

Childhood Acute Lymphoblastic Leukaemia (ALL)

**A Guide for
Parents**

Leukaemia Care
YOUR Blood Cancer Charity

Introduction

Being told that your child has acute lymphoblastic leukaemia (ALL) can be a shock and incredibly upsetting for everyone, particularly when you may never have heard of the disease. If you have questions about childhood ALL – what causes it, who it affects, how it affects your child's body, what symptoms to expect and likely treatments – this booklet covers the basics for you.

For more information, talk to your child's haematologist, clinical nurse specialist (CNS) or hospital pharmacist. You'll also find useful advice about how to get the best from your child's haematologist, plus practical advice on how to help important people in your life understand such a rare condition.

This booklet focuses on ALL in children. If you are looking for information about ALL in adults, please refer to our other booklet, Adult ALL.

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If you would like any information on the sources used for this booklet, please email communications@leukaemiacare.org.uk for a list of references.

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About Leukaemia Care

Leukaemia Care is a national charity dedicated to ensuring that people affected by blood cancer have access to the right information, advice and support.

Our services

Helpline

Our helpline is available 8.30am - 5.30pm on weekdays and 7.00pm - 10.00pm on Thursdays and Fridays. If you need someone to talk to, call **08088 010 444**

Nurse service

We have two trained nurses on hand to answer your questions and offer advice and support, whether it be through emailing nurse@leukaemiacare.org.uk, over the phone on **08088 010 444** or via LiveChat.

Patient Information Booklets

We have a number of patient information booklets like this available to anyone who has been affected by a blood cancer. A full list of titles – both disease specific and general information titles – can be found on our

website at www.leukaemiacare.org.uk/resources/filter-by-resource-type/information-booklets

Support Groups

Our nationwide support groups are a chance to meet and talk to other people who are going through a similar experience. For more information about a support group local to your area, go to www.leukaemiacare.org.uk/our-support-groups

Buddy Support

We offer one-to-one phone support with volunteers who have had blood cancer themselves or been affected by it in some way. You can speak to someone who knows what you are going through. For more information on how to get a buddy call **08088 010 444** or email support@leukaemiacare.org.uk

Online Forum

Our online forum, www.healthunlocked.com/leukaemia-care, is a place for people to ask questions anonymously or to join in the discussion with other people in a similar situation.

Patient and carer conferences

Our nationwide conferences provide an opportunity to ask questions and listen to patient speakers and medical professionals who can provide valuable information and support.

Website

You can access up-to-date information on our website, www.leukaemiacare.org.uk, as well as speak to one of our care advisers on our online support service, LiveChat (9am-5pm weekdays).

Campaigning and Advocacy

Leukaemia Care is involved in campaigning for patient well-being, NHS funding and drug and treatment availability. If you would like an update on any of the work we are currently doing or want to know how to get involved, email advocacy@leukaemiacare.org.uk

Patient magazine

Our quarterly magazine includes inspirational patient and carer stories as well as informative articles by medical professionals. To subscribe go to www.leukaemiacare.org.uk/resources/subscribe-to-journey-magazine

What is childhood ALL?

Acute lymphoblastic leukaemia (ALL) is a blood cancer that affects the lymphocytic white blood cells that are produced by the bone marrow. In ALL there is an excess number of lymphocytes in the circulating blood. These lymphocytes are abnormal and cannot help the body to defend against infections. When you have ALL, the marrow is not able to make enough normal blood cells, which may lead to a set of debilitating symptoms.

Acute does not mean how serious a disease is - it means that it comes on quickly and, if not treated, will progress quickly. Lymphoblastic refers to the presence of large numbers of lymphoblasts which are immature white blood cells (lymphocytes).

ALL can be diagnosed at any age but, unlike most forms of cancer, it is most common in childhood. It is the most common type of cancer in children.

This booklet is about ALL in children over the age of one year. ALL in children under one is very rare, and is treated differently. If you have a child under one year old, your child's doctor will give you detailed information about their outlook and treatment.

Leukaemia Care publishes a

separate booklet on adult ALL, which describes treatment of people over the age of 26 years. Teenagers and young adults (up to the age of 26 years) are typically treated in a similar way to children.

ALL in children usually responds very well to treatment and about nine out of ten (90%) of patients with this form of leukaemia are long-term survivors.

How common is childhood ALL?

