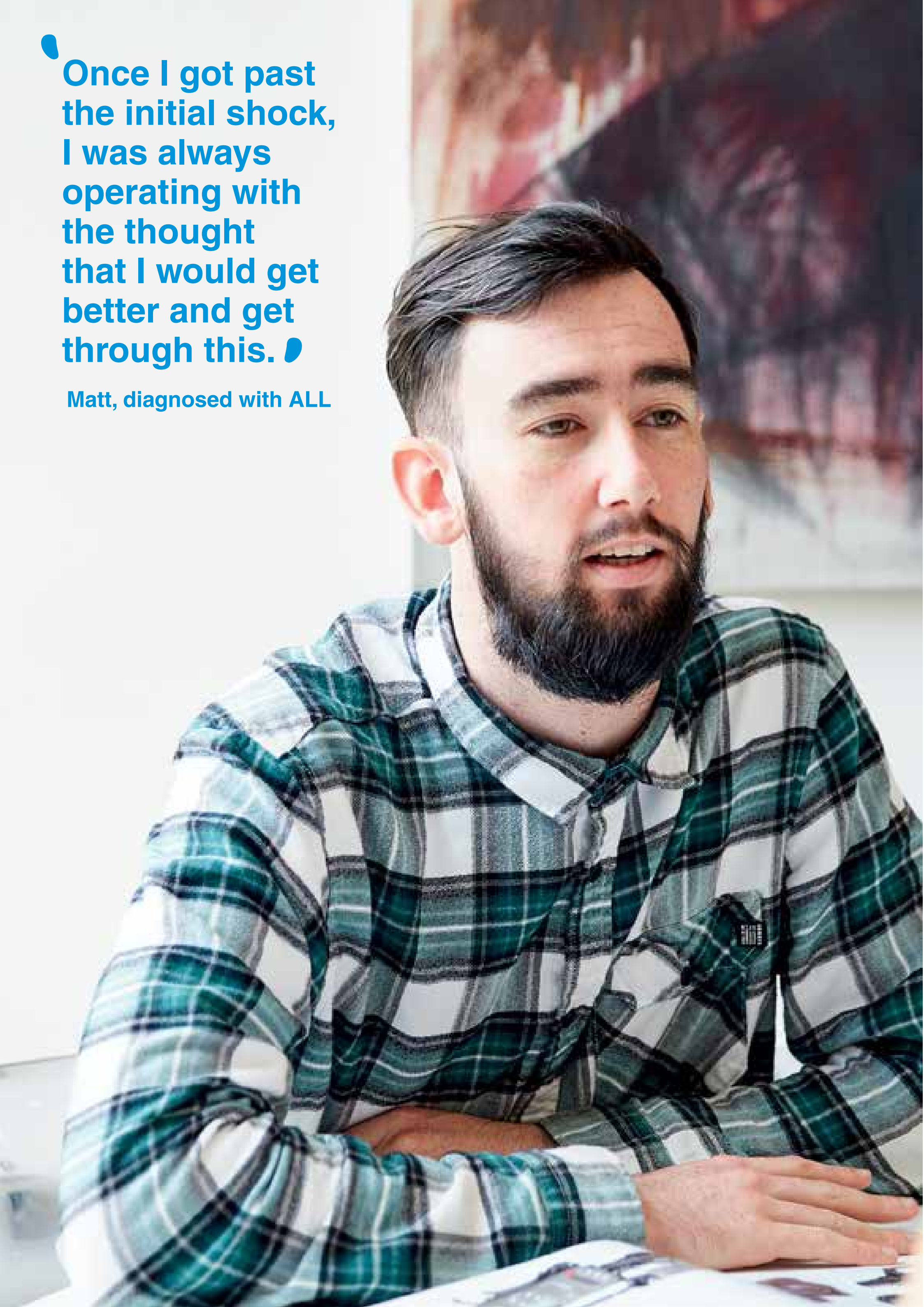
MACMILLAN
CANCER SUPPORT

UNDERSTANDING ACUTE LYMPHOBLASTIC LEUKAEMIA (ALL)



> Once I got past the initial shock, I was always operating with the thought that I would get better and get through this.

Matt, diagnosed with ALL

About this booklet

This booklet is about acute lymphoblastic leukaemia (ALL). It is for anyone who has been diagnosed with ALL. There is also information for carers, family members and friends.

The booklet explains what ALL is, and how it is diagnosed and treated. It also has information about coping with ALL and the different feelings you may have.

We hope it helps you deal with some of the questions or feelings you may have.

We cannot give advice about the best treatment for you. You should talk to your doctor, who knows your medical history.

How to use this booklet

This booklet is split into sections to help you find what you need. You do not have to read it from start to finish. You can use the contents list on page 3 to help you.

It is fine to skip parts of the booklet. You can always come back to them when you feel ready.

On pages 107 to 115, there are details of other organisations that can help.

