Bloodwise

# Acute lymphoblastic leukaemia (ALL) in children and young adults up to 16 years

For adults and children with blood cancer

bloodwise.org.uk

INFORMATION FOR PARENTS

*When we found out our child had leukaemia, we were in a state of shock and disbelief. There was so much to take in, it was overwhelming. Having everything written down at least meant that we could take our time and process the information on our own terms.*

A team of people helped produce this booklet. We'd like to thank a member of our Medical Advisory Panel, Dr Rachael Hough, 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 Kerry Baker.

Bloodwise staff revised the text to make it easy to read, and parents and carers of children with ALL checked it for understanding. A member of Bloodwise's Medical Advisory Panel, Dr Rachael Hough, is responsible for the content overall.

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



The information in this booklet is correct at the time it was printed (September 2015).
Date of next review September 2018.
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Registered charity 216032 (England & Wales) SC037529 (Scotland)

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

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

This booklet is one of many we make – you can find a list of our other booklets on page 94. For the very latest information, visit our website.

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

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


Our website


Another of our booklets

Another page of the booklet


Another website


Another organisation

# Contents



# Introduction

This is a booklet for parents or carers of children with ALL, and for people who know a child with ALL.

Being told that a loved one has 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 child's condition and feel a little bit more in control throughout this time. We'll answer as many of the questions you may have along the way as we can – from symptoms through to tests, treatment and living with ALL, and where you can get support.

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

# Acute lymphoblastic leukaemia at a glance

ALL is the most common type of childhood leukaemia – and in fact the most common type of childhood cancer too. Survival rates have increased dramatically over the past 50 years, with 90% of children with ALL now treated successfully.

### What is ALL?

ALL is a form of cancer that affects blood-producing cells in the bone marrow. It occurs when these cells don't mature properly and become cancerous.

### Who gets ALL?

ALL is the most common type of leukaemia in children. Boys are slightly more likely to develop ALL than girls; we don't know why.

### What's the outlook?

ALL is one of the most treatable cancers in children. The cure rate for ALL in children under 16 is now generally agreed to be around 90%. The disease can sometimes come back during or after treatment (known as a relapse). This makes it more difficult to treat, but there are still other treatment options if this is the case for your child.



**ALL can affect any child, but it's one of the most treatable cancers in children.**

### What are the treatments for ALL?

Chemotherapy is the main treatment for ALL. Your child will follow a treatment plan involving chemotherapy drugs, steroids and other medicines.

If your child experiences a relapse, they'll need more intensive treatment, which usually involves further chemotherapy or, rarely, a stem cell transplant.

Throughout your child's treatment, your healthcare team will support you, your child and your family.

### Can ALL lead to any other conditions?

A small number of children may develop health problems later in life as a result of treatment for ALL. We're constantly looking for ways to reduce the long term side effects of treatment.

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



# Blood, bone marrow and the immune system

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

## Blood

The blood has four important functions:

**Transport system**
It carries food, oxygen and proteins to different parts of the body. It also carries waste chemicals to the kidneys and lungs so they can be removed from the body.

**Defence system**
White blood cells are part of the immune system, which fights infections. This is the function that's most affected by ALL.

**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.

## Bone marrow, blasts and blood cells

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

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

A lot of blood cells are made in the bone marrow every second because our bodies need them. If everything's working normally, we make the right number of each type of cell to keep ourselves healthy. If there are too many or too few of any type of blood cell, this can make you unwell.

### Blood cells

Blood contains three types of cells: red blood cells, white blood cells and platelets. Red blood cells, platelets and some white blood cells (neutrophils, monocytes, eosinophils and basophils) are myeloid cells, made from myeloid stem cells. Other white blood cells, known as lymphocytes, are lymphoid cells, made from lymphoid stem cells.

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

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

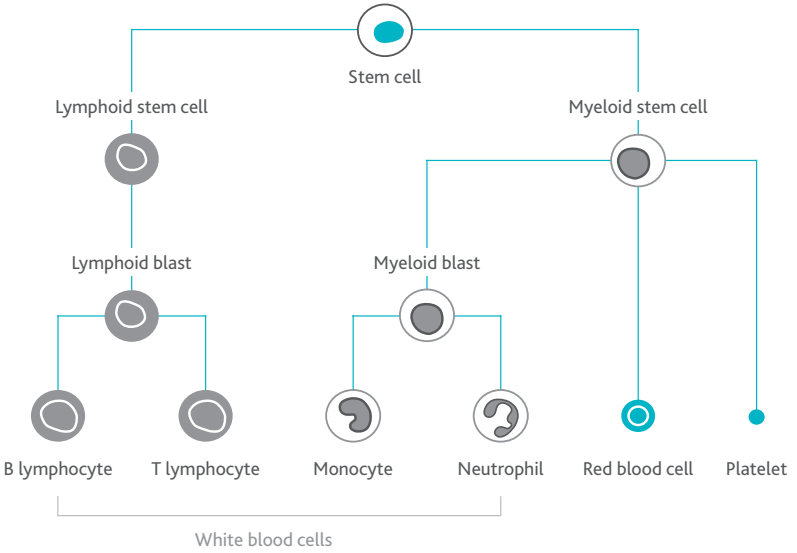
**Platelets (thrombocytes)**
These stick together at the site of any tissue damage and stop bleeding.

### 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. Normal blood ranges vary a lot in children of different ages. Your healthcare team can tell you what your child's normal range should be, and keep you updated on changes in your child's blood count throughout their treatment.



### Blood cell production




## The immune system

The 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: white blood cells and lymphocytes in particular play an important role in this. They circulate around your body in your blood, and fight infections.

There are lots of different kinds of lymphocyte, including ones called T cells and B cells. These can be affected when your child has ALL, which can increase the risk of infections. Your healthcare team can let you know about the ways to reduce your child's risk.

You can find more information about how to manage infections in our fact sheet **Understanding Infection**, which you can download from > **bloodwise.org.uk**

You're not alone: there are almost 300 children diagnosed with ALL each year in the UK. It's the most common type of childhood cancer.



# What is ALL?

ALL is a form of cancer that affects blood-producing cells in the bone marrow. The word 'acute' means developing quickly, while 'lymphoblastic' refers to the type of white blood cell affected by the condition.

When your child is healthy and everything's working normally, the lymphoid blast cells (see page 8) in your child's bone marrow mature into fully formed white blood cells called lymphocytes.