Childhood ALL is considered a rare disease as it affects about five in every 100,000 children per year. About one in 2,000 children will develop ALL by the age of 15 years. An average GP will only see about one or two cases in their working

life, which may lead to a delay in recognition of the diagnosis.

Although rare, ALL is the most common type of childhood leukaemia and affects boys slightly more often than girls. There are about 450 to 500 new cases diagnosed in the UK each year. Childhood ALL is most often diagnosed in children between about two to five years old.

There are several different types of lymphocyte (a type of white blood cell) – the main types are called B-cells and T-cells and have different jobs in the immune system. Most cases of childhood ALL are of a type called precursor B-cell ALL. This is also sometimes called common-ALL. This booklet describes diagnosis and treatment of common-ALL in children aged between one and 15 years old. If your child has a different type, or is older or younger, the differences in treatment will be explained to you by your child's doctor.

What causes childhood ALL?

In almost all cases of childhood ALL there is no apparent cause.

A few cases are associated with inherited genetic syndromes, such as Down syndrome, or some conditions that children are born with that affect the immune system, such as ataxiatelangiectasia and Wiskott-Aldrich syndrome. Exposure to high levels of radiation is known to increase the risk of developing ALL, but this is likely to account for very few, if any, cases in the UK.

Several things have been suggested as causes, including living near power lines or nuclear power plants, mobile phones or phone masts and chemicals. Studies have not confirmed any of these as a cause of childhood ALL.

There is some evidence that the timing and pattern of exposure to infections may affect the risk of developing childhood ALL, but this is not well understood. You cannot catch ALL from someone who has it and your child cannot pass ALL on.

Symptoms of childhood ALL

Before we discuss the symptoms of childhood ALL, it is important to understand how childhood ALL affects your child's body compared to someone who does not have childhood ALL.

In a child without ALL, bone marrow (the soft, fatty tissue inside your bones) contains blood stem cells that in time develop into mature blood cells - red blood cells (to carry oxygen to the tissues of your body); white blood cells (to fight infection and disease); or platelets (to help prevent bleeding by causing blood clots to form).

In a child with ALL, abnormal cells, called lymphoblasts, take over the bone marrow. Lymphoblasts are immature cells that normally divide to produce blood cells, which become mature and enter the blood. When the mature cells are worn out, they are cleared from the blood and broken down.

When a child has ALL, the marrow contains large numbers of lymphoblasts and other immature blood cells. The production of normal blood cells (red cells,

white cells and platelets) is reduced because of the leukaemia. The blood will almost always contain large numbers of lymphoblasts, which usually makes the diagnosis obvious. In rare cases, the blood count may be normal or there may be fewer than normal blood cells.

ALL patients have lower than normal numbers of red blood cells (anaemia), white blood cells (neutropenia) and/or platelets (thrombocytopenia). When all types of blood cells are lower than normal, this is called pancytopenia. These changes lead to most of the symptoms of ALL.

What are the most common symptoms of childhood ALL?

The most common symptoms of childhood ALL are fever (high temperature) and fatigue (excessiveness tiredness). Children may also bruise or bleed easily, for example, bleeding from the gums when brushing their teeth. The liver and/or the spleen (part of the immune system) may be swollen, which may show as a

swollen stomach. Lymph nodes (glands) may be swollen. Children may have bone or joint pains and, in very young children, the first signs may be reluctance to walk or to crawl.

Most children do not have all of these symptoms and a child may just be vaguely unwell, perhaps with paleness, lethargy (tiredness) or malaise (general feeling of being unwell). If a child is very unwell, or is persistently unwell, they should be taken to the GP.

To summarise, common symptoms and their causes are:

- Anaemia - looking pale, breathlessness, easy tiredness
- Low white cell count - frequent, persistent infections
- Low numbers of platelets - bruising and/or bleeding

A child with ALL may not show the typical signs of infection. If your child has any of the following signs or symptoms you should contact their GP or the hospital straight away:

- Raised temperature, cough or sore throat
- Confusion or agitation, especially if it comes on suddenly
- Your child suddenly or rapidly becoming more ill
- Fast heart beat and/or fast breathing
- Passing very little or no urine
- An increase in pain; if your child is not yet talking, you may see this as reluctance to walk or crawl

All of the signs or symptoms described are quite common in children. It is very rare for a child with these symptoms to be found to have a serious disease. It is important to diagnose ALL as soon as possible, so that treatments can start early.

It is accepted by experts that parents know their children best so, if you think your child is ill, you should always take them to a doctor.