Quotes

In this booklet, we have included quotes from people who have had ALL, which you may find helpful. These are from people who have chosen to share their story with us. This includes Matt, who is on the cover of this booklet. To share your experience, visit **macmillan.org.uk/shareyourstory**

For more information

If you have more questions or would like to talk to someone, call the Macmillan Support Line free on **0808 808 00 00**, 7 days a week, 8am to 8pm, or visit **macmillan.org.uk**

If you would prefer to speak to us in another language, interpreters are available. Please tell us, in English, the language you want to use.

If you are deaf or hard of hearing, call us using NGT (Text Relay) on **18001 0808 808 00 00**, or use the NGT Lite app.

We have some information in different languages and formats, including audio, eBooks, easy read, Braille, large print and translations. To order these, visit **macmillan.org.uk/otherformats** or call **0808 808 00 00**.

Help us improve our information. Scan the QR code below to tell us what you think.

Contents

THE BLOOD AND ALL

What is leukaemia?

Leukaemia is a cancer of the blood cells.

If you have leukaemia, your body makes some abnormal blood cells. These leukaemia cells behave differently from healthy blood cells.

There are different types of leukaemia.

This information is about acute lymphoblastic leukaemia (ALL). It is sometimes called acute lymphocytic leukaemia. Acute means that it develops quickly and needs to be treated straight away.

To help you understand ALL and its treatment, it is useful to know how blood cells are made and what they do (see pages 7 to 9).

The blood

Blood is made up of blood cells, which move around the body in a liquid called plasma.

Blood cells are made in the bone marrow. This is a spongy material found inside the bones. Some bones, such as the pelvis and backbone (spine), contain a type of bone marrow that makes blood cells.

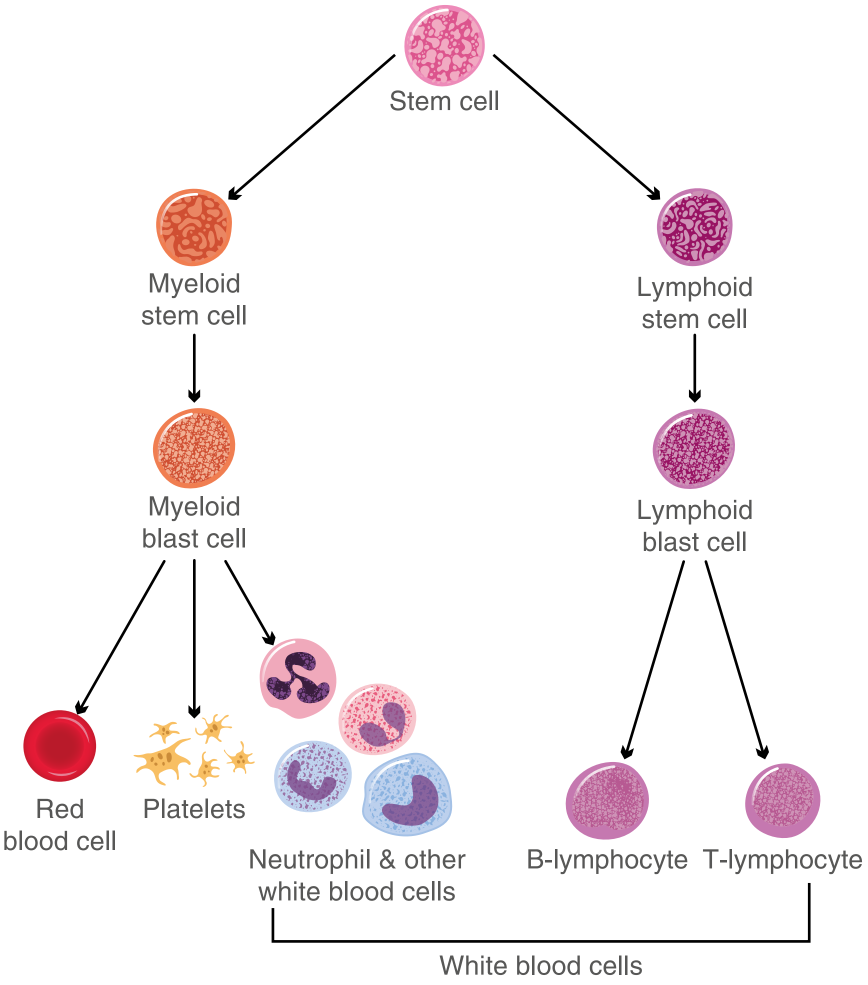
Normally, your bone marrow makes millions of new blood cells every day to replace ones that are old or damaged. This keeps the numbers of each type of blood cell at the right level so your body can work properly.

Every blood cell grows from a stem cell in the bone marrow. There are 2 types of blood stem cell:

- lymphoid stem cells, which make a type of white blood cell called lymphocytes
- myeloid stem cells, which make red blood cells, platelets and all other types of white blood cell.