All kinds of cancers involve changes in genes in the affected cells. In a child with ALL, a change occurs that means these lymphoid blast cells don't mature properly and become cancerous. These cancerous cells collect inside the bone marrow, which means there isn't room for enough normal blood cells to be made. This is what causes most of the signs and symptoms of ALL.

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You can find more information on the signs and symptoms of ALL on **page 15**, and more information on the tests used to diagnose ALL on **page 19**

ALL can affect any child. There are a number of factors which you can't control that can lead to ALL.



# Who gets ALL?

One of the most common questions asked by parents is 'Why did my child get leukaemia?'

Our researchers are working all the time to find out more about what causes ALL in children. At the moment we don't know what causes ALL, although changes which occur by chance in the genes of cells in the bone marrow happen in many patients. It's not possible to 'catch' ALL or any other type of leukaemia.

## Gender

Boys are slightly more likely to develop ALL than girls; we don't know why.

## Age

ALL can occur at any age in childhood.

## Family history

ALL can't be passed on from a parent to a child. Children with some genetic conditions (such as Down's syndrome) have a higher risk of developing ALL than other children.

## Radiation

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

It's important to remember that not everyone will get all of the symptoms listed – each child is different.



# Signs and symptoms

There are a range of signs and symptoms your child might get. A lot of them can be hard to spot, as they're similar to the symptoms they might get for a range of other illnesses. The important thing is to look out for symptoms that last longer than normal or seem out of the ordinary.

## Common signs and symptoms

ALL affects how your child's cells function, which can cause a number of symptoms. The most common ones that your child may experience before being diagnosed with ALL are:

### Anaemia

This means a low red cell count in the blood. This can cause:

- persistent tiredness and fatigue
- breathlessness, even when your child isn't active
- dizziness
- paleness.

### Bruising and bleeding

This is caused by a low platelet count in the blood.
This can mean:

- Your child is more prone to bruising than usual, which can occur without your child experiencing many bumps and knocks.
- Your child may experience unusual bleeding or bleeding that takes longer to stop. They may get nosebleeds or bleeding from the gums.
- Your child might develop a petechial rash. These are round, red or purple spots that appear on the skin that are caused by bleeding underneath the skin.

### Infections

This is caused by a low white cell count in the blood.
This can mean:

- frequent infections and fever, even if there are no clear signs of an infection.



*"Before being diagnosed with ALL, my son hadn't been right for a while. Nothing you could put your finger on, just not right."*

### Weight loss

This is caused by a high metabolism (the rate we burn energy from food). We don't completely understand why the metabolism is speeded up in children with ALL.

### Other symptoms

ALL can sometimes cause other symptoms; these are a result of the spread of leukaemia cells in the body.

- The lymph nodes in your child's neck may swell, which will look and feel like swollen glands.
- Your child might feel some pain in the stomach area if the liver and spleen enlarge.
- Your child may complain of bone pain; this is caused by the overcrowding of the leukaemia cells in the bone marrow.
- Your child may be feeling generally unwell.
- Your child may have night sweats.

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



# Diagnosis

Your child will have a set of tests to confirm whether they have ALL or not. At any time, you can ask your healthcare team to tell you why your child is having a certain test and what the results mean.

## Tests to diagnose ALL

The most important tests to find out if your child has ALL are the full blood count and bone marrow aspirate.

### 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. It also allows your child's doctors to look for leukaemia cells in the blood.

Your child will have this test quite often throughout their treatment and you may wish to keep track of the results of their blood counts. If you choose to do this, your child's consultant or specialist nurse will be able to explain what the results mean.

### Bone marrow aspirate (biopsy)

Your child's doctor will take a bone marrow sample to see how the blood is working inside your child's bone marrow. Your child will have this test a number of times throughout their treatment.

A small amount of bone marrow is taken from the pelvic bone using a needle (an aspirate). Your child's doctors will then look at the bone marrow sample under a microscope to assess for any disease which may be in it.

Your child will have their first bone marrow test when they're in hospital at the time of their diagnosis. However, almost all of your child's bone marrow tests after this can be done as an outpatient (meaning they won't need to stay in hospital overnight). The procedure is usually quick but it can be uncomfortable for the short time that the sample is being taken from the marrow. For this reason, the doctors will usually give your child a general anaesthetic so they'll sleep through the procedure.

### Bone marrow trephine (biopsy)

At the same time as the bone marrow aspirate is done, your child's doctor will also do a trephine biopsy. This is the removal of a core of bone marrow from the pelvic bone under the same anaesthetic. This sample provides information about the structure of the bone marrow and the number and distribution of the different blood cell types and cancer cells if present.



## Tests after diagnosis

If your child is diagnosed with ALL, the doctors will carry out a number of further tests. These will give them more information about the disease and help them decide how much treatment your child needs in order to have the best possible chance of being cured, with the least possible side effects.

### Lumbar puncture

Leukaemia cells can sometimes get into the fluid that surrounds the brain and spinal cord (known as cerebrospinal fluid or CSF). A lumbar puncture involves taking a small sample of CSF to check if there are any leukaemia cells in it. Your child's doctor will very carefully insert a needle between the bones of the lower spine into the space around the spinal cord and remove a few drops of CSF.

Your child will have a number of lumbar punctures throughout their treatment – not only at diagnosis stage. The doctors will give chemotherapy into the CSF at the same time as these lumbar punctures. This is in order to treat any leukaemia cells that may be present in the CSF, and to prevent the leukaemia from spreading to the CSF.

A lumbar puncture is usually done under general anaesthetic, just like the bone marrow test. For older children, the doctors may offer a sedative instead.

## Cytogenetics

All kinds of cancer, including blood cancer, involve changes in genes in the affected cells. The study of these changes is called cytogenetics or molecular genetics. These gene changes aren't the same thing as a faulty gene that you inherit from a family member which causes cancer.

Your child's doctors will carry out cytogenetic tests on cells from your child's blood or bone marrow samples to find out information about the exact changes present in the cells.

The results of cytogenetic tests are particularly important in helping the doctors decide how much treatment your child needs, and whether your child's condition is likely to respond to standard treatment.

## Minimal residual disease (MRD) test

'Minimal residual disease' refers to the small number of leukaemia cells that are still present in the bone marrow, even if your child is responding well to treatment. It's normal for there to be some MRD after the early stages of treatment and it doesn't mean that your child can't be cured with further treatment.

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.

The results of the MRD test will help your doctors decide how much treatment your child needs.



