
All about Leukaemia

An Easy Read Document



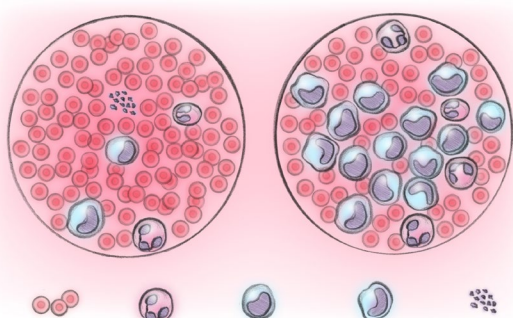
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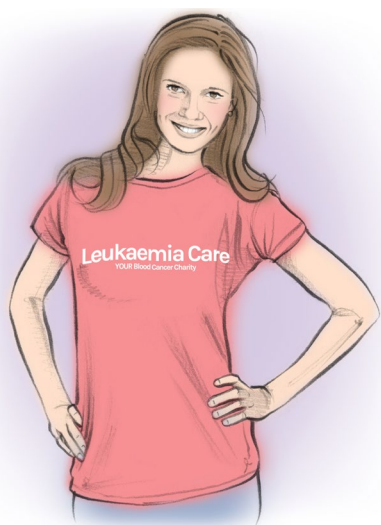


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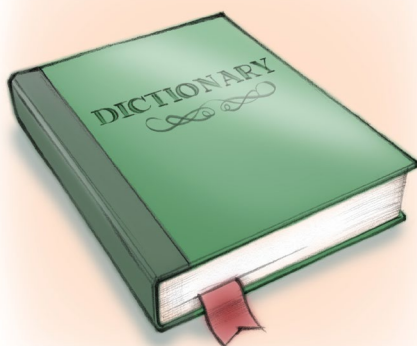
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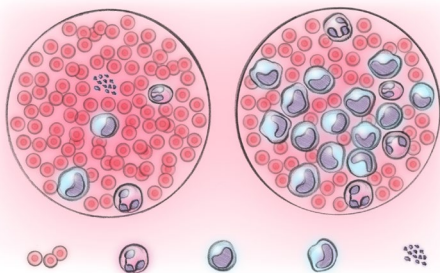
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About this booklet and Leukaemia



Leukaemia is a type of blood **cancer**.

It is a serious illness but there are treatments that can help.

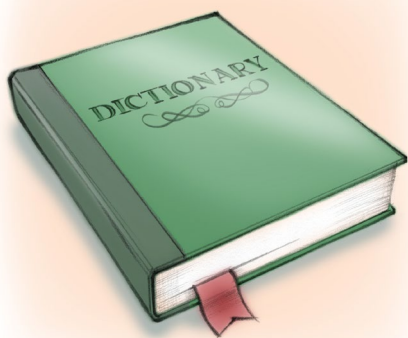
This booklet explains:

- What **leukaemia** is
- What tests you might have
- The different treatments you may receive

We use some difficult words in this booklet. When we use them, we put them in **bold** and explain them.

There is a list of words we use regularly on page 29.

We try to make sure we give you the right information. However, things are changing all the time, so please talk to your clinical nurse specialist or doctor as well.