Lymphoid stem cells are the cells that ALL affects.

How blood cells divide



The stem cell divides to make an early stage of the blood cell called a blast. Blast cells are young and not fully developed. They cannot do the job of a normal cell. Usually, they stay in the bone marrow until they are fully developed.

When a cell is ready, it moves from the bone marrow into the blood to do different jobs:

- White blood cells help fight and prevent infection. There are several types of white blood cell. The 2 most important are neutrophils that fight bacteria and lymphocytes that fight viruses.
- Red blood cells contain haemoglobin (Hb). This carries oxygen from your lungs to all the cells in your body.
- Platelets are very small cells that help blood to clot. They prevent bleeding and bruising.

Measuring your full blood count

The levels of these cells in your blood can be measured with a blood test called a full blood count (FBC). The table is a guide to the levels usually found in a healthy person.

Type of cell	Levels found in a healthy person
Red blood cells – measured in haemoglobin (Hb) levels in red blood cells	130 – 180g/l (men) 115 – 165g/l (women)
Platelets	150 – 400 x 10^9/l
White blood cells (WBC)	4.0 – 11.0 x 10^9/l
Neutrophils	2.0 – 7.5 x 10^9/l
Lymphocytes	1.5 – 4.5 x 10^9/l

These numbers can vary depending on:

- your age
- your sex
- your ethnic background.

Because of this, your hospital may use slightly different levels to the table. Your doctor or nurse can explain what levels they use.

The numbers may look complicated, but doctors and nurses use them in a simple way. For example, they may say ‘your haemoglobin is 140’ or ‘your neutrophils are 4’. You can ask your healthcare team to explain in more detail.

Most people with leukaemia soon get used to these numbers and what they mean.

Acute lymphoblastic leukaemia (ALL)

Acute lymphoblastic leukaemia (ALL) is a cancer that affects lymphocytes. Lymphocytes are a type of white blood cell. There are 2 main types of lymphocytes:

- B lymphocytes, or B cells
- T lymphocytes, or T cells.

Normally, lymphoid stem cells make blasts that develop into healthy B or T cells. Blasts are young, not fully developed blood cells.

But in ALL, some blasts are abnormal and do not develop fully. These abnormal blasts are called leukaemia cells. They cannot fight infection like normal lymphocytes. They also fill up the bone marrow. So, there is not enough space to make all the healthy white blood cells, red blood cells and platelets your body needs.

ALL is rare. Around 800 people in the UK are diagnosed with ALL each year. It can develop at any age. But it is more common in children, especially under 4, and in young people. It affects more men than women.

Types of ALL

The most common type of ALL is where the B cell lymphocytes are affected. This is called B-lymphoblastic leukaemia or B cell leukaemia.

If the T cells are affected, it is called T-lymphoblastic leukaemia or T cell leukaemia.

Your doctors will do tests to find out more about the leukaemia cells. This includes information about:

- other genetic changes inside the leukaemia cells
- proteins on the surface of the leukaemia cells.

The results can affect the type of drug treatment you have.

Philadelphia positive ALL

Some people with B cell leukaemia have a subtype called Philadelphia positive ALL (Ph+ ALL). This means tests have found a gene change inside leukaemia cells called the Philadelphia chromosome. This change only affects leukaemia cells. It is not inherited and cannot be passed on to your children.

If you have Ph+ ALL, your treatment will include a drug called a tyrosine kinase inhibitor (see pages 61 to 62). It targets the abnormal protein the gene change makes.

Causes and risk factors

Doctors do not know the exact cause of ALL. But research is going on all the time to find out more about it. Some people may have a change in a gene that makes them more likely to develop ALL. More research is needed to understand this.

There are certain risk factors that may increase the risk of developing ALL. Having one or more risk factors does not mean you will get ALL. People with no known risk factors can still develop it.

Genetic conditions

ALL does not run in families (it is not inherited) so other people in your family are not at increased risk of getting it.

People with certain genetic conditions have a higher risk of developing ALL. These include Down's syndrome, Fanconi's anaemia, Bloom's syndrome and ataxia-telangiectasia.

High levels of radiation

Being exposed to very high radiation levels increases the risk of developing ALL. For example, you may have been exposed to high radiation levels after a nuclear accident. In the UK, it is very unlikely anyone would be exposed to radiation levels high enough to increase their risk.

In certain parts of the UK, a natural gas called radon can pass from the soil into the foundations of buildings. Exposure to high levels of radon is not common. It is not a risk factor for ALL.

Previous chemotherapy

Having had certain types of chemotherapy in the past may increase the risk of ALL.

Symptoms of ALL

Most symptoms of acute leukaemia are caused by leukaemia cells filling the bone marrow (see page 11). This means healthy blood cells do not move into the blood as normal. The symptoms may come on suddenly over a few weeks.