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

You can find more information on the different phases of treatment on **page 39**

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You can find more information on how the MRD test is used on **page 40**

## Additional tests and scans

There are a number of other tests and scans your child may have throughout their treatment. These will help your doctors to see how the disease is responding to treatment, to look for any complications caused by the condition or its treatment, and to check for other problems such as infection.

The doctors will be very careful to make sure that your child isn't exposed to radiation unless absolutely necessary. During a CT scan or MRI scan you won't be able to be in the room with your child, but your child will usually be able to see you through a window and you'll be able to talk to your child over an intercom.

### X-ray

X-rays provide very good images of the denser tissues in the body, such as bone. Your child's doctors may use an X-ray when your child is first diagnosed, to check for infection or any other chest problems. ALL can cause the lymph nodes in your child's chest to enlarge. This can cause compression of the airways and major blood vessels. If an X-ray shows that this is happening, your child's doctors will begin treatment urgently to relieve the compression.

They may also use X-rays during treatment to monitor how well your child's responding to treatment and to check for chest infections, if their white cell count is low.



### CT scan

This is a form of X-ray that produces a detailed picture of the inside of the body. It's a painless procedure where your child will need to lie on a table that moves into a cylindrical tunnel while the pictures are taken. Their body isn't completely enclosed at any time and they'll be able to talk to the person who takes and assesses the images (the radiographer) during the procedure.

Your child may need to have some fluid dye injected into a vein to help the computer form a better image. For very young children (up to about five years of age) the whole procedure may be done under a general anaesthetic.

The results can take some time to reach your healthcare team, so don't worry if you don't hear about them straight away.

### Magnetic resonance imaging (MRI)

This scan uses radio waves rather than X-rays and produces images that can be analysed on a computer. Your child will lie on a table and the table will move them through the scanner. It's a painless procedure which can take up to an hour to perform.

Like for the CT scan, your child may need to have some fluid dye injected into a vein to help the computer form a better image. If necessary, your child will be given a sedative during the procedure. For very young children (up to about five years of age) the whole procedure may be done under a general anaesthetic.

### Liver function test

This is a blood test to check if the liver is working normally. It's a very important test for patients receiving chemotherapy, as many drugs are broken down in the liver. If the liver isn't working normally, the doctors may need to adjust your child's doses.

### Urea and electrolytes

This is a blood test to check how well the kidneys are working. It helps the doctors work out the doses of drugs your child needs, and will also show any damage that may have been caused either by the leukaemia or the treatment. It can also show if your child has become dehydrated.

## Your healthcare team

If your child is diagnosed with ALL, your hospital will give you the names and contact details of your child's 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 child's consultant

Children with ALL will be treated by a consultant who is an expert in treating children with blood cancer.



### Your clinical nurse specialist

Any family whose child is diagnosed with ALL will be 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 your child is first diagnosed, to discuss their condition.

Really make use of your clinical nurse specialist as they'll be with you right through your child's treatment. If your child is receiving treatment as part of a clinical trial, you may also be given a research nurse (this is a nurse with specialist knowledge of trials in ALL).

### Your multidisciplinary team

When your child is diagnosed with ALL, their condition is discussed at a multidisciplinary team (MDT) meeting. An MDT brings together doctors, nurses and any other specialist staff who'll be looking after your child. The MDT may also include non-clinical staff such as play specialists, social workers and teachers. All members of the MDT looking after your child will be specially trained in treating children.

A senior consultant usually leads these regular meetings. The team will discuss the best treatment for your child and every aspect of their care, including any changes in their condition.

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You can find more information on clinical trials on **page 42**

## Play specialists

For younger children, it may be difficult to explain some aspects of their treatment and they may be distressed by being in the hospital. One important way to help your child cope is through guided play.

All children's hospitals now employ play specialists on the ward. The play specialist is recognised as a key member of the team looking after your child. They help younger children to understand how their treatment will be given and how it might make them feel. They can also help your child to find an outlet for frustration or anger. The play specialist can also work with siblings, who may have some difficulty in coping with their sibling's cancer diagnosis as well as the disruption to their family routines.

## Shared care

Children with ALL will be admitted to a specialist centre for their initial diagnosis and the first stages of treatment. At later stages, it's usually possible to arrange for your child to have treatment and tests at a local hospital if this is more convenient. This is known as shared care. The specialist centre will still be responsible for your child's overall treatment and will see your child regularly.

If your child is a teenager, they may be treated on a specialist teenage cancer unit.



## Talking to other parents or carers

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

You may also want to contact a support organisation – many provide online support and meetings for parents and carers of children with conditions like ALL.

## Your child's other healthcare professionals

It's definitely worth telling other healthcare professionals your child sees – like their dentist or optician – about their diagnosis and the medication they're taking.


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 can find a list of support organisations on **page 71**

## Finding out more

After your child has 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 child's 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 child's consultant or key worker. If they can't answer your questions, they'll be able to tell you who to speak to.
- You may prefer to ask your child's clinical nurse specialist questions rather than your child's consultant, but do whatever works for you.
- Many people say they find it useful taking someone with them to consultations. If you'd find it helpful, you could ask them to take notes while you listen. You can choose who to take; it doesn't have to be a family member.
- If your child is staying in hospital and you'd like to have someone with you when you speak to your child's consultant, it might be useful to ask in advance what time the consultant is likely to speak to you. This way you can try to arrange for someone to be with you at that time.
- Some people find that joining a 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 may want to ask on **page 77** and room to write more questions on **page 82**

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**

## Telling people

You may find it stressful having to discuss your child's condition lots of times with family, friends and colleagues.

You may find it easier to ask a trusted family member or friend to be your 'information person' and ask them to keep people updated on yours and your child's 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 or your child may not want to tell many people about your child's condition. This is ok too, whatever works for you.

### Telling siblings and your child's friends

Talking to your child's brothers and sisters or friends about their condition can be a difficult thing to do. There are many agencies available that provide support and advice about how to explain it to children of different ages.

CLIC Sargent have some useful advice on talking to siblings of a child going through cancer > go to **clicsargent.org.uk** then search for **'brothers and sisters'**

The Children's Cancer and Leukaemia Group also produce booklets for both parents and siblings > go to **cclg.org.uk/our-publications**



### Telling your child's school

Telling your child's school can also be difficult, but they'll need to know as soon as your child is diagnosed. Your healthcare team can help you talk with the school and make arrangements.

