Acute lymphoblastic leukaemia (ALL) is a type of blood cancer. One-third of all childhood cancers are leukaemia, with approximately 400 new cases in the UK each year. Approximately, three out of four of these cases are acute lymphoblastic (ALL). ALL can affect children of any age but is more common in children aged 1-4 years old.

More children than ever are surviving childhood cancer. There are new and better drugs and treatments, and we can now also work to reduce the after-effects of having had cancer in the past.

It is devastating to hear that your child has cancer, and at times it can feel overwhelming but there are many healthcare professionals and support organisations to help you through this difficult time.

Understanding more about the cancer your child has and the treatments that may be used can often help parents to cope. We hope you find the information here helpful. Your child’s specialist will give you more detailed information, and if you have any questions it is important to ask the specialist doctor or nurse who knows your child’s individual situation.

This factsheet is published in conjunction with CCLG’s booklet entitled: ‘Children and Young People with Cancer: A Parent’s Guide’.

Leukaemia

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, which carry oxygen around the body
- platelets, which help the blood to clot and control bleeding
- white blood cells, which 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, however, 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 four main types of leukaemia:
- acute lymphoblastic (ALL)
- acute myeloid (AML)
- chronic lymphocyte (CLL)
- chronic myeloid (CML)

Chronic leukaemias usually affect adults and each type of leukaemia has its own characteristics and treatment. 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 leukaemic, the type of leukaemia may be known as T-cell or B-cell leukaemia.

This factsheet is about acute lymphoblastic leukemia (ALL).

Causes

The exact cause of ALL is unknown. Research is going on all the time into possible causes of this disease. Children with certain genetic disorders, such as Down’s syndrome, are known to have a higher risk of developing leukaemia. Brothers and sisters of a child with ALL (particularly identical twins) have a slightly increased risk of developing ALL themselves, although
this risk is still small.

Like all cancers, ALL is not infectious and cannot be passed on to other people.

**Signs and symptoms**

As the leukaemia cells multiply in the bone marrow, the production of normal blood cells is reduced. Children may therefore become tired and lethargic because of anaemia, which is caused by a lack of red blood cells. Children may develop bruises, and bleeding may take longer to stop because of the low number of platelets present in their blood (which help blood to clot). Sometimes, children suffer from infections because of low numbers of normal white blood cells.

A child is likely to feel generally unwell and may complain of aches and pains in the limbs or may have swollen lymph glands.

At first, the symptoms are just like those of a viral infection, but when they continue for more than a week or two, the diagnosis usually becomes clear.

**How ALL is diagnosed**

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 sent to the genetics department to look for any abnormal chromosomes, and for a test called MRD (minimal residual disease) 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.

**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 and 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 lasts 4-6 weeks. A bone marrow test is taken at the end of induction treatment to confirm whether or not the 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 and central nervous system (CNS) treatment**

The next phase of treatment is aimed at maintaining the remission and preventing the spread of leukaemia cells into the brain and spinal cord (the central nervous system, or CNS). CNS treatment involves injecting a drug, usually methotrexate lumbar puncture.

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 detail by your child’s doctor as it depends on your child’s response to treatment so far.

Further doses of chemotherapy treatment, called ‘delayed intensification’, are given to kill off any remaining leukaemia cells.

**Maintenance treatment**

This phase of treatment lasts for two years from the start of interim maintenance for girls and three years from the start of interim maintenance for boys. It involves the child taking daily and weekly tablets, some children also have monthly injections of chemotherapy and oral pulses of steroids and three-monthly intrathecal treatment.

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 transplantation**

Bone marrow treatment is only needed by a minority of patients and is used for children with ALL that is likely to come back following standard chemotherapy.

