Chronic lymphocytic leukaemia (CLL)
## My details

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

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<tr>
<th>Name and hospital number</th>
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<th>My NHS number</th>
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<th>My condition</th>
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<th>My contacts</th>
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<th>My consultant</th>
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<th>My key worker (usually your CNS)</th>
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<th>Other contacts</th>
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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 during the review.

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

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

The information in this booklet is correct at the time it was printed (August 2014).
Date of next review August 2016.
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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 throughout this time. We’ll try to answer as many of the questions you might have along the way – from symptoms through to tests, treatment and living with 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.

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 and it’s very rare in younger people.

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 normally found when you’re having a routine blood test or a blood test for something else. 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 – this is known as ‘watch and wait’. Your specialist will tell you when they think you might need start treatment and discuss your options with you. Active treatment for CLL usually involves chemotherapy drugs and antibodies. Some patients 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 patients (about 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.
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 four important functions:

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

Defence system
White blood cells are part of your immune system, which fights infections. 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. Here’s a table which shows how many of each type a healthy person has.

<table>
<thead>
<tr>
<th></th>
<th>WHITE BLOOD CELLS</th>
<th>RED BLOOD CELLS</th>
<th>HAEMOGLOBIN</th>
<th>NEUTROPHIL</th>
<th>PLATELETS</th>
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<td></td>
<td>(10^9/l)</td>
<td>(10^{12}/l)</td>
<td>(g/l)</td>
<td>(10^9/l)</td>
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<td>ADULT MAN</td>
<td>3.7 to 9.5</td>
<td>4.3 to 5.7</td>
<td>13.3 to 16.7</td>
<td>1.7 to 6.1</td>
<td>143 to 332</td>
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<tr>
<td>ADULT WOMAN</td>
<td>3.9 to 11.1</td>
<td>3.9 to 5.0</td>
<td>11.8 to 14.8</td>
<td>1.7 to 6.1</td>
<td>143 to 332</td>
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<tr>
<td>WEST INDIAN</td>
<td>2.8 to 9.8</td>
<td>1.0 to 6.5</td>
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<td>122 to 374</td>
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<tr>
<td>AFRICAN</td>
<td>2.8 to 7.8</td>
<td>0.9 to 4.2</td>
<td>115 to 342</td>
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(Some data unavailable for West Indian and African patients.)
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.

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.

All leukaemias start in stem cells or progenitor cells. Progenitor cells are similar to stem cells, but they only divide a certain number of times. Stem cells can divide again and again.

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. They then build up in the bone marrow, which means there isn’t room for enough normal blood cells to be made. This is what causes most of the symptoms that people with CLL get.

For more information on how to spot and treat shingles see page 58.

You can find more information about how to manage infections in our booklet > Supportive Care.
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 about 600 of these in your body. If you get an infection when you’re healthy, these can swell and become tender – these might feel like swollen glands.

Although CLL mainly affects the bone marrow, it can also cause swelling in lymph nodes because abnormal lymphocytes build up in them. The ones in your neck, armpits and groin are normally 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.
Who gets 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.

Unlike some other leukaemias, there’s no evidence to suggest that exposure to radiation is a risk factor.

There’s some evidence that exposure to certain agricultural chemicals may increase your chance of developing CLL, but this hasn’t been proven.

You’re not alone: CLL is the most common type of leukaemia in adults.
Who gets CLL?

CLL is more common in white people, we don’t know why.

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.

Again, experts don’t recommend testing family members for MBL unless they’re being considered as donors for a stem cell transplant.

You can find out more about MBL and CLL on our website > bloodwise.org.uk/CLLlinks. From there look for ‘CLL related disorders’.

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% of patients 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 a patient 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.

Again, experts don’t recommend testing family members for MBL unless they’re being considered as donors for a stem cell transplant.

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.
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 patients with CLL are diagnosed after routine blood tests or when a doctor finds swollen lymph glands at a check-up.

