Hairy Cell Leukaemia (HCL)

A Guide for Patients

Leukaemia Care
YOUR Blood Cancer Charity

Introduction

Being diagnosed with hairy cell leukaemia (HCL) can be a shock, particularly when you may never have heard of it. If you have questions about HCL – what causes it, who gets it, 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 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.

Version 2
Printed: 04/2018
Review date: 04/2020

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 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@leukaemiacare.org.uk**, over the phone on **08088 010 444** or via LiveChat.

Patient Information Booklets

We have a number of patient information booklets like this available to anyone who has been affected by a blood cancer. A full list of titles – both disease specific and general information titles – can be found on our website at **www.leukaemiacare.org.uk/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**, as well as speak to one of our care advisers on our online support service, LiveChat (9am-5pm weekdays).

Campaigning and Advocacy

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

Patient magazine

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

What is Hairy Cell Leukaemia?

Hairy cell leukaemia (HCL) is a blood cancer which affects the lymphocytic (antibody producing) white blood cells that are produced by the bone marrow.

To understand HCL 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 haematopoietic stem cells, 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 (granulocytes) that fight infection and disease. Granulocytes include neutrophils, monocytes, eosinophils and basophils.

A lymphoid stem cell becomes one of three types of lymphocytes (also 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.

In HCL there is an excess number of lymphocytes in the circulating blood. These lymphocytes are abnormal and cannot help the body to defend against infections. They are called hairy cells because the cells have fine projections on the surface – which look like hairs under the microscope. When you have HCL, the marrow is not able to make enough normal blood cells, which may lead to a set of debilitating symptoms.

Hairy cell leukaemia usually responds very well to treatment and patients with this form of leukaemia typically have a normal or near-normal lifespan.

HCL is very similar to a type of leukaemia called chronic lymphocytic leukaemia (CLL). Although the appearance of hairy cells is usually quite distinctive, this is not enough by itself to make the diagnosis. Special laboratory tests are needed to show whether you have HCL, CLL or another similar disease.

There is a condition called hairy cell variant (HCL-v) but this is now considered to be a separate disease which does not behave like HCL and is not treated in the same way. This information is about HCL only. If you have HCL-v, then your specialist will explain what this means and discuss treatment with you.

How common is HCL?

HCL is considered a rare disease as it affects fewer than 0.3 people in every 100,000 per year. It affects men about three to five times as often as women. There are about 200 new cases diagnosed in the UK each year.

That might explain why you probably haven't heard of it, or met anyone with the condition before. HCL is unheard of in children and is very rare in young adults. It is most commonly diagnosed in patients between 55 and 70 years of age.

What causes HCL?

The cause of HCL is not known. The only factors which are definitely known to increase the chance of developing the condition are older age and being male. You cannot catch HCL from someone who has it and you cannot pass HCL on to your children.

What are hairy cells?

The normal equivalent of the hairy cell is a type of white blood cell called a B lymphocyte. The function of a B lymphocyte is to produce antibodies which help the body to defend itself against infection. An important discovery has been the fact that a very high proportion, possibly all, hairy cells have a specific mutation of a gene called BRAF. This is not an abnormality which has been passed on by parents; the gene is

What is Hairy Cell Leukaemia? (cont.)

only abnormal in your hairy cells and not in your normal cells. This may help in confirming diagnosis of HCL and in developing new treatments.

Symptoms and diagnosis of Hairy Cell Leukaemia

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

In someone without HCL, 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 HCL, abnormal cells take over the bone marrow; the result is that the marrow is not able to make enough normal blood cells. The spleen is nearly always enlarged in hairy cell leukaemia. Sometimes the spleen is very large and this may cause discomfort or even pain.

Due to the inability of the bone marrow to make enough blood cells, HCL 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 hairy cell leukaemia.

What are the most common symptoms of HCL?

About a quarter of all patients have no symptoms at the time of diagnosis – typically these patients are identified because of abnormal results from a routine full blood count. Patients often go to their doctor with symptoms of fatigue, weakness and infection.

