Acute myeloid leukaemia (AML) in children

An information guide for parents, carers and families

The purpose of this guide is to give information about acute myeloid 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 leukaemia:
- acute lymphoblastic (ALL)
- acute myeloid (AML)

This guide is about **acute myeloid leukaemia (AML).**

What is AML?

Acute myeloid leukaemia (AML) is a type of blood cancer. Around 80 children develop AML in the UK each year. Less than a fifth of childhood leukaemia cases are AML. AML can affect children of any age; girls and boys are equally affected.

AML is an overproduction of immature myeloid white blood cells (blast cells). Cells that have started to show features of myeloid cells are said to show differentiation. Cells that do not show signs of becoming a particular type of white blood cell are known as undifferentiated.

There are different sub-types of AML. Knowing this is important to help doctors decide on the best treatment.

Causes of AML

The exact cause of AML 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 AML may have a slightly increased risk of developing AML themselves, although this risk is still very small. Children with bone marrow failure conditions may have an increased of developing AML.

AML 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 you press a glass 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 AML. 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.

There have been significant advances in understanding the genetic changes in leukaemia cells. These changes, (seen in about 75% of cases) are used to identify your child's subtype of leukaemia, help doctors to predict their response to treatment and monitor the cancer. As understanding of the genetic changes improves, it is likely that this will help to guide treatment in the future.

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 AML is to destroy the leukaemia cells and enable the bone marrow to work normally again. Chemotherapy is the main treatment for AML.

Chemotherapy 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.

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 usually involves two courses (cycles) of a combination of chemotherapy drugs. A bone marrow test will be taken after the first course of chemotherapy 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, the child's condition is referred to as being in 'remission'.

Consolidation treatment

After the first two courses of chemotherapy, if your child is in remission, further treatment is based on the results of the genetic and MRD tests on the bone marrow. Your child's doctor will explain this to you in more detail.

This phase of the treatment aims to destroy any leukaemia cells that may be left and to help stop the AML from coming back. Most children receive four courses (cycles) of chemotherapy in total.

Bone marrow transplant

Children at high risk of AML coming back following standard chemotherapy will have a bone marrow transplant to reduce the risk. This will usually be performed after 2 or 3 courses of chemotherapy when the child is in remission. Children in this group are identified based on the results of the genetic testing on the bone marrow and how the AML has responded to treatment. Children whose leukaemia returns after conventional treatment will also need a bone marrow transplant.

Central nervous system (CNS) treatment

AML may sometimes develop in the brain and spinal cord. This can be prevented by injecting chemotherapy drugs directly into the spinal fluid during a lumbar puncture (intrathecal chemotherapy). Intrathecal chemotherapy is usually given with the lumbar puncture performed at the time of diagnosis and before the second course of chemotherapy. Sometimes a more intensive treatment is needed, and the intrathecal drugs are given more frequently until all the regular chemotherapy has been completed.

Side effects during treatment

Treatment for AML 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

Clinical trials

Many children have their treatment as part of a clinical research trial. Clinical trials 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 leukaemia. 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 AML are cured. If the leukaemia recurs after initial treatment, it usually does so within the first three years. Further treatment can then be given.

Follow-up care

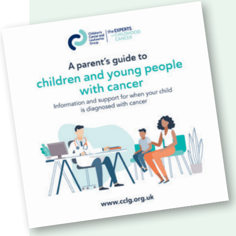
Long-term side effects (late side effects) are rare, and most children with AML grow and develop normally. Once treatment has finished, the doctors will monitor your child closely with regular appointments to be sure that the cancer has not come back and there are no complications. After a while, you 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.


Children's Cancer and Leukaemia Group | the EXPERTS in CHILDHOOD CANCER
A parent's guide to
children and young people with cancer
Information and support for when your child is diagnosed with cancer
www.cclg.org.uk

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

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 | the EXPERTS in CHILDHOOD CANCER

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Patient Information Forum

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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.

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