### Telling your GP

Your team at the hospital will keep your GP informed about your child's condition and the treatment they're having. They'll usually send your GP a letter with this information. As the parent, you'll often be sent a copy too. These letters can have a lot of medical terms in them which you may 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 may help to reassure you.

### Cancer and work

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

There's more information about cancer and how it can affect your work or study and your child's education on **page 62**

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'**

The treatment your child has will depend on their individual condition, their health and your wishes.



# Treatment

Throughout your child's treatment, your healthcare team will always discuss your child's treatment options with you. You'll be able to give your opinions and preferences and ask questions.

## Treatment planning

It's very important that your child starts treatment soon after being diagnosed, because ALL can be a fast-growing disease. Fortunately, most children respond very well to treatment and survival rates are high.

Most children in the UK who are diagnosed with any type of cancer enter what is known as a clinical trial. A clinical trial is where two or more treatment options are compared to see which brings the best results. They help researchers and doctors find new treatments and improve current ones. The current trial for childhood ALL is called UKALL 2011. The treatment explained in this section is the same whether your child is taking part in the trial or not.

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You can find more information about the UKALL 2011 clinical trial on **page 42**

*Throughout our child's treatment, no matter if it was a good day or a bad day, our specialist treatment team were amazing. They supported us throughout and were always there to answer any questions that we might have had.*

The standard treatment explained in this section isn't used for children under one year old. If your child is under one year old, your consultant will discuss your child's treatment options with you.

The aim of treatment for ALL is to get rid of the leukaemia cells and help your child's bone marrow to work normally again. Chemotherapy is the main treatment for ALL. Your child will have a combination of chemotherapy drugs according to a treatment plan (your healthcare team may call this a 'protocol' or 'regimen').

The treatment is divided into five phases, or 'blocks', which are explained in the next section beginning on page 39.

Some children will need more chemotherapy than others, and your healthcare team will adjust your child's treatment based on test results. Any time there's a change in your child's treatment plan, your healthcare team will discuss this with you.

## Treatment regimens

Based on the results of tests your child had when they were diagnosed, their age and their white cell count, your child will have one of three treatment plans, or regimens.

Regimen A uses the lowest intensity of treatment. This is the initial treatment plan offered to children under 10 years old and children with a low white cell count at diagnosis.

Regimen B is intermediate intensity. This is the initial treatment plan offered to children over 10 years old and children with a higher white cell count at diagnosis.

Regimen C uses the highest intensity of treatment. It isn't used at the start of treatment, but children may be moved onto this regimen later if not enough leukaemia cells have been cleared following the first part of treatment on regimen A or B, or if the cytogenetic tests show that there are certain genetic abnormalities present in their cells. If a child needs to be moved onto regimen C, they won't be moved back to a lower intensity regimen.

## Types of treatment

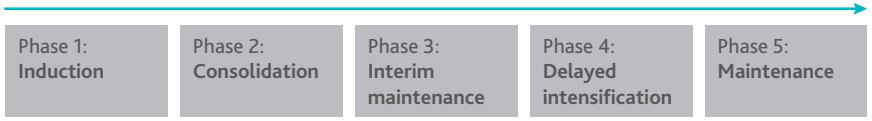
In each phase of treatment (see page 39) your child will have a combination of several different drugs. The drugs may be given in different ways:

- by mouth (oral) – as a tablet or solution
- into a blood vessel (intravenous or IV) – this may be as a single injection or by a 'drip' (infusion)
- into a muscle (intramuscular or IM) – as an injection
- into the fluid around the spine and brain (intrathecal or IT) – as an injection; this type of treatment uses the same procedure as the lumbar puncture (see page 21).

The following chemotherapy drugs are used in various combinations in treatment for childhood ALL:

- cyclophosphamide – intravenous
- cytarabine – intravenous
- daunorubicin – intravenous
- dexamethasone (a steroid) – tablets or liquid
- vincristine – intravenous
- intrathecal methotrexate – injected into the fluid around the spine and brain
- mercaptopurine – tablets or liquid
- oral methotrexate – tablets or liquid
- pegaspargase/crisantaspase – intramuscular.






## Phases of treatment

The total length of treatment is just over two years for girls and just over three years for boys. Treatment length is different for each because it's been found that if boys stop treatment at two years, it's more likely that their disease will return (this is known as a relapse).

This section gives an overview of the different phases of treatment. Your healthcare team will explain to you in detail which drugs your child will have and when, and can give you a chart to show this.

The treatment schedule is quite complicated and you'll need to follow it carefully during the outpatient stages of treatment. If you're having difficulty making sure your child receives all of the treatment at the right time, talk to your healthcare team – there are a number of different ways they can offer support.

### Phase 1: induction

The first phase of treatment is called induction. For the first five weeks of treatment, your child will have intensive chemotherapy treatment to get rid of as many leukaemia cells as possible.

Your child will need to stay in hospital for at least the first week or two because the doctors will need to monitor them closely for any complications from treatment.

The doctors will do further bone marrow tests during and at the end of this first phase to see how your child is responding to the treatment. After two weeks, some children on regimen A will move onto regimen C. This will happen if the results of your child's cytogenetic tests suggest that they need stronger treatment.

After four weeks, your child will have an MRD test (see page 22) to find out how many leukaemia cells are still in their bone marrow. If there are a low number of leukaemia cells present (this is called MRD low risk), your child will stay on the same treatment (regimen A or B). If there are a higher number of cells (this is called MRD risk), the treatment will move to the stronger regimen C.

### Phase 2: consolidation

When the induction phase is complete, your child will have further chemotherapy to clear remaining leukaemia cells from the blood and bone marrow, and also to prevent leukaemia cells from spreading into the brain and spinal cord (the central nervous system or CNS).

For most of this time your child will be able to stay at home and only visit hospital for treatment or check-ups (this is known as outpatient treatment). If your child has an infection or becomes ill at any stage during their treatment, they may need to return to hospital to stay in overnight or longer so doctors can monitor them closely.

The length of this phase and the type of chemotherapy your child will have is based on the results of the MRD test at the end of the induction phase.

- If your child is MRD low risk, then consolidation will last for either three weeks (regimen A) or five weeks (regimen B).
- If your child is MRD risk at the end of induction, then they'll move onto regimen C and consolidation will last for 10 weeks.
- If your child is on regimen B for induction, but the results of their cytogenetic tests during induction suggest that they need stronger treatment, then they'll move onto regimen C at the start of consolidation.