Diagnosis of childhood ALL

There are several tests that are carried out to confirm a diagnosis of ALL. Sometimes test results can take a little while. This can be an anxious and worrying time, but please remember that it is important that your child's medical team reach the correct diagnosis so that your child can receive the right treatment. Tests may include:

Full blood count

A blood sample is examined using an automatic cell-counting machine and by looking at a stained film under a microscope. If your child has ALL, the cell-counter will usually indicate that there are large numbers of abnormal white cells (lymphoblasts) in the blood. The appearance of stained blood cells is usually very typical of ALL. In rare cases, the blood count may be normal, or there may be lower than normal numbers of white blood cells.

Bone marrow examination

If the results of a blood sample show that your child may have ALL or another serious blood condition, a bone marrow sample will be taken, usually from the pelvis

bone. This is normally done under a general anaesthetic or sedation (older children may prefer to have a local anaesthetic) and does not take very long. The bone marrow sample is important to confirm the diagnosis and also for comparison with later samples to show how your child's ALL is responding to treatment.

Additional investigations

There are a number of special investigations that can be done to confirm the diagnosis and to help in planning treatment. These tests include cytogenetics, which looks at how the chromosomes in your child's leukaemia cells are different from in their normal cells, and immunophenotyping, which shows exactly the type of ALL. A test called MRD (minimal residual disease) will be done during treatment. MRD testing can detect even very small numbers of remaining leukaemia cells, which is important in planning the next phase of treatment.

The results of these specialised tests will be used in planning what treatment your child should

receive. The cytogenetics test will include testing for an abnormal gene called BCR-ABL. This is seen much more often in adult ALL than in childhood ALL; when it is present, standard treatment does not work very well, but a type of drug called a tyrosine kinase inhibitor (TKI) can be very effective.

Some of the tests will be repeated from time to time during your child's treatment and after this is finished. This is to see how well treatment is working, and to make sure that the ALL has not returned after treatment.

Your child will also have X-rays taken and other types of scans to check for infection and to see what parts of your child's body are affected by the ALL. ALL cells can sometimes get into the fluid around the brain and spinal cord (cerebrospinal fluid or CSF). For this reason, doctors will take a sample of this fluid to look for leukaemia cells. This is called a lumbar puncture and, like bone marrow sampling, is usually done under local anaesthetic and sedation in older children, and a general anaesthetic in younger children. Again, this test will need to be

repeated from time to time during treatment.

At any time, you can ask the doctors, nurses or other healthcare workers about your child's diagnosis and treatment. You can also find information about tests on the website Lab Tests Online UK: www.labtestonline.org.uk

Treating childhood ALL

Childhood ALL is one of the most treatable cancers in children.

Children with ALL may not start treatment straightaway because doctors need the result of tests to plan the ideal treatment. Any delay in starting will be short and will not affect results of treatment.

In the UK, about nine out of ten (90%) of children with ALL take part in clinical trials. The purpose of a clinical trial is to improve the outcomes of treatment.

Treatment options

Chemotherapy

Chemotherapy is the use of anti-cancer (cytotoxic) drugs to destroy cancer cells. It is the main part of treatment for ALL in children. The most common cell killing drugs used to treat ALL are:

- Vincristine
- Mercaptopurine
- Methotrexate
- Daunorubicin
- Cyclophosphamide

- Cytarabine
- Doxorubicin
- Peg-Asparaginase

As well as the cytotoxic drugs, it has been found that steroids are very effective in the treatment of ALL. The steroids used are artificial versions of natural substances made in your child's body. It is very important to understand that these steroids are very different from the drugs sometimes abused by athletes or bodybuilders. The steroid normally used for treatment of ALL is called dexamethasone.

Other drugs will be given to prevent infections and to manage side effects of ALL treatment. There are some unpleasant side effects of standard ALL treatment, ranging from hair loss (which normally grows back quickly). Much of the present research in treatment of ALL is aimed at reducing side effects and improving the quality of life during and after treatment.

In order to make it easier to give



Treating childhood ALL (cont.)

treatment, most children with ALL will have a central line inserted. This is a tube which goes into a blood vessel in your child's chest. If your child has a central line you will be shown how to look after this, to stop it from becoming blocked or from getting infected.

UKALL 2011 Clinical Trial

This phase 3 trial closed at the end of 2018. It was designed to test whether some children can safely have a lower total treatment amount (schedule A), and whether other children may benefit from having more intensive treatment (schedule C). Most children received standard treatment (schedule B). UKALL 2011 also included several treatment options, picked at random, to compare the results of slightly different treatment options.