**Testicular radiotherapy**

In some situations it may be necessary for boys to have radiotherapy to their testicles. This is because leukaemia cells can survive in the testicles despite chemotherapy.
Central nervous system (CNS) radiotherapy
Children who have leukaemia cells in their CNS when they are first diagnosed with ALL need more frequent lumbar punctures with intrathecal chemotherapy. Your child's specialist will discuss with you which treatment and how much of it your child needs, and will answer any questions you have.

Side effects of treatment
Many cancer treatments will cause side effects. This is because while the treatments are killing the cancer cells, they can also damage some normal cells.

Some of the main side effects of chemotherapy are:
- hair loss
- reduction in the number of blood cells produced by the bone marrow, which can cause anaemia (an increased risk of bruising, bleeding and infection
- loss of appetite
- feeling sick (nausea) and being sick (vomiting)

Steroid medicines can also cause side effects such as:
- increased appetite
- mood changes and irritability
- weight gain
- muscle weakness (especially in the legs)

Most side effects are temporary, and there are ways of reducing them and supporting your child through them. Your child's doctor or nurse will talk to you about any possible side effects. It is important to discuss any side effects your child is having with the team treating them, so that they know how your child is feeling.

Late side effects of treatment
A small number of children may develop late side effects, sometimes many years later. These include possible problems with puberty and fertility, a change in the way their heart works and a small increase in the risk of developing another cancer later in life. Your child's doctor or nurse will talk to you about any possible late side effects.

Clinical trials
Many children have their treatment as part of a clinical research trial. Trials aim to improve our understanding of the best way to treat an illness, usually by comparing the standard treatment with a new or modified version. Specialist doctors carry out trials for ALL.

If appropriate, your child's medical team will talk to you about taking part in a clinical trial and will answer any questions you have. Written information is provided to help explain things.

Taking part in a research trial is completely voluntary, and you'll be given enough time to decide if it is right for your child.

Treatment guidelines
Sometimes, clinical trials are not available for your child. This may be because a recent trial has just finished, or because the condition is very rare. In these cases, you can expect your doctors and nurses to offer treatment which is agreed to be the most appropriate, using guidelines which have been prepared by experts across the UK. The Children's Cancer and Leukaemia Group (CCLG) is an important organization which helps to produce these guidelines.

Follow-up care
Most children with ALL are cured. If the leukaemia recurs after initial treatment, it usually does so within the first three years. Further treatment can then be given.

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

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
As a parent, the fact that your child has cancer is one of the worst situations you can be faced with. You may have many emotions, such as fear, guilt, sadness, anger and uncertainty. These are all normal reactions and are part of the process that many parents go through at such a difficult time. It's not possible to address in this factsheet all of the feelings you may have. However, the CCLG booklet ‘Children & Young People’s Cancer; A Parent’s Guide’, 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.
Useful organisations

Children’s Cancer and Leukaemia Group (CCLG)
www.cclg.org.uk
CCLG supports the 1,700 children who develop cancer each year in the UK. It gives support to healthcare professionals involved in caring for children with cancer and is instrumental in the development of high standards of care.

CLIC Sargent
www.clicsargent.org
CLIC Sargent offers practical support to children and young people with cancer.

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

Leukaemia CARE
www.leukaemiacare.org.uk
Leukaemia CARE is a national charity that provides care and support to patients, their families and carers, through the diagnosis and treatment of leukaemia or an allied blood disorder.

Leukaemia & Lymphoma Research
www.beatingbloodcancers.org.uk
Supports research into the treatment of leukaemia and other related blood disorders in both children and adults.

References

This factsheet has been compiled using information from a number of reliable sources, including:

- CYPALL. Guidelines for treatment of children and young persons with acute lymphoblastic leukaemia and lymphoblastic lymphoma (Interim Guidelines 3). 2011

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CCLG supports the 1,700 children who develop cancer each year in Britain and Ireland. As an association for healthcare professionals involved in their care, it works to benefit children through development of the highest standards of care. CCLG is a major provider of accredited information for patients and families. CCLG booklets are available to download from our website.

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