Low numbers of red blood cells (anaemia)

A low number of red blood cells is called anaemia. If you have anaemia, you might:

- look pale
- feel very tired
- feel short of breath
- feel dizzy or light-headed
- have palpitations (feel your heart is beating quickly).

Low numbers of white blood cells

If you have too few healthy white blood cells, you might:

- keep getting infections
- feel unwell and run down
- have a sore throat or mouth
- have a fever or high temperature.

Low numbers of platelets

This can cause unusual bleeding such as:

- bruising without any obvious cause
- bleeding gums
- nosebleeds
- blood spots or rashes on the skin (petechiae)
- heavy periods.

Other symptoms

Other symptoms may include:

- a fever and sweats
- swollen lymph nodes – this is a common symptom
- unexplained weight loss
- bone pain
- swelling in the liver or spleen, causing a swollen or uncomfortable tummy.

Some people have no symptoms and leukaemia is found after a routine blood test. More often, symptoms appear over a few weeks and people usually feel ill quite quickly.

If you have any of these symptoms, you should always see your GP and have them checked. But remember, these symptoms can also be caused by other conditions that are not cancer.

> ‘I was getting very tired all the time, but I was working 2 jobs and riding my BMX in all my free time. Then I started getting pinpoint bruises on my feet and legs and things looked a bit strange. I thought maybe I should get them looked at.’

Matt

DIAGNOSING ALL

How ALL is diagnosed

Some people are diagnosed with ALL after being taken to hospital with symptoms (see page 15 to 16) that have developed quickly. Others go to see their GP about symptoms.

Your GP will examine you and arrange a blood test. If the result of the test is abnormal, your GP or a haematologist from the local hospital will contact you. A haematologist is a doctor who specialises in treating blood problems. They will arrange for you to be seen quickly at the hospital for further tests and possible treatment.

If you think you may be pregnant, let your doctor know. Some tests and treatments for leukaemia can be harmful to an unborn baby. If you are pregnant, you can usually still have tests and some treatments for leukaemia. But it is important to talk to your doctor so they can plan your care safely.

At the hospital

The haematologist will ask you about your general health and any medical problems you have had. They will examine you and do a blood test to:

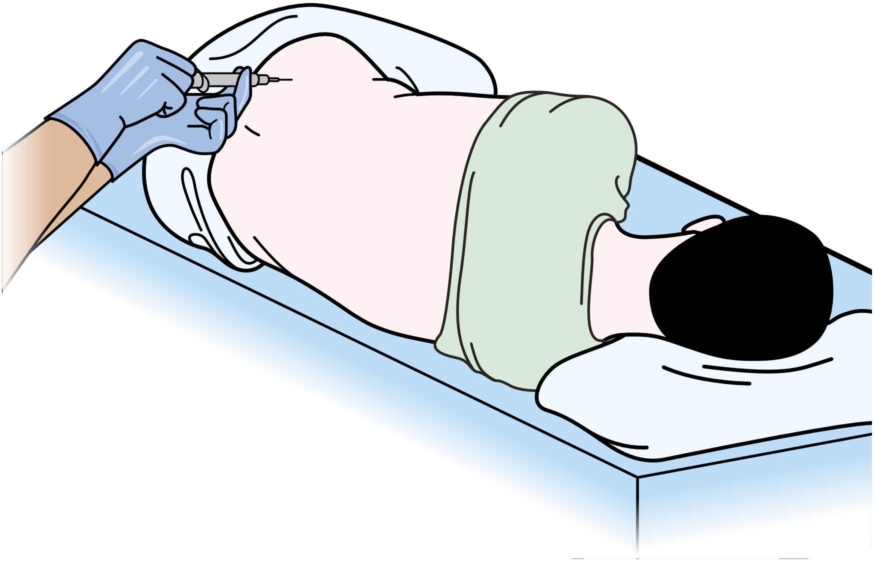
- check the numbers of the different types of blood cells in your blood – called a full blood count (FBC) – see page 10
- look for leukaemia cells.

If the haematologist thinks you might have leukaemia, they will arrange to take a sample of your bone marrow. You will usually see a specialist haematology nurse who will give you information and support.

Bone marrow biopsy

A doctor or nurse takes a small sample of bone marrow from the back of the hip bone (pelvis). The sample is sent to a laboratory to be checked for abnormal cells.

Bone marrow biopsy



You may have this test on a ward or in an outpatient clinic. It takes about 20 to 30 minutes.

Before the bone marrow sample is taken, you have local anaesthetic injections around the area to numb it. You can ask for medicine to help you relax. Or you may have gas and air (Entonox®) to breathe in through a mouthpiece or mask. This helps reduce any discomfort during the test.

The doctor or nurse passes a needle through the skin into the bone. They then draw a small sample of liquid from inside the bone marrow into a syringe. This is called a bone marrow aspirate. It can feel uncomfortable for a few seconds when the marrow is being taken.