ALLTogether Clinical Trial

This trial is scheduled to open in 2020.

When the trial opens, you will be given full information, and a

chance to ask questions about the trial, before being asked to decide whether your child should take part. If you decide your child should not take part, he or she will receive standard ALL treatment.

Stages of treatment

The exact length of each stage of treatment and the choice and dose of drugs used at each stage will vary according to the results of tests, and whether your child is in the trial. Importantly, almost all treatment is delivered as an outpatient. You will be given detailed information about your child's treatment and can ask questions at any time.

Induction phase

The aim of initial treatment (induction) is to reduce the number of abnormal cells to as low as possible (ideally to complete remission). This uses a combination of drugs given over four weeks. At the end of induction treatment, a bone marrow test will be repeated to check that most of the leukaemia has gone (complete remission). An MRD

test will also be performed on the bone marrow sample and the results of this will be used to plan the next phase of treatment.

Consolidation phase

The second phase of treatment (consolidation) is intended to destroy any remaining leukaemia cells. It uses fewer drugs and lower doses than induction treatment. This stage usually takes between three to ten weeks depending on regimen. The exact type of consolidation will depend on the results of the MRD test. Again, you will be given detailed information and a chance to ask questions.

Interim maintenance phase

Consolidation is followed by interim maintenance, which is a period of about two months of less intensive treatment before the fourth phase of treatment. Again, the exact treatment will depend on the treatment regimen being used.

Delayed intensification

The fourth stage of treatment is called delayed intensification, and lasts for seven or eight

weeks. The aim of this stage is to ‘mop-up’ any remaining leukaemia cells. Although this uses stronger treatment than interim maintenance, your child can normally be at home unless they develop any problems.

Maintenance phase

The last stage of treatment is the longest, and gentlest. It is called maintenance, and lasts for two years in girls and three years in boys. This is needed to prevent the disease from coming back. The difference in length between boys and girls is based on the results of earlier trials. This stage of treatment involves oral treatment with methotrexate (weekly) and 6-mercaptopurine (daily), along with vincristine IV chemotherapy every three months and oral steroids along with the vincristine for five days. The oral steroids will be taken every time the patient has the vincristine treatment.

During that period, blood counts need to be followed up regularly. During this stage, intrathecal methotrexate will be given by lumbar puncture every three months.

Treating childhood ALL (cont.)

Central nervous system treatment

In children with ALL, it is possible for leukaemia cells to get into the fluid around the brain and spine (cerebrospinal fluid or CSF).

This is called central nervous system (CNS) disease and, because drugs given in the normal way cannot penetrate into the CSF, it is necessary to give additional treatment. This is normally given during the consolidation stage and may consist of radiation treatment to the head and spine, injection of drugs into the CSF by lumbar puncture or high doses of anti-leukaemia drugs. The exact choice of treatment will depend on the results of lumbar puncture tests and the exact type of ALL. Some types of ALL are more likely than others to involve the CNS, but the majority of treatment in the CSF is given for disease prevention.

Stem cell transplantation

Stem cell transplantation is not often used now in childhood ALL because of the good results of

standard treatment. This means having strong chemotherapy, along with radiation therapy, to kill off the bone marrow followed by a transplant of healthy stem cells from a matched donor.

You can find more information about drugs used to treat your child's ALL (and any other medicines they are taking) at the eMC Medicine Guides website:
<https://www.medicines.org.uk/emc/>

Side effects

Unfortunately, treatments do come with some side effects, but your child is unlikely to experience all of them. It is difficult to predict exactly what side effects your child will experience as different people react to treatment in different ways. There are three types of side effects:

- 1. Short term side effects** – these side effects can last for a few days or weeks, but for some, can last for the duration of treatment.
- 2. Long term side effects** – these are side effects that last for a long period of time.

- 3. Late effects** – these are side effects that develop months or years after treatment has stopped.

For more information about late effects, we have a booklet which you can read on our website or order by contacting the Patient Advocacy team on **08088 010 444**

Your child's medical team will be able to answer any questions you might have on any side effects likely to be seen.

Short-term side effects

Short-term side effects can include:

- **Fatigue** – a common side effect of chemotherapy treatment. Fatigue is not simply tiredness that passes with rest; your child may feel generally tired all the time or may tire very easily after doing normal, everyday tasks.
- **Nausea and sickness** –

this can be well-managed with antisickness drugs (antiemetics).

