Acute Myelomonocytic Leukaemia (AMML)

A Guide for Patients

Leukaemia Care
YOUR Blood Cancer Charity

Introduction

Being diagnosed with Acute Myelomonocytic Leukaemia (AMML) can be a shock, particularly when you may never have heard of it. If you have questions about AMML – 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.

For more information, talk to your haematologist, clinical nurse specialist or hospital pharmacist.

This booklet was compiled by our Patient Information Writer Isabelle Leach and peer reviewed by Dr Steve Knapper.

Disclaimer: *All of our information has to adhere to a standardised process that ensures it is of the highest quality. Unfortunately, due to the rarity of AMML, we were unable to complete all of the reviews as part of the production process. However, we assure you that this information was created with the same values as that which has.*

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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In this booklet

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 – 5:00pm Monday - Friday and 7:00pm – 10:00pm on Thursdays and Fridays. If you need someone to talk to, call **08088 010 444**.

Alternatively, you can send a message via WhatsApp on **07500068065** on weekdays 9:00am – 5:00pm.

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** or over the phone on **08088 010 444**.

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/support-and-information/help-and-resources/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/support-and-information/support-for-you/find-a-support-group/**

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**.

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: **www.leukaemiacare.org.uk/communication-preferences/**

What is AMML?

Acute myelomonocytic leukaemia (AMML) is a rare type of acute myeloid leukaemia (AML) in which there is an increased production of immature neutrophil white blood cells and immature monocyte white blood cells in the bone marrow. These immature cancerous cells are called blasts.

AML is a group of cancers that affects the blood cells in the bone marrow. The blood cells multiply excessively and do not mature properly. In the majority of types of AML, the blasts are immature white blood cells.

There are several different types of white blood cells, and each has a different role:

Granulocytes - these cells contain small granules, hence their name:

- **Neutrophils** (60% of white blood cells) protect against bacterial infections and inflammation.
- **Eosinophils** (up to 5%) protect against parasites and allergens.
- **Basophils** (0.3%) create the inflammatory reactions during an immune response.

Mononuclear cells - these cells do not have any granules in their cells:

- **Lymphocytes** (25%) recognise bacteria, viruses and toxins, before producing antibodies to destroy them.
- **Monocytes** (6%) clear infection products from the immune system.

In AMML, it is the neutrophil and monocyte-producing white blood cells that are increased in the bone marrow. For AMML to be diagnosed, the peripheral blood or bone marrow must contain >20% blasts.

The 2016 World Health Organisation (WHO) Classification of Tumours of Haematopoietic and Lymphoid Tissues subdivides AML into several groups:

- AML with certain genetic abnormalities
- AML with myelodysplasia-related changes (myelodysplasia is from the Greek words *myelo*, meaning bone marrow, and *dysplasia*, meaning abnormal growth)
- AML related to previous chemotherapy or radiation
- AML not otherwise specified (i.e.,

cases of AML that do not fit into the above groups)

AMML is part of the latter, *not otherwise specified* AML group.

There are two types of AMML, one with and one without an increased eosinophil count. They are termed AML M4 and AML-M4eos in the French American British (FAB) classification.

Who is affected by AMML?

AMML represents 5-10% of all cases of AML. AMML occurs in all age groups, but tends to be a disease of older individuals (over the age of 60 years). The median age of patients with AMML is 50 years. AMML is slightly more common in males with a male-to-female ratio of 1.4.

In view of the rare incidence of AMML, there is not enough information available to determine if there is any race or geographical variation in patients with AMML.

What causes AMML?

The exact cause of AMML is unknown and is likely to vary between different patients. The cell origin of AMML blasts is thought to be the bone marrow (haematopoietic) stem cell. A stem cell is the most basic cell in the body that has the ability to develop into any of the body's specialised cell types, from muscle cells to brain cells. However, what may make these stem cells reproduce uncontrollably is if certain genetic mutations are acquired.

These genetic changes include rearrangements of the chromosomes which involve a change in the structure of the chromosome such as a deletion, duplication, inversion or translocation. A translocation is the transfer of one part of a chromosome to another part of the same or a different chromosome, resulting in a rearrangement of the gene.

One of the most common genetic abnormalities seen in patients with AMML is a change called inversion 16 where part of chromosome 16 becomes flipped around. Inversion 16 is usually associated with AML-M4eos.

Another chromosome rearrangement which is linked with AMML is 11q23/KMT2A.

Symptoms of AMML

The large numbers of abnormal, immature blasts that occur with AMML do not mature properly and take up space in the bone marrow meaning that healthy blood cells cannot be made. Signs and symptoms of AMML relate to the resulting anaemia (low levels of red blood cells), thrombocytopenia (low levels of platelets, which are small blood cells that help the body form clots to stop bleeding), and increased number of infections due to decreases in the number of normal white cell counts.