They may also take a small sample of the spongy bone marrow tissue. This is called a trephine biopsy. To do this, the doctor or nurse passes a thicker hollow needle through the skin into the bone marrow. When they take the needle out, it contains a small piece of bone marrow tissue.

You may feel bruised or sore for a few days after this test. Mild painkillers can help. If the pain gets worse, or you notice any bleeding from the area, tell your doctor.

Testing blood and bone marrow samples

Your blood and bone marrow samples are looked at under a microscope in the laboratory. Then you have tests to find out more about any abnormal cells. Tests may include the following.

Immunophenotyping

This looks for specific proteins on the surface of leukaemia cells. It helps identify the type of leukaemia and the type of blood cell (B or T cell) that has become abnormal (see page 11).

This test can also be used to look for very small numbers of leukaemia cells during, and at the end of, treatment.

Cytogenetics and molecular tests

These tests look for gene changes (mutations) inside the leukaemia cells, including the Philadelphia chromosome (Ph+ ALL) – see page 12. Tests may include:

- G-banding – the genetic material from a leukaemia cell is coloured using a dye that stains the chromosomes. The chromosomes are then examined using a special microscope.
- FISH (fluorescence in situ hybridisation) – this test looks for specific gene changes that may not be seen with G-banding. FISH looks at about 200 cells.
- PCR (polymerase chain reaction) – this is a very sensitive test that looks for specific gene changes that cannot be seen under a microscope. It looks at a million or more cells. This test can also be used to look for very small amounts of leukaemia during, and at the end of, treatment.

Your test results

Your doctor or nurse can explain which tests will be useful for you. The results give your hospital team more information about the exact type of ALL you have and help them plan the best treatment for you.

You may get some test results within a few hours. But it will probably be several days before all your results are ready. This can be an anxious time. It may help to talk to a family member, a close friend or your specialist nurse. Or you can talk to one of our cancer support specialists on **0808 808 00 00** (7 days a week, 8am to 8pm).

After diagnosis

Checking your general health

Your doctor will also arrange for you to have tests to check your general health. This will include blood tests for infections such as HIV and hepatitis. You may also have:

- x-rays to check your lungs and heart
- other heart tests such as an ECG (echocardiogram)
- more blood tests to check how your liver and kidneys are working.

Your doctor or nurse can give you more information about any tests you need. The results help them plan your treatment safely.

Tissue (HLA) typing

You will have this blood test if you might need a donor stem cell transplant (see pages 59 to 60) as part of your treatment. Your healthcare team use information about your tissue type to find a possible stem cell donor for you.

Your tissue type is made up of different proteins on the surface of your cells. These are called human leukocyte antigen (HLA) markers. Doctors use your HLA markers to match you with a donor. They compare your tissue type with close relatives, or with volunteer unrelated donors on a registry. Doctors look for the best matched donor available for you.

Lumbar puncture

A lumbar puncture is a test that checks for leukaemia cells in the fluid around the brain and spinal cord. Together, the brain and spinal cord are called the central nervous system (CNS). The fluid is called cerebrospinal fluid (CSF).

You usually have a lumbar puncture test done on the ward or in the day unit. The doctor numbs the area of skin over the lower spine with a local anaesthetic injection. They then feel for a space between 2 bones (vertebrae) in the lower spine and put in a thin needle. They collect a sample of CSF and send it to the laboratory for tests.

After the lumbar puncture, the doctor takes the needle out and puts a small dressing over the skin.

Most people do not have any problems with this test, although it may cause tingling down the back of your legs when the needle is put in. This is normal and does not cause any damage, but it can be worrying if you are not expecting it. Some people have a headache afterwards. It can help to drink plenty of water before and after the test and to lie down for at least 30 minutes afterwards. You can ask your nurse for some mild painkillers.

Your data and the cancer registry

When you are diagnosed with cancer in the UK, some information about you, your cancer diagnosis and your treatment is collected in a cancer registry. This is used to plan and improve health and care services. Your hospital will usually give this information to the registry automatically. There are strict rules to make sure the information is kept safely and securely. It will only be used for your direct care or for health and social care planning and research.

Talk to your doctor or nurse if you have any questions. If you do not want your information included in the registry, you can contact the cancer registry in your country to opt out.

> **‘You don’t expect to get ill when you’re young.’**
>
> **Matt**


ST. GEORGE'S
SIMULATION
TEAM
HOSPITAL

TREATING ALL

Treatment overview

Treatment for ALL starts as soon as possible after diagnosis. It usually lasts for up to 2 years. Your treatment plan will depend on:

- the type of ALL you have (see page 12)
- whether there are gene changes (mutations) in the leukaemia cells
- whether the leukaemia cells produce certain proteins
- your general health.

If there is a suitable clinical trial available, your doctor will talk with you about it (see page 67). If not, you have the standard treatment. The standard treatment is based on the latest clinical trial results for ALL in the UK.