- **Infection** - all children with ALL can be expected at some point to get an infection that requires treatment with antibiotics.
- **Bleeding** – chemotherapy can make your child more prone to bleeding, especially from the nose or gums.
- **Diarrhoea** – this can be well-managed with medication.
- **Sore mouth** – chemotherapy can cause inflammation of the tissue inside your child's mouth.
- **Loss of taste and appetite** – your child's taste and appetite can be affected during treatment so it's important to encourage them to drink plenty of fluids to stay hydrated. There are food supplements that may help maintain their energy levels.
- **Organ dysfunction** – chemotherapy can affect the functioning of your child's liver, kidneys or lungs.

Treating childhood ALL (cont.)

- **Hair loss** – your child may want to wear a wig or some form of headwear if affected by hair loss. The healthcare team will be able to chat to you about options to manage this side effect. It is important to reassure your child that their hair will grow back.

Long-term side effects

Fatigue

The fatigue will improve when treatment ends, but it can take six to 12 months following treatment until your child will feel back to normal.

Loss of fertility

This is incredibly rare with current ALL treatments, but some of the drugs used can cause temporary or permanent infertility. Your child's doctor will talk to you about this in more detail before treatment starts. The effect of treatment on their child's fertility is a common concern that many parents have. However, as treatment for ALL usually needs to start as quickly as possible, there's not always enough time to store sperm or eggs. This

approach may, in any case, not be possible for younger children.

If your child is having treatment for ALL, you should discuss the options for protecting your child's fertility with their doctor. You can write down any questions you have so that you are clear about the treatment and the effect it's likely to have on your child before it starts. Some drugs have less effect on fertility than others, and it is often possible for a child successfully treated for ALL to later have healthy babies. Unfortunately, children who have had a stem cell transplant after high doses of chemotherapy or whole-body irradiation are more likely to be permanently infertile. It is natural to worry about the effects of treatment on any children your child might have after treatment. However, evidence from clinical studies has shown that any cancer treatment a child has does not lead to an increased risk of cancer or other health problems in their children.

Heart damage

Some of the drugs, such as anthracyclines, used to treat

ALL may affect the heart. This does not affect everyone and, if it does occur, it is usually a temporary side effect because healthcare teams are careful to limit the doses. However, in some people it can lead to long-term heart problems. Your child's heart function will be carefully monitored during and after treatment, and the drugs given may be altered if any heart problems occur.

Secondary cancers

Secondary cancer is a cancer that has developed after treatment for another cancer has finished. Chemotherapies are known to cause secondary cancers, the most common of which are myelodysplastic syndromes (MDS) and leukaemia, mainly acute myeloid leukaemia (AML). The types of chemotherapy whose anti-cancer action is to damage DNA in normal cells may result in secondary cancers in the future. Possible risks of second cancers should not influence the use of effective treatments. Your child's doctor will advise you on how to consider the relatively low risks

involved.

Treatment of relapsed childhood ALL

Almost all children have a good initial response to treatment with blood counts returning to normal, which is called remission. Unfortunately, in some cases the disease will come back, which is known as relapse. When a relapse happens while a child is on maintenance treatment, there is a good chance that this will respond well to repeating the initial treatment.

When relapse happens early in treatment, this tends not to respond to repeating the previous treatment. In this case, one treatment option is a stem cell transplant. If your child has a relapse or is being considered for a stem cell transplant, you will be given detailed information and a chance to ask questions about what this means.

Supportive care

Supportive care includes treatment to prevent infections and to manage them when they

Treating childhood ALL (cont.)

happen, as well as treatment to deal with the side effects of ALL treatment. Improvements in supportive care have played a crucial part in improving the survival of children with ALL.

Because both ALL and its treatment affect the body's ability to produce healthy blood cells, most children with ALL need transfusions of red blood cells and often of platelets. It is not possible to transfuse white blood cells, but it is now possible for your child to have injections of growth factors, which help the body to produce more white cells. This will reduce the frequency and severity of infections.

Much of the supportive care is based on good nursing care, but protecting your child from infection outside the hospital is very important. You will be given information on this and will be shown how to recognise infection, or other complications, and who to contact and what to do.

If your child is at school or a playgroup, then measles and chickenpox are particular risks. The hospital staff will help you to

explain to your child's school or playgroup what precautions are necessary.