Some patients may notice early symptoms and signs such as:

› tiredness  
› swollen lymph nodes  
› frequent infections.

Other people may notice the symptoms below, which might mean you need to have treatment soon after you’re diagnosed. Some patients have one or two of the symptoms; others may have all of them:

› weakness  
› fatigue  
› night sweats  
› weight loss  
› repeated infections.
I found it quite hard to tell what symptoms to be concerned about, because so many of them are quite common with things like colds. I found the best thing to do was just to check each and every one out with my healthcare team.

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
- losing weight quickly, when you’ve not been dieting
- having swollen lymph nodes or swellings in your neck, armpits or groin, or under your collarbone
- 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. If you notice any of these symptoms, contact your hospital team:

- raised temperature
- cough or sore throat
- confusion or agitated behaviour, especially if it comes on suddenly
- 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.
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 patients 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.
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.

Lymph node biopsy
Most patients 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 leukaemia or SLL.

Or much more rarely for new patients, it might be due to another condition called Richter’s syndrome (a different type of lymphoma). A small number of CLL patients 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 then to ‘order information’. From there look for a factsheet called ‘Transformation of CLL’.

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**Normal blood film**

Red blood cell  
Platelet  
Neutrophil  
Lymphocyte

**Abnormal blood film**

Red blood cell  
Platelet  
Neutrophil  
Lymphocyte
Diagnosis

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 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 patients with MBL.

See page 17 for more information about MBL.

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 using a needle from the hip bone. 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 assess 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.

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.
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 patients 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 helps with staging, as it can 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
CLL patients won’t usually have an MRI scan. When they are used, it’s usually if you have a chronic sinus infection, or if the CLL is affecting unusual sites, 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.
Fluorodeoxyglucose positron emission tomography (FDG PET or 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 an MRI, 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. It can also show if you’re dehydrated. You’ll usually have your kidneys checked every time you have an appointment at the hospital.

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.
Further tests
There are several further tests which some patients 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. These tests can identify groups of patients who might need treatment. The 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 can help doctors to decide on the 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 a drug called fludarabine, which is often used to treat CLL. Less than 10% of patients will have this abnormality at the time when they need treatment. However if this is the case, 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 they will always be there – it just means they’re too small to detect.

Chromosomal abnormalities
This is the most important prognostic marker, see cytogenetics, page 34.

Zeta-associated protein 70 (ZAP–70) and CD38 antigen
This tests for the presence of these proteins on or inside the CLL cells.

IgHV gene status
If a patient has CLL cells with unmutated IgHV genes their condition may progress more quickly. This test is only done once, as the result won’t change.

β2-microglobulin (β-2M)
Almost all cells in the body have a protein on their surface called β2-microglobulin (β-2M). There are large amounts of β2-M protein on the surface of lymphocytes, so this is a useful test for finding out the number of CLL cells in your body.

Immunophenotyping
ZAP70 and CD38 are examples of immunophenotyping you might have to give a clearer picture 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.

You can find more information on tests and scans for CLL on our website > bloodwise.org.uk/CLLlinks

There’s a website supported by the Department of Health which has more information on tests > labtestsonline.org.uk
If you’re diagnosed with CLL, your hospital should give you the names and contact details of your consultant, clinical nurse specialist and other members of your healthcare team – there’s space to write them at the back of this booklet if you want to. You can then use these details to contact your team if you have any questions you want to ask when you’re not in the hospital.

Your consultant
Most patients with a blood cancer are treated by a haematologist – a doctor who specialises in treating patients with blood diseases. Some patients 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 cancer patients are normally given a key worker, usually a clinical nurse specialist. They are your point of contact with the rest of your healthcare team. You may like to have a meeting with your clinical nurse specialist when you’re first diagnosed, to discuss your condition. Really make use of your clinical nurse specialist as they’ll be with you right through your cancer journey.

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

Talking to other patients
You 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 patients have side effects from a drug and other patients don’t.