The aim of treatment is to get rid of the leukaemia cells as quickly as possible, so your bone marrow can work normally again. This is called remission.

You may have different treatments, such as:

- chemotherapy, which is the main treatment (see pages 45 to 55)
- steroids which you have with chemotherapy (see pages 57 to 58)
- a stem cell transplant using stem cells from someone else (a donor) – this is done to reduce the risk of ALL coming back, or if ALL comes back (see pages 59 to 60)
- targeted therapy using drugs such as imatinib, if you have Philadelphia positive ALL (Ph+ ALL) – see pages 61 to 64.
- immunotherapy drugs, such as rituximab (see pages 61 to 64).

If you have other health problems, your doctor may advise having less intensive treatment. This has a lower risk of serious side effects. The aim of this treatment is to control the leukaemia for as long as possible.

Phases of treatment

Treatment is usually given in 3 phases:

- induction treatment (see page 46), to get rid of the leukaemia cells in your blood and bone marrow (remission)
- consolidation (or intensification) treatment (see page 47), to get rid of any remaining leukaemia cells in areas such as the brain or spinal cord
- maintenance treatment (see page 48), to reduce the risk of leukaemia coming back.

You have some treatment as an inpatient in hospital, usually during induction. You may have to stay in hospital for a few weeks at a time. This may be longer depending on your side effects. If you have a stem cell transplant, you will need to stay in hospital for several weeks.

You usually have maintenance treatment as tablets. You take these at home. This is the longest phase of your treatment.

Your doctor and nurse will talk to you about your treatment plan and what to expect.

Having tests during treatment

During treatment, your doctors and nurses will take blood, bone marrow and lumbar puncture samples to check for leukaemia cells. The results of these tests help doctors:

- find out how well your treatment is working
- see whether the leukaemia is more likely to come back
- decide what treatment you may need next to give you the best chance of a cure.

If your tests show very small numbers of leukaemia cells, or none, the doctor will say you are in remission.

Sometimes very small numbers of leukaemia cells are still found after chemotherapy. This is called minimal residual disease (MRD) – see page 47. This can affect the treatment you need to have.

If ALL comes back

If ALL comes back after treatment, it may be possible to have more treatment with chemotherapy, targeted or immunotherapy drugs, or CAR-T cell therapy (see page 64). The aim is to get a second remission. Some people go on to have a stem cell transplant when they are in remission again.

Supportive care

Leukaemia and its treatment cause side effects, such as low levels of blood cells. These side effects can be serious. Your doctor will monitor them and give you supportive treatment to prevent or manage them. This may include having:

- red blood cells or platelets given into a vein
- drugs to prevent infections
- drugs to prevent or manage side effects of treatment.

Sometimes treatment does not get rid of the leukaemia or cannot control it any longer. If this happens, you will have supportive or palliative care to help control any symptoms.

We have more information about palliative care in our booklet **Coping with advanced cancer** (see page 102).

Planning your treatment

Your treatment will be planned by a team of specialists. This team is called the multidisciplinary team (MDT). It usually includes:

- haematologists – doctors who treat and diagnose leukaemias and blood disorders
- specialist haematology nurses – nurses who give information about leukaemia, and support during treatment
- a transplant coordinator – someone who arranges and manages stem cell or bone marrow transplants (see pages 59 to 60)
- radiologists – doctors who look at scans and x-rays to diagnose problems
- pharmacists – experts who give out medicines and give advice about taking medicines.

The team may also include other healthcare staff, such as social workers, dietitians, counsellors and psychologists.

During your treatment, someone from the MDT will be your main contact. This is usually a specialist haematology nurse. This is who we mean when we mention specialist nurse in this information. They will give you their contact details. If you have questions or need advice about your treatment, they will be able to help.

Talking about treatment decisions

Before you have any treatment, your doctor will explain its aims. They will usually ask you to sign a form saying that you give permission (consent) for the hospital staff to give you the treatment (see page 38). No medical treatment can be given without your consent. Before you are asked to sign the form, you should be given full information about:

- the type and extent of the treatment
- its benefits and disadvantages
- any significant risks or side effects
- any other treatments that may be available.

If you do not understand what you have been told, tell the staff straight away. Leukaemia treatments are complex, so it is common to need to go over it again. It is a good idea to have a family member or friend with you to help you remember the discussion.

You will usually be given written information about your treatment, including a treatment schedule.

Making treatment decisions

Treatment for ALL usually has to start quickly. If you do not feel ready to make a decision about your treatment, ask your doctor how long you can have to think about it.

Without treatment, ALL is life-threatening. You may decide not to have treatment even when your doctor advises you to have it.

If you refuse treatment, your decision must be respected. But your doctor needs to make sure you have all the information you need to make your decision. You need to understand all your treatment options and what will happen if you do not have the treatment. Always talk to your doctor about any concerns you have, so they can give you the best advice.

