
Chronic Myelomonocytic Leukaemia (CMML)

A Guide for
Patients

Leukaemia Care
YOUR Blood Cancer Charity

Introduction

Being diagnosed with chronic myelomonocytic leukaemia (CMML) can be a shock, particularly when you may never have heard of it before, and may even have had no obvious symptoms. If you have questions about CMML – 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.

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

This booklet was originally compiled by Ken Campbell, MSc (Clinical Oncology). The rewrite was put together by Lisa

Lovelidge. The booklet has been peer reviewed by Dr Steve Knapper and we are also grateful to Adrian Thomas, our patient reviewer, for his valuable contribution.

Throughout this booklet you will see a number of quotations. These are the real experiences and words of blood cancer patients so will hopefully help you to understand your disease and situation a bit better.

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/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.leukaemicare.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@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/communication-preferences/**

What is CMML?

Chronic myelomonocytic leukaemia (CMML) is a form of blood cancer which affects the myeloid cells, which include red cells, platelets and some white blood cells. When you have CMML, the bone marrow may not be able to make enough of certain types of normal blood cells (such as red cells, neutrophils – a type of white blood cell - and platelets) and may make too many of other types of blood cells (such as monocytes – a type of white blood cell), which can lead to a set of debilitating symptoms.

The term chronic does not describe how serious the CMML is. It refers to the fact that it develops and progresses slowly. This is in contrast to acute, which describes a condition that develops rapidly and, unless treated, progresses quickly. CMML is called 'myelomonocytic leukaemia' because there may be increased numbers of abnormal, immature myeloid cells and higher than normal numbers of white blood cells called monocytes in the blood.

To understand CMML 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 first become a myeloid stem cell or a lymphoid stem cell.

A myeloid stem cell then becomes one of three types of mature blood cells:

1. Red blood cells that carry oxygen and other substances to all tissues of the body.
2. Platelets that form blood clots to stop bleeding.
3. White blood cells (granulocytes) that fight infection and disease.

Granulocytes include neutrophils, eosinophils and basophils.

A lymphoid stem cell becomes one of three types of lymphocytes (also white blood cells):

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

Although it is called leukaemia, CMML is actually one of a group of conditions called myeloproliferative/ myelodysplastic neoplasms. 'Myeloproliferative' means that the bone marrow is producing too many myeloid blood cells, while 'myelodysplastic' means that the blood cells that are produced are abnormal and may not mature normally into working blood cells. The abnormal blood cells are removed from the blood which means that, even though the bone marrow is making more blood cells than normal, there may be too few healthy blood cells in the circulation. In CMML, about half of all cases have a high number

of white cells at diagnosis and are more like myeloproliferative neoplasms, while the remainder are more like myelodysplastic neoplasms with low or normal white cell numbers at diagnosis. It is not clear whether these are separate diseases or different stages of the same disease.

If you would like more information about MDS, ET, PV or MF, you can order one of our booklets by calling the helpline on **08088 010 444** or by emailing Patient Services support@leukaemiacare.org.uk

There are three types of CMML, which differ in the percentage of a type of immature cells, called blasts, which are present in the blood and bone marrow. This classification was developed by the World Health Organization (WHO) to help work out the outlook for each patient, and is known as the WHO classification. The three types are defined as:

1. **Type 0 CMML** - Blast cells

What is CMML? (cont.)

make up fewer than 2 in every 100 (2%) of the white cells in blood and less than 5% blast cells in bone marrow.

- 2. Type 1 CMML** - Blast cells make up 2 to 4 in every 100 (2-4%) of the white cells in blood and/or 5% to 9% blast cells in bone marrow
- 3. Type 2 CMML** - Blast cells make up between 5 and 19 in every 100 (5-19%) of the white cells in blood, 10% to 19% blast cells in bone marrow and/or when any Auer rods (granular material that form elongated needles in blast cells) are present.

If there are more than 20 blasts in every 100 white cells in the blood or bone marrow, the diagnosis is acute myeloid leukaemia (AML), which is a more aggressive form of leukaemia. CMML progresses into AML in 15 to 30 of every 100 people with CMML (15-30%). This change from CMML to AML is called transformation.

With life expectancy decreasing and the chance of progressing to AML increasing with each type. Type 0 CMML has the best outlook,

and type 2 CMML has the worst prognosis.