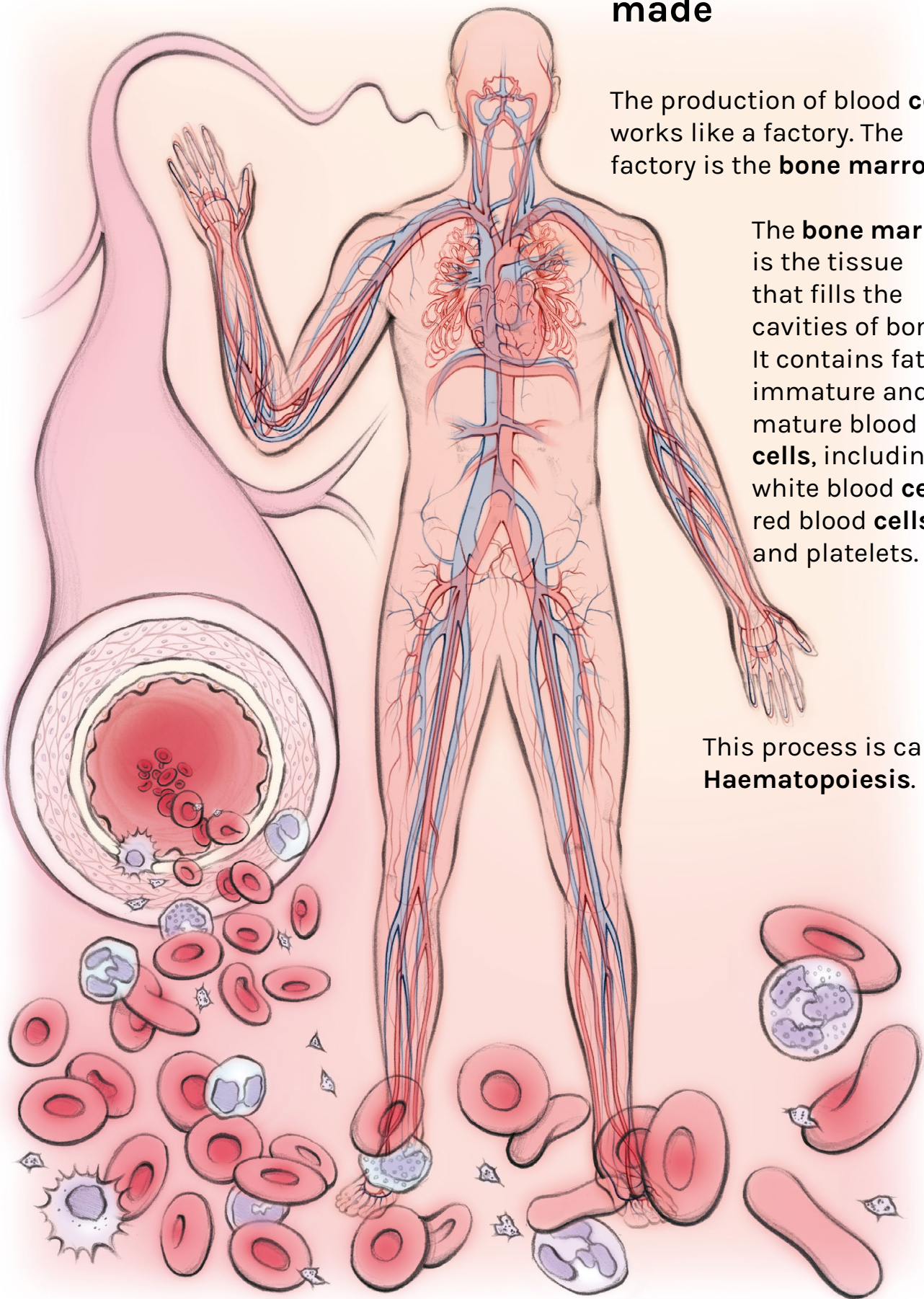


How blood cells are made

The production of blood **cells** works like a factory. The factory is the **bone marrow**.

The **bone marrow** is the tissue that fills the cavities of bones. It contains fat, immature and mature blood **cells**, including white blood **cells**, red blood **cells** and platelets.

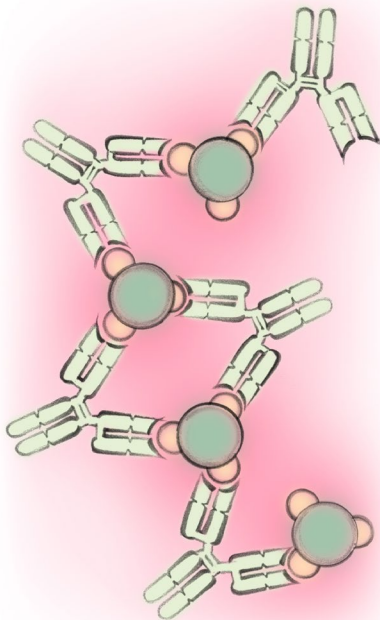
This process is called **Haematopoiesis**.



There are three types of blood **cells**:

1. Red blood **cells** that contain haemoglobin and carry oxygen and other substances to all tissues of the body.
2. White blood **cells** that form part of the immune system and defend the body against infection and disease.
3. Platelets which are small **cells** that form blood clots to stop bleeding.

There are five major types of white blood **cells**: neutrophils, **lymphocytes**, monocytes, eosinophils and basophils.



1. Neutrophils protect against bacterial infections and inflammation.
2. **Lymphocytes** recognise bacteria, viruses and toxins, to which they produce **antibodies** and destroy.
3. Monocytes clear infection products from the immune system.
4. Eosinophils protect against parasites and allergens.
5. Basophils create the inflammatory reactions during an immune response.