Benefits and disadvantages of treatment

Treatment for leukaemia has possible benefits but also possible risks. You may want to think carefully about these before you decide about your treatment plan.

Treatment that aims to cure the leukaemia may involve some disadvantages such as:

- longer stays in hospital – usually for several weeks at a time
- short-term side effects that may need treatment
- a risk of permanent side effects such as infertility (see page 42).

Many people decide to have this treatment because the chance of curing the leukaemia outweighs these disadvantages. But there is still a risk the leukaemia may not be cured.

Some people will have treatment that aims to control the leukaemia rather than cure it. This means lower doses of chemotherapy and a lower risk of side effects. It may also mean less time in hospital. This means it may be more suitable for people who:

- are not fit enough to cope with more intensive treatment
- do not want the risks of more intensive treatment.

But with this treatment, the leukaemia is less likely to go into remission or stay in remission (see page 30 to 32).

It can help to talk to your family or friends about your treatment options. You and your doctor can decide together on the best treatment plan for you. Your doctor is an expert in the best treatments. But you know your preferences and what is important to you.

Giving your permission (consent)

Doctors need your permission (consent) before you have any treatment. They will give you all the information you need to make your decision. We explain this in our section on talking about your treatment decisions (see pages 35 to 37).

You can give consent in writing when you sign a form that your doctor gives you, agreeing to a treatment. Or it can be a spoken (verbal) agreement with your doctor. Your doctor records your consent in your patient notes.

You may decide not to have treatment even when your doctor advises you to have it. If you refuse treatment, your decision must be respected. But your doctor needs to make sure you have all the information you need to make your decision.

You need to understand all your treatment options and what will happen if you do not have the treatment. Always talk to your doctor about any concerns you have, so they can give you the best advice.

Second opinion

A second opinion is an opinion from a different doctor about your treatment. It can take some time to arrange, and treatment for ALL usually needs to be started as soon as possible.

If you think you want a second opinion, talk to your specialist doctor or GP first. Tell them your concerns or ask them to explain anything you do not understand. This might help reassure you.

If you still want a second opinion, you can ask your specialist doctor or GP to arrange it. They are usually happy to do this. You may have to travel to another hospital to get a second opinion. Getting a second opinion could delay your treatment. Check with your doctor if this delay could be harmful to you.

If the doctor you see for the second opinion gives you the same advice, this can reassure you. Sometimes they give you other treatment options to think about.

We have more information about getting a second opinion on our website. Visit **macmillan.org.uk**

Before starting treatment

After you have had your tests and are diagnosed with ALL, your doctors will want to start treatment straight away. Your doctor or specialist nurse will talk to you about what to expect. You may have questions you want to ask them or concerns you want to talk over. It is important to talk about these with your hospital team.

Where treatment is given

You usually have your treatment in a hospital that offers specialist treatments such as chemotherapy and stem cell transplants. These are usually larger hospitals, so you may have to travel for your treatment and appointments.

If you are a teenager or young adult

Some hospitals have cancer units for teenagers and young adults (TYAs). These are sometimes called TYA units. Not every hospital has these, but you may be offered the option. You may have to travel further from home to have treatment at one of these units. Other hospitals may have a specific ward or area for TYAs.

Having your treatment in a TYA unit means you can be with other young people. There may be a kitchen you can use or spaces to relax and meet friends. The staff are trained in looking after young people with cancer.

You might not be able to go to a hospital that has a TYA unit, or you may choose not to. This may mean you are treated on a cancer ward for adults. But you will still be referred to the specialised TYA team and offered psychological and social support from them. Your leukaemia treatment will be the same wherever you have it.

> **‘They said I would be in a special ward with other young people. I met 2 other young guys who got diagnosed with the same thing. That really helped.’**
>
> **Matt**

Fertility

Some drugs used to treat leukaemia can affect being able to get pregnant or make someone pregnant (your fertility). Your doctor or nurse will talk to you about this before you start treatment. They will explain how your fertility may be affected. Treatments such as stem cell transplants have a high risk of causing permanent infertility. If you have a partner, you may want them to be involved in these discussions. This is a lot to think about when you are already dealing with leukaemia.

You may be able to have fertility preservation before treatment. But because treatment needs to start quickly, this is not always possible. It may be possible to collect and save sperm. But the process for collecting and storing eggs takes time. This would delay the start of your treatment and may not be safe for you.

We have more information about fertility preservation on our website. Visit **macmillan.org.uk**

Contraception

Even if your treatment is likely to affect your fertility, you may still be able to get pregnant or make someone pregnant. You should use contraception to prevent a pregnancy if you have sex during treatment and for several months after treatment finishes. The drugs used to treat leukaemia can be harmful to an unborn baby. Ask your doctor or specialist nurse for more information.

