
Childhood Acute Myeloid Leukaemia (AML)

Leukaemia Care

YOUR Blood Cancer Charity

Please note that this booklet has surpassed its review date. However, during this unprecedented time, we think it is important to still offer you the information you need. We will have the updated version of this booklet made available as soon as possible.

If you have any medical queries, please call our helpline on 08088 010 444.

A Guide for Parents

Leukaemia Care

YOUR Blood Cancer Charity

Introduction

Being told that your child has acute myeloid leukaemia (AML) 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 AML – 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 AML in children. If you are looking for

information about AML in adults, please refer to our other booklet, **Adult AML**.

Booklet originally compiled by Ken Campbell, MSc (Clinical Oncology). The rewrite was put together by Lisa Lovelidge and reviewed by Nikolousis Manos and reviewed by parent Joanne Hardman.

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

In this booklet

Introduction	2
In this booklet	3
About Leukaemia Care	4
What is childhood AML?	6
Symptoms of childhood AML	8
Diagnosis of childhood AML	10
Treating childhood AML	14
Prognosis of childhood AML	20
Everyday life and childhood AML	22
Talking about childhood AML	26
Glossary	29
Useful contacts and further support	31

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 9.00am - 10.00pm on weekdays and 9.30am - 12.30pm on Saturdays. 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@leukaemicare.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.leukaemicare.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.leukaemicare.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@leukaemicare.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.leukaemicare.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@leukaemicare.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.leukaemicare.org.uk/resources/subscribe-to-journey-magazine

What is childhood AML?

Acute myeloid leukaemia (AML) is a blood cancer which affects the myeloid cells, which include red cells, platelets and some white blood cells. When you have AML, it stops the body producing enough of these cells.

The term acute does not describe how serious the AML is. It refers to the fact that it develops rapidly and, if not treated, gets worse quickly. This is in contrast to chronic leukaemia which develops and progresses slowly. Chronic leukaemia is very uncommon in children.

To understand AML, it is helpful to understand how blood cells are normally produced. Blood cells are produced in the bone marrow, which is spongy tissue found inside bones. Each day, the bone marrow produces more than a trillion new blood cells to replace those that are worn out. Blood stem cells divide to produce either mature blood cells or more stem cells. Only about one in 5,000 of the cells in the bone marrow is a stem cell. A blood stem cell, also called a haematopoietic stem cell, may become a myeloid stem cell or a lymphoid stem cell.

A myeloid stem cell becomes one

of three types of mature blood cells:

- Red blood cells that carry oxygen and other substances to all tissues of the body.
- Platelets that form blood clots to stop bleeding.
- White blood cells that fight infection and disease. The shortest lived white cells are called neutrophils.

A lymphoid stem cell becomes a lymphoblast cell and then one of three types of lymphocytes (white blood cells):

- B lymphocytes that make antibodies to help fight infection.
- T lymphocytes that help B lymphocytes make the antibodies that help fight infection.
- Natural killer cells that attack cancer cells and viruses.

Children with AML produce too many immature cells (blast cells) which populate the blood and bone marrow. Over time, these abnormal cells will accumulate and begin to fill up the bone marrow, preventing it from producing healthy blood cells.

There are several different subtypes of AML, and the type your child has will depend on which type of myeloid cell is mainly being produced in excess. One important subtype is called acute promyelocytic leukaemia (APML) and it makes up about one in 10 cases of AML. Knowing whether or not your child has APML is important because it is treated very differently to other subtypes.

Special tests will be done to distinguish between APML and other types of AML.

How common is childhood AML?

AML in childhood is rare. Usually, it affects older adults. In the UK, around 2,300 people are diagnosed with AML each year. Of these, 70 are children – 15% of all leukaemias in children and 5% of

all childhood cancers.

What causes childhood AML?

In most cases, there is no obvious cause for childhood AML and both boys and girls have about the same likelihood of developing AML.

In the vast majority of cases, AML does not run in families. There have been very unusual family cases where AML affects more than one generation. This is very rare, and, in almost all cases, there is no cause for anxiety or for screening tests.

