
Adult Acute Myeloid Leukaemia (AML)

A Guide for
Patients

Leukaemia Care
YOUR Blood Cancer Charity

Introduction

Being diagnosed with acute myeloid leukaemia (AML) can be a shock, particularly when you may never have heard of it. If you have questions about AML – what causes it, who it affects, how it affects your body, what symptoms to expect and likely treatments – this booklet covers the basics for you.

This booklet focuses on adult AML. If you are looking for information about children with AML, please refer to our other booklet Childhood AML.

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

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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 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 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 your body producing enough of these cells and it overproduces tumour cells in the bone marrow replacing the normal 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 usually progresses slowly.

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.

People 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 you have will depend on which type of myeloid cell is mainly being produced in excess. One important subtype is called acute promyelocytic leukaemia (APML or APL) and it makes up about one in 10 cases of AML. Knowing whether or not you have 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 AML?

AML is rare. Just over 3,000 cases of AML are diagnosed in adults in the UK each year. It accounts for about one in three cases of leukaemia in adults, and about nine out of 10 cases of acute leukaemia in adults.

What causes AML?

In most cases, there is no obvious cause for AML. But there are certain things which are known to be linked to a higher chance of developing this illness.

Age

AML is more common in older people, aged 60 and above. It can develop at any age but it is uncommon in children and young adults. The average age at diagnosis is between 65 and 70 years, and 6 in 10 cases are diagnosed in people aged 70 years and over.

Gender

AML is slightly more common in men than in women.

Genetic factors

In the vast majority of cases, AML does not run in families. There have been cases of families 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. There are some genetic conditions, such as Down's syndrome, which are known to lead to an increased chance of

What is AML? (cont.)

developing AML

Being overweight or obese

Being overweight or obese increases the risk of developing AML.

Environment

Some chemicals and high levels of radiation may increase the chance of developing leukaemia. The most common chemical cause is smoking, which is thought to be linked to about one in four cases.

Previous treatment

Some patients can develop AML after being previously treated with either chemotherapy or radiotherapy. This type of AML is called treatment-related AML (tAML).

Other bone marrow diseases

AML can sometimes affect people who already have a bone marrow disease. The bone marrow diseases most often associated in this way are myelodysplastic syndrome (MDS) and the myeloproliferative neoplasms

(MPN).

For more information on MDS, Essential Thrombocythaemia (ET), Polycythaemia vera (PV) and Myelofibrosis (MF), call the helpline on **08088 010 444** to order a hard copy booklet or go to **www.leukaemiacare.org.uk**



Symptoms of AML

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

In someone 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 someone with AML, there are very large numbers of immature blood-forming cells (blasts) in the bone marrow. These are abnormal and do not produce healthy working blood cells. Usually, but not always, the blood contains immature cells, including blast cells.

Due to the inability of the bone marrow to make enough working blood cells, AML patients often have 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 patients with AML will have symptoms when they are

diagnosed. However, not everyone experiences all of the symptoms together. Rarely, the condition may be found by chance when a routine blood test is carried out for something else. The most common signs and symptoms are caused by the bone marrow being unable to produce enough normal blood cells.

Symptoms which may be seen include:

- Fatigue
- Frequent and recurrent infections
- Fever and night sweats
- Malaise (general feeling of illness)
- Purpura (small purple spots on the skin)

- Unusual bleeding e.g. nose and gums
- Unexplained weight loss

Other signs and symptoms (which may only occur in some forms of APML) include:

- Bone pain
- Enlarged liver/spleen
- Swollen gums
- Skin lumps
- Enlarged lymph glands
- Bleeding, which may be a particular problem in APML

Some patients 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.

Diagnosis of AML

If AML is suspected, you'll have a set of tests to confirm the diagnosis. If you're diagnosed with AML, you will also have further tests to determine the right treatment for your cancer. It's important that you know and understand your diagnosis so you can ask questions and be fully informed of what to expect. Your consultant will be able to write it in the front of this booklet if that would help you.

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 medical team reach the correct diagnosis so that you can get 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. In AML, there are typically more white cells than normal. Immature blood-forming cells (blasts) are seen in the blood; these are normally only found in the bone marrow.
- **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 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. You 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 local anaesthetic.

Other tests which may be done include:

- **Lumbar puncture** - a sample of cerebrospinal fluid (CSF) is taken from the spine to see whether there are leukaemia cells in the nervous system. This is only done for types of AML which are likely to enter the CSF.
- **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 tests and their results, you can ask your doctor or your specialist nurse. 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 AML is risk grouping. There are three risk groups in AML; high, standard and low risk. Risk classification is based mainly on the cytogenetic changes seen in the AML cells and refers to the chance of the cancer coming back (relapse).

