Acute lymphoblastic leukaemia (ALL)
My details

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

Name and hospital number

My NHS number

My condition

My contacts

My consultant

My key worker (usually your CNS)

Haematology ward

Haematology clinic

Out of hours

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

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

This information has been developed for and with people with blood cancer. It’s written in line with national guidelines and created with health professionals from our dedicated Medical Advisory Panel, so you know it’s accurate and up to date.

This booklet is one of many we offer – you can find a list of our other booklets on page 98. For the very latest information, visit our website.

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

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

A team of people helped produce this booklet. We’d like to thank a member of our Medical Advisory Panel, Doctor Adele Fielding, for her 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 Gemma Trout.

Bloodwise staff revised the text to make it easy to read, and patients have checked it for understanding.

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 (March 2015).
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Introduction

This is a booklet for adults with ALL, and their family and friends.

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

There’s sure to be a lot of information to take in at this time, and many patients can forget what they were told when diagnosed. So please use this booklet for notes and as a reference for you and your family and friends.

We hope this booklet will help you understand your condition and feel in control. We’ll try to answer questions you might have along the way – from symptoms through to tests, treatment and living with ALL, 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, always talk to your specialist as well as getting information from this booklet and other places.
Acute lymphoblastic leukaemia at a glance

Anyone can get ALL, but it’s more common in younger and older people and less common in middle-age. Generally, most people who have treatment will go into remission (a good initial response to treatment), although there is a chance of relapse (the cancer coming back).

What is ALL?
ALL is a form of cancer that affects blood-producing cells in the bone marrow. It happens when these cells don’t mature properly, and grow too fast.

Who gets ALL?
ALL is the only type of leukaemia that happens more often in children than in adults. When it does occur in adults, it’s more likely to affect younger adults and it’s least likely in middle age. ALL then starts to occur more often in older age. We don’t know the reason for this pattern.

What’s the outlook?
The outlook is different for each person with ALL. The best person to tell you about this is your consultant, or someone on your healthcare team. Generally, after active treatment, up to eight in ten people can expect to have what’s called remission: a good initial response to treatment, so that no leukaemia cells can be seen in your blood or bone marrow when looked at under a microscope (although this may not mean you’re completely cured).

What are the treatments for ALL?
The best treatment for you will depend on your individual situation, including your age and general health, and the type of ALL you have.

It’s important to start treatment quickly with ALL, so it may feel like everything’s happening quite fast.

Chemotherapy is the main treatment for ALL. You’ll be offered a treatment plan involving chemotherapy drugs, steroids and other medicines, which are used to help prevent you from getting infections during the chemotherapy. In some cases, a stem cell transplant (also known as a bone marrow transplant) is part of the treatment.

When I was diagnosed I was told that most people with ALL tend to go into remission after they have treatment, which I found reassuring.

ALL is a form of cancer that affects blood-producing cells in the bone marrow.
Knowing the basics about blood, bone marrow and your immune system is useful.

Blood, bone marrow and your immune system

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

Your blood
The blood has four important functions:

Transport system
It carries food, oxygen and proteins to different parts of your body. Your blood also carries waste chemicals to the kidneys and lungs, which then get rid of them.

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

Communication system
Hormones are your body’s messengers, giving instructions to various organs. These chemicals are carried around in the blood.

Repair system
Your blood contains cells and chemicals that can seal off damaged blood vessels and control bleeding.
Blood cells

Blood contains three types of cells: red blood cells, white blood cells and platelets. Each type has several different jobs to do in the body. You'll learn all the terms below as your treatment goes on. Your team will talk to you about them regularly.

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

White blood cells are an important part of the immune system, fighting and preventing infection. There are five different types of white blood cell: neutrophils, lymphocytes, monocytes, eosinophils, and basophils.

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

Bone marrow and how blood cells are made

All blood cells are made in the soft material inside your bones (bone marrow). This process starts off with a very basic kind of cell, called a stem cell. Stem cells go through various stages until they become mature, and are transformed into the different types of blood cells.

When stem cells first divide, they create two types of more specialised stem cells:

› lymphoid stem cells
› myeloid stem cells

Next, these stem cells go on to form immature blood cells called lymphoid blasts or myeloid blasts.

After maturing further, lymphoid blasts eventually end up as one specific type of white blood cell, called a lymphocyte. The myeloid blasts continue on to form all the other white blood cell types. They also form the red blood cells and platelets.
How many of each type of blood cell should you have?

Your bone marrow produces a huge number of blood cells 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. You may feel unwell if your body is making too many or too few of any type of blood cell.

Everyone has slightly different numbers of each type of blood cell, depending on age, gender and ethnicity. If you’re healthy, the amount you have of each type normally stays the same. Here’s a table that shows how many of each type an average healthy person has. You might find this information useful when your doctor or nurse is explaining results from your blood tests.

<table>
<thead>
<tr>
<th></th>
<th>WHITE BLOOD CELLS</th>
<th>RED BLOOD CELLS</th>
<th>HEMOGLOBIN</th>
<th>NEUTROPHIL</th>
<th>PLATELETS</th>
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<tr>
<td></td>
<td>(10^9/l)</td>
<td>(10^12/l)</td>
<td>(g/l)</td>
<td>(10^3/l)</td>
<td>(10^9/l)</td>
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<tr>
<td>CAUCASIAN</td>
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<tr>
<td>ADULT MAN</td>
<td>3.7 to 9.5</td>
<td>4.3 to 5.7</td>
<td>13.3 to 16.7 (133-167)</td>
<td>1.7 to 6.1</td>
<td>143 to 332</td>
</tr>
<tr>
<td>CAUCASIAN</td>
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</tr>
<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 (118-148)</td>
<td>1.7 to 6.1</td>
<td>143 to 332</td>
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<tr>
<td>AFRO-CARIBBEAN</td>
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<td></td>
<td>1.0 to 6.5</td>
<td>122 to 374</td>
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</tr>
<tr>
<td>AFRICAN</td>
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<td></td>
<td>0.9 to 4.2</td>
<td>115 to 342</td>
<td></td>
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</tbody>
</table>

(Some data unavailable for Afro-Caribbean and African patients.)