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

Your other healthcare professionals
It’s definitely worth telling other healthcare professionals you see – like your dentist or optician – about your diagnosis and any medication you’re taking.
Finding out more

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

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

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

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

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

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

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

You can find a list of questions you might want to ask on page 71 and room to write more questions on page 74.
Many patients 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.

**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.

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 then search for ‘work’.

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“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’.”
Many patients with CLL don’t need to start treatment straight after they’re diagnosed, and some patients 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.

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

If 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.

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.
The most widely used combination for patients starting treatment for the first time is three drugs: fludarabine and cyclophosphamide, with rituximab – you might hear it being called FCR.

Fludarabine and cyclophosphamide are tablets 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 also hear the words infusion, intravenously, or IV mentioned.

FCR is given as cycles of treatments. You’ll normally have treatment each day for three to five days and then have a break of three to four weeks with no treatment. This is repeated every 28 days up to six times – each period of treatment and rest is called a ‘cycle’.

Alemtuzumab
This monoclonal antibody isn’t usually given anymore as it’s now an unlicensed drug and only available through a compassionate access programme. However, it may be used if your cytogenetic blood tests (see page 34) show that fludarabine isn’t likely to work for you.

Alemtuzumab is usually given alone, again in cycles; your healthcare team will tell you exact timings. It’s usually given as an injection just beneath the skin (subcutaneous). You might be given steroids at the same time.

Bendamustine and chlorambucil
If you’re older or have other medical problems, your healthcare team might decide that FCR or alemtuzumab aren’t suitable treatments for you. If this is the case, you might be offered chlorambucil or a newer drug called bendamustine; these are now often given with Rituximab. Chlorambucil is given as tablets you take by mouth (orally), one tablet each day for one week every four weeks, and for up to 12 cycles. Bendamustine is given as an infusion on the first two days of a four week cycle, for up to six cycles.

Ofatumumab
You’re most likely to be offered ofatumumab if:

- you’ve not responded well to initial treatment (known as refractory CLL)
- your CLL has come back quickly after initial treatment and your healthcare team don’t think that treating you with the same drugs again will work (drug resistance).

Ofatumumab should be available in all haematology oncology centres. It’s given as an infusion and your healthcare team will tell you how many courses you’ll have, and when.

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 > bloodwise.org.uk/patient-information
Most CLL patients don’t have radiotherapy; however, if your spleen is swollen and uncomfortable, local radiation treatment to shrink it might be helpful.

On very rare occasions patients might have an operation to remove their 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.

### Radiotherapy

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 CLL patients. This is because the risks of a transplant aren’t justified for patients with a slowly developing disease like CLL. For some patients – especially those whose disease is progressing more quickly – a transplant may provide a cure, but there isn’t enough evidence to be sure of this yet.

There are two main types of stem cell transplant:

- **Autologous or autograft** – this uses the patients’ own stem cells (this is no longer offered to CLL patients).
- **Allogeneic or allograft** – this uses donor stem cells and is a high-risk procedure.

### Stem cell transplant

You can find out more about stem cell transplants in our booklet [Bone marrow and stem cell transplantation](#).

You can find out more about drugs used to treat CLL on our website [bloodwise.org.uk/CLLlinks](http://bloodwise.org.uk/CLLlinks).

### 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
- diarrhea
- extreme tiredness
- infections
- low blood pressure
- low platelet count
- low red cell count (anaemia)
- mouth sores
- nausea and vomiting.

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 patients 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.
When will I start treatment?

If you don’t need to start treatment straight away, you may be placed on ‘watch and wait’. This means that you’ll have regular check-ups, either at your GP surgery or in hospital, to monitor your condition. It’s really important for you to go to these, as this is when you and your consultant can talk about how you’re feeling and whether you might need to start 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 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 fatigue, fever or 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 may not be given 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. If you do have successful 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.

If your CLL comes back soon after your first FCR treatment or other chemo-immunotherapy, or if your second treatment with FCR doesn’t work well, 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:

- for fit patients – alemtuzumab followed by a transplant
- for less fit patients – alemtuzumab, bendamustine or ofatumumab.