You can read more about this acute form of leukaemia in our booklet on adult AML. You can order one of our booklets by calling the helpline on **08088 010 444** or by emailing Patient Services support@leukaemiacare.org.uk

How common is CMML?

CMML can happen at any age but is most often seen in older adults; the average age at diagnosis is over 75 years old. CMML affects men about twice as often as women, especially in older patients. There are only about 450 cases a year in the UK.

CMML in children is known as juvenile myelomonocytic leukaemia (JMML) and is different from the disease in adults. This booklet is about CMML in adults.

What causes CMML?

For most cases of CMML the cause

is not known. You cannot catch CMML from someone who has it and you cannot pass CMML on to your children.

It is sometimes seen in people who have been treated for other forms of cancer; this only affects a very small percentage of cancer patients, and accounts for about 10% of CMML cases. This is known as therapy-related CMML (t-CMML). Therapy-related CMML is treated in the same way as other cases but may not respond as well to treatment.

Symptoms and diagnosis of CMML

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

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

In someone with CMML, abnormal cells take over the bone marrow; the result is that the marrow is not able to make enough normal blood cells. Although the marrow is producing more cells than normal, many of these are abnormal and do not mature into working blood cells.

Due to the inability of the bone marrow to make enough normal blood cells, CMML patients often have lower than normal numbers of red blood cells (anaemia), white blood cells (neutropenia) and/or platelets (thrombocytopenia). When all types of blood cells are lower than normal this is called

pancytopenia. These changes lead to some of the symptoms of CMML.

What are the most common symptoms of CMML?

The most common symptoms of CMML are:

- Fatigue
- Weight loss
- Breathlessness
- Frequent bruising
- Unusual bleeding, e.g. from gums
- Frequent, persistent infections

Other symptoms can include:

- Sweats
- Itchiness (pruritus)
- Bone pain (arthralgia)
- Muscle pain (myalgia)
- Skin lumps or rashes
- Enlarged lymph glands
- Fluid around the lungs (pleural effusion)
- Enlarged spleen/liver – this

enlargement may cause abdominal discomfort and, because the spleen lies next to the stomach, this enlargement may cause a feeling of early fullness when eating.

These symptoms can also be the result of side effects of medication or related to other illnesses.

Diagnosing CMML

The main tests used to diagnose CMML are a full blood count, with a blood film looked at under the microscope, a bone marrow sample and specialised tests to rule out other similar conditions. The characteristic features of CMML are a high number of monocytes in the blood (monocytosis) and typical abnormal-looking immature blood-forming cells, which are not normally seen in the blood.

Most patients will have more than one full blood count before the diagnosis of CMML is considered. This is because there are other illnesses, such as infections, which can cause changes in the blood similar to those seen in CMML. When an infection is present, the blood count returns to normal as

the infection clears up. In CMML, the abnormal blood results will persist.

One of the specialised tests that your doctor may organise is to look for an abnormality called BCR-ABL. This is an abnormal 'fusion gene' – BCR and ABL are two genes which are normally found on different chromosomes (chromosomes 9 and 22). The BCR-ABL gene forms when the two chromosomes swap over part of their DNA. If this gene is present it indicates the diagnosis is chronic myeloid leukaemia (CML), which although sounding similar is a very different type of leukaemia and is treated differently to CMML.

In about 30 patients out of every 100 (30%), there will be other cytogenetic abnormalities in the genetic make-up of the abnormal cells. These changes are only present in the abnormal cells; they are not inherited and cannot be passed on to children. One of the most common affects a gene called TET – this is present in about half of all CMML patients.

Another important gene is called PDGFR. If a PDGFR fusion

Symptoms and diagnosis

CMML (cont.)

abnormality is picked up, this indicates a rare sub-type of CMML that has a very good chance of responding well to treatment with a type of drug called a tyrosine kinase inhibitor (TKI). These drugs are not effective in the majority of CMML patients that don't have the PDGFR abnormality.