Adapted with permission from ‘A beginner’s guide to blood cells’, Dr Barbara Bain; Blackwell Oxford; 1996
Your immune system is a network of cells, tissues and organs, which protects your body against infection. Lymphocytes – which flow around your body in your blood play an important role in your immune system’s quick reaction to infections. Because ALL affects your immune system, and because the treatment also affects your immune system and bone marrow, you may be more prone to getting infections.

You can find more information about how to manage infections in our booklet > Supportive care

Your lymphatic system
The lymphatic system is an important part of the immune system. A network of thin tubes called lymph vessels run around your body. The vessels collect fluid called lymph and return it to your blood. Lymph bathes all the cells in your body. It contains lots of lymphocytes, carries nutrients and takes away bacteria from infected areas.

Along the lymph vessels are small lumps of tissue called lymph nodes or lymph glands. There are many of these in your body. It may be possible for you to feel normal lymph nodes in the neck and groin, particularly if you’re slim. If you get an infection when you’re healthy these nodes can swell and become tender (swollen glands).

As lymphocytes pass through the lymph nodes they are changed and ‘activated’ to fight certain types of infection.

Your spleen is also part of your lymphatic system. It can do some of the same work as the lymph nodes. It also filters out old or damaged cells from the blood stream and helps to fight infection.
What is ALL?

ALL is a form of cancer that affects blood-producing cells in the bone marrow. The cells affected in ALL are lymphocytes.

ALL affects cells called lymphoblasts (or blast cells, for short). They’re a type of white blood cell, which are a vital part of your immune system. Lymphoblasts are the immature cells that should develop into lymphocytes, in your bone marrow.

Your body needs new lymphocytes all the time, and it usually makes the right amount. When people have ALL this process goes wrong. The blast cells reproduce too quickly, and they don’t mature properly. We’ll refer to these immature blast cells as leukaemia cells.

The leukaemia cells build up in your bone marrow and eventually there’s no room for normal blood cells to be made there. So your body doesn’t have enough white blood cells, red blood cells, or platelets to work properly.

ALL develops more quickly than some other blood cancers, so quick diagnosis and treatment are really important.

Our researchers are continually making new discoveries that help us understand ALL: how it develops and how we can treat it.
Types of ALL

There are different subtypes of ALL. The treatment you’ll have may differ depending on which specific type you’re diagnosed with. There are different types of lymphocytes, known as B cells and T cells. When you have ALL, it usually affects one type or the other, so doctors will say you have either:

› **B cell ALL** (this is the most common type)
› **T cell ALL** (more common in young people and men)

**Philadelphia positive ALL**
There’s a third type of ALL called Philadelphia positive ALL, which around one in four people with ALL have.

This is where the leukaemia cells divide more often and live longer than usual because of a very specific fault. To explain this fault we’ll give a very brief explanation of chromosomes.

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

There are 23 pairs of chromosomes in each cell in your body. When cells divide to form new cells, normally the chromosomes stay the same in each new cell.

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

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

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

If doctors can detect the BCR-ABL1 fusion gene, it can help them to diagnose ALL – and also monitor your response to treatment. The standard treatment for Philadelphia positive ALL is drugs that inhibit the tyrosine kinase enzyme and block its effects.

**Other subtypes of ALL**
There are numerous other genetic subtypes of ALL. Some of them are known to be related to better or worse outlooks, although, at present, there are no specific therapies for these subtypes and they are all treated in the same way. This is a very active area of research for scientists internationally.
Who gets ALL?

We don’t know exactly what causes ALL yet. What we do know is that it’s not possible to ‘catch’ ALL or any other type of leukaemia. Below are some factors that may affect a person’s chances of getting ALL.

**Age**

ALL is the only type of leukaemia that happens more often in children than in adults. When ALL does happen in adults, it’s more likely to affect younger people. It’s less likely in middle age, and then starts to occur more often again in older people. We don’t know the reason for this pattern.

**Gender**

ALL is slightly more common in men than women. We don’t know why.

**Family history**

As far as we know, adult ALL doesn’t usually run in families. There are some rare cases where this can happen, but it doesn’t apply to most people.

**Radiation**

Radiation in high doses can lead to leukaemia, but it’s unlikely to cause many cases in the UK, if any at all.

It’s important to remember that none of your lifestyle choices have contributed to this condition.
It's important to remember that not everyone will get all of these symptoms – each individual is different.

Signs and symptoms

The main signs and symptoms you get with ALL are due to you not having enough normal blood cells, because there are too many blast cells in your bone marrow. This can cause a number of symptoms, which may make you feel run down, or like you've got the flu. The four most common signs and symptoms are:

**Fatigue**
This is caused by anaemia (a low red cell count in your blood).

This can lead to:
› tiredness that lasts a long time
› breathlessness, even when you're resting
› chest pain.

**Bruising and bleeding**
This is caused by a low platelet count in your blood.

This can mean:
› bruising easily
› bleeding from your gums or nose
› bleeding from wounds, which is hard to stop
› black, tarry stools or stools that are streaked with red, because of bleeding in your gut
› headaches, or difficulty speaking or moving parts of the body, because of bleeding into the brain.
Signs and symptoms

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 of them with my healthcare team.

