support.

› 0808 808 0000 › [macmillan.org.uk](http://macmillan.org.uk)

Cancer Research UK

Offers information about different conditions, current research and practical support.

› 0808 800 4040 › [cancerresearchuk.org/about-cancer](http://cancerresearchuk.org/about-cancer)

### CLL Support Association

Provides information and support for people with CLL (and related conditions) and their family and friends. They also send regular newsletters and hold patient meetings for their members. You can connect with other patients on CLLSA's online community.

- › 0800 977 4396 (telephone helpline)
- › [info@cllsupport.org.uk](mailto:info@cllsupport.org.uk) › [cllsupport.org.uk](http://cllsupport.org.uk)
- › [healthunlocked.com/cllsupport](http://healthunlocked.com/cllsupport) (online community)

### Lymphoma Association

Provides emotional support and information to anyone with lymphatic cancer and their families, carers and friends.

- › 0808 808 5555 › [lymphomas.org.uk](http://lymphomas.org.uk)

### Leukaemia Care

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

- › 01905 755 977 (general enquiries)
- › or 08088 010 444 (Care Line)
- › [care@leukaemicare.org.uk](mailto:care@leukaemicare.org.uk) › [leukaemicare.org.uk](http://leukaemicare.org.uk)




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General financial advice is available from [cancerresearch.org](http://cancerresearch.org), [macmillan.org.uk](http://macmillan.org.uk) and [leukaemicare.org.uk](http://leukaemicare.org.uk)

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

### Association of British Insurers (ABI)

Provides information about getting travel insurance and contact details for specialist travel companies.

- › 020 7600 3333 › [abi.org.uk](http://abi.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](mailto:enquiries@biba.org.uk) › [biba.org.uk](http://biba.org.uk)

## Financial advice

### Citizens Advice Bureau (CAB)

Offers advice on benefits and help with filling out benefits forms.

- › 03444 111 444 (England) › or 0344 477 2020 (Wales)
- › [citizensadvice.org.uk](http://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](http://gov.uk)

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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 the tests, for example not eating beforehand?
- › How long will it take to get the results?

## Treatment – general

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

## Type of treatment

### Chemotherapy and chemo-immunotherapy

- › What type of chemotherapy 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 chemotherapy regimen (course) will I be given?  
Will I be given it by mouth, injection or drip (into a vein)?
- › Will my treatment be continuous or in blocks of treatment (with a break in-between)?

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

### Stem cell transplant

- › Is a transplant an option for me?
- › 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?

# Glossary

## Antibodies

Antibodies are proteins which help fight infections in your body. Your lymphocytes (white blood cells) produce these naturally but you can also be treated for CLL using antibodies that are created in a laboratory. These are called monoclonal antibodies.

## B lymphocyte or B cell

A type of white blood cell normally involved in producing antibodies to fight infection.

## Blood count, full blood count or FBC

A blood test that counts the different types of cells in your blood.

## Bone marrow

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

## Chemotherapy

Treatment using anti-cancer drugs; it can be a single drug or a combination of drugs. Chemotherapy is used to kill cells or stop them growing and dividing. Although it's aimed at the cancer cells, the treatment also affects normal cells which divide quickly, such as those in the hair and gut.

## Clinical nurse specialist

A qualified nurse who specialises in a particular clinical area. Some deal with all blood cancers while others may specialise in myeloma, lymphoma

or another specific area. Your nurse specialist can provide information and expert advice about your condition and treatment.

## Clinical trial

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

## Cytogenetics

The study of the structure of chromosomes. Cytogenetic tests (or FISH tests) are carried out on samples of blood and bone marrow taken from leukaemia patients. They aim to find any changes which could be linked to the disease. They can also help doctors to decide on the treatment you'll have.

## Fatigue

Fatigue is a feeling of extreme tiredness which doesn't go away after rest or sleep. It might be caused by the CLL itself or might be a side effect of treatment. It's one of the most common problems that people with cancer have.

## Immune system

The network of cells, tissues and organs which protect your body against infection.

## Leukaemia

Often referred to as 'cancer of the blood', leukaemia is divided into many different types – some which develop faster (acute), and others which develop more slowly (chronic). People with leukaemia have large numbers of abnormal blood cells, usually types of white blood cell, which take over the bone marrow and often spill out into the blood stream. 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 foreign materials. It contains white blood cells that fight infection.