There are three types of **lymphocytes**:

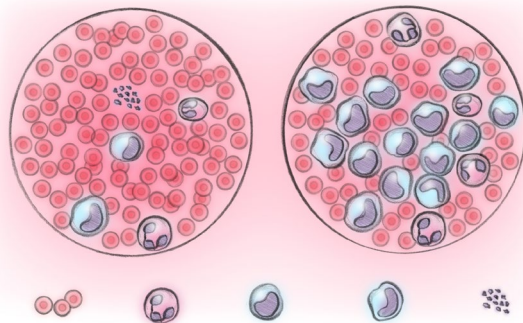
1. **B-lymphocytes (B-cells)** seek out and immobilise bacteria, viruses and toxins that invade the body.
2. **T-lymphocytes (T-cells)** destroy the invading organisms immobilised by the **B-cells** as well as any body **cells** that have become cancerous.
3. Natural killer **cells** that attack **cancer cells**.



Leukaemia is a **cancer** that grows from special white blood **cells**. White blood **cells** normally help us fight illness and stay well.

Leukaemia cells crowd out normal **cells** in the blood and **bone marrow** which means they are not able to work properly.

There are four main types of **leukaemia**:



- 1. Acute Myeloid Leukaemia (AML)** – patients with this disease produce too many immature myeloid blast **cells** and the **leukaemia** progresses rapidly. Blast cells are immature **cells** found in the **bone marrow** which are not fully developed.
- 2. Acute Lymphoblastic Leukaemia (ALL)** – patients with this produce too many lymphoblasts and the **leukaemia** progresses rapidly. Lymphoblasts are immature abnormal **lymphocytes**.
- 3. Chronic Myeloid Leukaemia (CML)** – patients with this produce too many **granulocytes** and other myeloid **cells**. CML normally progresses slowly, but can become acute.
- 4. Chronic Lymphocytic Leukaemia (CLL)** – patients with this produce too many **lymphocytes** and the **leukaemia** progresses slowly.



Why do people get this type of cancer?

Doctors do not really know what causes **leukaemia**.

You cannot catch **cancer** from someone else and you cannot give it to anyone else.

It cannot be passed on from parent to child.

In a number of **leukaemias**, patients have abnormal chromosomes, but **leukaemia** is not thought to be an inherited disease.

Different types of Leukaemia

Acute leukaemia

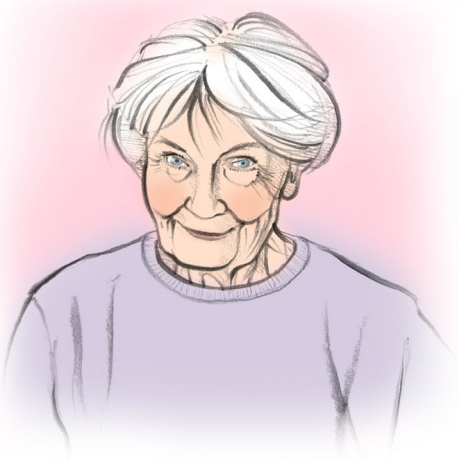
The two main types of acute **leukaemia** are called acute myeloid leukaemia and acute lymphoblastic leukaemia.

Acute Myeloid Leukaemia (AML)

You can get this at any age. However, with an average age at diagnosis of 67 years, this disease is far more common in the elderly.

Acute Lymphoblastic Leukaemia (ALL)

This is much more common than acute myeloid **leukaemia** in adults. The majority of ALL cases occur in children under the age of 15 years with a second peak of incidence in people around 40 years of age.



Chronic leukaemia

The three main types of chronic **leukaemia** are called chronic myeloid leukaemia, chronic lymphocytic leukaemia and hairy cell leukaemia.

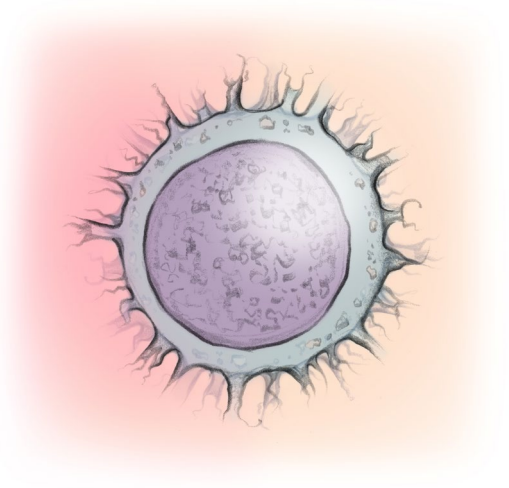


Chronic Myeloid Leukaemia (CML)

This is a slow progressing form of **leukaemia**. It is most common in adults aged 60 to 65 years old.