If your child is MRD risk, your doctors will carry out extra MRD tests halfway through and at the end of consolidation. If these show that the disease isn't responding to the treatment, then your consultant will talk to you about which alternative treatment options might be most effective.



### Phase 3: interim maintenance

For children on regimen A and B, this third phase lasts for about two months and gives a break of less intensive treatment between consolidation and delayed intensification (phase 4). The main treatment during this period will be oral chemotherapy, and your child will be able to stay at home for most of the time.

Children on regimen C will have a more intensive course of chemotherapy involving methotrexate. Your child's doctor will explain to you exactly how this treatment is given because this will depend on whether your child is taking part in the UKALL 2011 clinical trial or not.

### Phase 4: delayed intensification

Delayed intensification will last for seven or eight weeks depending on whether your child is MRD low risk or MRD risk. The aim of this phase is to give intensive chemotherapy at a time when the number of leukaemia cells is very low, to clear as many of them as possible. Your child will mainly be an outpatient for this phase of treatment.

### Phase 5: maintenance

This is the longest but gentlest phase of treatment. It lasts for just under two years for girls and just under three years for boys. It reduces the risk of the disease coming back. Your child will mainly be an outpatient for this phase of treatment.

By the time your child has moved onto maintenance therapy they may be well enough to resume their normal activities, including attending school regularly. However, recovery time varies a lot in children and some may take a little longer to get back to their normal activities, even if they're feeling much better physically – this is normal too.

## UKALL 2011 clinical trial

Today, around 90% of children with ALL can be cured. One of the most important reasons we've made this progress has been because of the information gathered from clinical trials. A clinical trial is when two or more treatment options are compared to see which brings the best results. They help researchers and doctors find new treatments and improve current ones.

Most children in the UK diagnosed with ALL are eligible to enter the UKALL 2011 trial. In most ways, the treatment children in the trial get isn't very different from the standard treatment outlined on pages 39–41. The same drugs are used to treat children whether or not they're taking part in the trial; it's important to understand that your child will be receiving effective treatment whether they're taking part in the trial or not.

The study is comparing slightly different ways of using these drugs, to see whether the same results can be achieved with fewer side effects and also to prevent the disease from returning in children whose ALL responds slowly to treatment.

Your healthcare team can support you and answer any questions that may help you decide whether to enter your child into the trial. You can change your mind about your child being in the trial at any time, and your child's safety and wellbeing is always the first priority.



### Who is eligible for the UKALL 2011 trial?

Only a small number of children aren't eligible for the trial. These are:

- children who are less than one year old at the time of their diagnosis
- children who have a type of ALL called FAB L3 - these children will have a different course of treatment that's more effective for this type
- children who have a particular chromosome abnormality called Philadelphia positive ALL, which means they may be more likely to experience a relapse. If your child has started on the trial and their cytogenetic tests show that they have this abnormality, they'll be withdrawn from the trial and your consultant will talk to you about which alternative treatment options might be most effective
- children who have received previous treatment for leukaemia, because this trial is looking at how to treat newly diagnosed children.

## How the trial works

The UKALL 2011 trial is what's known as a randomised trial. This means that patients are randomly assigned to different treatments (known as treatment arms) usually by a computer.

This method means that neither the parents nor doctors influence which treatment any child gets. This helps make sure that the results aren't biased in any way. Equal numbers of children are treated on each treatment arm, and at the end of the trial the results are compared.



The trial is investigating changes to the standard treatment used in phase 3 (interim maintenance) and phase 5 (maintenance) of your child's treatment.

In the interim maintenance phase, the trial is testing whether a higher dose of the chemotherapy drug methotrexate is better at preventing ALL from returning than the standard dose.

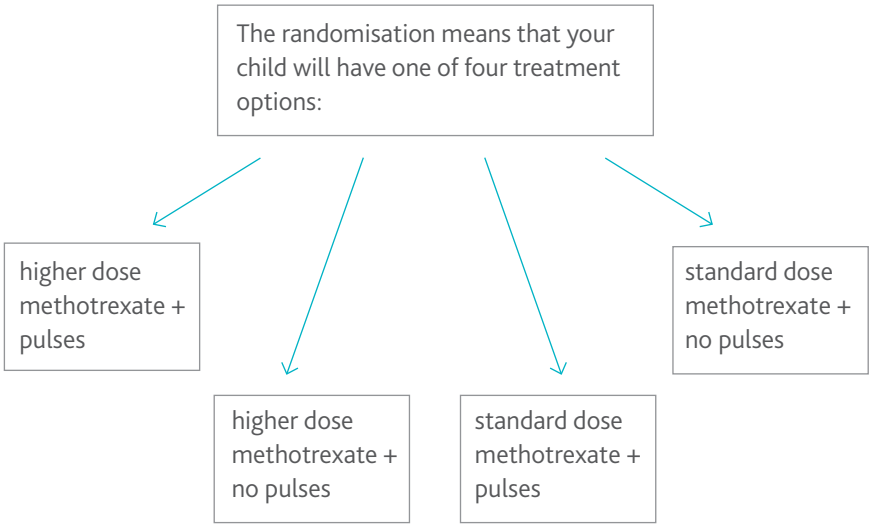
In the maintenance phase, the trial is studying whether part of the standard maintenance treatment (known as 'pulses') can be safely removed. These pulses involve doses of the chemotherapy drug vincristine and the steroid dexamethasone. They can cause some of the unpleasant side effects of standard maintenance.

48

You can find more information on the side effects of steroids on **page 48**

For more information on clinical trials, read our booklet > **Clinical trials**

For more information about the UKALL 2011 clinical trial, please see the trial parent information sheet, which your team will be able to provide




At the end of your child's induction treatment, your healthcare team will give you an information sheet which explains the treatment in the second randomisation in more detail.



7 You can find more information on how blood and blood cells work on **page 7**

## Supportive care

As well as the phases of treatment described, your child will need care to prevent and treat infections, and to deal with the side effects of treatment.

### Preventing and treating infections

If your child gets an infection, they may need intensive treatment with intravenous antibiotics or antifungal drugs. They'll also take an antibiotic for two days each week throughout their treatment, to reduce the risk of a particular type of pneumonia which can sometimes happen in patients with a weakened immune system.

### Transfusions

The drugs used in your child's treatment will reduce the number of normal blood cells made by their bone marrow. This means they're likely to need red blood cell transfusions and platelet transfusions at times during their treatment.