A prognostic scoring system has recently been developed – this is called the CMML Prognostic Scoring System (CPSS) and uses a combination of factors to predict how well CMML is likely to respond to standard treatment. The system is based on four factors:

1. WHO subtype – CMML-0, CMML-1 or CMML-2
2. White blood cell count
3. Presence or absence of certain gene abnormalities
4. Whether or not regular blood transfusions is necessary

Using these factors, it is possible to define four groups of patients, referred to as 'low risk', 'intermediate-1', 'intermediate-2' and 'high risk', which differ in how well they are likely to do with standard treatment and in how likely they are to go on to develop AML.

Treating CMML

For most CMML patients the disease is treatable, but not curable. The only potential cure is a stem cell transplant using healthy blood-producing stem cells from a donor (allogeneic transplant). This treatment is only realistic for younger or fitter patients because it uses strong chemotherapy (and sometimes additional radiation therapy) to kill off the unhealthy marrow and is usually followed by several months of therapy to suppress the immune system.

Most patients with CMML are treated with drugs (chemotherapy), the most commonly used being hydroxycarbamide (sometimes referred to as hydroxyurea) and azacitidine. They may also receive treatment called 'supportive therapy' to deal with the problems caused by having low blood counts; this may include red cell and platelet transfusions and antibiotics to prevent and treat infection. Your doctor may suggest you consider taking part in a trial of one of the new drugs

being studied. If this is the case, you will be given full information and a chance to ask questions. If you decide not to take part in a trial, you will receive the best available treatment.

Watch and wait

If you have no symptoms when you are first diagnosed with CMML and you have no high-risk factors, your haematologist may suggest a 'watch and wait' approach. This usually involves regular check-ups and blood counts, as well as your haematologist advising you on ways to live a healthy lifestyle. If symptoms develop or the disease progresses, you may then start a suitable treatment.

If you would like more information about Watch and Wait, you can order one of our booklets by calling the helpline on **08088 010 444** or by emailing Patient Services support@leukaemiacare.org.uk

Treating CMML (cont.)

Supportive therapy

Many of the symptoms of CMML are caused by the lack of enough normal blood cells. In some situations this may be treatable by the use of drugs called growth factors, which increase production of red blood cells to correct anaemia (erythropoietin) or of white blood cells to potentially reduce the risk of infection (G-CSF). Transfusions of red blood cells may be needed if erythropoietin therapy is inappropriate or unsuccessful and platelet transfusions may be needed if the platelet count is too low.

Supportive therapy may also include other measures to protect against infection such as preventative antibiotics, and vaccination.

The supportive care required will differ depending on the number of normal blood cells present.

Treatment options

The standard treatment for CMML is chemotherapy but, although

this may help to control the disease, it may have unpleasant side effects, and is not a cure. As mentioned, there are some drugs which may only work when specific genetic abnormalities are present. Stem cell transplantation is potentially curative, but is only suitable for a minority of patients.

You can find more information about drugs used to treat your CMML (and any other medicines you are taking) at the eMC Medicine Guides website: www.medicines.org.uk/emc/

Chemotherapy

Chemotherapy is the use of anti-cancer (cytotoxic) drugs to destroy cancer cells. It is usually quite effective in helping to control CMML.

There are three main drugs used in treatment of CMML:

1. Hydroxycarbamide (hydroxyurea)
2. Cytarabine (ara-C)
3. Azacitidine (although this is only given to those with the non-proliferative type of CMML-2)

Hydroxycarbamide and cytarabine are drugs that can kill abnormal cells and have been in use for some time to treat various blood cancers. These drugs are generally used when the CMML has more 'myeloproliferative' features, which means that the main problem is excess production of affected blood cells.

In other cases, which are more similar to a condition called myelodysplastic syndrome (MDS), the main problem is the production of abnormal blood cells that do not mature and work correctly. In this type of CMML, the main treatment used is azacitidine, which works in a different way. Azacitidine belongs to a class of drugs called 'hypomethylating agents' (HMA) and works by affecting the way in which the CMML cells switch genes on and off. Another HMA, called decitabine, is being studied to see if this gives better results than azacitidine.

As mentioned in the section on diagnosis, in the small minority of CMML cases (less than 4%) where a certain genetic abnormality

known as a 'PDGFR fusion' is present, a class of drugs called tyrosine kinase inhibitors (TKIs) may be very effective. The most commonly-used drug in this class is imatinib. These drugs have been in use for some years to treat another disease called chronic myeloid leukaemia (CML).