Chronic Lymphocytic Leukaemia (CLL)

This is also a slow progressing form of **leukaemia**. Slightly more men than women tend to be affected by CLL. The average age at diagnosis is 72 years. About 10% of CLL patients are reported to be younger than 55 years.



Hairy Cell Leukaemia (HCL)

This is a very rare form of **cancer** which is approximately five times more common in men and has an average age at diagnosis of 52 years.

Signs which may mean you have Leukaemia

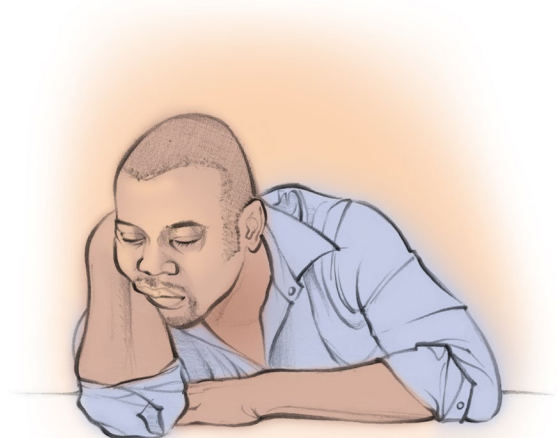


Some people notice symptoms while others find out when doctors test them for something else or they have routine tests.

Symptoms:

There might be symptoms like:

- Infections that won't go away
- Losing weight for no reason
- Feeling extremely tired
- Bleeding and bruising
- Bleeding gums
- Fine purplish red rash (Purpura)
- A cough or trouble breathing
- High temperature
- Bad stomach pain
- Abdominal discomfort (enlarged spleen)
- Swollen glands
- Paleness



Tests for Leukaemia



Your GP will send you to a hospital for tests to find out if you have **leukaemia**.

You will normally see a doctor called a **Haematologist** who treats blood diseases or **cancers**.

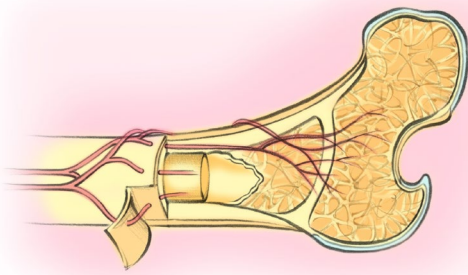
Blood tests

You will have blood tests to see how many healthy and abnormal blood **cells** are in your blood (your blood count).

You might also have a blood test to see how well your liver and kidneys are working.



Bone marrow test



Bone marrow is the soft part in the middle of some bones where blood **cells** are made.

The doctor might want to see if there is **leukaemia** present in your **bone marrow**.

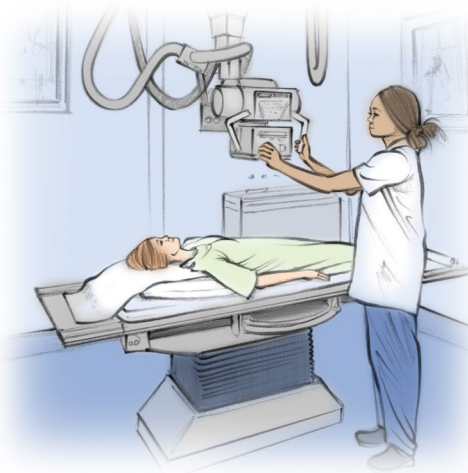
A special needle will be used to take a small piece of marrow from your hip bone.

The doctor will numb your skin first but it can still hurt.

You can ask for medicine to help you relax while the **bone marrow** test is done, such as:

- Entonox (gas and air)
- Sedation (they can put you to sleep)

X-rays and scans



The doctors might use x-rays and scans to look inside your body to look for infection. They do not hurt.

Finding out about your tests



For acute tests, you can get your result back on the same day.

For special tests, it can take between two and 10 days to get results.

Your doctors need to find out as much as they can to give you the right treatment:

- You will be examined.
- They will ask you about your past health.
- They will ask you if you take any medicines.

What does the 'stage' mean?