Infections
This is caused by a low white cell count in the blood. This can lead to infections and fevers that last for longer or happen more than normal.

Weight loss
This is caused by a high metabolism (the rate you burn energy from food). We don’t completely understand why the metabolism speeds up in people with ALL.

Other symptoms
You or your doctor may also notice that your lymph nodes (glands) are enlarged. You may notice these in your neck but they could be in several places around your body, such as your armpit or groin. Your doctors may also feel an enlarged spleen or liver when they examine your abdomen (stomach). In T cell ALL, enlarged lymph nodes in the chest might show up on an X-ray.

It’s important to remember that many of the symptoms seen in ALL can also happen in people who have common, less serious conditions.

Because leukaemia is rare and the symptoms are common, it can sometimes take some time to diagnose. Once your doctors do suspect leukaemia, they’ll act quickly to make sure you get the tests and treatment you need.
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

Your doctors will perform laboratory tests to confirm whether you have ALL, and what type you have. Your doctor starts by looking at the big picture, and then narrows in on your exact diagnosis.

Tests to diagnose ALL

It can be hard to understand how doctors know you have leukaemia, when there’s nothing like a lump you can see, as you might get with other cancers. Your doctors diagnose leukaemia by looking at your blood, your bone marrow and your genes. Your doctors will go through the following tests to confirm a diagnosis of ALL:

Full blood count

A full blood count (FBC) measures the number of each type of cell in your blood: red cells, white cells and platelets. Your GP may send you for this test because you’re unwell and they don’t understand why, or you might have one as part of a routine check-up.

You’ll have a blood sample taken, then, in the laboratory, automated machines very accurately count your blood cells. If the count is too high or too low, a small drop of your blood is smeared onto a slide and the doctor or a senior scientist will look at it under the microscope.

If your FBC shows that you may have ALL, you’ll need to go to hospital for more tests. If you’re diagnosed with ALL, you’ll have regular FBCs to monitor your condition during and after treatment.
Your doctors will probably want to take a bone marrow sample. This is the most accurate way of diagnosing the type and level of leukaemia you have. Sometimes it’s not possible to make a diagnosis from a blood sample alone, because there may be leukaemia cells in your bone marrow, but not circulating in your blood yet. A bone marrow test is also useful at this point because it can be used to compare your blood cells after treatment to see how well you’ve responded.

Here’s what happens: you’ll lie on your side and a small needle will be used to give some local anaesthetic (only numbing a specific area of the body) into the skin around the back of your hip bone. Using an aspirate (a larger needle which is inserted into the bone), a small amount of bone marrow is taken from your hip bone; this procedure is called a bone marrow aspirate. A piece of bone may also be taken using a different needle, and this is called a trephine.

Taking the sample is usually quite quick, but it may feel painful while it’s being done. For this reason, patients are usually offered sedation if they want it. This may be using gas and air (more familiarly used during childbirth) or with an injection into the veins.

You’ll be advised not to take ibuprofen-based painkillers during this time, as they can cause bleeding which can be especially dangerous if you have a low platelet count.

Your doctors will then look at your bone marrow sample under a microscope.

This test gives your doctors more information about:

- the structure of your bone marrow
- the types of blood cell in your bone marrow
- the number of blood cells in your bone marrow (too many or too few).

The results can also tell them if the blood cells in your bone marrow are cancerous.
Cytogenetics
Every kind of cancer, including blood cancer, changes the genes of the affected cells. These gene faults are not the same thing as genes passed through families (the fault is only on your leukaemia cells).

The study of these gene changes is called cytogenetics or molecular genetics. Cytogenetic tests are usually done on cells from your blood or from your bone marrow, before you start any treatment.

Information about these gene changes is very important. It’s these cytogenetic tests that will tell your doctors what subtype of ALL (B cell, T cell or Philadelphia positive) you have, and therefore what your treatment is likely to be.

Flow cytometry
(flowmophenotyping)
Flow cytometry, or immunophenotype analysis, looks at the pattern of proteins on the surface of your leukaemia cells. Samples from your bone marrow or blood cells 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 a leukaemia cell, but not to a normal cell.

As the cells pass through a machine, the results are plotted on a graph, showing how many leukaemia cells are present, and what type they are. This test can confirm a diagnosis of ALL, and tell your doctor exactly which type of ALL you have.

“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.”

For more about subtypes of ALL > see page 16
Additional tests

Depending on how well you are after you’re diagnosed, your doctors may want to do additional tests. These tests aren’t routine and some aren’t necessarily done at diagnosis, so don’t worry if your doctors don’t suggest you have them.

Lumbar puncture

Leukaemia cells can get into the fluid that cushions your brain and spinal cord. This fluid is called the cerebrospinal fluid, or CSF. A lumbar puncture is a test to see if there are leukaemia cells in your CSF. The doctor inserts a thin needle into your spine, to collect a sample of the fluid. You’ll have a local anaesthetic to numb the area first. After fluid has been collected, drugs used to treat ALL will be injected through the needle (which are safe to give in this way).

It’s likely that you won’t have sedation during lumbar punctures, as it’s useful for patients to be awake to report any symptoms.

Often, you won’t need a lumbar puncture when first diagnosed, but you’ll generally need several during the course of your treatment.
Imaging (scans)

X-ray
X-rays provide very good images of the denser tissues in the body, such as bone. Your doctors may use an X-ray when you’re first diagnosed, to check for infection or any other chest problems.