Symptom frequency at presentation:

- Enlarged spleen – eight out of ten patients.
- Enlarged liver - two out of ten patients.
- Infection – between one and two out of ten patients.
- Pancytopenia - about one in three patients.

Symptoms and diagnosis of Hairy Cell Leukaemia (cont.)

Diagnosis of HCL

If HCL is suspected, you'll have further tests to confirm the diagnosis. You will usually see a haematologist (a doctor who specialises in blood disorders). The haematologist will take your full medical history, carry out a physical examination and take further blood tests to determine how many different types of blood cells there are in your blood sample. This is known as a full blood count (FBC) and will indicate the number of abnormal white blood cells you have.

If you have hairy cell leukaemia, it's likely your red blood cell neutrophils and platelet counts will be low. Also, monocytes which is part of the white cells will be extremely low.

A bone marrow sample may also be taken which will give the haematologist more detailed information about your condition. The sample is usually taken from the back of your hip bone (pelvis). You will be given local anaesthetic to numb the area. The doctor will then pass a needle through the skin into the bone and draw a small sample of liquid marrow into a syringe (bone marrow aspirate). After this, the doctor will take a small core of marrow from the bone (a trephine biopsy). Both samples will be looked at later under a microscope.

You may feel bruised and have an ache for a few days after the test. This can be eased with mild painkillers.

What happens next?

Your individual situation and health history, as well as the ways you respond to treatment, can all affect your prognosis (the predicted outcome of the disease). HCL affects people differently, and an individual's prognosis may vary depending on a number of factors, such as age, blood count and symptoms. A very high proportion of patients will have a very good response to treatment. The lifespan of most patients with HCL will be normal or near-normal.

If there are no symptoms caused

by spleen enlargement and the numbers of normal blood cells are not greatly reduced, you may not require any treatment when you are diagnosed. If this is the case, you will have regular blood counts and physical check-ups – this is known as watch and wait, or active monitoring. If you are on watch and wait and you experience any new health problems, you should let your haematologist know.

If you have any concerns, contact your haematologist.

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 Hairy Cell Leukaemia

The aim of treatment is to reduce the number of abnormal cells to as low as possible. It is generally accepted that standard treatment will not cure HCL; but it does offer a very high chance of a normal lifespan with a good quality of life.

The following key factors will help your haematologist to work out when to start treatment:

- The number of normal red blood cells and white blood cells
- Symptoms caused by enlargement of your spleen or by low levels of normal blood cells

The first treatment for HCL is usually successful and many people remain in remission for a long time without further treatment. Many patients, however, will relapse and require re-treatment, which is usually successful. If the relapse is more than 2 years after the first treatment, re-treatment is usually with the same chemotherapy drug. If the relapse is less than 2 years after the first treatment, another chemotherapy drug is likely to be used. Rituximab may be added to the chemotherapy. Other treatment options for a relapse include newer drugs or a stem cell transplant.

Treatment options

Watch and wait

If you have no symptoms when you are first diagnosed with HCL and your blood counts are not very low, your haematologist may suggest a 'watch and wait' approach; this usually happens in around 10% of people with HCL. 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.

You can find more information about drugs used to treat your HCL (and any other medicines you are taking) at the eMC Medicine Guides web site **www.medicines.org.uk/guides**

Chemotherapy

Chemotherapy is the use of anti-cancer (cytotoxic) drugs to destroy cancer cells. It has a very high success rate in the treatment of HCL. It does not cure the disease but it gives very good control and most patients can expect a normal or near-normal lifespan.

The main drugs used first to treat HCL are pentostatin (2-deoxycoformycin or dcF) and cladribine (2-chlorodeoxyadenosine or CDA), which are purine analogues. These drugs work in a similar way by blocking the hairy cell from dividing.

Your haematologist or clinical nurse specialist will explain the possible side effects of any chemotherapy treatment you may have.