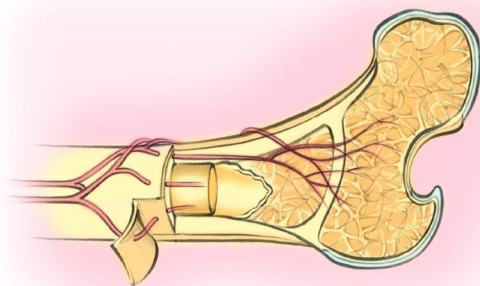
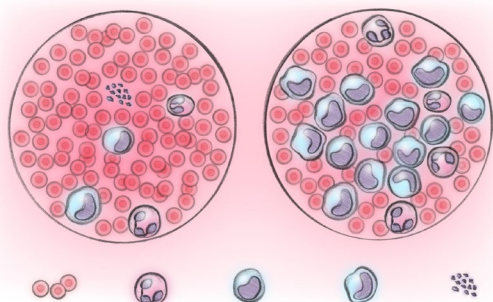
Cancer staging is a rating process to determine the extent of a **cancer** in the body and where it is located.

Understanding the stage of your **leukaemia** will help your doctor plan the best treatment for you.

CLL is the only form of **leukaemia** where staging is used.

Two staging systems exist.

1. **The Binet system** - This is used mainly in the UK and Europe. It has three stages from A to C. C is the most advanced stage.
2. **The Rai system** - This is more widely used in the United States. It has five stages, from 0 to IV. IV is the most advanced stage.



This system takes into account the patient's blood **cell** count results and if the **leukaemia** has spread.

How doctors treat Leukaemia



Planning your treatment

A team of doctors and other experts will look at your tests and plan your treatment.

This is called a multi-disciplinary team meeting. They may call it an MDT meeting.

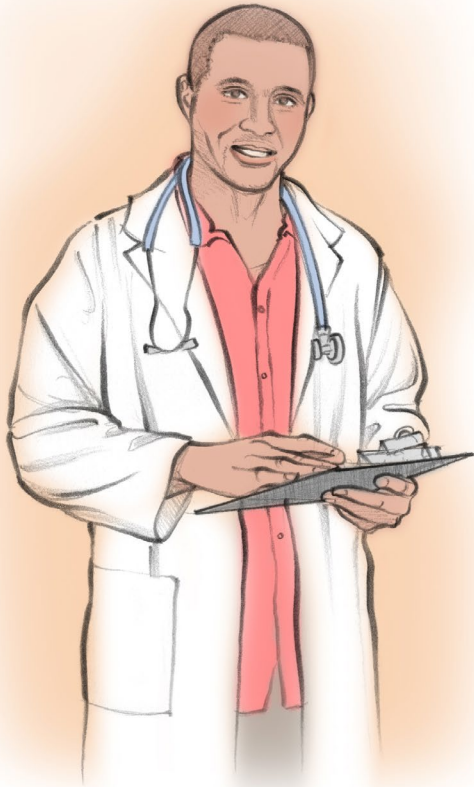
Your doctor will talk to you about:

- Whether they are trying to cure your **leukaemia** or control it for as long as possible.
- Whether you will stay in hospital for treatment or whether you can just visit the hospital for treatment.
- When you start your treatment. For acute patients, treatment starts immediately.
- The types of treatment you will have.
- Whether the treatment will have any **side effects**.
- How long treatment will last.
- How you may feel about the treatment.

You will receive a lot of information about your condition.

It is okay to ask questions and have someone with you to help you remember everything.

You can also talk to your clinical nurse specialist if you are worried or want to ask questions. You will have one of these nurses assigned to you when you are diagnosed.



Different types of treatment



Acute leukaemia patients

Most people go into hospital immediately after diagnosis.

Later on, you might receive treatment in a day unit or have oral chemotherapy at home.

Chronic leukaemia patients

Patients with chronic disease tend to receive day care. This means you will travel to the hospital for treatment.

You may also receive daily chemotherapy at home. This will involve taking tablets every day.

You will not have all of the following treatments, but might have more than one. Your doctor will tell you which ones are right for you.



Watch and wait

Some people with chronic lymphocytic **leukaemia** do not need treatment right away.

The doctor will keep checking you and will only start the treatment if the **leukaemia** grows. Treatment will be started if you have large lymph glands, the number of **cells** in your blood is no longer normal, or the **leukaemia** is making you ill.

Chemotherapy

This may be a single drug or combination of drugs that will kill the cancer blood **cells**.

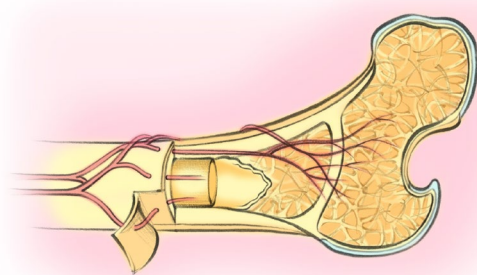
Your treatment will last several months and you will have drugs some weeks but not others. You may be kept in hospital for some time.