### Central line

Your child will usually have a tube, known as a central line, inserted into a large blood vessel. The central line can be used for taking blood as well as giving treatment and other medicines, and means the doctors won't have to use a needle each time your child has their treatment.

There are various types of central lines used, and your healthcare team will show you how to care for the central line.

### Feeding tube

Sometimes a child may find it difficult to eat or drink because of the side effects of chemotherapy. If this is particularly difficult, your child may need to be fed through a tube going directly into their stomach. In this case, your healthcare team will show you how to give feeds and how to care for the tube.

## Side effects

There are some potential short term and long term side effects from treatment for childhood ALL.

Children have different responses to their treatment. Even if two children are having the same treatment, they may have a different experience. So your child 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 about potential side effects with your healthcare team.

### Short term side effects from chemotherapy

Your child may experience some short term side effects from their chemotherapy treatment. They include:

- an achy feeling
- constipation
- diarrhoea
- extreme tiredness
- hair loss
- infections
- rashes
- sore mouth/mouth ulcers
- nausea and vomiting
- increased risk of bleeding/bruising.

Your child is unlikely to have all of these, and it's important to remember that they are only temporary, but they can occur regularly. If your child does have side effects, tell your healthcare team as they may be able to help with them – there are medicines your child can take to help with nausea and vomiting, for instance.

### Short term side effects from steroids

Steroid treatment can also cause side effects, such as:

- increased appetite
- mood changes and irritability
- weight gain (especially around the face and stomach)
- muscle weakness (especially in the legs)
- high blood sugar levels, which may require medication.

Again, if your child has any of these side effects it's worth discussing this with your healthcare team as they may be able to help with them.



### Long term side effects from chemotherapy

A small number of children may develop health problems later in life as a result of treatment for ALL. The current clinical trial is looking for ways to reduce the long term side effects of treatment.

The long term effects of chemotherapy depend on the intensity of your child's treatment and, in some cases, the total amount of drugs your child takes. It's difficult to know exactly which drugs are responsible for which long term effects in situations like childhood ALL, where combinations of drugs are given over long periods of time. Your specialist will offer you detailed advice before your child begins their treatment.

### Fertility

You may be worried about the effect of treatment on your child's fertility. It's a concern that many parents have, and your specialist will be able to discuss this with you before your child begins their treatment.

Lots of research has suggested that the overall risks to fertility are very low. The majority of children who are treated for ALL won't go on to have any problems with their fertility.

It's also natural to worry about the effects of treatment on any children your child may have later in life. Lots of evidence from clinical studies has shown that a parent who's had cancer treatment doesn't have an increased risk of cancer or other health problems in their children.

## Follow-up

Your child's follow-up will mostly look out for signs of relapse and treatment complications.

At the end of treatment, your child will have a bone marrow test to check that the bone marrow has been cleared of leukaemia cells. During the first year after your child finishes their treatment, they'll normally have a check-up every two to three months. Your child will have blood tests at these check-ups, but no further bone marrow tests will be done during follow-up if your child's blood test results are normal. After one year, your child's check-ups will get less and less frequent, until they're given every year at five years and onwards.

It's very important to make sure that your child's GP is aware of the treatment they've had for ALL. If your child becomes ill later in life, it's important to make sure that the doctors looking after them are aware of their medical history. Even for unrelated conditions, the diagnosis and choice of treatment may be more difficult if your child's medical history isn't available.

If you wish, you can complete a treatment diary with a full record of your child's diagnosis, the types of treatment and the total amount of treatment they've had. Your healthcare team should also give you an 'end of treatment summary' containing all of this information when your child finishes their treatment.



## Relapse

If your child has a good initial response to treatment, with no leukaemia cells detectable, this is called complete remission.

Sometimes the condition can return after complete remission has been achieved: this is called relapse. This can happen either during treatment or after treatment has finished.

Although relapse is often harder to treat, especially if it happens early during treatment, there are still effective treatment options. Your child's consultant will discuss these in detail with you in the event that your child experiences a relapse.

When a relapse happens late in treatment, or after treatment is complete, there's a good chance that your child can be treated successfully again.

Relapse sometimes happens in the fluid around the brain and spinal cord (this is called a CNS relapse) or in the testis in boys. This is called an extramedullary relapse.

In the near future, there'll be a clinical trial to determine the best treatment for relapsed ALL.

### Stem cell transplant

Most children with ALL will respond very well to chemotherapy and won't need a stem cell transplant. However, a stem cell transplant is sometimes used to treat ALL which hasn't responded well enough to initial chemotherapy, or in children who have relapsed. Stem cells can be taken from a brother or sister, or an unrelated donor.

In the unlikely event that your child needs a stem cell transplant, your consultant will give you detailed advice on what's involved and the risks and benefits.

There's more information on stem cell transplants in our booklet > **The seven steps: blood stem cell and bone marrow transplants**

Every child is different, so your consultant and healthcare team are the best people to ask about your child's likely outlook (prognosis).



# The outlook

The outlook for most children with ALL is good, with a very high chance of long term survival, despite the small chance of the disease coming back.

In the most recent UK trial to be completed (UKALL 2003), around 90% of children aged under 16 who were treated for ALL were considered cured.

Some rare types of childhood ALL are more difficult to treat, so the outlook may vary. Your consultant will be able to tell you how these factors affect your child's outlook.

## Talking about your child's prognosis

Even though the chance of survival is high, you may find it hard to ask or talk about your child's prognosis. Sometimes those close to you may want to know your child's prognosis, even if you prefer not to know. However, your healthcare team aren't allowed to give this or any other information to anyone – not even family members – without you and/or your child's permission. Try to decide early on who you and your child want to know about your child's condition, then tell your healthcare team – you can change your mind any time.

Your healthcare team look after you and your child's emotional needs, as well as your child's physical needs.



# Everyday life and ALL

Caring for a child with ALL is stressful for you and other family members, including siblings.

Your healthcare team will support you but, if possible, do consider asking family and friends for help and to lend an ear – often a support network like this can help family life tick along, especially at times when you might need to focus all your attention on your child.

## Looking after your family emotionally

Being told your child has ALL is likely to be extremely upsetting and you'll almost certainly experience many different emotions. Friends and family can offer a great deal of support, but it might be hard for them to understand the long term emotional impact your child's ALL will have on you and your child.

Your healthcare team should look at your family's 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 child's treatment and beyond, as treatment can take a long time and you may experience many different emotions at different stages.