A small number of patients 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.
Your follow-up will depend on what type of treatment, if any, you’re having. If you’re treated with FCR and your illness responds well, it might be years before you need any more treatment.

Your consultant will explain how often you’ll come back for follow-up checks – these appointments are really important so do make sure you get to them.

Follow-up

Protecting yourself against infections
If you’ve been treated with a fludarabine-based drug combination or chlorambucil, bendamustine, alemtuzumab or steroids, then you’re likely to have an increased risk of infection during treatment and for several months after. It’s worth asking for advice on what precautions you may need to take. Do then contact your healthcare team if you think you have an infection, or if you’re poorly and you’re not sure why.

Prophylaxis treatment
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 prophylaxis (or preventative) treatment.

Blood transfusions after treatment
If you’ve been treated with fludarabine, bendamustine or alemtuzumab and you then need a blood transfusion, you’ll need to receive irradiated blood (or blood that has been treated with radiation). This kills any white cells in the blood going into you and protects you against a possible transfusion reaction.

You should be given a card by your consultant or clinical nurse specialist 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.

CLL and skin cancer
People with CLL have a slightly higher risk of developing skin cancer, whether they have had treatment or not. You may need to 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 after your CLL treatment and/or you’ve had an infection. This is called G-CSF and is a small injection given under the skin (subcutaneously) for 3–5 days. The injection doesn’t hurt but may sometimes cause some aching in your back or other bones.

For more information, read our booklet on clinical trials > Taking part in a clinical trial.

You can find details of current CLL trials on a website provided by Leeds Teaching Hospitals > haematologyclinicaltrials.co.uk/diseases/8

You can find a list of UK trials on the UK Clinical Trials Gateway > www.ukctg.nihr.ac.uk

You can get a bracelet or ‘dog tag’ from a charity called MedicAlert > medicalert.org.uk or 01908 951 045.
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, patients with CLL have an improved prognosis than previously.

CLL generally progresses very slowly and survival can be measured in decades. It might progress more quickly in a small number of patients, and they may need treating 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.
Your healthcare team should look after your emotional needs, as well as your physical ones.

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.

“Everyone is different, but I found it useful to talk to someone about my feelings and experiences.”
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/patient-support

You might like to get in touch with an organisation which can offer support for you and people close to you > see page 67 for a list of good organisations.

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 can 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.

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.

Vaccination
It’s a good idea for all CLL patients to have the flu vaccine each year – your GP might contact you about this but if they don’t then you can request the vaccine yourself. It might not work as well for people with CLL but will still offer some protection.

If you have CLL, avoid having any live vaccines. Fortunately only a few vaccines are live, including yellow fever, oral polio vaccine, measles and shingles.

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

We have a booklet on dietary advice > Dietary advice for patients with neutropenia.
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 patients with chronic conditions use complementary therapies. However many complementary therapies are said to stimulate the immune system. In CLL it’s immune system cells which have become abnormal, so 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.

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

We make a booklet on complementary and alternative therapies > Complementary and alternative therapies (CAM).
Everyday life and CLL

60 Everyday life and CLL

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

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

You might need to bring in written proof of your diagnosis from your healthcare team, which 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 arrangements for ‘people with disabilities’ and cannot discriminate against you. An example of a reasonable arrangement would be if you need time off to go to hospital for treatment. Your employer or college has to allow this and isn’t allowed to reduce your pay or make you take the time as unpaid leave.

Getting to hospital
If you’re being treated as an outpatient (not staying in overnight) you might need to 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 the effects of cancer or the treatment) you can apply for a medical exemption certificate for any drugs you need for these reasons. Application forms are available from your GP surgery or hospital clinic.

Practical support

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.

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.
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 this surface protein 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.

New tests
We know that every person’s disease is different. For some patients, 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 turning these findings into a quick and cheap diagnostic test, which would help doctors decide when and how best to treat a newly diagnosed patient.