Your haematologist or clinical nurse specialist will explain the possible side effects, advantages and potential disadvantages of any chemotherapy treatment.

Stem cell transplant

For younger patients with high-risk features, a stem cell transplant may be recommended. This means having chemotherapy to kill off the bone marrow followed by a transplant of healthy stem cells from a matched donor. There are two types of donor transplant which can be done. For fitter or younger patients, a type called a myeloablative transplant uses very strong doses of chemotherapy and radiotherapy. This has the advantage of minimising the risk of the CMML returning (a

Treating CMML (cont.)

relapse), and may cure CMML, but is very toxic. People who respond better to standard treatment are more likely to have a favourable outcome when they have a stem cell transplantation.

If a patient is well enough to have a transplant, but not fit enough for myeloablative transplant, a procedure called reduced intensity conditioning (RIC) transplant may be considered. A RIC transplant uses lower doses of pre-transplant chemotherapy (conditioning), which means that it is less dangerous but there may be a higher chance of relapse.

If you are being considered for a stem cell transplant, your haematologist will explain in detail what this will involve, and the possible risks and benefits.

If you would like more information on stem cell transplants, including side effects, you can order our two booklets by calling the helpline on **08088 010 444** or by emailing Patient Services support@leukaemiacare.org.uk

New treatments and treatments on the horizon

There are several different types of new drugs being studied for possible use in CMML but, at present, these are in early stage trials and, except perhaps decitabine, are unlikely to be used routinely in the near future. Some of the drugs being studied are likely to be used only for specific groups of patients as they target genetic abnormalities that are not found in all CMML cells.

Prognosis of CMML

Doctors often use survival rates as a standard way of discussing a patient's prognosis. Some people may want to know the survival statistics for patients with their form of cancer, whilst others may not find that useful or may not want to know. If you want to know the prognosis for your blood cancer you can discuss this with your consultant.



Living with CMML

After a diagnosis of CMML, you may find that it affects you both physically and emotionally. This chapter will talk about both of these aspects.

Emotional impact of CMML

Being told you have cancer can be very upsetting. Some of the symptoms of CMML can be hard to cope with and, because of this, you may need emotional, as well as practical, support. Being diagnosed with a rare disease can affect the whole of you, not just your body, and can impact you emotionally at any point of your journey. 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.

"There was a total overwhelming feeling of helplessness and being out of control of my normal everyday life. But I had to carry on regardless for everyone else."

Looking after you

Following a diagnosis of CMML you may want to make changes to your lifestyle to try to stay as well as possible after your diagnosis and during treatment. Don't try to change too much at once. Adopting a healthy way of living is about making small, manageable changes to your lifestyle.

A healthy lifestyle includes having a well-balanced diet and being physically active. With some of the side effects you may be experiencing, 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.

One of the most commonly reported side effects of the treatment of CMML is fatigue. This isn't normal tiredness and doesn't improve with sleep.



Living with CMML (cont.)

Some general tips on how to deal with fatigue include:

- Have a regular lifestyle – try going to bed and waking up at approximately the same time every day and try to avoid lying in.
- Take part in regular, gentle exercise to maintain your fitness levels as much as possible.
- Reserve your energy for what you find important and build rest periods around those times.
- Before going to bed avoid stimulants such as alcohol, coffee, tea or chocolate, or using laptops, tablets or mobile phones.
- Keep your bedroom quiet and at a comfortable temperature.
- Talk about your worries with family, friends or your doctor or nurse, or patient support groups.
- Discuss your fatigue with your doctor or nurse.

"Don't get me wrong, it's hard living with a chronic condition. I get tired a

lot and have to be careful of picking up infections, as my immune system is lower than others. But all in all, I will not let it take over my life. I don't intend on fighting it; it will have to fight me."

You can find more information about living well with Leukaemia, go to: www.leukaemiacare.org.uk/support-and-information/information-about-blood-cancer/living-well-with-leukaemia/

Practical support Work and finances

Being diagnosed with CMML can sometimes lead to difficulties relating to your work life. Your diagnosis may lead to temporary sick leave or a reduction in working hours, but it can also mean that you have to stop work altogether. You may need to make an arrangement with your employer for times when you may need to go into hospital or for those times when you may not be well enough to go into work.