Low risk

This describes patients who have a good chance of being cured and a low risk of relapse. These patients may not need a stem cell transplant but may have one if they do relapse.

Standard/Intermediate risk

These patients are neither high or low risk and may or may not need a

stem cell transplant.

High risk

Patients in this category have a high risk of relapse and will undergo intensive treatments. They may have a stem cell transplant if suitable for them.

Many patients with high risk disease will do very well following treatment. It is also, unfortunately, not always true that a patient with low risk disease will not relapse.

Your risk group can change whilst you're being treated but your medical team will be able to provide updates relating to your 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 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 patients previously

diagnosed with MDS or with features similar to MDS.

- 3. Therapy-related myeloid neoplasms** - AML in patients 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 patients with AML start treatment soon after diagnosis. You can refuse treatment at any time, but it is important that you understand clearly what might happen in this case. If your haematologist does not think you need 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 treatment will take your wishes into account.

Treating AML

Almost all patients will start treatment at, or soon after, the time of diagnosis.

But there are some factors to consider in treatment planning:

- Fitness levels and whether or not intensive chemotherapy would do more harm than good.
- Age – your age can affect how well your body responds to treatment.
- Whether there's a high risk of relapse.

If they are otherwise fit, even elderly patients can usually receive treatment.

AML is potentially curable with standard treatments but the proportion of patients who can be cured depends on the age and fitness of the patient at the time of diagnosis.

Treatments for AML

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

You'll receive most of your induction and consolidation treatment as an inpatient in hospital, but you will get to go home between courses. You'll be regularly monitored and may also receive blood or platelet transfusions, if you need them to help support your body.

The following information is about treatments in general for AML. If you would like detailed information about specific treatments, including stem cell transplants, call **0808 010 444** or go to **www.leukaemicare.org.uk**

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.

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.

Induction treatment is followed by consolidation treatment.

Consolidation

Consolidation treatment is given after remission induction to kill remaining leukaemia cells and reduce the risk of a relapse. In AML, it uses cytarabine along with combinations of drugs which work in different ways to reduce the risk of drug resistance.

There are lots of different options for consolidation therapy which are chosen on an individual basis.

Stem cell transplant

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

A stem cell transplant is suitable for younger and fitter patients although with the use of reduced intensity transplants this can be expanded to patients above the age of 70 with good performance status, and can be offered to high risk patients as part of initial treatment. If this is an option for you, then your haematologist will discuss it with you and give you the chance to ask questions.

Central Nervous System (CNS) AML

Uncommonly, some patients have problems with their central nervous system (CNS) and AML cells may be found in the CSF, the fluid which surrounds the brain and the spinal cord; this is known as CNS AML. CNS AML occurs in

Treating AML (cont.)

approximately one in 50 cases at the time of diagnosis.

On these rare occasions, examination of the CSF will take place using a lumbar puncture (a fine needle is inserted between the bones of the lower spine under anaesthetic). If you are found to have AML cells in the CSF, chemotherapy drugs can be injected into the CSF. This is called intrathecal injection.

Treatment of relapse

Although most patients with AML achieve remission, many patients will relapse. A relapse is a return of AML after a time without symptoms or signs of AML in blood counts.

If you relapse, a stem cell transplant will be considered if you are fit enough. If this is not an option, then a clinical trial may be offered where you will have the opportunity to be treated with the newest available treatments which may not be given outside of the trial.

For more information on relapse in AML call the helpline on **08088 010 444** to order a hard copy booklet or go to **www.leukaemiacare.org.uk**

AML treatment in older adults

There are several reasons why treatment tends to be less successful for older patients; these include:

- High risk AML is more common in older patients.
- Older patients are more likely to have other medical problems, which may limit how much treatment they can receive.
- Older patients are more likely to have AML following treatment for other cancers; this type of AML often responds less well to treatment (secondary AML).

In older patients, the AML cells are more likely to become resistant to treatment. However, healthy, older patients may respond very well to

treatment, especially if they have low risk AML.

Patients that are over 75 years of age or have another health problem have a higher risk of experiencing complications from AML treatment. A class of drugs called hypomethylating agents may be more suitable for older patients, as they may be less toxic and cause less visits to the hospital. These work by controlling the way in which the cell switches genes on and off; the main ones currently in use are called azacitidine and decitabine. Newer treatments that are becoming available may also cause fewer side effects.

Palliative care

During treatment, you may come into contact with a palliative care team who can help to control some of the symptoms you may be experiencing.

Not all treatments, sadly, are successful and sometimes patients have to be told that the disease is too progressive for any treatment to control it. That conversation will most likely be

started by your medical team and most hospitals will have palliative care teams that have experience in dealing with end of life and related symptom control.