CT scan
A CT (computed tomography) scan is a type of X-ray. You’ll lie on a table that moves into a cylindrical tunnel while the pictures are taken. You may need to have a dye injected into one of your veins, to help get a better image. This is not a routine test during the diagnosis and treatment of ALL but there may be specific reasons it needs to be done, such as if you have a swollen liver or spleen at diagnosis.

MRI scan
Another type of scan is an MRI (magnetic resonance imaging). 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. You may need to have an injection of some dye. An MRI is not a routine test done during diagnosis and treatment of ALL, but there may be specific reasons it needs to be done.

PET scan
A PET (positron emission tomography) scan is similar to an MRI, but you’re injected with a radioactive sugar. The levels of radiation used are very small and won’t harm you or anyone nearby. Again, this test is not necessarily routinely done at diagnosis, but it may be done if you have swollen lymph nodes, and doctors want to diagnose. It may also be done to compare your results after treatment.
Blood tests

Liver function tests
This is a blood test to check if your liver is working normally. It’s very important if you need chemotherapy, as many drugs are broken down in the liver. If your liver isn’t working normally, it might 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 need. It’ll also show if you’re dehydrated, and any damage that may have been caused either by the cancer or your treatment. You’ll usually have your kidneys checked every time you have an appointment at the hospital.

Infection screening
When you’re diagnosed with ALL, you’ll also have a general health check-up. This will help work out if you’ll be particularly vulnerable to side effects from treatment. You’ll have a range of tests to check your heart, liver and kidney function. It’s also routine to be tested for HIV, hepatitis B and hepatitis C, so that if you have these conditions without knowing, they can be treated at the same time as your ALL treatment.

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

There’s a website supported by the Department of Health, which has more information on tests > labtestsonline.org.uk
**Your healthcare team**

*If you’re diagnosed with ALL, your hospital will give you the names and contact details of your consultant, clinical nurse specialist and other members of your healthcare team – there’s space to write them in 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 blood cancer have a haematologist as their main doctor. A haematologist specialises in treating people with blood diseases. Your consultant will be an expert in treating your specific condition.

**Your clinical nurse specialist**

They are your key point of contact with the rest of your healthcare team. You may like to see your clinical nurse specialist when you’re first diagnosed, to talk about ALL and your care.

Your clinical nurse specialist will be with you right through your treatment, and you can always go to them with any worries or questions. They get to know you well, and can support you and your family and friends, and help you access resources that could help you through your treatment. Many patients say it can be really helpful to have them by their side at every step.

**Your multidisciplinary team**

When you’re diagnosed with ALL, your care is discussed at a multidisciplinary team (MDT) meeting. An MDT brings together doctors, nurses and any other specialist staff who’ll 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 like 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 others 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.

You can find a list of support organisations and their contact details on page 77.
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, so do whatever works for you.

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

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

› 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.

Your questions

You can find a list of questions you might want to ask on page 83

You can read about the experiences of other people who are going through, or have been through, the same thing on our website > bloodwise.org.uk/patient-support
Your questions
There's more information about cancer and how it can affect your work or study on page 70

You can find a list of support organisations on page 77

I didn’t know whether to tell people I had cancer and at first only told people on a need-to-know basis – I didn’t know if people would understand. But I’ve found since telling people that I’ve largely continued to be treated as ‘me’ rather than ‘me with cancer’.

Telling people
Many people tell us that keeping in touch with loved ones during their cancer treatment 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.

Talking to children and teenagers
Talking to children and teenagers about your cancer diagnosis can be a difficult thing to do. There are many agencies to support you and offer you advice about how to explain it to children of different ages.

Telling your GP
Your team at the hospital will keep your GP informed about your condition and any treatment you’re having. They’ll usually send your GP a letter with this information.

As the patient, you’ll often be sent a copy too. These letters can have a lot of medical terms in them, which you might not have heard before. Or you might read something that worries you. If this happens, let your hospital or GP know. A quick chat with them might help to reassure you.

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

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

Macmillan also produce a booklet on talking to children about cancer > go to macmillan.org.uk then search for ‘talking to children and teenagers’
Your treatment will depend on your individual condition, your general health and your wishes.

Treatment

Throughout your treatment, your healthcare team will always discuss your treatment options with you. They’ll want to hear what you think, answer your questions, and explain anything you’re unsure about.

Treatment planning

It’s very important to start treatment soon after you’ve been diagnosed, because ALL can develop quickly. It may feel like things are happening very quickly, but don’t be afraid to ask as many questions as you need to.

Your doctor will recommend a treatment plan and talk to you about what it will involve. Treatment plans are tailored to each individual, so if you meet someone else with ALL, they might be having different treatments. Some treatment programmes (also called protocols) are very intensive, while others are less intensive. What’s right for you depends on your age, general health and the type of ALL you have.
You may be offered less intensive treatment in older age. The disease becomes more difficult to cure with older people. We don’t know the reason for this – it could be down to the underlying genetics of the disease in older patients, or it could be due to the fact that the intensive treatment cannot be tolerated as well in older age.

However, treatment decisions are never based on age alone, but on general health and fitness. Your wishes are always taken into account.

Your treatment plan may need to change along the way. If this happens, your healthcare team will explain why, and talk to you about the different options available to you.

Most people in the UK who are diagnosed with ALL are invited to join a clinical trial.

Steroids
Most people will begin steroid treatment while their treatment plan is being confirmed. The steroids will start working to get rid of the leukaemia cells.

“...My specialist team supported me throughout my treatment and were always there to answer any questions that I might have had...”