Down's syndrome

There are some genetic conditions, such as Down's syndrome, which can increase the chance of developing AML. This type of AML is treated differently to standard AML. If this is the case for your child, their consultant will provide detailed information. Children born with Down's syndrome may also develop a leukaemia-like blood condition called transient abnormal myelopoiesis (TAM) which usually goes away without treatment.

Symptoms of childhood AML

Before we discuss the symptoms of childhood AML, it's important to understand how AML affects the body, compared to someone who doesn't have AML.

In a child without AML, 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).

Production of new blood cells is very closely controlled to balance the loss of worn out cells or cells lost by bleeding or damage. About one in 5,000 cells in the bone marrow is a blood-forming stem cell; these can divide to produce more stem cells or to develop into working blood cells. An average adult produces about one trillion new blood cells each day. The healthy number of different types of blood cells varies between people but is usually kept within fairly narrow limits. The white blood count may temporarily rise

after exercise, but changes like this usually do not last very long and are perfectly normal.

In a child with AML, there is an overproduction of immature myeloid white blood cells in the bone marrow, where the cells divide but do not mature into healthy, working blood cells. Usually, but not always, the blood contains immature cells, including blast cells, too.

Due to the inability of the bone marrow to make enough working blood cells, the immature cells fill up the bone marrow, leading to lower than normal numbers of red blood cells (anaemia), mature 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 some of the symptoms of AML which are described below.

What are the most common symptoms of AML?

The majority of children with AML

will have symptoms when they are diagnosed. However, they are often difficult to spot as they can often be confused or mistaken for symptoms of other less serious illnesses.

If your child develops any new symptoms, they get worse or last longer than normal, contact your GP straightaway.

Symptoms include:

- Your child may feel more tired or breathless than normal
- They may pick up infections more easily that last longer and are persistent
- Unusual bruising and bleeding
- Bone pain
- Enlarged liver or spleen
- Swollen gums

Some children with AML who have a very high white cell count may develop a condition called leukostasis, in which blood flow is slowed down because of thickening of the blood

Because your child is more at risk of picking up an infection, contact your hospital team if they develop any of these symptoms:

- A raised temperature (38°C or higher)
- Coughing
- Confusion or agitation
- Rapid heartbeat and fast breathing
- Shivering
- Quickly becoming ill
- Increased pain

Diagnosis of childhood AML

If AML is suspected, your child will have a set of tests to confirm the diagnosis. If your child is diagnosed with AML, they will also have further tests to determine the right treatment for their cancer. It's important that you know and understand your child's diagnosis, so you can ask questions and be fully informed of what to expect.

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 they can receive the right treatment.

Tests may include:

- **Full Blood Count (FBC)** - this is a simple blood test which measures the number of red cells, white cells and platelets in the blood.
- **Cytogenetics** - Cytogenetics is the study of gene changes and investigates the genetic differences between AML cells and normal cells. Cytogenetic results are important for the WHO classification of AML and for risk classification.
- **Bone marrow samples** - In

most cases, your child's doctor will take a bone marrow sample, where a small amount of bone marrow is taken from the hip bone using a fine needle (an aspirate), to look at the cells. They may also have a sample of bone marrow taken from the core using a larger needle (a trephine) to look at the structure of the bone marrow. This is performed under general anaesthetic for children.

Other tests which may be done include:

- **Lumbar puncture** - in childhood AML, a sample of cerebrospinal fluid (CSF) is taken from the spine to see whether there are leukaemia cells in the nervous system. In AML, cells can get into the nervous system, which protects them from some treatment.
- **X-rays, ultrasound or scans (CT or MRI)** - To monitor impact on organs of the body.

Blood tests and bone marrow samples will be repeated throughout treatment to monitor response.