Follow-up

It is very important that any child who has been treated for ALL should have a follow-up programme in place to watch for late effects and deal with these promptly.

Once your child's treatment is finished, they will need to have regular check-ups at the hospital. These will be frequent at first, probably every one to two months, then every few months until they become yearly at five years and onwards. The purpose of follow-up is to monitor your child and look for signs of relapse or complications and monitor their growth.

If you notice any new symptoms or something is worrying you, you should contact your child's medical team as soon as possible.

New treatments and treatments on the horizon

Most of the improvements in the

outcome of childhood ALL have come not from new drugs but from improvements in supportive care and in finding better ways to use existing drugs. One important area of research is into ways to use the patient's immune system to kill off leukaemia cells. If successful, this approach would cause much less damage to healthy tissues and less severe long-term effects of treatment.

Much of the research on potential new drugs is being carried out in adults with ALL, who have poorer results with standard treatment. If new drugs are developed, it is likely that there will be clinical trials to see if they may be a good option for treatment of children.

Prognosis

The outlook for children with ALL has improved greatly over the last 50 years. At one time, almost all children diagnosed with ALL would die of their disease; now about 90% will live for at least five years.

If you are concerned about your child's prognosis, you can discuss

this with your child's medical team.

Everyday life and childhood ALL

Having a child who has been diagnosed with an aggressive blood cancer like ALL can be difficult for both the child as well as you, the parent, and other family members.

Emotional impact of Childhood ALL

Being told your child has cancer will be incredibly upsetting. It can be especially difficult with acute leukaemia as your child will have become ill quite suddenly and have to start treatment quickly. There is usually very little time to take in information and start to cope with it.

Childhood ALL is a rare condition and, because of this, both you and your child may need emotional support. It is likely that you will experience a range of complex thoughts and emotions, some of which may feel strange or unfamiliar to you. It is important to know that these feelings are all valid and a normal response to your child's illness.

Your child's emotional needs will also be assessed as they go through their treatment as they will inevitably feel confused, distressed and anxious

throughout their treatment. If your child has siblings, they may also need support to deal with what is happening as life may change temporarily for them too.

CLIC Sargent has some excellent information on how to talk to siblings about their brother or sister's cancer at: <https://beta.clicsargent.org.uk/life-with-cancer/my-brother-or-sister-has-cancer/>

Remember that support does exist for you whenever you need it and many people feel that talking to someone who is independent to your situation can really help. Our Patient Advocacy staff are on hand to chat on **08088 010 444**. You may feel that you need additional support in the form of a counsellor. You can find

accredited counsellors at bacp.co.uk or your GP will be able to put you in touch with one.

Our booklet on the emotional impact of a blood cancer provides lots of useful information that could help you cope. To request your copy, call **08088 010 444** or download through the website at [www.leukaemiacare.org.uk](http://leukaemiacare.org.uk)

Physical impact of Childhood ALL

Following a diagnosis of ALL, your child may display some physical symptoms which may be due to the leukaemia, or down to the side effects of treatment.

Fatigue

It is normal for your child to feel extremely tired most of the time as a result of their cancer and treatment. Small bouts of activity

can be useful at relieving fatigue – however, don't make them play if they are exhausted. Encourage small amounts of play, with lots of rest breaks.

Diet

Diet plays an important part in coping with cancer and its treatment and recovery. In hospital, your child will be fed a well-balanced diet with the nutrition they need to help them cope with their treatment and fight off infection.

Infection

One of the most common problems following a diagnosis of ALL is infection, as your child's body is not able to fight infections as well as normal – this is known as immunosuppression. Ordinary infections may occur more often and be more severe or longer lasting. They may also get ill from infections with germs that normally live in the body without causing problems, but which grow more rapidly when their immune system is not working – these are called opportunistic infections.

If you think your child may have

Everyday life and childhood ALL (cont.)

an infection, you should contact their doctor straightaway.

Common symptoms of infection include:

- Fever – a raised temperature (38°C or higher)
- Sore throat
- Diarrhoea
- Cough
- Excessive tiredness
- Redness around the central line

The signs and symptoms of infection may be less obvious with childhood ALL, so if you are in any doubt, it is best to contact your child's doctor and ask for advice.

Vaccines

Your child will need to have boosters of their childhood vaccinations once their immune system has recovered – this is usually around six months after chemotherapy finishes. Your child's medical team will be able to advise you on which vaccinations are needed and which ones should not be given

for a set period of time.