Early symptoms of AMML include:

- Fever
- Fatigue
- Weakness
- Weight loss
- Shortness of breath

Things you might also notice include:

- Pale appearance
- Minute red spots in the skin
- Easy bruising and bleeding
- Frequent minor infections
- Poor healing of small cuts

Involvement of AMML outside the bone marrow is rare, but, if it does occur, it tends to be in the spleen, lymph nodes, tonsils and skin, or sites such as the brain, testes, and ovaries which can be sanctuaries for cancer cells.

Additionally, cases of AMML presenting in the gastro-intestinal tract have been described. Although uncommon, cases of excessive development (hypertrophy) of the gums and involvement of the colon with abdominal pain, bleeding, diarrhoea, or obstruction have also been reported.

Diagnosis of AMML

For the majority of patients, a diagnosis of AMML can be made on the basis of examining a blood and bone marrow sample. Immunophenotyping and chromosome analysis enables other types of leukaemia to be excluded in difficult cases.

In order to make a diagnosis of AMML, the following characteristics are required by the 2016 WHO Classification of Tumours of Haematopoietic and Lymphoid Tissues:

- Increased production of both granulocytic and monocytic blast cells. Blasts must make up more than 20% of nucleated cells in the blood or bone marrow.
- Mature neutrophils and their precursors must make up >20% of bone marrow cells.
- Mature monocytes and their precursors must also make up >20% of bone marrow cells.
- Finally, the AMML should not qualify for inclusion in any of the other AML groups: AML with certain genetic abnormalities, AML with myelodysplasia-related changes or AML related to previous chemotherapy or radiation.

For further details of the diagnosis and clinical features of AML, please see the information booklet on our website at **www.leukaemiacare.org.uk**

The following tests are used to reach a diagnosis of AMML:

Full blood count

A full blood count, with a breakdown of the different white cell counts to determine which white cells are involved and which are increased, is the first test to be done.

Blood film and bone marrow aspirate slides

Examination of the blood and bone marrow samples is the main requirement for the diagnosis of AMML as it will clearly show the cells required for a diagnosis according to the 2016 WHO Classification characteristics described previously.

The bone marrow sample is vital

for establishing a diagnosis. A bone marrow biopsy involves the collection of a sample of bone marrow from the hip bone, normally under local anaesthesia (but usually done with a general anaesthetic in children).

The blood and bone marrow samples are examined under the microscope to determine the number and type of cells present and the level of haematopoiesis (the process by which blood cells are formed).

Chromosome analysis (cytogenetics)

Although chromosome abnormalities have been linked to AMML such as inv(16)(p13q22) and 11q23/KMT2A, they can also be seen in other subtypes of AML, and are therefore not conclusive for making a diagnosis. Nevertheless, knowledge of a patient's chromosome abnormalities is extremely important for predicting response to treatment and prognosis.

Immunophenotyping

Immunophenotyping is a process which can diagnose and classify leukaemias, and help guide their treatment. In the laboratory, antigens or markers on the surface of blast cells from the patient's blood or bone marrow samples are examined to check for any cancer blast cells. The immunophenotyping is routinely performed by flow cytometry.

Flow cytometry processes blood and bone marrow fluid by adding specific antibodies that have been tagged with fluorescent markers. These antibodies bind to corresponding antigens on the cancer blast cells. The flow cytometer can then rapidly measure the size and structures of thousands of cells.

Flow cytometry of patients with AMML shows two separate types of cancer cells:

- Monocyte blast cells which are positive for CD14, CD64, CD11b, CD11c, CD36, CD68 and CD163
- Blast cells which are positive for the antibodies CD13, CD33, CD65, and CD15

As with chromosome

Diagnosis of AMML (cont.)

abnormalities, the immunophenotypes seen in AMML are also seen in other subtypes of AML, and are therefore not conclusive for making a diagnosis. However, knowledge of a patient's immunophenotypes is useful to exclude other types of leukaemia in difficult cases.

Prognosis of AMML

After being treated with standard induction therapy, more than 80% of AML patients <60 years achieve remission, but in patients >60 years, less than 50% of patients go into remission. However, this rate increases when patients are treated intensively.

The long-term survival for patients with inv(16) is around 60% to 70%.

In patients who have relapsed, the duration of their first complete remission is an important indicator for prognosis, as it is related to the likelihood of a second complete remission and overall survival. Patients relapsing within six months of induction treatment have a significantly poorer prognosis compared with patients who relapsed after a period longer than six months. Patients who are refractory to first-line treatment generally have a poor prognosis.

