Children's Cancer and Leukaemia Group | the EXPERTS in CHILDHOOD CANCER

Acute lymphoblastic leukaemia (ALL) in children

An information guide for parents, carers and families

The purpose of this guide is to give information about acute lymphoblastic leukaemia to help you understand more about the type of cancer your child has.

Information in this guide should be used to support professional advice specific to your child's diagnosis. If you have any questions, it is important to ask your child's medical team.

What is leukaemia?

One third of all childhood cancers are leukaemia, with approximately 500 new cases in the UK each year.

Leukaemia is a cancer of the white blood cells. All blood cells are made in the bone marrow, the spongy substance at the core of some bones in the body.

Bone marrow contains:
- red blood cells - carry oxygen around the body
- platelets - help blood to clot and control bleeding
- white blood cells - help fight infection

There are two different types of white blood cells; lymphocytes and myeloid cells (including neutrophils). These white blood cells work together to fight infection. Normally, white blood cells develop, repair and reproduce themselves in an orderly and controlled way. In leukaemia, the process gets out of control and the cells continue to divide in the bone marrow, but do not mature.

These immature dividing cells fill up the bone marrow and stop it from making healthy blood cells. As the leukaemia cells are not mature, they cannot work properly. This leads to an increased risk of infection.

There are two main types of acute leukaemia:
- acute lymphoblastic (ALL)
- acute myeloid (AML)

This guide is about **acute lymphoblastic leukaemia (ALL).**

What is ALL?

Acute lymphoblastic leukaemia (ALL) is a type of blood cancer. Around 400 children develop ALL in the UK each year. Most leukaemia cases are acute lymphoblastic (ALL). ALL can affect children of any age but is more common in children aged 1-4 years old.

ALL is a cancer of immature lymphocytes, called lymphoblasts or blast cells. There are two different types of lymphocytes; T-cells and B-cells. Often, leukaemia occurs at a very early stage in the immature lymphocytes, before they have developed into either T-cells or B-cells. However, if the cells have developed this far before becoming leukemic, the type of leukaemia may be known as T-cell or B-cell leukaemia.

Causes of ALL

The exact cause of ALL is not known. Research is going on all the time into possible causes of this disease. Children with certain genetic disorders, such as Down's syndrome or Li-Fraumeni syndrome, are known to have a higher risk of developing leukaemia. Brothers and sisters of a child with ALL have a slightly increased risk of developing ALL themselves, although this risk is still very small. ALL is not infectious and cannot be passed on to other people. It is important to remember that nothing you have done has caused your child's cancer.

Signs and symptoms

As the leukaemia cells multiply in the bone marrow, the production of normal blood cells is reduced. Children may:

- become tired and lethargic
- develop bruises
- take longer to stop bleeding
- have bleeding gums or heavy nosebleeds
- have a purplish rash on the skin that does not disappear when a glass is pressed against it
- have infections
- develop fevers and sweating, especially at night.
- feel unwell and have aches and pains in the limbs
- have swollen lymph glands.

At first, the symptoms may be like those of a viral infection. This can make it hard to diagnose but over time the diagnosis usually becomes clear.

How it is diagnosed

A variety of tests and investigations may be needed to diagnose ALL. A blood test usually shows low numbers of normal white blood cells and the presence of the abnormal leukaemia cells. A sample of bone marrow is usually needed to confirm the diagnosis. A sample is also tested to look for any abnormal genetic changes and measurable residual disease (MRD) analysis.

A test called a lumbar puncture is done to see if the spinal fluid contains any leukaemia cells. A chest X-ray is also done, which will show if there are any enlarged glands in the chest. Other tests may be necessary, depending on your child's symptoms. These tests will help to identify the precise type of leukaemia and help doctors decide on the best treatment. Any tests and investigations that your child needs will be explained to you.

Treatment

The aim of treatment for ALL is to destroy the leukaemia cells and enable the bone marrow to work normally again. Chemotherapy is the main treatment for ALL which uses anti-cancer drugs to destroy cancer cells. It is given according to a treatment plan (often called a protocol or regimen). The treatment is given in several phases, or 'blocks', which are explained below.

Depending on a number of factors including your child's age, initial white blood cell count, genetic changes in the leukaemia cells and response, they will be assigned to a specific treatment group. The first six months or so involve more intensive treatment, followed by a lower intensity phase. The majority of treatment will be given as an outpatient, usually in a dedicated Day Case Unit.

Induction

This phase involves intensive treatment, aimed at destroying as many leukaemia cells as possible and is usually started within days of being diagnosed. The induction phase lasts 4-6 weeks. A bone marrow test is taken at the end of induction treatment to confirm whether or not your child still has leukaemia. The sample that is taken is looked at under a microscope and when there is no evidence of leukaemia, your child's condition is referred to as being in 'remission'.

During induction, your child will receive chemotherapy into the spinal fluid (intrathecal chemotherapy). This is an essential part of treatment, even if leukaemia cells are not visible on the lumbar puncture test. Children who have visible leukaemia cells or signs of blood cells in the spinal fluid will receive extra doses.

Consolidation and central nervous system (CNS) treatment

The next phase of treatment is aimed at maintaining the remission by giving additional chemotherapy directed at the central nervous system.

After this consolidation treatment, there is a recovery period which is called interim maintenance. This is when more drugs will be given to try to keep the leukaemia in remission. The exact details will depend on which arm of treatment your child follows and will be discussed in depth by your child's doctor as it depends on your child's response to treatment so far. This is followed by a block of more intensive chemotherapy called 'delayed intensification', before going into maintenance.