### Helping siblings

Brothers and sisters of a child with leukaemia may have some difficulty in coping with their sibling's cancer diagnosis as well as the changes to family routine. They may resent the extra attention given to the affected child, then feel guilty about this resentment. Your healthcare team can give you advice on how to work through this with them.

If there are brothers or sisters who are at school or playgroup, it's important to let their teachers or carers know they're under stress at home. It's also important to keep the school or playgroup informed so you can find out if your child's brother or sister has been in contact with an infection.

You may find it helpful to contact one of the organisations listed on **page 71**. These organisations also offer support for family members.


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**



## Looking after your child physically

### Changes in your child's condition

While your child is having outpatient treatment, they'll be able to spend most of their time at home and only visit hospital for treatment or check-ups. However, because of your child's condition and the side effects of the treatment, they're at an increased risk of developing an infection.

There are some signs and symptoms that it's important to look out for while your child is having treatment. If your child develops any of the following symptoms, you should contact your hospital team immediately:

- a raised temperature
- cough or sore throat
- confused or agitated behaviour, especially if this comes on suddenly
- quickly becoming more ill
- fast heartbeat and breathing
- difficulty in passing urine or not producing urine
- suddenly increasing pain.

If you notice any change in your child's general health, or if there are any other symptoms which are worrying you, contact your key worker. They'll be able to arrange for the doctors to see your child if needed. If your child is on shared care, your first point of contact is normally the paediatric oncology shared care unit. Your healthcare team will also give you emergency numbers to contact if your child is unwell out of usual working hours.

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

## Measles and chickenpox

It's particularly important to be careful about exposure to measles or chickenpox. Your healthcare team will give you detailed advice and, if appropriate, a letter will be sent to your child's school or playgroup to explain the situation.

## Keeping active

Your child may feel tired a lot (fatigue). This may be caused by their illness or their treatment. It isn't the same as normal tiredness, which improves with rest and sleep.

It's worth encouraging your child to keep as active as they can, because evidence shows that this could help to make their symptoms less severe. However, they'll need to stop and rest more often than before their illness.

In childhood ALL, fatigue is particularly linked to periods of steroid treatment, although fatigue may happen at any time. If you think your child is being affected by fatigue, you might want to ask your consultant or specialist nurse for advice on the best way to deal with it.

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



We have a booklet on dietary advice > **Eating well with neutropenia**

## Diet

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

Because your child's immune system may not be working as normal, you'll need to take extra care against infections that they may get from food. Their body won't be able to destroy germs and resist infection as easily, so be careful about food 'use by' dates and things like keeping cooked and raw meat separate in the fridge.

A diet for people with a weakened immune system is known as a neutropenic diet. Your healthcare team will be able to give you more information about this diet.

## Vaccination

Your child will need to have booster doses of childhood vaccinations. These are usually given around 6 months after the end of chemotherapy, once their immune system has had the chance to recover. Your healthcare team will advise you on this.

### Shingles

Shingles is an infection of a nerve and the skin around it. It can affect your child if they've had chickenpox, even if they had it a long time ago, as it's caused by the same virus which can lie dormant in the body for years. Your child is more likely to get shingles while they're being treated for ALL because their immune system won't be working as well as normal.

Shingles has some quite obvious symptoms. If you think your child has 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 the 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 treating any form of cancer. We don't recommend that you use any alternative therapy in place of proven medical care.**

Always let your healthcare team know about any complementary treatments you're considering for your child. They may advise you to avoid certain therapies because of specific risks to do with your child's condition or the treatments they're having. In other cases they may say a therapy is okay as long as you take specific precautions.

### Herbal medicines

Herbal preparations may be safe for a healthy person but they could be dangerous when combined with chemotherapy.

### Acupuncture

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

## Practical support

### Work, education and domestic arrangements

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

You may need to make a short term arrangement with your employer or college at the time when your child is diagnosed so you can have time off to take them to hospital. If you have to stay in hospital with your child during treatment, you'll probably need to make a more formal agreement.

You may need to bring in written proof of your child's diagnosis from your healthcare team, which makes clear the effect your child's diagnosis and treatment could have on your ability to work or study.

If you have other children or if you're a carer, you may need support during your treatment, including making alternative care arrangements for the people you look after. Your child may have unplanned stays in hospital because of infection, for example – it's helpful to have plans in place just in case.

Children's hospitals will often have educational staff and schools to provide teaching while your child is an inpatient. The hospital teaching staff will work very closely with your child's school to make sure they keep up to date. They'll also encourage your child to keep in contact with their classmates.



Attending a hospital school will give your child a chance to mix with other children. The healthcare team works very closely with the teaching staff to make sure that your child isn't at risk from infection. This may mean there are times when your child isn't able to join in with other children.

### 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. The Equality Act provides rights for people not to be directly discriminated against or harassed because they have an association with a 'protected person'. This can apply to a carer or parent of a child with cancer.

CLIC Sargent have some useful advice on making arrangements for your child's education, and also have some resources for teachers that you may find it useful to pass on > go to **clicsargent.org.uk** then search for **'education'**

The Citizen's Advice Bureau produce a fact sheet about how the Equality Act protects carers > search online for **Equality Act 2010: What do I need to know as a carer?**

## Getting to hospital

You will need to make a lot of visits to the hospital in charge of your child's care over a long period of time. If you find this hard because of transport or any other reason, you can ask your consultant if your child can have any of their 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 they're having.

You may 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 may be the last thing on your mind if your child has 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 may be able to receive. These may 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 soon after your child's diagnosis. Alternatively, your hospital may be able to arrange for an advisor from somewhere else to visit you.



Macmillan Cancer Support 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 74**

Our researchers are making discoveries that will have a positive impact for children 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.

## UKALL 2011 clinical trial

We're funding the UKALL 2011 clinical trial (see page 42) to refine treatments for children with ALL. Our previous research has helped doctors to better personalise chemotherapy for these patients, and now nine in 10 children survive for at least five years.

First, the initial treatment can be tailored according to each child's carefully established level of risk. Secondly, the child's early response to this therapy can be monitored to decide whether to use less or more treatment. So for many children who are able to undergo a less intense treatment course, harmful side effects during and after their treatment are minimised and fewer suffer relapses.

But the chemotherapy is still gruelling, and patients can experience long term health complications as a result. Through the trial, we're looking to improve survival even more and also – by further reducing the intensity of treatment – bring about improvements in quality of life.