Up to 50% of patients with AML do not have any chromosome abnormalities. Among the AML patients who do have chromosome abnormalities, the most common abnormalities which are associated with AMML are inv(16)(p13q22) and the 11q23/KMT2A chromosome rearrangement. Inv(16) is associated with a good response rate to chemotherapy and a better clinical outcome than the other types of AML. On the other hand, the KMT2A-AFDN fusion transcript of t(6;11)(q27;q23) is linked with a very poor prognosis.

Treating AMML

The main aim for the treatment of AMML is to achieve and maintain complete remission. Complete remission, defined as <5% of blasts in the bone marrow, and recovery of blood cell counts to normal, is the long-standing standard for the assessment of response to treatment. This definition of complete remission is described as morphological complete remission as it is based on the numbers of blast cancer cells remaining in the bone marrow. Morphological in biology means relating to the form and structure of organisms.

Complete remission has been achieved when:

- Blood cell counts return to normal
- Less than 5% of cancerous blast cells are present in the bone marrow

It has become apparent, however, that patients with morphological complete remission are still at risk of relapse and death because there may still be remaining cancer cells in other areas of the body. This is called minimal residual disease (MRD). MRD is a measure of the presence of leukaemia at a molecular level anywhere in the body, rather than at a cellular level just in the bone marrow.

Patients who are negative for MRD have a lesser risk for relapse and increased survival. Moreover, the presence of MRD before an allogeneic stem cell transplant (SCT) is a strong indicator of patients with a higher risk of relapse and shorter survival compared with patients who did not have any MRD. MRD can also be used to assess patients' risks and treatment response.

Overview of treatment

Ideally, treatment for patients with AMML would be to achieve complete remission with induction chemotherapy, followed by allogeneic SCT, or maintenance treatment; whichever is in the best interest of the patient.

Nearly all patients will receive chemotherapy, to which a targeted therapy drug may be added if required. For patients in complete remission, an allogeneic SCT can be performed. Radiation therapy and surgery can be

used in special circumstances. Normally, treatment will start as soon as possible as AMML can progress very quickly.

Treatment phases

- **Induction phase:** This treatment is intended to kill the majority of the cancerous blasts in the blood and bone marrow and to restore normal blood cell production.
- **Consolidation phase:** In this phase, remaining leukaemia cells in the body are ideally destroyed.

In general, intensive chemotherapy involves a total of three to four cycles of chemotherapy. Usually one to two cycles will be called induction and the other two cycles will be called consolidation.

For the last 30 to 40 years, treatment of AML, including AMML, has involved the combination of anthracycline chemotherapy drugs and the chemotherapy drug cytarabine. Anthracycline drugs, such as daunorubicin or idarubicin, interfere with the DNA and reproduction of white blood cells, including the leukaemia blast cells. Cytarabine also acts by disrupting DNA function.

Induction Therapy

Standard induction therapy generally consists of cytarabine being given twice daily for ten days, combined with an anthracycline drug for three days.

Many AMML patients will now also receive gemtuzumab ozogamicin (Mylotarg) which is an anti-CD33 antibody conjugated to the chemotherapy drug calicheamicin. This was approved by NICE to be given in combination with daunorubicin and cytarabine chemotherapy for patients not known to have adverse risk cytogenetics in 2018.

If remission is not achieved, induction therapy can be repeated or a different chemotherapy drug tried. Several studies - with the aim of improving the complete remission rate in patients - have tried using different anthracycline drugs, higher doses of cytarabine, or adding in other drugs such as etoposide, fludarabine, or cladribine. However, there is no conclusive evidence that any

Treating AMML (cont.)

of these options are any more effective than the cytarabine and daunorubicin combination.

Patients with heart disease cannot be treated with anthracyclines. Additionally, some chemotherapy drugs, including mitoxantrone, can have cardiovascular side effects by worsening existing heart disease. Therefore, patients with heart disease are often given different chemotherapy drugs such as fludarabine.

Consolidation Therapy

Chemotherapy

Consolidation therapy may be further chemotherapy, often with higher doses of the same drugs used for induction therapy, or an allogeneic SCT. The choice of treatment will depend on the patient's age, their physical fitness and detection of any chromosomal abnormalities which linked with a likelihood of relapse. Older patients (above the age of 60 years old) or those in poor health may not be able to tolerate the intensive consolidation therapy.

High-dose cytarabine is still used as the standard consolidation for patients <60 years of age.