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. It is often worth taking time to explain CMML 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 means that legally your employer cannot discriminate against you and must make reasonable arrangements and adjustments relating to your disease.

Macmillan has published a booklet about financial support following a diagnosis of cancer. They can also give you personal advice over the phone via their helpline on **0808 808 00 00** and you can discuss which benefits you are eligible for. Some Macmillan centres can arrange face-to-face meetings with a benefits advisor. They can also provide financial assistance in the form of grants – ask your nurse in the hospital how to apply.

As CMML is regarded as a cancer, you will also be entitled to apply for a medical exemption certificate which means that

you are entitled to free NHS prescriptions. Your GP or specialist nurse at the hospital can provide you with the details how to apply for this. If you are undergoing chemotherapy you may qualify for a Blue Badge to help with hospital car parking. To apply for a badge contact your local council.

You can find more information on practical issues on our website at: www.leukaemiacare.org.uk/support-and-information/information-about-blood-cancer/living-well-with-leukaemia/practical-issues/

Talking about CMML

Talking to your haematologist

CMML 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 else 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 CMML.

Remember, if you choose to start any form of complementary

therapy outside of your medical treatment, discuss this with your haematology consultant or clinical nurse specialist, 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 CMML.

For help with talking to your haematologist, you can access more information on CMML, including questions to ask your medical team, at www.leukaemiacare.org.uk/support-and-information/information-about-blood-cancer/blood-cancer-information/leukaemia/chronic-myelomonocytic-leukaemia/ which features a list of questions which you may want to ask.

Talking to other people

Telling people you have a rare condition like CMML 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 CMML if they want to know more in-depth details.

"I made a conscious decision to be very open about my illness. Telling family was tough. But I encouraged people to ask questions."

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 isn't always what people really want to hear. In many ways, the more you communicate with them the better.

Talking about CMML (cont.)

These points may help you:

- Explain that you have a condition that means your bone marrow does not function properly, and that this affects the number of blood cells it produces
- Explain your symptoms (maybe 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.

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

Glossary

Acute Leukaemia

Leukaemia is cancer of the white blood cells. Acute Leukaemia means it progresses rapidly and aggressively, and usually requires immediate treatment.

Anaemia

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

Acute Myeloid Leukaemia (AML)

Acute myeloid leukaemia (AML) is a type of blood cancer that starts from young white blood cells called granulocytes or monocytes in the bone marrow.

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.

Chronic

A human health condition or disease that is persistent or otherwise long-lasting in its effects. The term chronic is usually applied when the course

of the disease lasts for more than three months.

Chronic leukaemia

A type of blood cancer that affects the white blood cells. This tends to progress over many years.

Fatigue

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

Granulocyte

A type of white blood cell which is characterised by the presence of granules in the cytoplasm. They are important for fighting infection, particularly bacterial infections.

Haematologist

A doctor who specialises in diseases affecting the blood. They are concerned with any abnormality of the blood, including blood cells and coagulation. Some diseases of the blood include anaemia, leukaemia, lymphoma, polycythaemia and haemophilia.

Juvenile Myelomonocytic Leukaemia (JMML)

Juvenile myelomonocytic leukaemia (JMML) is a serious chronic leukaemia (cancer of the blood) that affects children mostly aged 4 and younger. The name JMML now encompasses all diagnoses formally referred to as juvenile chronic myeloid leukaemia (JCML), chronic myelomonocytic leukaemia of infancy, and infantile monosomy 7 syndrome.

Lymphocyte

A type of white blood cell which forms the body's immune system.

Neutropenia

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

Stem cell transplant (SCT)

A stem cell transplant is a treatment for some types of cancer as well as other blood diseases and disorders of the immune system. A stem cell transplant involves the administration of chemotherapy plus or minus radiotherapy as conditioning followed by infusion of stem cells. The stem cells engraft and form a new immune system.

Thrombocytopenia

A disorder characterised by abnormally low levels of thrombocyte, also known as platelets, in the blood.

Tyrosine Kinase Inhibitor (TKI)

A drug which blocks the action of a tyrosine kinase (particular type of enzyme in the cell).

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

Registered charity
259483 and SC039207

Leukaemia Care
YOUR Blood Cancer Charity

