All about Leukaemia
An Easy Read Document
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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.

The booklet explains:

- what leukaemia is
- what tests you might have
- the different treatments you might get

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 33.

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

The production of blood cells works like a factory.

This process is called Haemopoeisis.
Lymphocytes

This is a white blood cell.

There are three types of lymphocytes:

1. B lymphocytes that make antibodies to fight infection

2. T lymphocytes that help B lymphocytes

3. Natural killer cells that attack cancer cells and viruses

Granulocytes or neutrophils

This is also a type of white blood cell. It helps to fight infection and illness.
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 your normal cells 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**

2. **Acute Lymphoblastic Leukaemia (ALL)** - patients with this produce too many **lymphoblasts**

3. **Chronic Myeloid Leukaemia (CML)** - patients with this produce too many granulocytes and other myeloid **cells**

4. **Chronic Lymphocytic Leukaemia (CLL)** - patients with this produce too many **lymphocytes**
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.
Different types of Leukaemia

Acute Leukaemia

The two main types of acute leukaemia are called Acute Myeloid and Acute Lymphoblastic.

Acute Myeloid (AML)

You can get this at any age. It most likely happens to people over the age of 60. It is uncommon to get this before the age of 45 years.

Acute Lymphoblastic (ALL)

This is much more common than acute myeloid leukaemia in adults. It mostly happens to people who are aged over 55 years old or children.
Chronic leukaemia

The three main types of chronic leukaemia are called Chronic Myeloid, Chronic Lymphocytic and Hairy Cell.

Chronic Myeloid (CML)

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

Chronic Lymphocytic (CLL)

This is also a slow progressing form of leukaemia. It is most common in older people and affects males more than females.

Hairy Cell (HCL)

This is a very rare form of cancer. This usually affects older people or men.
Things that might mean you have Leukaemia

Some people notice changes in their body because of leukaemia.

Other people only find out when doctors test them for something else.

For many patients with CLL, for example, they have no symptoms until the time they are diagnosed.
Symptoms:

There might be symptoms like:

- Infection that won’t go away
- Losing weight for no reason
- Feeling extra tired
- Bleeding and bruising
- Bleeding gums
- Fine red rash (Purpura)
- A cough or trouble breathing
- High temperature
- Bad stomach pain
- Abdominal discomfort (enlarged spleen)
- Swollen glands
- Paleness
- Weight loss
Tests for Leukaemia

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

This doctor is called a **Haematologist** if they treat blood diseases or **cancers**.

**Blood tests**

You will have blood tests to see how many healthy 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 a soft part in the middle of some bones. It is where blood cells are made.

The doctor might want to see if there is leukaemia in there.

They will use a special needle 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 they do this:

- 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 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 if you take any medicines.
What does the ‘stage’ mean?

This is based on your disease type. Staging is not used for patients with AML, ALL or CML.

But, there are a number of things that can affect its seriousness:

- The height of the white cell count
- Age
- Prior history of blood disorder
- Chromosome mutations/abnormalities
- Bone damage

CLL is the only form of leukaemia where staging is used. There is the Rai system or Binet system.

The Rai system has five stages, from I to IV, with IV being the most advanced.

The Binet system runs from A to C, with C being the most advanced.
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 a 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 will visit for treatment
- when to start your treatment. For acute patients, treatment starts immediately
- the types of treatment you will have
- where you will have the treatment
- whether the treatment will have any side effects
- how long treatment will last
- how you feel about the treatment
You will get a lot of information.

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

You can talk to a specialist Haematology nurse if you are worried or want to ask questions.
Different types of treatment

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

**Acute leukaemia patients**

Most people go into hospital immediately after diagnosis.

**Chronic leukaemia patients**

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

Some people with a 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. They will start treatment if you have large lymph glands, the normal cells disappear from the blood or the leukaemia is making you ill.

Chemotherapy

This is a mixture of drugs that will kill the cancer blood cells.

Your treatment will last for 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.
Hickman Line
Known as a central line or Groshong line, this is placed into a vein in your chest after the area is made numb.

PICC Line
This is a long, thin tube 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.

Antibodies
Our body makes antibodies to help us fight infections.

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 shower
This helps to keep the 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.

Diet

Watching what you eat can help your emotions and play an important role in helping you recover after treatment. To work out a plan that works best for you, you should talk to your hospital doctor or dietician.

Medications

There are a number of different medications that you can be put on 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 are put on depends on:

- what type of leukaemia you have
- any side effects that you may get
- 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.
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 cancer 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 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 hospital any more.

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 you.
How we can help

Help line: **08088 010 444**

This phone number is free to ring.

Weekdays 9.00am - 10.00pm and Saturdays 9.00am - 12.30pm

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 exactly what they are going through.

[www.leukaemiacare.org.uk/one-to-one-buddy-support](http://www.leukaemiacare.org.uk/one-to-one-buddy-support)

**Support groups**

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

[www.leukaemiacare.org.uk/support-groups](http://www.leukaemiacare.org.uk/support-groups)

**Website**

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

[www.leukaemiacare.org.uk](http://www.leukaemiacare.org.uk)
Journey magazine

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

www.leukaemiacare.org.uk/journey-magazine

Free information

Our office line on: 01905 577977

Or email: care@leukaemiacare.org.uk

Open Monday to Friday 9am – 5:30pm
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: info@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 help line: 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
These are a type of protein that can be used as a treatment for Leukaemia.

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

Cancer
A disease that cause unhealthy cells to grow in your body

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.
Haemopoeisis

The production of blood cells.

Hickman line

Sometimes called a central line, this drip is placed into the vein in the centre of your chest.

Late effects

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

Leukaemia

This is a cancer that effects the white blood cells.

Lymphocytes

There are three types of this white blood cell: B lymphocytes, T lymphocytes and natural killer cells.

Side effects

This is something that happens because of the treatment you are having.

Stem cells

These are very basic cells that can grow into different kinds of blood cells to do different jobs in the body.
Staging

This is how doctors label how serious the cancer is.

Trials

This is how treatments are tested.

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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
care@leukaemiacare.org.uk

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