Allogeneic stem cell transplantation (SCT)

An allogeneic SCT is the transplantation of bone marrow stem cells from a matching donor such as a sibling, parent or child. Typically, stem cells will be taken from MUDs (matched unrelated donors), who will be found through national bone marrow registries. The allogeneic SCT helps re-establish a healthy bone marrow. Patients are given high doses of chemotherapy to destroy any cancerous cells, and then healthy cells from the donor are transplanted into the recipient.

An allogeneic SCT is known to reduce the risk of leukaemia returning more than standard chemotherapy, but it is associated with potentially serious complications, including graft versus host disease (GVHD) and increased risk of infections. For this reason, allogeneic SCTs tend only to be used in patients who have a greater risk of relapse.

Treatment for elderly or frail patients

Older patients (>60 to 70 years) or patients with poor health may not be able to tolerate the intensive consolidation therapy given to the younger (<60 years) and fitter patients. Older patients are normally given lower intensity therapies such as subcutaneous cytarabine (administered under the skin), azacitidine or hydroxycarbamide. Hydroxycarbamide is an oral chemotherapy that prevents cell division to lower the white blood cell count. This may help temporarily relieve pain which can be caused by a high white blood cell count.

In some instances, elderly or frail patients can be treated with other chemotherapy drugs such as azacitidine. These drugs help induce remission and control the progression of AML for a while and are generally used when patients who have 20-30% blasts in the bone marrow at the time of diagnosis.

Other treatments

Clinical trials

The majority of newly-diagnosed AML patients in the UK currently get treated under one of the national trial protocols (including AML18 or 19 for patients who are fit enough to receive intensive therapy and LI-1 for older, frailer patients).

Central nervous system treatment

The central nervous system (CNS) consists of the brain and spinal cord. In patients where leukaemia cells have spread to the CNS (this is relatively rare), chemotherapy may be injected directly into the fluid which surrounds the brain and spinal cord (known as the cerebrospinal fluid) to remove any remaining leukaemia cells.

Cytarabine can be administered into the cerebrospinal fluid, two to three times per week until all the leukaemia blast cells have been removed, followed by three further injections of the same dosage. Alternatively, cytarabine can be given every other week for approximately six cycles in

Treating AMML (cont.)

special situations (for example, if the patient has very high levels of white blood cells).

Radiation therapy of the CNS may also be performed, but this is rare. Radiation therapy consists of irradiation of the brain and spinal cord with high doses of X-rays or proton beams.

Supportive treatment

Supportive treatment is made available to all patients. This concentrates on treating any symptoms or complications that arise so that the patient is as comfortable as possible.

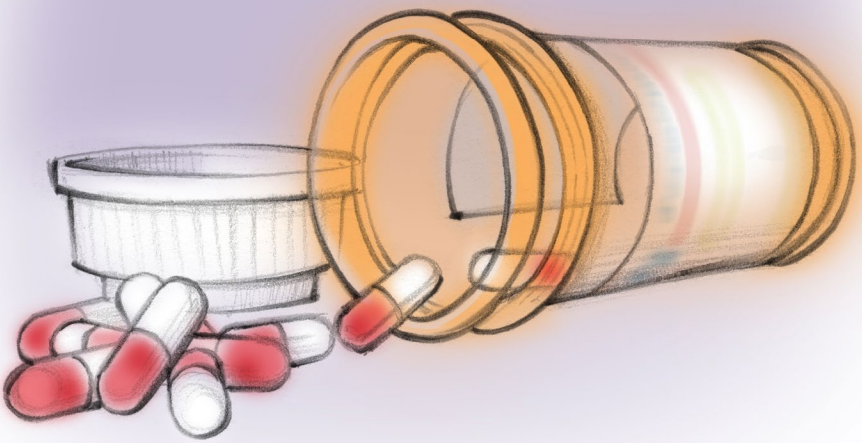
Supportive treatment consists of blood and platelet transfusions and administration of hydroxycarbamide. Induction chemotherapy destroys the leukaemia cells, but also most of the normal bone marrow cells, therefore patients may need antibiotics as well as blood product transfusions.

Treatment of relapsed and refractory disease

In spite of recent improvements in the treatment of patients with newly diagnosed AML, up to 40% of patients will not achieve remission. Moreover, of the patients who do achieve a first complete remission, 50% to 70% may relapse within three years.

Patients for whom AMML has returned (relapsed) or those who did not respond to induction therapy (refractory), re-induction treatment can be given. Alternatively, clinical trials can be offered or more novel drug approaches may be used.

If a patient relapses and a 'curative strategy' is being pursued they will have to undergo some form of reinduction chemotherapy, then consolidation with an allogeneic SCT if a second remission is achieved. However, if a patient is not felt to be suitable for further intensive treatment (and especially if they have relapsed following allogeneic SCT) then a more palliative approach will be taken.