Stem Cell Transplant

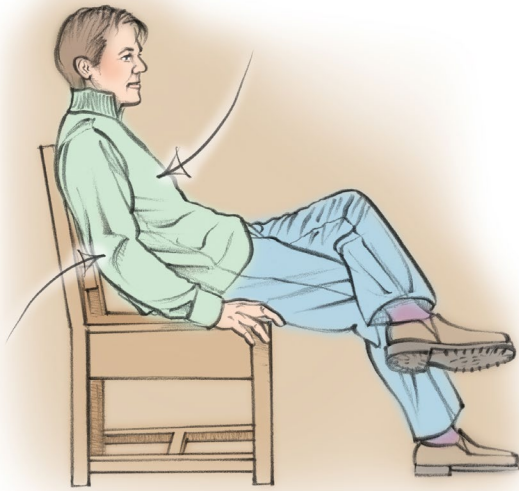
This is a way of replacing damaged **bone marrow cells**.

The donor **cells** will either be your own from before you started treatment or someone else who was found to be a match.



PICC Line

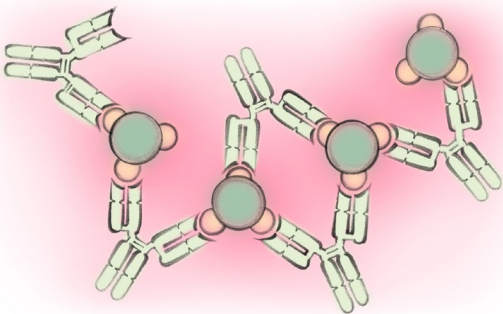
This is a central line that is placed into the vein above the bend of your elbow until it reaches the vein in your chest. The area will be made numb before the tube is put in.



Hickman Line

Hickman® line is the brand name for a central venous line which is a long, thin, hollow tube that is inserted into a vein in your chest.

It is used to give chemotherapy treatment or other drugs. Another brand of central venous line is the Groshong® line.



Antibodies

This is a large protein made by your immune system to destroy germs, such as bacteria or viruses, which enter the body.

Scientists have found ways to make them help the body kill the **leukaemia cells**.



Isolation

You may be told that you need to stay away from other people or be kept in your own room in the hospital. It is to prevent you from getting any infection during treatment.



Mouth care

This helps to keep your mouth clean to prevent infection, including a common side effect of chemotherapy called mucositis.

Hair loss

Hair loss can be caused by chemotherapy or radiotherapy. You may lose all of your hair, some of your hair or none of it. It can also affect your eyelashes, eyebrows and body hair.

Speak to your doctor if you would like some help dealing with your hair loss. They can signpost where to get wigs or head scarves, for example.



Medications

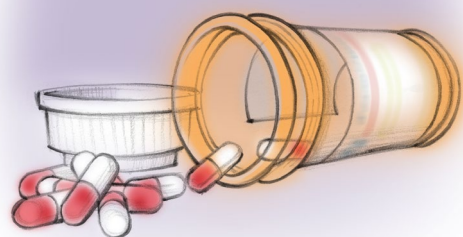
There are a number of different medications that you may be given to help treat your **leukaemia**. It may be that during treatment, you take more than one type or even switch medications.

The type of medication you may be given depends on:

- What type of **leukaemia** you have
- Any **side effects** that you may have
- How you respond to the treatment

General factors including age can also affect this.

For more information on the medication you take, speak to your doctor.





Diet

A healthy diet after your treatment can help you recover physically and emotionally. To work out a plan that works best for you, you should talk to your hospital doctor or dietician.

Keeping happy

Diagnosis and treatment affect peoples' emotions differently. Trying to stay positive and calm can sometimes be helped through meditation and relaxation.

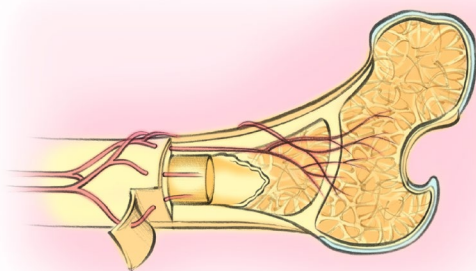
It may also be useful to speak to someone about your **leukaemia** and how you are feeling about it. This might be a friend, a family member or an external support service.