Measles, chickenpox and shingles

Measles and chicken pox are common in childhood. You will be given advice from your child's medical team on what to look out for and how to avoid exposing your child to these viruses.

Practical support

Caring for a child with ALL may affect your own personal arrangements with regards to work or home life.

You should contact your employer to inform them of your situation and you may need to make the appropriate arrangements with your employer regarding your working arrangements. You may need to negotiate a reduction in working hours or need to make an arrangement with your employer for times when you may need to go into hospital with your child. Many organisations will be very sympathetic and do what they can to help.

Your child's consultant or GP can arrange letters to confirm their

diagnosis and the effects it may have on your work life to your employer. It is often worth taking time to explain childhood ALL to your employer, as it is likely they will never have heard of the disease.

It is important for you to know that people with any form of cancer are covered by law by the Equality Act. This law covers parents and carers of a child with cancer. This means that legally your employer cannot discriminate against you because of your child's cancer.

Cost of cancer

Having a child with cancer can have an impact on your finances, especially if you have had to give up work and are having to find the money for additional costs, such as travel to and from hospital.

There is support available to you through benefits advisors and Macmillan. Macmillan has published a booklet about financial support following a diagnosis of cancer. They can also give you personal advice over the phone via their helpline on **0808**

808 00 00 and you can discuss the benefits for which you are eligible. Some Macmillan centres can arrange face-to-face meetings with a benefits advisor. They can also provide financial assistance in the form of grants – ask your child's clinical nurse specialist in the hospital how to apply.

Talking about childhood ALL

Talking to your child's haematologist

Childhood ALL is a rare condition, so it is important for you to develop a good working relationship with your child's haematologist, so you are fully informed about what to expect.

The following gives advice on working well with your child's haematologist:

- If it is an initial consultation, take along a list of your child's current medications and doses, and a list of any allergies they may have.
- If your child has a complicated medical history, take a list of diagnoses, previous procedures and/or complications.
- Make a list of questions to take to your child's appointment. This will help the discussion with their haematologist.
- It can be useful to repeat back what you have heard so that you can be sure that you fully understood.
- Note information down to help

you remember what was said.

- Be open when you discuss your child's symptoms and how they/you are coping. Good patient-doctor communication tends to improve outcomes for patients.

Other tips:

- Bring someone along to the appointments. They can provide support, ask questions and take notes.
- Do not be afraid to ask for a second opinion – most haematologists are happy for you to ask.

Talking to other people

Telling people your child has cancer can be incredibly upsetting and hard to explain, and disclosing information over and over again can be exhausting.

There are lots of ways to deal with this and no way is the right way. You may wish to only tell close family and friends.

If your child is currently at school, certain symptoms of ALL and side effects of treatment

may make it difficult for them to continue their education, especially during treatment, so it might be useful for you to have a conversation with your child's school to implement a plan of action tailored to your child's circumstances.

You may find it easier to provide people with basic information and give them information leaflets or booklets like this one about ALL if they want to know more in-depth details. Alternatively, some people 'nominate' a spokesperson who keeps everyone updated for you, whilst others find it easier to set up a blog or Facebook page that documents their feelings and keeps people up-to-date at the same time.

Remember that many people will have never heard of ALL and, unfortunately, it will mostly fall to you to educate them as best as you can. Where possible, it is advisable to let people know what you find helpful and unhelpful, in terms of what others say and do. Often people make assumptions and do what they think helps. For example, recounting stories of others they know with a similar

diagnosis, encouraging you to look ahead and stay positive is not always what people really want to hear. In many ways, the more you communicate with them the better.

These points may help you:

- Explain that your child has a condition that means their bone marrow does not function properly, and this affects the number of blood cells it produces
- Explain your child's symptoms (maybe they are tired, or have a lot of pain)
- Explain what you need (maybe more help day-to-day, or someone to talk to)

You could also consider the following when telling people about your child's diagnosis:

- **Find out more** - Try to find out as much as you can about your child's condition from reliable internet sources, charitable organisations or your child's consultant haematologist. The more you know, the more you can share.

Talking about childhood ALL (cont.)

- **Have a print-out to hand**
 - It may help to have some information to hand to share with family and friends. This will take the pressure off you having to remember everything they may want to know.
- **Explain your needs** - Try and be clear about what your needs may be. Perhaps you need help with the weekly food shop, help with cooking dinner, or someone to drive you to and from appointments. You may find that friends and family are pleased that they can do something to help you.
- **Be open about how you feel** - Do not be afraid of opening up about how you feel, as people who care will want to help you as best they can. Talk as and when you feel comfortable, so those around you will know when you need them most.