If you want to know more about

your child's tests and their results, you can ask their doctor or CNS. You can also find information about tests on the website Lab Tests Online UK www.labtestsonline.org.uk

Risk grouping

The most important part of classifying childhood AML is risk grouping. There are three risk groups in AML; high, standard and low risk and your child will be classified into a risk group based on the results of the tests they had at diagnosis. Risk grouping is a way of estimating how likely it is that treatment will be successful.

Children in the low risk group often do well following conventional treatment. Children in the high risk category may need another type of treatment to achieve remission (no evidence of leukaemia cells in the body). However, many patients with high risk disease do respond well to treatment and sometimes, children in the low risk category do not. Your child's risk group can change whilst they're being treated, but their medical team will be able to provide ongoing updates relating to their condition.

Classification of AML

There are also two systems used to classify AML; the French- American- British (FAB) and the World Health Organization (WHO) systems. The main difference is that the FAB system is mainly based on the appearance of the AML cells under the microscope, while the WHO system also uses information on the specific genetic changes in the AML cell (cytogenetics).

Diagnosis of childhood AML (cont.)

FAB classification

FAB Subtype	Description
M0	AML minimally differentiated
M1	AML with minimal maturation
M2	AML with maturation
M3	Acute promyelocytic leukaemia
M4	Acute myelomonocytic leukaemia
M4 eos	Acute myelomonocytic leukaemia with eosinophilia
M5	Acute monocytic leukaemia
M6	Acute erythroid leukaemia
M7	Acute megakaryoblastic leukaemia

This is an older classification system, but is still widely used and is particularly useful for initial classification before cytogenetic results are available. It is based mainly on the appearance of the AML cells under the microscope, sometimes using special stains. It does not relate to the severity of AML; in other words, M7 is not more severe than M0 or vice-versa.

WHO classification

The WHO classification uses the same elements as the FAB system, but places an emphasis on cytogenetic data, which is not used in the FAB system. There are five main categories in the WHO system:

- 1. AML with recurrent genetic abnormalities** - The abnormal cells have certain specific genetic changes.
- 2. AML with myelodysplasia-related changes** - AML in children previously

diagnosed with MDS or with features similar to MDS.

- 3. Therapy-related myeloid neoplasms** - AML in children who have previously had chemotherapy and/or radiation therapy.
- 4. Myeloid proliferations related to Down's syndrome** - This only occurs in children.
- 5. AML not otherwise categorised** - does not fall into above categories.

What happens next?

Because AML progresses rapidly, virtually all children with AML start treatment soon after diagnosis. You can refuse treatment for your child at any time, but it is important that you understand clearly what might happen in this case. If your child's haematologist does not think your child needs treatment, you cannot insist on starting treatment, but

this is rare with AML. You can ask for a second opinion at any time. As far as possible, all decisions about your child's treatment will take your wishes into account.

Treating childhood AML

Almost all children with AML will start treatment at, or soon after, the time of diagnosis. Childhood AML has better outcomes and is often curable with standard treatments compared to AML in adults. It is important to discuss the outlook (prognosis) with your child's medical team, because it is affected by various factors such as the risk group.

The main reason a child may not start treatment would be if their general medical condition makes treatment too risky. This is very rare and if it affects your child you will be given full information by their specialist.

Treatment options for AML

Initial treatment of AML usually consists of chemotherapy and is divided into two phases - induction and consolidation.

Your child will receive most of their induction and consolidation treatment as an inpatient in hospital, but may be able to go home between courses. They'll

be regularly monitored and may also receive blood and platelet transfusions or be treated for infections with antibiotics.

Conventional chemotherapy should take about five or six months and involves four courses of treatment each lasting four to six weeks. Two courses will be given during the induction phase to try and achieve remission. The other two courses will aim to prevent relapse.

Chemotherapy

Chemotherapy is the use of anti-cancer (cytotoxic) drugs to destroy cancer cells. Chemotherapy will also damage some normal cells, which means that there are side effects.

For children, chemotherapy is given as intensive treatment, which means higher doses and/or treatment over a longer period of time. Some of the drugs are given directly into a vein (intravenously), others are given by mouth (orally), and others are injected into the spinal fluid (intrathecal).