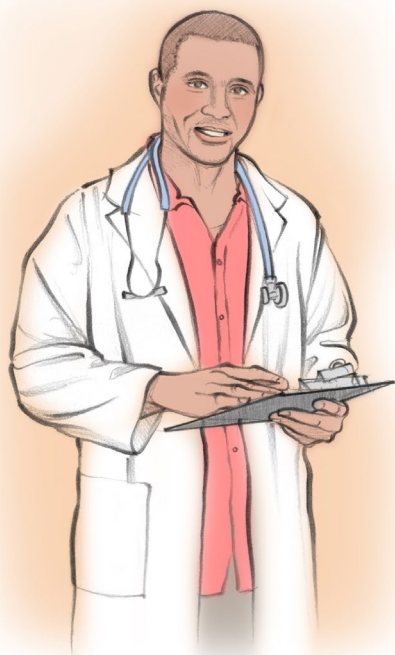


Stem cells

Some people with **leukaemia** have **stem cell** therapy to help them get better as part of their treatment pathway.

Stem cells are given through a drip into your central line. They help your **bone marrow** work again and make new blood **cells**. It needs help with this after strong chemotherapy.





Side effects

Before you start your treatment, the doctor or nurse will tell you what to expect.

They will tell you how to look after yourself and help you with any **side effects**.

Most **side effects** only last a short time.

Other **side effects** might start a long time after you finish your treatment. These are called **late effects**.

Research and trials

Research is the way doctors get answers to questions about diseases and treatments.

Trials are ways to test treatments.

Not all hospitals do trials but you can ask your doctor about this.

You do not have to take part in a **trial**. If you do take part, you can change your mind and stop if you want to.





What happens after the treatment?

When your treatment ends

Doctors can treat **leukaemia** well but it can take you some time to get over the treatment.

Some people feel tired for many months and catch more colds or other infections.

Your doctors and nurses will tell you what to expect.

Remember to ask them if you are worried about **side effects** or health problems after treatment.

It is important to stop smoking, eat well and look after yourself.

You should go for any health checks your doctor offers you.

Check-ups



At first you will probably go back to the hospital every week.

If you stay well you will then go every six to 12 months.

These checks are to look out for any return of your **leukaemia** and to make sure you are getting better.

The doctor will ask how you feel and perhaps do blood tests.

If you stay well after two to five years, your doctor might say that you don't need to come to the hospital anymore.

Some people have a type of **leukaemia** that comes and goes. If you have this type, your doctor will ask you to keep coming for regular checks. You will have to go back to hospital for more treatment from time to time.



If the Leukaemia comes back

You might feel worried if your **leukaemia** comes back (this is called a relapse) but the **leukaemia** can usually be treated again.



Where to get help and support



It can be frightening to find you have **leukaemia** and have to go for tests and treatment.

The changes will also affect your family and friends.

Everyone copes in different ways but it can help to talk to other people about how you feel.

This might be your family, people at the hospital or others who are trained to do this.

There are lots of organisations that can help.

How we can help

Help line: **08088 010 444**

This phone number is free to ring.

Weekdays 9:00am - 5:00pm. On Thursdays and Fridays, it is also open from 7:00pm - 10:00pm.

You, your family or friends can phone us to talk about **leukaemia** or how you are feeling.



Buddy support

Our one-to-one buddy support is available for patients to chat to a trained volunteer, someone who knows what you are going through.

bit.ly/BuddySupportService

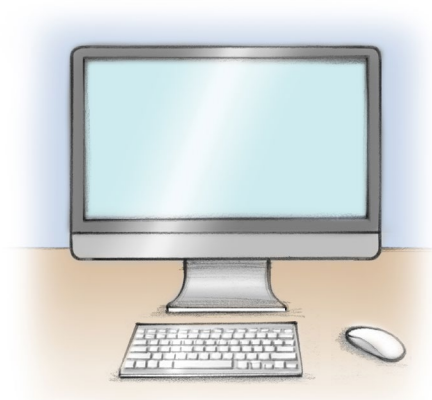




Support groups

Our blood cancer support groups provide help and support to patients, carers and their families from all over the UK.

bit.ly/LCSupportGroups



Website

Here you can find more information about what you have been told.

www.leukaemiacare.org.uk

Leukaemia Matters magazine

Our popular quarterly magazine is packed full of useful information and patient stories, as well as updates from Leukaemia Care.