Maintenance treatment

The remainder of treatment consists of lower intensity chemotherapy known as maintenance. Although this phase is of lower intensity, it is hugely important as part of the overall treatment plan. This consists of:

- daily and weekly tablets
- monthly chemotherapy injections and oral steroids
- three monthly intrathecal treatment

Your child will have regular hospital visits and have their blood counts monitored to check that they are having the optimal chemotherapy doses during this phase. Children will be able to take part in their normal daily activities as soon as they feel able to. Most children return to school before beginning maintenance treatment.

Bone marrow transplant

A minority of children who have ALL that is likely to come back following standard chemotherapy may need a bone marrow transplant.

Testicular radiotherapy

Sometimes boys need to have radiotherapy to their testicles. This is because leukaemia cells can survive in the testicles despite chemotherapy.

Side effects during treatment

Treatment for ALL can cause side effects, and your child's doctor will discuss these with you before the treatment starts. It is important to discuss any side effects your child is having with their medical team so that they know how they are feeling and can decide how best to support your child.

Most side effects are short-term and gradually disappear once treatment stops. Side effects can include:

- feeling sick (nausea) and being sick (vomiting)
- temporary hair loss
- tiredness
- low blood count leading to an increased risk of infection and bruising and bleeding (sometimes blood and/or platelet transfusions are needed)
- a sore mouth and tummy
- diarrhoea

Steroid medicines can also cause side effects including:

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

Clinical trials

Many children have their treatment as part of a clinical research trial. Clinical trials and studies are carried out to try to improve our understanding of the best way to treat an illness, usually by comparing the standard treatment with a new or modified version. Clinical trials mean there are now better results for curing children's cancers compared with just a few years ago.

Your child's medical team will talk to you about taking part in a clinical trial and will answer any questions you have. Taking part in a research trial is completely voluntary, and you'll be given plenty of time to decide if it's right for your child. You may decide not to take part, or you can withdraw from a trial at any stage. Your child will still receive the best treatment available.

National treatment guidelines

Sometimes, clinical trials are not available for your child's cancer. This may be because a recent trial has just finished, or because the specific type of leukaemia is very rare. In this case, your doctors will offer the most appropriate treatment, using guidelines which have been agreed by experts across the UK. Children's Cancer and Leukaemia Group (CCLG) is an important organisation which helps to produce these guidelines.

Late side effects

Months or years later some children may develop late side effects from the treatment they have had. These may include a reduction in bone growth, a change in the way the heart, lungs and kidneys work, a risk of infertility and a small increase in the risk of developing another cancer in later life. For more information please visit www.cclg.org.uk/living-beyond-cancer

Your child's doctor or nurse will talk to you about any possible late side effects and will keep a close eye on possible long-term side effects in follow-up clinics.

Relapse

Most children with ALL are cured. If the leukaemia comes back after initial treatment, it usually does so within the first three years. Further treatment can then be given.

Follow-up care

Long-term side effects (late side effects) are rare, and most children with ALL grow and develop normally.

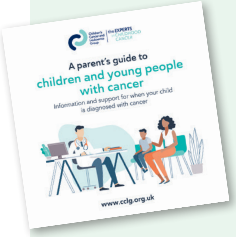
Once treatment has finished, the doctors will monitor your child closely with regular appointments to be sure that the cancer has not come back and there are no complications. After a while, you will not need to visit the clinic so often.

If you have specific concerns about your child's condition and treatment, it's best to discuss them with your child's doctor, who knows the situation in detail.

Your feelings

It's devastating to hear that your child has cancer and you may feel overwhelmed, but there are many professionals and organisations to help you through this difficult time. You may have many feelings, such as fear, guilt, sadness, anger, and uncertainty. These are all normal and are part of the process that many parents go through.

It's not possible to address in this guide all of the feelings you may have. However, the CCLG booklet 'A parent's guide to children and young people with cancer' talks about the emotional impact of caring for a child with cancer and suggests sources of help and support.
Your child may have a variety of powerful emotions throughout their experience of cancer. The Parent's Guide discusses these further and talks about how you can support your child.



The CCLG booklet 'A parent's guide to children and young people with cancer' is available FREE of charge from your child's hospital

All CCLG booklets and leaflets can be downloaded or ordered from our website:

www.cclg.org.uk/publications

i USEFUL ORGANISATIONS

Children's Cancer and Leukaemia Group (CCLG) publishes a variety of free resources to order or download.
www.cclg.org.uk

Young Lives vs Cancer offers practical support to children and young people with cancer and to their families
www.younglivesvscancer.org.uk

Macmillan Cancer Support offers support and advice to those affected by cancer.
www.macmillan.org.uk

Leukaemia CARE provides care and support through the diagnosis and treatment of leukaemia or an allied blood disorder
www.leukaemiacare.org.uk

Blood Cancer UK Funds research and provides information and support
www.bloodcancer.org.uk

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Children's Cancer and Leukaemia Group (CCLG) is a leading national charity and expert voice for all childhood cancers.

Each week in the UK and Ireland, more than 30 children are diagnosed with cancer. Our network of dedicated professional members work together in treatment, care and research to help shape a future where all children with cancer survive and live happy, healthy and independent lives.

We fund and support innovative world-class research and collaborate, both nationally and internationally,to drive forward improvements in childhood cancer. Our award-winning information resources help lessen the anxiety, stress and loneliness commonly felt by families, giving support throughout the cancer journey.

Our work is funded by donations. If you would like to help, text 'CCLG' to 70300 to donate £3. You may be charged for one text message at your network's standard or charity rate. CCLG (registered charity numbers 1182637 and SC049948) will receive 100% of your donation.

If you have any comments on this factsheet, please contact us at publications@cclg.org.uk