Side effects

Unfortunately, treatments do come with some side effects but you may not experience all of them. It's difficult to predict exactly what side effects you'll experience as different people react to treatment in different ways. Your medical team will be able to answer any questions you might have on any side effects you may experience.

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. Short term side effects include:

- **Fatigue** – a common side effect of chemotherapy treatment. Fatigue isn't simply tiredness which passes with rest; you may feel generally tired all the time or you may tire very easily after doing normal, everyday tasks.

Treating AML (cont.)

- **Nausea and sickness** - this can be well-managed with anti-sickness drugs.
- **Infection** - all patients with AML will at some point get an infection which requires treatment with antibiotics.
- **Bleeding** - chemotherapy can make you 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 the mouth.
- **Loss of taste and appetite** - your taste and appetite can be affected during treatment so it's important you drink plenty of fluids to stay hydrated. There are food supplements which can be taken to help maintain your energy levels.
- **Organ dysfunction** - chemotherapy can affect the functioning of your liver, kidneys or lungs.
- **Hair loss** - you may want to

wear a wig or some form of headwear if you're affected by hair loss. Your healthcare team will be able to chat to you about your options.

Long term side effects

- **Fatigue** - The fatigue will improve when treatment ends, but it can be a little while until you feel back to normal.
- **Loss of fertility** - Some of the drugs used to treat AML can cause temporary or permanent infertility. Your doctor will talk to you about this in more detail before you start your treatment. The effect on treatment on fertility is a common concern that many patients have, and one that also impacts on their partners and families too. However, as treatment for AML usually needs to start as quickly as possible, there's not always enough time to store sperm or embryos.
- If you're having treatment for AML at an age when you're thinking about having children, now or in the future, you should discuss the options for

protecting your fertility with your doctor. Your doctor knows the details of the treatment you're having, and is the best person to answer your questions. You can write down any questions you have so that you are clear about your treatment, and the effect it's likely to have on you, before it starts.

- Some drugs have less effect on your fertility than others, and it is common for couples to go on to have healthy babies after one partner has been treated for AML. Unfortunately, people who've had a stem cell transplant after high doses of chemotherapy or whole-body irradiation are more likely to be permanently infertile.
- It's natural to worry about the effects of treatment on any children you might have after your 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.

- **Heart damage** - Some of the drugs (anthracyclines) used to treat AML may affect the heart. This doesn't affect everyone and, if it does occur, it's usually a temporary side effect because healthcare teams are careful to limit the doses you have. However, in some people it can lead to long term heart problems. Your heart function will be carefully monitored during and after treatment, and the drugs you're given may be altered if any heart problems occur.

Follow-up

Once your treatment is finished, you'll 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 annual at five years and onwards. The purpose of follow-up is to monitor you and look for signs of relapse or complications.

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

Treating AML (cont.)

After treatment, you may still have some physical effects to cope with. It's important to remember that it can take some time for you to fully recover, so try not to expect too much of yourself too soon. How quickly things improve will depend on the treatment you've had, your age and general health.

New treatments and treatments on the horizon

There are several new types of drugs being studied or recently approved for the treatment of AML. Most of these fall into the following groups:

- 1. 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.
- 2. Histone deacetylase inhibitors** - These are drugs which interfere with the way in which AML cells switch genes on and

off.

- 3. Targeted therapies** - These work in different ways but they are all targeted to specifically attack the leukaemia cells, 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 the weak points of leukaemia cells.
- 4. FLT3 and IDH inhibitors (trials are currently running in the UK)** - FLT3 and IDH are two of the most common genes to become abnormal in AML (IDH positive 10% of patients Flt-3 25% of patients). A number of drugs have been developed which target these genes.

Your prognosis

Each patient with AML will have a different outlook (prognosis) following treatment as it will depend on many factors such as age, overall fitness, your AML subtype, how well you respond to treatment and your risk group. Every individual is different so your medical team are the best people to ask about your likely outlook.

Overall, around 20% of patients with AML will survive for five years or more after they are diagnosed. Younger people, however, tend to have a better prognosis with 50% of those aged 18 to 65 years surviving for at least five years.

Generally, the younger you are, the more likely you are to respond better to treatment. Younger people are better at coping physically with the very intensive treatments they have to go through.

In terms of risk groups, patients in the low risk group who are treated with chemotherapy (and not a stem cell transplant) have about a 70% - 90% chance of long

term survival (surviving to five years or more after remission). High risk patients do have a poorer prognosis but tend to respond well to receiving a stem cell transplant.

It is important to remember that your prognosis can change, especially if you respond well to treatment.

Taking about your prognosis

Talking about your prognosis can be a daunting and difficult topic to discuss. You may find that whilst you don't want to know your prognosis, family members and friends do.