Types of treatment
The best treatment for you will depend on your individual situation. Generally, treatment for ALL can be divided into:

› **Active treatment**, which is aimed at getting rid of the leukaemia cells and helping your bone marrow work normally again.

› **Supportive care**, which helps you feel better and supports your body through some of the problems caused by ALL and the treatment.

Everyone will receive supportive care, whether they have intensive or non-intensive treatment. Some people may choose not to have any active treatment, or the doctors might not recommend it as the best option. If this happens, patients may choose an approach called palliative care to help control the symptoms of ALL, and improve quality of life. The palliative care team will be able to support both you and family members.
Clinical trials
A clinical trial is a planned medical research study involving patients. These studies are done with the aim of looking for new treatment options and improving 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 offered outside of the trial. You’ll be very closely monitored and have detailed follow-up.

A clinical trial often involves testing the best current treatment available against one that could be better. It’s important to note that whether your treatment is a part of a trial or not, your safety and wellbeing is always the first priority.

The UK has a proud history of conducting clinical trials in ALL, which have contributed significantly to developing and improving treatments for patients with the disease. It’s highly likely that you will be approached by your doctors and nurses to consider taking part in one of the major, ongoing national trials, and specific information will be given to you at the time. If you’re not given information about one of our national trials (such as UKALL 14 for younger/fitter patients and UKALL 60+ for older/or less fit), and you believe you would be interested, you should ask your doctor about it.

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

Phases of treatment
Chemotherapy is the main active treatment for ALL. You’ll be offered a combination of chemotherapy drugs in line with your treatment plan (your healthcare team may call this a protocol or regimen).

Your treatment will be divided into three phases, or ‘blocks’. This section gives an overview of the different phases of treatment.

Your healthcare team will explain to you in detail which drugs you’ll have and when during each phase. Your doctors may be able to give you a chart with this information on too.
**Phase 1: remission induction**

The aim of this first phase of treatment is to get you into remission. This involves using several chemotherapy drugs in combination. The goal is to clear the cancer cells completely from your bone marrow and blood. This works for about nine in ten people.

The length of this treatment stage depends on your individual situation. It usually lasts between three weeks and two months.

Because there’s a risk of infection or bleeding, you’re likely to spend all, or most, of this stage in hospital, with your doctors and nurses close by.

**Philadelphia positive ALL**

If you have this type of ALL, your treatment will be quite different. Doctors use drugs called tyrosine kinase inhibitors (or TKI) to treat it. A drug called imatinib is one example of a TKI. These drugs target the abnormal protein produced by the cancer cells. When combined with standard chemotherapy, these drugs can greatly increase the chance of a cure for people with this kind of ALL.

**Intrathecal chemotherapy**

Around this time, you may also have what’s called intrathecal chemotherapy to give extra protection to your brain and spinal cord. Chemotherapy drugs will be injected into the cerebrospinal fluid (or CSF) around your spine to try and prevent leukaemia cells from entering the fluid. This procedure is the same as a lumbar puncture (see page 31). After the standard lumbar puncture, and after fluid has been removed, the drugs are carefully introduced.

**Testing for remission**

When your initial chemotherapy is finished, doctors will look at samples of your blood and bone marrow under a microscope. If they can’t see any leukaemia cells, this means you’re in remission.

**Minimal residual disease tests**

Increasingly, minimal residual tests (MRD tests) are being used to test for remission in ALL, particularly within clinical trials.

When your doctors look at blood cells through a microscope, the lowest number of leukaemia cells they can detect is about one leukaemia cell in 20 normal cells. The MRD test is much more sensitive and can detect leukaemia cells at levels as low as one leukaemia cell in 100,000 normal cells.
**Phase 2: consolidation**

This phase is also sometimes called post-induction or post-remission therapy.

It's possible that some leukaemia cells could still remain after your initial chemotherapy, even if doctors can't see any under the microscope. So when the induction phase is finished, you'll have further chemotherapy to clear any leukaemia cells that might remain in your blood and bone marrow.

You might have the same chemotherapy drugs as in the remission induction phase, with other drugs added. The drugs might be changed around so the leukaemia cells don't become resistant to them.

This stage usually lasts for several months. For most of this time you may be able to stay at home, only visiting hospital for treatment or check-ups (this is known as outpatient treatment). If you have an infection or become ill at any stage during your treatment, you may need to return to stay overnight in hospital for a while.

**Stem cell transplant**

Some people may be offered a stem cell transplant (also called a bone marrow transplant) during this phase.

Transplants can make you feel very unwell and can bring complications, so doctors would look at a number of factors before offering you one, including your age and general health, and how well you responded to your initial treatment.

A transplant aims to give you healthy stem cells, which then produce normal blood cells. There are two types of stem cell transplant:

- allogeneic or allograft – this uses stem cells from another person (a donor)
- autologous or autograft – this uses your own stem cells but is rarely used for ALL.

**Phase 3: maintenance**

Maintenance therapy aims to prevent relapse and usually involves low doses of chemotherapy and steroids. The maintenance phase is really important because without it, there's a higher chance that the ALL could come back, even if you seem to be in full remission. We don't know why this happens, but we do know that having maintenance therapy gives much better results in the long term.

This stage usually takes about two years. Unless you get an infection or have a relapse, you shouldn't need to stay in hospital and most people on maintenance therapy can go back to work or college.

There's more information on stem cell transplants in two of our other booklets
> Bone marrow and stem cell transplantation
> Seven steps: blood and bone marrow transplantation
Treatment of relapse

As many as nine out of ten adults with ALL will go into remission (this doesn’t necessarily mean that they’re cured).