Seeing your doctor

Your symptoms

Whatever symptoms you have, make sure you write a list of all of them to share with your doctor as they may be important to the treatment.

Your appointment

Arranging an appointment with your GP will be one of the first things you will need to do when you start to notice symptoms. Pick a time convenient for you that you know you will be able to attend.

Your preparation

It is important to know exactly what you would like to ask your doctor. Make a list of your questions and leave spaces for the answers so you can write them down when you see the doctor. This way you can go into the appointment ready and prepared.

Examples of questions to ask the doctor:

- What tests will be needed?
- What will the tests show?
- How long will it take to get the results back?
- How common is this condition?
- What sort of treatment will be needed?
- How long will the treatment last?
- How will I know if the treatment has worked?
- What will the side effects be?
- Are there any foods or medications that need to be avoided?
- Will I be able to go back to work?
- Where can I get help with claiming benefits and grants?
- Where can I get help dealing with my feelings?

Talking to your doctor

Be honest with your doctor; there is no need to feel embarrassed about anything. If you saw your healthcare team before seeing your doctor, be sure to share with your doctor everything your healthcare team told you about

your condition, the blood tests that were performed, and the next steps. Ask also if any intensive treatment or palliative care will be needed.

Your support

If it helps, take a family member or friend in with you for support. Some people also take a pen and paper in to make notes, and repeat back to their doctor everything they have been told to ensure that they are on the same page, and that nothing has been missed or forgotten.

The next steps

Always ensure that you leave the GP surgery, or the hospital, having shared everything you know about the condition, with all of your questions answered, and knowing exactly what the next steps are, whether it is more tests, further treatment or palliative care. You can ask for a summary letter of the consultation to have everything in writing. Your doctor will generally send a letter like this to your GP.

Furthermore, be sure to access all of the other support available to you as this may be able to help you with your feelings towards the diagnosis and treatment.

Telling your family

Planning who to tell

Telling your family and friends what is happening can be difficult.

You may want to create a list of people you want to tell, starting with close family and friends, and then extending it beyond, from your colleagues at work to friends in your neighbourhood.

Planning what to say

It is important to know what you want to say and exactly how much you want people to know. Being clear in your mind about that before speaking to anyone will make this a much smoother experience. Know the story that you want to tell, the diagnosis, the prognosis, the next treatment steps, and what you expect will happen physically and emotionally. Be sure to speak to people in an environment where both of you can hear each other clearly and where there are likely to be no interruptions.

How to say it

Using a conciliatory tone will help keep both yourself and the other person calm.

Deliver what you have to say slowly, calmly, concisely, and sentence by sentence to allow the other person time to take in the information. Be sincere, and hold their hands if you need to.

You can use the following sentences to help you articulate what you need to say:

- "This is going to be difficult, but I need to tell you something."
- "I've had some bad news but there's a good chance that everything will be okay after treatment."
- "You know I have been feeling unwell for a while. Some tests have been done and they've found out what's wrong."

How to respond

Naturally people will feel sad and concerned for you. Everyone deals with this type of news in their own way, from shock and silence, to questions and support.

Invariably, people respond

positively, which in turn means you will respond back positively.

Accepting help

Sometimes people feel guilty if they get cancer, that it's their fault, and that they will be a burden on those around them. This is where your loved ones come in, so make sure you do ask for and accept offers to help and support you. Do not try to cope on your own. If they offer to help, tell them that you will get in touch when you need them.

Repeating yourself to different people can become burdensome. Your network of family and friends can help you out by telling those beyond them about your current situation. You can receive help from us on how to tell your family and friends. You can visit **www.leukaemiacare.org.uk**, or call **08088 010 444**, to find out more.

Managing your emotions

Being told that you have cancer may be difficult for you to deal with.

You may have a positive demeanour, which will obviously be helpful to you during the next steps in the management of the condition. However, you may experience a range of emotions, including uncertainty, isolation, anxiety, anger, sadness and depression. Understanding each emotion and developing ways that help you deal with them will help you move forward with your life.

Uncertainty

You may think "what happens next?". You may be unsure about your health and what the future holds for you. You may or may not have had meetings with your healthcare team to discuss the next steps. Once you have a clear path set out in front of you, you will be able to develop a clearer picture of where you are headed.

Gaining a sensible balance between being vigilant about your symptoms and carrying on with your life will help ease any anxieties. Help, care, kindness and support will be available to you from your healthcare team, and you will have access to counsellors and therapists if and when you need it.

Isolation

If you have received a diagnosis of AMML, you may feel alone.