## Lymphocyte

A type of white blood cell which is involved in the immune defences of the body.

## Lymph vessels

Small tubes which make up a network which runs around your body. They carry a fluid called lymph.

## Mutation

A small genetic change to DNA. These changes can be caused by exposure to hazardous chemicals or copying mistakes when a cell was dividing.

If the mutation affects the way cells normally work it can lead to a disease.

## Spleen

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

## Stem cells

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

## T lymphocyte or T cell

A type of white blood cell which matures in the thymus (this is why they're called a T cell). They're involved in controlling immune reactions and fighting infections. The uncontrolled production of this type of cell causes T-cell leukaemia or lymphoma.

## Radiotherapy

The use of radiation in treatment. Radiotherapy kills cancer cells in the area of the body being treated, so it can be an effective treatment for diseases which affect a particular part of the body such as lymphoma and myeloma. It's also sometimes used in CLL if you have a swollen spleen.

## 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 Line team are just a call or email away. Call us on **0808 2080 888** Mon–Fri 10am–4pm, email [support@bloodwise.org.uk](mailto:support@bloodwise.org.uk) or visit us at [bloodwise.org.uk](http://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.



For more information, go to [bloodwise.org.uk](http://bloodwise.org.uk)

## 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.

### Jump 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](https://facebook.com/bloodwise.uk)

[twitter.com/bloodwise\\_uk](https://twitter.com/bloodwise_uk)

### Partner with us

We're always looking for companies who share our vision and energy.

## Get in touch

Visit [bloodwise.org.uk/get-involved](http://bloodwise.org.uk/get-involved), call 0207 504 2200 or email [hello@bloodwise.org.uk](mailto:hello@bloodwise.org.uk)

## Your feedback

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

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

Email us at [information@bloodwise.org.uk](mailto: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.



For our patient information, go to  
[bloodwise.org.uk/patient-support](http://bloodwise.org.uk/patient-support)

## Information booklets

Booklets which are available free of charge:

### Reference

### Description

BWALL	<b>Leukaemia</b> Acute lymphoblastic leukaemia (ALL)
BWAML	Acute myeloid leukaemia (AML)
BWAPL	Acute promyelocytic leukaemia (APL)
BWCLL	Chronic lymphocytic leukaemia (CLL)
BWCML	Chronic myeloid leukaemia (CML)
BWCHALL	<b>Childhood leukaemia</b> Acute lymphoblastic leukaemia (ALL) in children and young adults up to 16 years
BWCHAML	Acute myeloid leukaemia (AML) in children and young adults up to 16 years
BWHL	<b>Lymphoma</b> Hodgkin lymphoma (HL)
BWNHLHIGHGRADE	High-grade non-Hodgkin lymphoma (NHL)
BWNHLOWGRADE	Low-grade non-Hodgkin lymphoma (NHL)
BWMM	<b>Other</b> Myeloma
BWMDS	Myelodysplastic syndromes (MDS)
BWMPN	Myeloproliferative neoplasms (MPN)
BWSEVEN	<b>Treatment and beyond</b> The seven steps: blood stem cell and bone marrow transplants
BWCT	Your guide to clinical trials
BWDAPN	Eating well with neutropenia
BWMYDIARY	Diary for anyone affected by blood cancer

## Fact sheets

We have the following fact sheets available online at [bloodwise.org.uk](http://bloodwise.org.uk)

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

# Bloodwise

The **blood cancer research** charity

Please donate today to help  
Bloodwise beat blood cancer

- › Go to [bloodwise.org/donate](http://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](mailto: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

Start date     Expiry date     Issue no

**Make your donation worth an extra  
25p for every £1 at no extra cost to you!**

*giftaid it*

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:

.....

.....

.....

.....

### 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**

# My details

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

My name and hospital number

My NHS number

My condition

My contacts

My consultant

My key worker (usually CNS)

Haematology ward

Haematology clinic

Other contacts

# Bloodwise

The **blood cancer research** charity

39–40 Eagle Street, London WC1R 4TH

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

020 7504 2200 (Reception); 0808 2080 888 (Support Line)

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