Unfortunately though, some people relapse (the ALL comes back). Relapse often happens because some leukaemia cells remain, often because they’ve become resistant to the drugs you’re being treated with.

If you do relapse you may be offered the opportunity to go on another clinical trial looking at new treatments for relapsed ALL, which uses a different treatment plan, or protocol.

The first step in treating relapsed ALL is usually to repeat the remission induction programme. This treatment might need to be more intense than the first time around. In medical studies, a second try at induction remission therapy has worked for 40-70% of people.

At this stage, a doctor may recommend a stem cell transplant.

Some people may decide not to have active treatment any more. Instead they can ask for palliative care, which focuses on relieving their cancer symptoms and improving quality of life.

Supportive care

At the same time as you’re having active treatment for your illness, you will also be offered supportive care (which is different to palliative care). Supportive care involves help with preventing infections, and offering blood transfusions, mouth care, diet advice, pain management and dealing with complications you may get from the ALL and the treatment.

Here are some examples of supportive care you might be offered while you have active treatment:

Drugs to protect your kidneys
When tumour cells are destroyed, they release a chemical called uric acid, which can damage the kidneys. Drugs called allopurinol and rasburicase can help. It’s also important to drink plenty of fluids, to reduce the risk of kidney problems.

Platelet transfusion
At the start of active treatment, the main side effect is suppression of your bone marrow (a decrease in the amount of blood cells produced). One result is a low platelet count, which can lead to heavy bleeding. A platelet transfusion can help to protect you against this.

Red blood cell transfusions
Another result of bone marrow suppression is low haemoglobin, which can cause anaemia. This can make you feel unwell, so regular blood transfusions can be really beneficial.

Preventing infections
Because ALL and the treatment reduce your white blood cell count, you’ll be more vulnerable to infections. So your healthcare team will take care to protect you from infection at all times. You may also be offered a treatment called a growth factor (commonly known as G-SCF). This stimulates your bone marrow to make more neutrophils, and it helps you to recover from the effects of the treatment.

Fitting a central line
Most chemotherapy for ALL will be injected into the bloodstream through a vein (intravenous infusion).
Drugs will usually be given directly into a tube, known as a central line, inserted into a large blood vessel. This line is kept in over the whole period that you have treatment, so there’s no need for repeated needle-pricks and there’s less risk of infection. There are different types of central line; these include:

› Hickman line – there are a few types of central line that can be put under the skin in your chest; this is the name of one of the most common ones

› PICC line – a central line that’s put into your arm.

For more information on the effects of cancer and its treatment on relationships, sex and fertility, please see our booklet Chemotherapy – what do I need to know?

For more information on managing these and other problems, read our booklet on supportive care > Supportive care

Fertility
Before your active treatment starts, you should also talk to your healthcare team about how it might affect your ability to have children, if that’s relevant and important for you. Active treatment can affect your fertility. Because treatment for ALL has to start so quickly, there isn’t usually time to preserve a woman’s eggs. Men sometimes have a chance to freeze their sperm for the future.

If you do go on to have children, studies have shown that your treatment will have no impact on their health. Similarly, apart from in rare cases, the likelihood of your child getting ALL would be no greater than any other child. Your healthcare team will be able to discuss your options with you, and refer you to a fertility department, if appropriate.
Side effects

There are some potential side effects from treatment for ALL. Different people have different responses to their treatment. Even if two people are having the same treatment, they may have a different experience. So you might not get all of these side effects – try to bear this in mind when you read about them. You may also like to talk to your healthcare team about possible side effects.

Short term side effects from chemotherapy
You may experience some short term side effects from chemotherapy treatment. They could include:

- an achy flu-like feeling
- constipation
- diarrhoea
- bruising and bleeding
- extreme tiredness (fatigue)
- hair loss
- infections
- rashes
- a sore mouth or mouth ulcers
- nausea and vomiting
- abnormalities of liver function (this doesn’t usually cause symptoms, but sometimes people may become jaundiced).

You’re unlikely to have all of these, and it’s important to remember that they’re only temporary. If you do have side effects tell your healthcare team, as they may be able to help you manage them. There are medicines you can take to help with nausea and vomiting, for instance.

Long term side effects from chemotherapy
With any type of chemotherapy, there’s always, at least, a small risk of long term side effects. These could include problems with the thyroid, heart or lung. The risk of long term side effects will depend on how many cycles of treatment you’ve had, the treatment intensity and whether you’ve had a transplant or not. Every case is individual, so your healthcare team will talk to you about this in more detail.

Short term side effects from steroids
Steroids can cause side effects such as:

- increased appetite
- mood changes and irritability
- weight gain
- muscle weakness (especially in the legs).

Again, if you have any of these side effects it’s worth discussing this with your healthcare team, as they may be able to help.

There’s more information on chemotherapy in another one of our booklets > Chemotherapy – what do I need to know?

For more information about supportive care, see one of our other booklets > Supportive care
Follow-up

Going to your follow-up appointments is really important if you’ve had ALL. Your healthcare team will stay on the lookout for any signs of relapse, or complications from your treatment. The appointments can also help you adjust to everyday life again – it can feel very different once you’ve had ALL and your treatment has finished.

In some ways, you can think of your follow-up care as starting during the maintenance phase of your treatment. At this stage, you’ll have checks every two or three weeks. Then it’ll be more like every two or three months. Gradually, your checks will become less frequent, until you’re only having them once a year.

When you’re in complete remission, and have moved on to maintenance treatment, your lifestyle can get back to normal in almost every way. You should be able to return to work and take up your regular activities again. You should be able to resume your sex life if you want to, enjoy a healthy diet and drink alcohol within sensible limits.