If you're struggling to come to terms with your child's diagnosis and prognosis, you can speak to us on our helpline. Call us on **08088 010 444**

Glossary

Anaemia

A medical condition in which the red blood cell count or haemoglobin is less than normal.

Bone marrow

The soft blood-forming tissue that fills the cavities of bones and contains fat, immature and mature blood cells, including white blood cells, red blood cells, and platelets.

Central line

A tube that is inserted into a large blood vessel either in the chest or arm, so blood samples can be taken easily, and drugs can be given without the use of needles.

Fatigue

Extreme tiredness, which is not alleviated by sleep or rest. Fatigue can be acute and come on suddenly, or chronic and persist.

Full blood count or FBC

A blood test that counts the number of different blood cells.

Leukaemia

A cancer of the blood with many

different subtypes. Some forms are acute (develop quickly) and others are chronic (develop slowly). Leukaemia is an excess number of abnormal cells in the blood, usually white blood cells, which stop the bone marrow working properly.

Neutropenia

Low levels of neutrophils (a type of white blood cell) in the blood, leading to increased susceptibility to infection.

Pancytopenia

Deficiency of red cells, white cells, and platelets in the blood.

Platelet

A disc-shaped blood cell that assists in blood clotting. During normal blood clotting, the platelets clump together (aggregate).

Spleen

An organ that filters the blood. It removes old blood cells and helps to fight infection. It sits under the ribs on the left of the body.

Glossary (cont.)

Stem cells

Cells that have the potential to develop into many different or specialised cell types.

Thrombocytopenia

Deficiency of platelets in the blood.

White blood cell

One of the cells the body makes to help fight infections. There are several types of white blood cells. The two most common types are the lymphocytes and neutrophils.

If you would like more definitions of terms you may come across during your child's blood cancer journey, you can order our A - Z of Leukaemia by calling Patient Advocacy on **08088 010 444**

Tell us what you think!

If you would like to give us some feedback about this patient information booklet, please hover over the code to the right using your phone or tablet's camera. Click the link as it appears and this will take you to a short web form to fill in.

Suitable for Android, iPhone 7 and above.



Useful contacts and further support

There are a number of helpful sources to support you during your diagnosis, treatment and beyond, including:

- Your haematologist and healthcare team
- Your family and friends
- Your psychologist (ask your haematologist or CNS for a referral)
- Reliable online sources, such as Leukaemia Care
- Charitable organisations

There are a number of organisations, including ourselves, who provide expert advice and information.

Leukaemia Care

We are a charity dedicated to supporting anyone affected by the diagnosis of any blood cancer. We provide emotional support through a range of support services including a helpline, patient and carer conferences, support group, informative website, one-to-one buddy service and high-quality patient information. We also have a nurse on our help line for any medical queries relating to your diagnosis.

Helpline: **08088 010 444**
www.leukaemiacare.org.uk
support@leukaemiacare.org.uk

Bloodwise

Bloodwise is the leading charity into the research of blood cancers. They offer support to patients, their family and friends through patient services.

020 7504 2200
www.bloodwise.org.uk

Cancer Research UK

Cancer Research UK is a leading charity dedicated to cancer research.

0808 800 4040
www.cancerresearchuk.org

Macmillan

Macmillan provides free practical, medical and financial support for people facing cancer.

0808 808 0000
www.macmillan.org.uk

Maggie's Centres

Maggie's offers free practical, emotional and social support to people with cancer and their families and friends.

0300 123 1801
www.maggiescentres.org

Citizens Advice Bureau (CAB)

Offers advice on benefits and financial assistance.

08444 111 444
www.adviceguide.org.uk

Leukaemia Care is a national charity dedicated to providing information, advice and support to anyone affected by a blood cancer.

Around 34,000 new cases of blood cancer are diagnosed in the UK each year. We are here to support you, whether you're a patient, carer or family member.

Want to talk?

Helpline: 08088 010 444

(free from landlines and all major mobile networks)

Office Line: 01905 755977

www.leukaemiacare.org.uk

support@leukaemiacare.org.uk

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One Birch Court,
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Registered charity
259483 and SC039207

Leukaemia Care
YOUR Blood Cancer Charity