Alternatively, you may feel dealing with your cancer allows you to be around those closest to you. Being around your family and friends can be positive and negative.

Let them know what you do and don't want to do, how you do and don't wish to be treated, and what you do and don't feel comfortable talking about. Sometimes, it is difficult for your family, friends and colleagues to understand what you are feeling and going through. Being clear will help create the kind of positive, supportive, and caring environment that will help as you move forward with your life.

Anxiety

Being fearful of the unknown, especially when we are feeling threatened, is natural. You may

experience an increased heart rate, rapid breathing, and muscle tension. These things help us to face a danger or run away. These changes in you are part of the 'fight or flight' response. Any feeling of discomfort, pain or even another appointment with your healthcare team may elicit such responses, and give you sleepless nights or feelings of worry. This is completely natural.

Such reflexes and responses will ease over time with the building of daily routines and planning things for the future, which will help you to cope with the physical effects of anxiety. Cognitive behavioural therapy can help you deal with your worrying thoughts.

Anger

Feeling angry at the cancer diagnosis is natural and normal. You may be angry with yourself, with the healthcare team or with family and friends. You may display your anger as impatience, irritability and frustration with people and things that would not normally bother you.

Understanding exactly what is making you angry will help you deal with your feelings effectively. In addition, setting yourself achievable, but demanding, goals will help reduce the anger and impatience, especially with each passing success. Don't forget to congratulate yourself for each successfully completed task, however small.

Physical exercise is a great way to release your anger and frustrations, and channel energy positively with no negative impact on the body. Talking about feelings and letting them out will also help stop you lashing out at people and keep things calm.

Sadness and depression

You may feel a sense of loss for how safe you once felt. You may also feel that your illness is a heavy burden on those around you. You might be feeling low, which is a natural effect of your situation and the illness, treatment and recovery process. However, if this low mood persists for more than several weeks, and you feel hopeless, and

Managing your emotions (cont.)

lose interest and pleasure with things in life, then you may have depression.

Your first steps should be to speak to your loved ones around you about your mood and state of mind, and then contact your GP. You may lift the way you feel by engaging in activities that you were enjoying before the diagnosis and connecting back with your life. Only do as much as you can and try and talk about your thoughts and feelings. This will help lighten your burden and put things into perspective. If you have made any acquaintances or friends in the same position as you, talk to them over coffee as they will understand what you are facing.

Self-confidence

Being forced to adjust from your daily routine during the visits to the hospital for treatment can take its toll. This interruption of your life can impact on how you feel about your appearance and how you feel emotionally. In turn, this can knock your self-confidence and self-esteem.

Your feelings of relief, hope and optimism have just been replaced with their polar opposites.

You can gradually build your self-confidence and self-esteem back up by engaging in the activities you did before the diagnosis, and socialising with family, friends, and those in the same position as you. This will help create a supportive atmosphere to get you back to your old self.

Mindfulness and relaxation

Simple practices from mindfulness and relaxation techniques can help you calm the mind, release tension and ease any pain.

- Put yourself in a relaxing environment, sitting or lying down comfortably.
- Loosen your clothing so you can move more freely.
- Calmly breathe in through your nose, and out through your mouth, developing a steady natural rhythm, focusing on your chest and abdomen as you

do so.

- Visualise that you are inhaling positivity and exhaling negativity.

By taking some time out of your day to do these exercises, you can help quieten your mind and remove the stress of coming to terms with your diagnosis, so you feel calmer and more relaxed.

Survivorship

Someone who is living with or is beyond a cancer diagnosis can be considered a cancer survivor.

Survivorship can be defined as:

"...cover[ing] the physical, psychosocial and economic issues of cancer, from diagnosis until the end of life. It focuses on the health and life of a person with cancer beyond the diagnosis and treatment phases. Survivorship includes issues related to the ability to get healthcare and follow-up treatment, late effects of treatment, secondary cancers and quality of life. Family members, friends and caregivers are also part of the survivorship experience."

When living with cancer, you will face new challenges to cope with from physical to psychological and social ones. Survivorship aims to provide personalised care based on improving your health, wellbeing, quality of life, and your confidence and motivation, to help you manage. Survivorship also focuses on your health and life with cancer after the end of treatment until the end of life. At this point, your routine of meeting frequently with your healthcare professionals also ends, so you may feel a mixture of emotions from relief to fear, anxiety and uncertainty about the future. You may wonder how you will slot back into your life after coming through the treatment period.

Your survivorship pathway began at the point when you were diagnosed with AMML. By this point, you will have been starting to receive support for work, finance, and personal relationships through to managing pain, fatigue and making positive lifestyle changes, such as starting a healthy diet and gentle exercising.