You won’t normally need to stay in hospital any more, unless you relapse or get a severe infection. If someone you live with catches an infection, you might want to ask your healthcare team whether you need to take any special precautions.

After treatment, you can also travel and go on holiday. You might be able to have any travel vaccinations (jabs) you need, but check it’s ok with your consultant first. In particular if you’re taking steroids or you’ve had a stem cell transplant, you should never have a vaccination without talking to your consultant first.

If you’re having treatment from any doctor who isn’t your main consultant or GP, make sure you tell them that you’re having treatment for ALL, or that you’ve had it in the past.

For more information on companies offering specialist travel insurance to people who have or have had cancer, see page 81.
Every person is different, so your consultant and healthcare team are the best people to ask about your likely outlook (prognosis).

The outlook

The outlook is different for each person with ALL. The best person to talk to about your individual prognosis is your consultant, or someone on your healthcare team. Generally, up to eight in ten people can expect to be in remission after active treatment (although this may not be a complete cure).

There are a number of factors which may affect your outlook. The main ones your healthcare team will look at are:

- **your age and general state of health**: ALL is typically easier to treat in younger people
- **your white blood cell count at the time you’re diagnosed**: the lower it is, the better your response to treatment is likely to be
- **the type of ALL you have**.

Talking about your prognosis

You may find it hard to ask or talk about your prognosis. This might be more difficult at first, and you might feel more ready to do this later on, once you’ve had more time to think about it.

Sometimes those close to you may want to know, even if you prefer not to. 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.
Your healthcare team should look after your emotional needs, as well as your physical ones.

Everyday life and ALL

If you’ve been diagnosed with ALL, you might feel 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.

Your healthcare team 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. You may be offered referrals to counselling and the opportunity to speak to the complementary therapy team, if this is something you think you’d find useful.

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

When you’ve finished your treatment it’s important to contact your healthcare team at the hospital straight away if you notice any new symptoms, don’t wait for your next check-up. Symptoms to watch out for include:

› swollen glands
› bleeding/bruising
› infections
› a temperature
› increasing fatigue
› night sweats.

Keeping active
You might feel tired a lot (fatigue). This might be caused by your condition 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 of any particular exercise programme improving 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.

You may hear healthcare professionals talk about a neutropenic diet. This means a diet for people with a weakened immune system. Your healthcare team will talk to you about this.

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

You might also like to get in touch with an organisation which can offer support for you and people close to you > see page 77
Vaccination
It’s a good idea 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 ALL but will still offer some protection.

If you have ALL, avoid having any live vaccines during your active treatment. Fortunately only a few vaccines used in the UK are live. The most commonly used ones are MMR (mumps, measles and rubella) and shingles. The yellow fever vaccine, occasionally needed for travel to certain areas, is also a live vaccine.

Shingles
Shingles is the 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, as it’s caused by the same virus, which can lie dormant in your body for years. You’re more likely to get shingles if your immune system isn’t working well. The drug acyclovir is usually given to all patients during ALL treatment to prevent this from happening.

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 which then crust over.

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

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

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

There’s some evidence that some complementary therapies may help, particularly with the side effects of standard treatment. If you’re considering using any form of complementary therapy it’s very important to tell your healthcare team, as some treatments may interfere with the standard treatments you’re having.

We have a booklet on complementary and alternative therapies

Complementary and alternative therapies (CAM)
Practical support
If you work or are studying you might want to talk to your employer or college about your condition, or ask someone to do it for you. Most employers will do all 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. When you have to stay in hospital for your initial 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 ALL 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. Employers and places of study are required by law to make reasonable arrangements for people with disabilities and can’t discriminate against you.

An example of a reasonable arrangement would be if you need time off to go to hospital for treatment. Your employer or college has to allow this. They aren’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 visiting 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 explain which benefits you might be able to receive. These benefits might be especially useful if you’re on a low income or you’re unemployed.

If you’re worried you can ask to speak with an advisor as soon as possible after your diagnosis. Alternatively, your hospital might 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.

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

For a list of other organisations with useful information about your finances, see page 80
Our researchers are making discoveries that will have a positive impact for people with ALL.

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 ALL research projects going on. Here’s an overview of some of the things our researchers are looking into.

Targeted therapies

Some cancers can start when genes responsible for controlling cell growth and division are altered so the normal stop/go signals are disrupted. One type of fault is when bits of chromosomes – the packets of genetic material in our cells – swap around. This can shunt genes together that are usually far apart.

Because the DNA template of genes is used to make various proteins in our cells, these hybrid cells often generate abnormal ‘fusion proteins’. When this occurs in bone marrow cells, these rogue proteins can trigger the cells to grow out of control and cause acute leukaemias – such as ALL – to develop.
Philadelphia positive ALL forms because of a fusion protein. This type of fusion protein is the most common genetic fault found in adult ALL patients and these patients have the poorest clinical outlook, so new treatments are desperately needed. It produces an enzyme known as tyrosine kinase, which activates abnormal signal patterns causing cells to grow out of control. However, if there’s too much of this activation, the leukaemia cells die. By understanding this over-production, scientists in Cambridge are hoping to develop new, precisely targeted therapies.

At University College London, researchers are following ALL patients over 60 years old who are taking part in a clinical trial. This is to understand how certain genetic faults drive the disease and how different faults affect the outlook for individual patients. The aim is to provide a foundation to develop tests that better predict and monitor response to therapy, leading to more tailored treatment approaches.