You can find more information about the latest CLL research on the Cancer Research UK website > go to cancerresearchuk.org and search for ‘CLL research’.

"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."
Places you can get help and support

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

Bloodwise
We offer patient information online and in free printed booklets.
› 020 7504 2200  › patientinformation@bloodwise.org.uk
› bloodwise.org.uk

Macmillan Cancer Support
Offers practical, medical, financial and emotional support.
› 0808 808 0000  › macmillan.org.uk

CancerHelp UK
(Cancer Research UK’s patient support service)
Offer information about different conditions, current research and practical support.
› 0808 800 4040  › cancerresearchuk.org/cancer-help
CLL Support Association
Provides information and support for patients 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 › cllsupport.org.uk
› 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

Leukaemia Care
Offers patient information, a 24 hour care line and support groups for people affected by leukaemia, lymphoma, myeloma, myelodysplastic syndromes, myeloproliferative neoplasms and aplastic anaemia.

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

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

› 0808 808 0000 › macmillan.org.uk

Association of British Insurers (ABI)
Provides information about getting travel insurance and contact details for specialist travel companies.

› 020 7600 3333 › abi.org.uk

British Insurance Broker’s Association (BIBA)
Offers advice on finding an appropriate BIBA-registered insurance broker.

› 0870 950 1790 › enquiries@biba.org.uk › biba.org.uk

Financial advice
Citizens Advice Bureau (CAB)
Offers advice on benefits and help with filling out benefits forms.

› 08444 111 444 (England) › or 0844 477 2020 (Wales)
› adviceguide.org.uk

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

› gov.uk

General financial advice is available from CancerHelp UK, Macmillan Cancer Support and Leukaemia Care. See pages 67–68 for contact details.
It can be a good idea to write down the questions you want to ask before each appointment.

Questions to ask

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

Tests

› What tests will I have?
› What will 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?
Questions to ask

› 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 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?
If you’re diagnosed with blood cancer you need to know that there are people who can help. You want to know what it means, what’s going to happen, what the treatment is like and what your chances of living a normal life are. You need to know someone is there for you.

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

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

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

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

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

As one of the UK’s leading blood cancer charities, we feel both the responsibility and the opportunity that we have to make patients’ lives better.
We don’t get any government funding: it’s the money raised by our incredible supporters that lets us continue our life-saving work. It’s because of them that we can offer our patient information free of charge to blood cancer patients, so we’d like to say a big thank you to everyone who gives so generously to us.

Our patient services

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

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

How we raise money

If you – or anyone close to you – ever feels able to make any kind of donation, large or small, it will help us continue our life-saving work. Our patient information is available to download, order or read online. You can also blog about your journey there and read about other people’s blood cancer experiences.
How you can get involved

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

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

[bloodwise.org.uk/patient-support](http://bloodwise.org.uk/patient-support)

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

[bloodwise.org.uk/focus-groups](http://bloodwise.org.uk/focus-groups)

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

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

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

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

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

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

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

[bloodwise.org.uk/challenges](http://bloodwise.org.uk/challenges)
How you can get involved

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

bloodwise.org.uk/corporate

Corporate fundraising

Local fundraising

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

bloodwise.org.uk/localfundraising

Special events

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

bloodwise.org.uk/special-events

Being part of our online community

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

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

Shop with us

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

bloodwise.org.uk/shop
Your feedback

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

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

To fill in a short survey about our patient information online, please go to > bloodwise.org.uk/bookletsurvey

Other booklets

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

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

Myeloma
› Myeloma

Related conditions
› Myelodysplastic syndromes (MDS)
› Myeloproliferative neoplasms (MPN)

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

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

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

Glossary

B lymphocyte or B cell
A type of lymphocyte 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 patients with cancer have.

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, testes, 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.

**Progenitor cell or precursor cell**
An immature cell in the bone marrow that produces mature blood cells. It can only divide a certain number of times whereas a stem cell can divide again and again.

**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.
Bloodwise
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