Your individual needs will be identified and addressed, including:

- Dealing with the emotional impact of receiving an AMML diagnosis, which may have created feelings of uncertainty, fears of recurrence and difficulties in planning for the future. These will be discussed with you to develop an individualised care plan with

support from social care staff and therapists, as you need it.

- Improving your quality of life through efficient and co-ordinated care during treatment, with effective communication within the treatment team, and a positive attitude.
- Taking care of any comorbidities – that is, other medical conditions and diseases – and offering a cancer rehabilitation based on your clinical needs as assessed by informed professionals, and ensuring compliance with the National Cancer Rehabilitation Pathways and Rehabilitation Peer Review requirements.
- Providing you with a treatment summary from the diagnosis of your condition to the end of treatment. This would include any ongoing medication and noting possible symptoms that may occur in the future. You would also be provided details of who to contact in addition to your GP for any concerns you may have.
- Preparing you fully for the impact of the treatment, the physical and physiological side effects of treatments and the psychological impact of AMML in general. You will be provided physical equipment, and taught about various coping strategies to adapt to your new situation.
- Supporting you with advice for social and financial difficulties, including caring responsibilities, your inability to participate in social activities, any debt and financial worries from not being able to work, and perhaps the need to return to work before you feel ready.
- Receiving health and nutrition advice from a nutritionist on following a healthy and balanced diet to help improve your general health and wellbeing. The World Cancer Research Fund published a report for cancer survivors which suggests that even small dietary and lifestyle changes can produce large health benefits.

Palliative care

Palliative care, also known as supportive care, involves a holistic or "whole person" approach, which includes the management of pain and symptoms as well as psychological, social and spiritual support for you and your loved ones.

Palliative care aims to reduce the symptoms, control the AMML, extend survival, and give you and your loved ones the best quality of life possible. Your doctor will discuss the options with you in detail before you decide the next steps.

Who provides palliative care?

Palliative care will be provided by a team of health and social care professionals trained in palliative medicine who will coordinate the care.

These professionals can include your GP, hospital doctors and nurses, community nurses, hospice staff and counsellors, social care staff, physiotherapists, occupational therapists, complementary therapists, and religious leaders, if you would like this. The palliative care services may be provided by the NHS, local council or a charity. You may receive day-to-day care at your home and at the hospital.

What is the clinical course?

You will have a number of treatments, and be prone to frequent infections because of the AMML and the impact of the treatments. The therapy may continue because of potential remission and/or useful palliation.

Various pains and other clinical complications can occur such as:

- **Bone pain:** Radiotherapy and/or oral steroids, and sometimes non-steroidal anti-inflammatory drugs (NSAIDs), may be used with caution, because they can interfere with the immune system and kidney function.
- **Bone marrow failure:** Blood and platelet transfusions are provided to prevent and fight recurrent infections and bleeding episodes.

- **Oral problems:** Analgesic mouth washes and topical ointments may help with ulceration. Chewing gum, and mouth washes, have been shown to help with dry mouth, tooth decay and oral thrush.
- **Night sweats and fever:** These can also place a heavy burden on carers because of so many changes of night clothes and bedding.
- **Pathological fractures:** Orthopaedic intervention and subsequent radiotherapy, with consideration given to prophylactic pinning of long bones and/or radiotherapy to prevent fractures will be performed. This will reduce the likelihood of complex pain syndromes developing.
- **Spinal cord compression:** Immediate high single daily dose oral steroids will be given.
- **Back pain from wedge and crush fractures of the vertebrae of the spinal column:** Treatments can include analgesics, antidepressants and/or anticonvulsant medication used in tandem with opioids.
- **Hypercalcaemia:** Treatment is usually with intravenous hydration and intravenous bisphosphonates.
- **Loss of appetite:** Low-dose steroids may temporarily boost the appetite, while small, frequent and appetising meals and supplement drinks will also help.

End of life care

When does end of life care begin?

If the treatment hasn't worked and you are going through palliative care, end of life care may be offered. End of life care begins when it is needed and may last a few days, months or years.

What does end of life care involve?

End of life care is support for people who are in the last few months or years of their life. The aim is to help patients enjoy a good quality of life until they die, and to die with dignity. The professionals looking after you will ask about your wishes and preferences on how to be cared for and put these into action. They will also provide support to your family, carers and loved ones. You will be able to decide where you will receive end of life care, be it at home or in a care home, hospice or hospital. The same will be true of where you would like to die. Wherever this is, you will receive high quality end of life care.

Who provides end of life care?