Tackling treatment resistance

ALL can affect either of two types of white blood cell – the majority affect those known as B-cells whilst the rest affect T-cells. Researchers have discovered that nearly half of high risk patients with T-cell ALL have similar genetic errors. These errors mean that other genes are continuously switched on, not only causing leukaemia in the first place but possibly causing resistance to chemotherapy. Our scientists in London are using zebrafish to screen new drugs that selectively kill abnormal T-cells while sparing normal T-cells. The aim is to develop effective drugs that are lethal to leukaemia cells in high risk T-cell ALL patients, but with fewer side effects to the patient.

Other scientists in Newcastle are also studying drug resistance in ALL. Leukaemia cells often stop responding to therapies because they develop new genetic faults that help the remaining leukaemia cells to find new ways to survive and grow, potentially leading to a hard-to-treat cancer coming back. By studying ALL cells before and after treatment, as well as mice with leukaemia, these researchers hope to discover how treatment-resistant disease can be best targeted with new therapies.

Viral therapy

Taking a different approach, these London researchers are aiming to exploit the natural ability of viruses to infect and kill cells. The researchers are genetically ‘reprogramming’ measles viruses to selectively infect and kill ALL cells from adults, leaving normal cells unharmed. To avoid the patients’ natural immunity that might clear the measles virus therapy, the researchers are investigating how to best combine the modified measles virus with two drugs: one that weakens certain immune responses, and one that might make the ALL cells more recognisable to the virus.
There are lots of organisations out there who offer information and support to people affected by ALL.

Places you can get help and support

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

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

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

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

› 0808 2080 888  patientservices@bloodwise.org.uk

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

› 0808 808 0000  macmillan.org.uk

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

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

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

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

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

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

› 0303 303 0303  
› anthonynolan.org

BPositive
Patient support group for people with leukaemia.

› bpositive.org.uk

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

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

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

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

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

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

Macmillan Cancer Support Grants
A Macmillan grant is a one-off payment for adults, young people or children with cancer, to cover a wide range of practical needs.
› macmillan.org.uk/HowWeCanHelp/FinancialSupport/MacmillanGrants

Travel insurance

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

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

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

Questions to ask

It’s easy to forget the questions you wanted to ask when you’re sitting with your healthcare team and trying to take in lots of new information. Some people find it useful to write down the questions they want to ask, before they get there.

Tests

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

› Will I need to have treatment? If so, when?

› What does the treatment do?

› Is there a choice of treatments?

› Is there a clinical trial that I could join?

› What’s likely to happen if I decide not to have the treatment my healthcare team recommended?

› If I don’t need to start treatment straight away, how will I know when I need to start it?

› Who do I contact if I take a turn for the worse?

› Who can I contact if I have any questions?

› Is there any written information available or any recommended websites?

My main treatment

› What type of treatment will I have?

› Will I have to stay in hospital?

› If not, how often will I need to go to hospital as an outpatient?

› What drug regimen will I be given? Will I be given it by mouth, injection or drip (into a vein)?

› Will my treatment be continuous or in blocks of treatment with a break in between?

› How long will my treatment last?

› What side effects could I get from my treatment?

› Can side effects be treated or prevented?

› Will they affect me all the time or only while I’m taking certain drugs?

› What are the fertility risks with treatment and what options are available to me to protect my fertility?

› What effect is the treatment likely to have on my daily life?

› Will I be able to carry on working or studying?

› Will I need to take special precautions, for example against infection?

› Will I need to change my meal times or work my drugs around these?

Stem cell transplant

› Is a transplant an option for me?

If I’m having a transplant:

› How long will I be in hospital for?

› Do I have to be in isolation?

› How long will it be before I get back to normal?
Choosing the right treatment for you

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

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

Follow-up

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

Relapse

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

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

We take a leading role in research into blood cancers; we ensure patients have access to innovative clinical trials where possible; we provide information; and we’re a voice of influence when it really counts.

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

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

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

As one of the UK’s leading blood cancer charities, we feel both the responsibility and the opportunity that we have to make patients’ lives better.
Our patient services
We put the patient at the heart of everything we do. We strive to help everyone affected by a blood cancer to live the best possible quality of life, for life. Alongside our ongoing commitment to support vital medical research into the cause and cure of blood cancers, we’re developing and delivering quality support and services for patients, their family, friends and carers to help with the emotional and practical impact of blood cancer.

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

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

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

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

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

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

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

bloodwise.org.uk/patient-support

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

bloodwise.org.uk/focus-groups

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

bloodwise.org.uk/cycling

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

bloodwise.org.uk/running

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

bloodwise.org.uk/triathlon

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

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

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

bloodwise.org.uk/corporate

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

bloodwise.org.uk/localfundraising

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

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

bloodwise.org.uk/special-events

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

Corporation fundraising

Local fundraising

Special events

Being part of our online community
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:

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

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

**Blasts**
A term used to describe very immature cells in the bone marrow. It’s often used as a shorthand to describe leukaemia cells.

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

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

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

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

**Fatigue**
Fatigue is a feeling of extreme tiredness which doesn’t go away after rest or sleep. It’s one of the most common problems that patients with cancer have.

**Flow cytometry**
The study of physical and chemical characteristics of blood using laser beams.

**Intrathecal**
A method of giving drugs by injecting them into the cerebrospinal fluid, which bathes and protects the brain and spinal cord.
**Lumbar puncture**
A test to remove a sample of cerebrospinal fluid (CSF). It’s also a way of injecting a drug into the fluid. In ALL, leukaemia cells can sometimes be present in the CSF.

**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 normally involved in producing antibodies to fight infection.

**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.
Bloodwise
For adults and children with blood cancer

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