It is important to remember that your doctor cannot tell anyone else about your prognosis without your permission and only you can decide who you want to know about your condition. Everybody copes with it in different ways, and there's no right or wrong way to deal with it.

Everyday life and AML

Being diagnosed with an aggressive blood cancer like AML can be difficult physically, practically and emotionally.

Emotional impact of AML

Being told you have cancer can be very upsetting. It can be especially difficult with acute leukaemia as you often get ill suddenly, and have to start treatment quickly.

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 illness.

Looking after you

Following a diagnosis of AML, you may wish to make changes to your lifestyle. It's important to know your limits and don't try to change too much at once. Adopting a healthy way of living is about making small, manageable changes to your lifestyle.

Diet

Diet plays an important part

in coping with cancer and its treatment and recovery. A well-balanced diet can help you feel stronger, have more energy, and recover more quickly.

Exercise

With some of the side effects you may be experiencing, such as fatigue, the idea of getting out and being active may be the last thing you want to do. But it is important to try and stay as active as possible to make you feel better and reduce some of the symptoms or side effects you may be experiencing.

Speak to your CNS about exercises that may be suitable for you.

Infection

One of the most common problems following a diagnosis of AML is infection. The signs and symptoms of infection may be less obvious when you have AML.

Common symptoms of infection include:

- Fever – a raised temperature (38°C or higher)
- Aching muscles
- Diarrhoea
- Headaches
- Excessive tiredness

If you have any doubts, or think you may have an infection, you should contact your doctor straightaway.

Vaccines

Vaccinations may not work as well when you have leukaemia, but it is still recommended that you have your annual flu vaccine.

Shingles

If you have previously been exposed to chickenpox, you may develop a painful nerve condition called shingles. You may be able to receive a vaccine against shingles so should talk to your doctor about this.

Practical support Work and finances

Being diagnosed with AML means you will need to start treatment straightaway and so you, or someone you know, will need to contact your employer to inform them of your situation. Your condition will mean that you will need to be at hospital a lot at first and may need to negotiate a reduction in working hours.

Your consultant or your GP can arrange letters to confirm your diagnosis and the effects it may have on your work life to your employer.

There are also a number of benefits you and your carer might be entitled to receive, which may help you if you are no longer able to work or have to reduce your hours after being given a cancer diagnosis.

Talking about AML

Talking to your haematologist

AML is a rare condition. It is important for you to develop a good working relationship with your haematologist so you are given the best treatment possible for you.

The following gives advice on working well with your haematologist:

- If it's an initial consultation, take along a list of your current medications and doses, and a list of any allergies you may have.
- If you have a complicated medical history, take a list of diagnoses, previous procedures and/or complications.
- Make a list of questions to take to your appointment. This will help the discussion with your 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 symptoms and how you are coping. Good patient-doctor communication tends to improve outcomes for patients.

Other tips:

- Bring someone along to your appointment. 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.

You need to tell your haematologist if...

You're having any medical treatment or taking any products such as prescribed medicines, over the counter treatments or vitamins. It is important to understand that treatments, including complementary therapies, which are perfectly safe for most people, may not be safe if you are being treated for AML. Remember, if you choose to start any form of complementary therapy outside

of your medical treatment, speak to your haematology consultant or CNS, prior to beginning it. It is important to understand the difference between complementary therapies, used alongside standard treatment, and alternative therapies, used instead of standard treatment. There is no evidence that any form of alternative therapy can treat AML.

For help with talking to your haematologist, you can download free copies of our 'Questions to ask your medical team' at www.leukaemiacare.org.uk/resources which features a list of questions which you may want to ask.

Talking to other people

Telling people you have a rare condition like AML can be hard to explain. You might find it useful to let your close family and friends, as well as your employer know about your health condition. It might be easier to provide people with basic information and give them information leaflets about AML if they want to know more in-depth details.

It is probably best to focus conversations on the symptoms that you are experiencing, how the condition affects you and how you feel about it. Often people misunderstand and, unfortunately, it will mostly fall to you to educate them as best as you can. Where possible, it's 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, saying you look well, recounting stories of others they know with a similar diagnosis, encouraging you to look ahead and stay positive, which isn't 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 you have a condition that means your bone marrow does not function properly, and this affects the number of blood cells it produces.
- Explain your symptoms (maybe

Talking about AML (cont.)

you 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 condition, from reliable internet sources, charitable organisations or your 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.

- **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 would like more information about AML, including booklets on treatments and relapse, speak to our Patient Services team by calling **08088 010 444** or emailing **support@leukaemicare.org.uk**

Alternatively, go to our website at **www.leukaemicare.org.uk**

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.

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.leukaemicare.org.uk

support@leukaemicare.org.uk

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

Registered charity
259483 and SC039207

Leukaemia Care
YOUR Blood Cancer Charity