For the minority of patients whose disease does not respond to purine analogues, there are other drugs available. These include interferon, which was widely used to treat HCL before purine analogues were available, and fludarabine, which is chemically similar to cladribine and is widely used to treat a condition called chronic lymphocytic leukaemia (CLL). A drug called rituximab has also been widely used to treat CLL and may be valuable when HCL does not respond to purine analogues.

There are several new drugs which are being studied for use in HCL and it is possible that one, or more, of these may prove useful in treating those very rare cases of HCL which does not respond to current treatments.

Cladribine and Pentostatin (Purine analogues)

These drugs have changed the outlook for patients with HCL. In almost all cases, HCL responds well to purine analogues. Cladribine is the preferred choice because it can be given as a single course of treatment over one week, whereas pentostatin has to be given as repeated treatments over a period of up to six months. Both drugs can be

Treating Hairy Cell Leukaemia (cont.)

given into a vein; cladribine can also be given as injections just under the skin (subcutaneously). Treatment guidelines currently recommend subcutaneous cladribine given once a day for five days.

Purine analogues affect the body's immune system and may reduce your blood counts by affecting the bone marrow's production of normal blood cells. As a result, any active infection will be treated before cladribine or pentostatin therapy is started. It is recommended that any patient who has been treated with purine analogues and who later needs a blood transfusion should be given irradiated blood. This is to reduce the risk of a condition called transfusion-related graft versus host disease. This can happen when a patient's immune system is not working properly and healthy immune cells in the donor's blood damage the patient's tissues. Irradiated blood is not radioactive and is just as safe and effective as any other blood transfusion.

While you are being treated with cladribine or pentostatin, you will be carefully watched for any sign of infection. You may be given drugs to prevent some virus infections if your lymphocyte count is very low. If this applies to you then you will be given detailed information. Your haematologist or clinical nurse specialist will explain any special precautions you may need to take and will answer all your questions.

Cladribine or pentostatin may cause nausea and/or vomiting but this can usually be controlled by taking drugs called anti-emetics at the same time.

Rashes are also a side effect of cladribine in particular and it's best not to receive allopurinol at the same time for this reason.

A long-term follow-up of patients treated with purine analogues has confirmed that they are safe and are very effective as initial treatment for almost all patients with HCL, as well as for treatment of relapses.

Rituximab (Mabthera™)

Rituximab is a monoclonal

antibody which has been used widely to treat a condition called CLL and which may be useful if your HCL comes back (relapses) after responding to treatment. Monoclonal antibodies are drugs that recognise, target and stick to particular proteins on the surface of cancer cells. They can stimulate the body's immune system to destroy these cells. Rituximab may be given with purine analogues. The most common side-effects of rituximab are similar to those for purine analogues. Patients often have rashes or other mild reactions after their first rituximab treatment but this is usually easily controlled and is less common when the antibody is given again.

Splenectomy (surgical removal of the spleen)

This was a standard treatment for HCL before effective drugs became available. It may be an option if your enlarged spleen is painful and causing complications and your blood count results are reasonably normal. If you have a splenectomy, it may take some time for a splenectomy to improve your condition, so it is recommended that you do not have any treatment for at least six months. This will allow doctors to tell whether the splenectomy is working well to control your HCL. After this time, you will have regular blood tests and will start drug treatment if these show that your HCL is progressing.

Interferon Alpha

Interferons are proteins that occur naturally in our bodies and help us fight infection. They can also be given as medications and are used to treat many types of disorders.

Interferon alpha can be used to treat HCL – usually only in cases where the numbers of normal blood cells are very low and a very quick response is needed. Once the blood count has improved interferon can be stopped and treatment with cladribine or pentostatin given instead.

Interferons are made by several drug companies and are known by several brand names. They are given as an injection just under the skin and suppress the production of blood cells and

Treating Hairy Cell Leukaemia (cont.)

reduce spleen size. It can also reduce bone marrow fibrosis and itching.

Some people may not be able to tolerate the side effects, which include flu-like feelings, nausea, headaches and diarrhoea.

You should inform your haematologist or clinical nurse specialist if you are experiencing any of these side effects, as there are often ways of controlling them.