Treating childhood AML (cont.)

Induction

Remission induction, often just called induction, is the use of chemotherapy to induce remission, ideally complete remission (CR) which means that no leukaemia cells can be found in the blood using standard tests. It is important to understand that remission, even CR, does not mean cure; if treatment stops at this point, almost all patients will relapse – their AML will return.

Consolidation

Consolidation treatment is given after remission induction to reduce the risk of a relapse (return of AML). In AML, cytarabine is used along with combinations of drugs that work in different ways, to reduce the risk of drug resistance. If your child has high risk AML, a stem cell transplant may be recommended as consolidation treatment. Usually children only have a stem cell transplant if their AML returns after remission (relapse).

Stem cell transplant

A stem cell transplant involves the use of high-dose treatment to kill as many as possible of the leukaemia cells. This also destroys the bone marrow's ability to make new blood cells, so the child is given healthy stem cells.

Children tend to do better than adults when they are given a stem cell transplant. However, it does require higher doses of chemotherapy and may have more severe side effects, which is why it is not done for all children.

Central Nervous System (CNS) AML

Sometimes, AML cells may be found in the cerebrospinal fluid (CSF), the fluid which surrounds the brain and the spinal cord; this is known as Central Nervous System (CNS) AML. CNS AML occurs in approximately five to ten in 100 children at the time of diagnosis or at relapse.

Children will normally have chemotherapy drugs injected into the CSF (intrathecal injection).

Usually, this is enough to kill any leukaemia cells in the CSF, if any are found after two courses of intrathecal injections, your child may receive radiotherapy to prevent a relapse.

Treatment of relapse

Although most children with AML achieve remission, some will relapse. A relapse is a return of AML after a time without symptoms or signs of AML in blood counts. About 30% of children with AML will relapse.

For children who have relapsed, a repeat of remission induction followed by a stem cell transplant is recommended. If this happens to your child, the specialist will discuss the treatment options and likely outlook with you.

Supportive care

Supportive care is not directed at treating the disease but rather at controlling the symptoms and side effects caused by the disease.

This can include:

- Antibiotics to treat bacterial infections

- Antifungals to treat fungal infections
- Eye drops
- Blood and platelet transfusions
- Heart scans to check that the chemotherapy is not affecting the heart in any way

Side effects

Unfortunately, treatments such as chemotherapy do come with some side effects as they damage healthy cells as well as cancer cells.

It's difficult to predict exactly which side effects your child will experience as they vary with each drug. However, they are usually temporary.

Short term side effects

Short term side effects can last for a few days or weeks, but for some, can last for the duration of treatment. Side effects your child may experience include:

- Hair loss
- Nausea and vomiting
- Weight loss

Treating childhood AML (cont.)

- Fatigue
- Infection - all patients with AML will at some point get an infection which requires treatment with antibiotics
- Bleeding and bruising - chemotherapy can make your child more prone to bruising and bleeding

Long term side effects

Long term effects can be a result of chemotherapy but depends on the drugs used.

Loss of fertility

Some of the drugs used to treat AML can affect your child's fertility in later life and their chances of conceiving in the future.

Your child's medical team will talk to you about this in more detail before they start treatment and your child will have the chance to discuss this with their healthcare team as they mature and develop into adulthood.

It's natural to worry about the effects of treatment on any children your child might have after their treatment. However,

evidence from clinical studies has shown that any cancer treatment a parent has doesn't lead to an increased risk of cancer or other health problems in their children.

Follow-up

Once your child's treatment is finished, they'll need to have regular check-ups at the hospital. These will be frequent at first, probably 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.