## Treating relapsed ALL

Although the majority of children with ALL go into remission, for those children who relapse the outlook is not as promising. Our researchers are conducting a key laboratory project as part of the largest ever clinical trial for children with relapsed ALL. The clinical trial is truly global in its scope and will involve more than 1,000 children from 20 countries across the world, with the aim of standardising treatment.

The lab project is analysing the genes and cells of the UK patients on this trial to determine biological markers (features) that enable us to gauge how the disease is progressing and how the patient is responding to particular drugs. This will help devise personalised tests to guide doctors in deciding the most effective and least gruelling treatment for each child.

In addition, they will develop new tools that will allow a global laboratory network to support future trials of promising new biological therapies. These next-generation drugs are more targeted and less toxic, so they could save thousands of lives in the future, as well as substantially improving quality of life during and after treatment.



## Understanding how ALL starts

Our research has revealed that in many childhood leukaemias the first key genetic faults occur in the womb. Our scientists are now characterising the additional genetic errors incurred after birth that cause the cells to grow out of control and lead to ALL. We're also supporting research into rare but fast-growing leukaemias that develop very early in life, under 12 months of age.

The outlook for babies with ALL is relatively poor, with only just over half surviving for longer than five years. The research is looking for the unique developing blood cells that carry a key genetic fault to see whether this fault alone is enough to transform them into leukaemia cells shortly after birth, and what other genetic events – if any – may be needed in order for the transformation to happen.

All of this research could provide crucial information on how ALL in children and babies starts – an important step in designing better, kinder treatments for these babies and possibly stopping these diseases developing in the first place.

There are lots of organisations out there who offer information and support to children and families 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**

### Children with Cancer
Provides practical support for young cancer patients and their families.

› **020 7404 0808** › **childrenwithcancer.org.uk**



### Teenage Cancer Trust
Provides specialist units and nurses for children and teenagers with cancer. They also have an education team that visit schools to raise awareness of cancer and provide a support network so that patients, their families and friends can meet others in a similar situation.

› **020 7612 0370** › **hello@teenagecancertrust.org**
› **teenagecancertrust.org**

### CLIC Sargent
Provides clinical, practical, financial and emotional support to help young patients and their families.

› **0300 330 0803** › **clicsargent.org.uk**

### The Children's Cancer and Leukaemia Group
Brings together healthcare specialists who care for children with cancer and also offers support and information to parents.

› **0116 249 4460** › **cclg.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 public services including financial support, rights and employment.

› **gov.uk**



## Travel insurance

### Macmillan Cancer Support
Provides information about what to consider when looking for travel insurance, along with recommendations from the Macmillan online community.

› **0808 808 0000** › **macmillan.org.uk**

### 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 child's healthcare team and trying to take in lots of new information. Some parents or carers find it useful to write down the questions they want to ask at an appointment before they get there. Here are some questions you may like to ask at different times.

## Tests

- What tests will my child have?
- What will the tests show?
- Where will my child 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 my child for the tests, for example not giving them anything to eat beforehand?
- How long will it take to get the results?

## Treatment – general

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

## Type of treatment

### Chemotherapy

- What type of treatment will my child have?
- Will my child have to stay in hospital?
- How often will my child need to go to hospital as an outpatient?



- What treatment regimen will my child be given? Will it be given by mouth, injection or drip (into a vein)?
- Will my child's treatment be continuous or in blocks of treatment (with a break in between)?
- How long will my child's treatment last?
- What side effects could my child get from their treatment?
- Can side effects be treated or prevented?
- Will side effects affect my child all the time or only while they're taking certain drugs?
- What effect is the treatment likely to have on my child's daily life?
- Will my child be able to carry on going to school or playgroup?
- Will I need to take special precautions, for example to protect my child against infection?
- Will I need to change my child's meal times or work my child's drugs around these?

### Choosing the right treatment for your child

If you're asked to choose between treatments for your child, you may 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 child's quality of life?

## Follow-up and relapse

### Follow-up

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



### Relapse

- How will doctors know if the cancer has relapsed?
- What are the options for more treatment?
- What will the treatment involve? Will it be different from my child's initial treatment?
- Will there be any side effects from more treatment?
- Is my child's prognosis likely to change with more treatment?

# Notes

# Glossary

*Anaemia*
A low red blood cell count causing fatigue and breathlessness.

*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.

*Central nervous system*
Part of the body's nervous system, consisting of the brain and spinal cord.

*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 (CNS)*
A qualified nurse who specialises in a particular clinical area. Some deal with all blood cancers while others may specialise in leukaemia, myeloma, lymphoma or another specific area. Your nurse specialist can provide information and expert advice about your child's 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 need to sign a consent form for your child to participate in a clinical trial, so you'll always be aware if your child's 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 likely to 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 also 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.

*Minimal residual disease (MRD) test*
This test lets doctors check exactly how many leukaemia cells are left in the bone marrow. It helps them work out how well your child is responding to their treatment.

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

# About us

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

## We're here to make things clear

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

## We're here to listen, support and connect

Our Support Line team are just a call or email away. Call us on **0808 2080 888,** Mon–Fri, 10am–4pm, email **support@bloodwise.org.uk** or visit us at **bloodwise.org.uk** to join our online community.

## We're here to beat blood cancer

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

Go to **bloodwise.org.uk** for more information.



# Getting involved

Help us beat blood cancer.

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

## Give a gift

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

## Take on a challenge

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

## Beat blood cancer locally

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

## Join us online

Every like, share, tweet and mention could mean someone finds out about our services and raises awareness of blood cancer.

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

## Partner with us

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

## Get in touch

Visit **bloodwise.org.uk/get-involved**, call **020 7504 2200** or email **hello@bloodwise.org.uk**

# Your feedback

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

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

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

# More information

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

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

For our patient information, go to
**bloodwise.org.uk/info-support**



# Information booklets

Booklets which are available free of charge:

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

# Fact sheets

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

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

# More information from Bloodwise

You can order more information by:

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

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

**Please send me some information**

Title ..... First name ..... Surname .....

Address .....

Postcode ..... Email ..... Phone .....

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

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**Keep in touch**

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

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

☐ Please don't contact me by post

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

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

# My details

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

My name and hospital number

My NHS number

My condition

My contacts

My consultant

My key worker (usually CNS)

Haematology ward

Haematology clinic

Out of hours

Other contacts

Bloodwise

The **blood cancer research** charity

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

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