Interferon is very rarely used nowadays because newer chemotherapy drugs work so well.

New treatments and treatments on the horizon

Because standard treatment with purine analogues is so effective against HCL, most studies of new treatments are concentrating on treatment of relapses of HCL or HCL that does not respond to standard treatment. The most promising treatments include BRAF inhibitors and immunotoxins.

Vemurafenib (Zelboraf™)

Vemurafenib is a BRAF inhibitor. BRAF is a gene which helps to control cell division. Mutations of the BRAF gene have been reported in several types of cancer including HCL. HCL is characterised by nearly all patients having the BRAFV600E mutation. Vemurafenib targets this mutation. Early studies indicate that this drug is effective against HCL, even in people who have experienced multiple relapses after purine analogue treatment or who do not response to purine analogues, but the dose and length of time that treatment is needed still needs to be worked out. Vemurafenib may be very valuable for treatment in cases where existing drugs do not work, or have stopped working. It will require a lot more research and clinical trials before it is decided whether this should be part of standard treatment for HCL.

There are several other drugs which work in a similar way to vemurafenib, but which may be effective in patients for whom vemurafenib does not work, or

has stopped working. These are called dabrafenib, trametinib and ibrutinib. Ibrutinib is already approved for treating patients with relapsed B-cell cancers or B-cell cancers that do not respond to standard treatment. However, more research and clinical trials will be needed to decide what if any role they should have in treatment of HCL.

Another approach to treatment of HCL, with or without the BRAF V600 mutation, is the use of monoclonal antibodies (see Rituximab above), which have very toxic compounds attached (immunotoxins). The toxic compounds cannot be used as conventional drugs because their side-effects would be too severe. By attaching them to a monoclonal antibody, they can be made to attack only the HCL cells. Again, it will take more research and clinical trials to establish whether these are an improvement on existing treatment.

Living with Hairy Cell Leukaemia

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

Emotional impact of HCL

Being told you have cancer can be very upsetting. Although the outlook for many HCL patients is a positive one, it is a blood cancer and a rare condition 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.

It is important to remember that with current treatments, you can expect a good response and live a long, normal life.

Looking after you

You can live a long and normal life with HCL but 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 HCL is fatigue. This isn't normal tiredness and doesn't

Living with Hairy Cell Leukae (cont.)

improve with sleep.

Some general tips how to deal with fatigue include:

- Have a regular lifestyle – try going to bed and waking up 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.

Practical support

Work and finances

Being diagnosed with HCL 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 HCL 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 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 HCL 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 of how to apply for this.

Talking about Hairy Cell Leukaemia

Talking to your haematologist

HCL 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 HCL. Remember, if you choose to start any form of complementary therapy outside of your

medical treatment, consult your haematology consultant or clinical nurse specialist (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 HCL.

For help with talking to your haematologist, you can find information at **www.leukaemiacare.org.uk/support-and-information/information-about-leukaemia/blood-cancer-information/leukaemia/hairy-cell-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 HCL 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 HCL 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 or 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.

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.

Talking about Hairy Cell Leukaemia (cont.)

- 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 a factsheet 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 one on our website for you to download.
- **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

Anaemia

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

Chronic Lymphocytic Leukaemia (CLL)

A cancer that effects the blood and bone marrow derived from lymphocytes.

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.

Hairy Cell Leukaemia (HCL)

Hairy cell leukaemia is one of the rarest types of leukaemia, which is cancer of the white blood cells. It gets its name from the fine, hair-like strands around the outside of the cancerous cells, which are visible under a microscope.

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.

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 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).

Glossary (cont.)

Red blood cell

The blood cell that carries oxygen. Red cells contain haemoglobin, which permits them to transport oxygen (carbon dioxide).

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.

Thrombocytopenia

Deficiency of platelets in the blood.

White blood cell

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

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

Tell us what you think!

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

Suitable for Andriod, 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 are 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

Health & care information you can trust
The Information Standard Certified Member