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

The number of new drugs available for treating childhood AML is increasing. There are several new types of drugs being studied for the treatment of AML. Most of these fall into the

following groups:

- **Histone deacetylase inhibitors**
- These are drugs which interfere with the way in which AML cells switch genes on and off.
- **Targeted therapies** - These work in different ways but they are all targeted to specifically attack the leukaemia cell, whereas most other chemotherapy drugs affect normal cells too. One type of targeted therapy is the use of antibodies to carry chemotherapy drugs directly to the leukaemia cell. Another type attacks weak points of leukaemia cells.
- **FLT3 and IDH inhibitors** - FLT3 and IDH are two of the most common genes to become abnormal in AML. A number of drugs have been developed that target these genes.
- **Immunomodulatory drugs (IMiDs)** - Immunomodulatory drugs have been widely used to treat other forms of blood cancer and are now being studied for use in AML. The way in which they work is not fully

understood but they affect the immune system. They are mostly being studied in adults but, if results are promising, they may be used to treat childhood AML.

Prognosis of childhood AML

Children respond incredibly well to treatment and long term survival for children with AML has improved significantly due to better risk assessment, treatment, and supportive care. However, every individual is different, so your child's medical team are the best people to ask about their likely outlook.

About 90% of children will achieve remission after initial treatment but approximately 30% of children will relapse. The long term outlook may not be as good for these children, but usually, the longer they have been in remission, the better the outlook with consequent treatment.

When measuring how well patients do with a particular disease, experts look at survival of five years. More than 60% of children with AML will survive for five years or more after they are diagnosed. If your child achieves remission for five years, this is usually considered to be cured.

Taking about your child's prognosis

Talking about your child's prognosis can be a daunting and difficult topic to discuss. You may find that whilst you may want to know your child's outlook, others may not.

It is important to remember that you do not need to know what your child's outlook is if you do not want to. Whatever you decide, you can change your mind at any time. Remember to talk to your child's medical team about your wishes if it is something you would prefer not to talk about. Everybody copes with it in different ways, and there's no right or wrong way to deal with it.



Everyday life and childhood AML

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

The diagnosis can also have an impact, physically, practically and emotionally for everyone involved. This chapter will talk about all of these aspects.

Emotional impact of AML

Being told your child has cancer will be incredibly upsetting. It can be especially difficult with acute leukaemia as your child will have gotten 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.

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's happening as life may change temporarily for them, too.

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.

Physical impact of AML

Following a diagnosis of AML, 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



Everyday life and childhood AML (cont.)

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. A well-balanced diet can help them feel stronger, have more energy, and recover more quickly.

Infection

One of the most common problems following a diagnosis of AML 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 which 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 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 central line

The signs and symptoms of infection may be less obvious with childhood AML, 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 shouldn't be given for a set period of time.

Measles and chickenpox

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 AML may affect your own personal arrangements with regards to work or home life.

You should contact your employer to inform them of your situation. 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 AML 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.

Talking about childhood AML

Talking to your haematologist

AML 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 haematologist:

- If it's 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.
- Don't 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 right or wrong way. You may wish to only tell close family and friends, your employer and child's school. You may find it easier to provide people with basic information

and give them information leaflets about childhood AML 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 which documents their feelings and keeps people up-to-date at the same time.

Remember that many people will have never heard of childhood AML. Where possible, it's advisable to let people know what you find helpful and unhelpful. Often people make assumptions and do what they think helps. 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 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.
- **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. We have information on our website for you to print out.
- **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.

Talking about childhood AML (cont.)

- **Be open about how you feel** - Don't 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.

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

A condition in which the number of neutrophils (a type of white blood cell) in the bloodstream is decreased.

Pancytopenia

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

Platelet

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

Platelet count

A normal platelet count in a healthy individual is between 150,000 and 450,000 per microlitre of blood. In general, low platelet counts increase bleeding risks.

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 blood cancer journey, you can order our A - Z of Leukaemia by calling Patient Services 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.leukaemicare.org.uk
support@leukaemicare.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

Leukaemia Care,
One Birch Court,
Blackpole East,
Worcester,
WR3 8SG

Leukaemia Care is registered as a charity in England and Wales (no.1183890) and Scotland (no. SC049802).

Company number: 11911752 (England and Wales).

Registered office address: One Birch Court, Blackpole East, Worcester, WR3 8SG

Leukaemia Care
YOUR Blood Cancer Charity