A team of health and social care professionals may be involved in the end of life care, including hospital doctors and nurses, your GP, community nurses, hospice staff and counsellors, social care staff, physiotherapists, occupational therapists or complementary therapists, and religious leaders, if you would like this. If you are being cared for at home or in a care home, your GP will have overall responsibility for your care with the support from community nurses, along with your family and friends.

What choices do I have in terms of end of life care?

Deciding where you want to die can be a difficult choice to make. Working out what you and your loved ones want, together with seeing what services are available can help to make the decision a little easier.

- **Staying at home:** A place of familiarity, surrounded by loved

ones, may be something that will be reassuring. External care professionals will be able to visit your home to make sure your symptoms are looked after.

- **Hospices:** These are specialised in looking after those with life-limiting illnesses and those who are coming to the end of their life. Hospices are staffed with care professionals who are able to keep an eye on you, make sure that symptoms are controlled and offer a number of services to make the stay as comfortable as possible. For more information on the care that they can provide, go to **https://www.hospiceuk.org/**
- **Residential care/nursing homes:** If you think that your stay may be a few months or more, then a nursing home may be more suitable than a hospice. These can be private or run by a charity or the local council so be sure to check if there are any fees.
- **Hospitals:** Although you may be used to staying in a hospital ward, the care routine cannot always be tailored to patients' specific needs. Pressures on the NHS mean that your stay will only be as long as strictly required. As soon as the condition requiring hospital admission has been resolved, you will need to go back to your home or nursing home. However, a number of specialists will be available to help look after specific problems, and a number of hospitals also have a designated palliative care team for patients who require them.

Whatever your choice, speak with your GP or healthcare team who will able to help you put everything into place.

Glossary

Allogeneic Stem Cell Transplant

A transplant of stem cells from a matching donor.

Anaemia

A condition where the number of red blood cells, which contain haemoglobin and transport oxygen to body cells, are reduced. This may be due to a lack of iron, leukaemia, or sickle cell disease.

Antibody

A large Y-shaped protein produced by B-cell lymphocytes in response to a specific antigen, such as a bacteria, virus, or a foreign substance in the blood. The antibodies neutralise the bacteria and viruses.

Antigen

A toxin or other foreign substance which induces an immune response in the body, especially the production of antibodies.

Blast Cells

Immature cells found in the bone marrow. They are not fully developed and therefore do not carry any particular function within the body. In normal humans, up to 5% of the cells found in the bone marrow are blast cells.

Bone Marrow Failure

The term used when the bone marrow is unable keep up with the body's need for white and red blood cells and platelets.

Chemotherapy

Drugs that work in different ways to stop the growth of cancer cells, either by killing the cells or by stopping them from dividing.

Chromosomes

Thread-like structures which carry the genes, and are located in the nuclei of every cell in the body. There are 46 chromosomes (23 pairs) in humans.

Complete Remission

Complete remission is said to have occurred when the following conditions have been met:

- Blood cell counts return to normal
- Less than 5% of blasts (abnormal, immature cancer cells) are still present in the bone marrow

Fatigue

Tiredness and weakness rendering the patient unable to work or perform usual activities.

Genes

Genes are made up of DNA which stores the genetic information required to make human proteins.

Immunophenotyping

A process that uses antibodies to identify cells based on the types of antigens or markers on the surface of the cells. This process is used to diagnose specific types of leukaemia and lymphoma by comparing the cancer cells to normal cells of the immune system.

Leukaemia

A group of cancers that usually begin in the bone marrow and result in high numbers of abnormal white blood cells. These white blood cells are not fully developed and are called blasts or leukaemia cells. Depending on the type of white blood cell involved, the leukaemia will have varying characteristics, such as being acute (develops quickly) or chronic (develops slowly).

Neutrophil

White blood cells involved in fighting infection,\ specifically bacterial infections and inflammation.

Platelets

One of the types of blood cells which help to stop bleeding.

Prognosis

An indication of how well a patient is expected to respond to treatment based on their individual characteristics at the time of diagnosis or other timepoints in the disease.

Refractory Leukaemia

Leukaemia for which treatment does not result in a remission, or that gets worse within six months of the last treatment. However, the leukaemia may be stable.

Relapsed Leukaemia

A relapse occurs when a patient initially responds to leukaemia treatment, but after six months or more, response stops. This is also sometimes called a recurrence.

Glossary (cont.)

Thrombocytopenia

Low levels of platelets, which are small blood cells that help the body form clots to stop bleeding.

Translocation

In genetics, a translocation is the transfer of one part of a chromosome to another part of the same or a different chromosome, resulting in rearrangement of the genes.

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

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Leukaemia Care
YOUR Blood Cancer Charity