You can read previous editions of the magazine at: **bit.ly/LeukaemiaMatters**

Or you can subscribe to receive a copy at: **bit.ly/LCCommunicationPreferences**

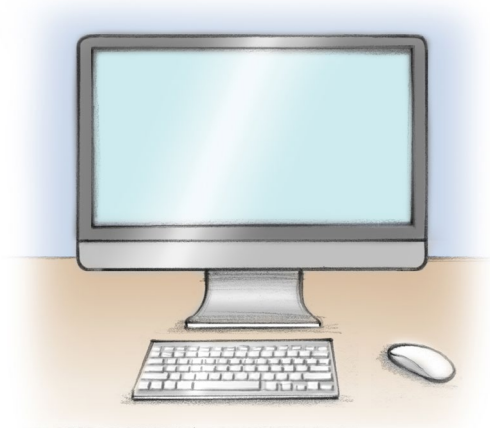


Free information

Our office line: **01905 755977**

Or email: **support@leukaemiacare.org.uk**

Open Monday to Friday 8:30am – 5:00pm.



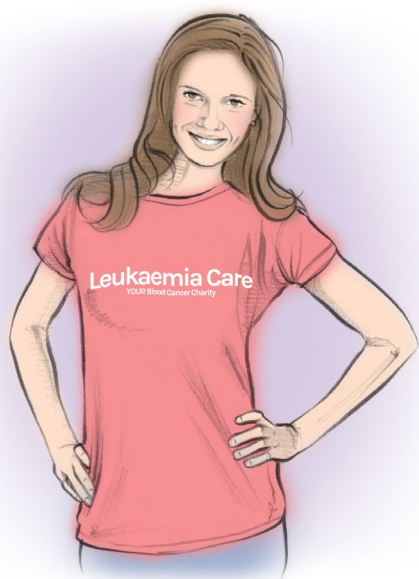
How you can help us

Please tell us what you think about this booklet.

It will help us write better information about people with **leukaemia**.

You can email **communications@leukaemiacare.org.uk** or use our other contact details.

You can find them on the next page.



How to contact us

Website: www.leukaemiacare.org.uk

Freephone helpline: **08088 010 444**

Office line: **01905 755977**

Email: info@leukaemiacare.org.uk

Write to:

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

What the words mean

Antibodies

A large protein made by the immune system to destroy germs such as bacteria or viruses which enter the body.

Bone marrow

Soft blood-forming tissue that fills the cavities of bones. It contains fat, immature and mature blood cells, including white blood cells, red blood cells and platelets.

Cancer

A disease where cells in a specific part of the body grow and reproduce uncontrollably. The cancerous cells can invade and destroy surrounding healthy tissue, including organs.

Cells

This is what most living things are made of.

Granulocytes

A type of white blood cell that fights infection and illness.

Growth factors

This is something that encourages cells to get larger and multiply.

Haematologist

This is a doctor who looks at blood disorders or organs that make blood.

Haematology

This is the study of medicine and treatment to do with blood.

Haemopoiesis

The process by which blood cells are formed.

Hickman line

Hickman® line is the brand name for a central venous line which is a long, thin, hollow tube that is inserted into a vein in your chest. It is used to give chemotherapy treatment and other drugs.

Late effects

These are a type of side effect that can start many years after treatment has ended.

Leukaemia

A group of cancers that usually begin in the bone marrow and result in high numbers of abnormal blood cells. These cells are not fully developed and are called blasts or leukaemia cells. Depending on the type of blood cell involved, there are different types of leukaemia.

Lymphocytes

A type of white blood cell that are vitally important to the immune response. There are three types of lymphocytes: B-cells, T-cells and natural killer cells.

Side effects

Unwanted symptoms caused by some medical treatment.

Stem cells

Most basic cells in the body that have the ability to develop into any of the body's specialised cell types, from muscle cells to brain cells.

Staging

Staging in terms of cancer is a rating process to determine the extent of a cancer in the body and where it is located.

Trials

Trials are the way doctors get answers to questions about diseases and treatments.

Printed: 09/2019

Review date: 09/2022

Thank you to our former nurse Shirley Aston for writing this booklet and our Patient Information Writer Isabelle Leach for updating it.

We are also grateful to Robert Marcus for peer reviewing and Juliet Percival for drawing the illustrations as well as Thea Wilson, Gary Hunter, Lin Addy and Helen Laude for providing their valuable comments as patient reviewers.

Leukaemia Care is a national charity dedicated to providing information, advice and support to anyone affected by a blood cancer.

Around 9,900 new cases of leukaemia 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

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Leukaemia Care is registered as a charity in England and Wales (no.1183890) and Scotland (no. SC049802).
Company number: 11911752 (England and Wales).
Registered office address: One Birch Court, Blackpole East, Worcester, WR3 8SG

Leukaemia Care
YOUR Blood Cancer Charity