We have advice on sex and contraception during and after treatment in our section on looking after yourself (see pages 79 to 80).

Getting your line put in

Many treatments for ALL are given into your bloodstream through a line put into a vein. To have your induction treatment (see page 46), you usually have a short, thin tube called a cannula. This goes into a vein in the back of your hand or in your lower arm. A cannula can stay in place for several days if needed.

Before you start your consolidation treatment (see pages 47 to 48), you have a central line or PICC line put in. A central line is a long, thin tube that goes into a vein in the chest. A peripherally inserted central catheter (PICC) line goes into a vein in the upper arm. It is threaded through to a vein in the chest.

These are used to give you chemotherapy and other treatments. They stay in place for several months. Your doctor or nurse can take blood samples from your line. You can have antibiotics, fluids and blood transfusions through it too.

A doctor or nurse puts your line in. They use a local anaesthetic to numb the area first. You may also be given a sedative to help you relax. The doctor or nurse will explain how to look after the line. They will arrange any support you need. If you are worried about your line, contact your team in the chemotherapy clinic or on the ward.

We have more information about lines on our website and in our booklet **Understanding chemotherapy** (see page 102).

‘I was straight off to chemotherapy. They got a PICC line in, so I was on chemo non-stop about 4 or 5 times a week.’

Matt

Chemotherapy

Chemotherapy uses anti-cancer (cytotoxic) drugs to destroy leukaemia cells. Cytotoxic means toxic to cells. The drugs disrupt the way leukaemia cells grow and divide, but they also affect normal cells.

Chemotherapy is the main treatment for ALL. It is usually given in 3 main phases and may take up to 3 years. You have most of the drugs through your line into a vein (intravenously) – see page 43. You take others by mouth as tablets.

You will also have chemotherapy into the fluid around your spine and brain. This is called intrathecal chemotherapy.

You will usually have chemotherapy as part of a clinical trial (see page 67).

Depending on the type of ALL you have, you may have a targeted therapy drug or an immunotherapy drug along with your chemotherapy (see pages 61 to 64).

Some people go on to have an allogeneic (donor) bone marrow transplant as their best chance of a cure (see pages 59 to 60). This is more common if you have Ph+ ALL (see page 12).

If you have other health problems, you may have lower doses of chemotherapy and other drugs to control ALL for as long as possible. This is called less intensive treatment. It has less risk of serious side effects and may be easier to cope with. You may be able to have some treatments as an outpatient.

Induction treatment

The aim is to quickly get rid of the leukaemia cells in your blood and bone marrow. This will allow your bone marrow to work normally again. This is called remission.

You usually need to stay in hospital to have your first chemotherapy treatment. You may also need to stay for a few weeks after until your blood cells recover. You will need a lot of support from nursing and medical staff. They will monitor you closely for side effects, such as infection. You may need blood or platelet transfusions because your blood cell count will be low for a few weeks. You may also need antibiotic and antiviral drugs to prevent or treat infection. This is called supportive therapy.

You may need 1 to 2 cycles of chemotherapy. You usually have a combination of 2 or 3 different drugs. Induction chemotherapy may include the following drugs:

- a steroid (prednisolone or dexamethasone), which everyone will have
- cyclophosphamide
- vincristine
- doxorubicin, daunorubicin or idarubicin
- asparaginase
- methotrexate
- rituximab, a targeted therapy drug, if you have B cell ALL (see page 11).

We have more information about these drugs on our website. Visit **macmillan.org.uk/cancer-information-and-support/treatments-and-drugs**

Testing for remission

After chemotherapy, your marrow and blood cells start to recover. You will have a bone marrow biopsy (see pages 21 to 22) and blood tests to check if you are in remission or not. If tests show very small numbers of leukaemia cells (minimal residual disease) or none, your doctor will say you are in remission (see pages 30 to 33).

Consolidation treatment

This phase of your treatment is to get rid of any remaining leukaemia cells, particularly in areas such as the brain or spinal cord. You will have more intensive chemotherapy in hospital. But you can also have some treatments as a day patient. As with induction, you will need a lot of supportive care.

The drugs used generally include the same as those used during induction. Some other drugs that may also be used include:

- cytarabine
- mercaptopurine
- vincristine.

Some people may go on to have a stem cell transplant from a donor after 2 or more cycles of chemotherapy. This depends on:

- the risk of ALL coming back
- how you are likely to cope with this treatment.

You are more likely to need a donor stem cell transplant if tests show certain genetic changes inside the leukaemia cells, such as Ph+ ALL (see page 12).

Chemotherapy into the spine

You will also have chemotherapy into the fluid around your spine and brain (cerebrospinal fluid) This is called intrathecal chemotherapy. You have it to prevent leukaemia cells spreading to the spine or brain (central nervous system) or to treat any leukaemia cells that may be there.

It is done using a lumbar puncture (see page 26). A doctor or nurse injects a small amount of chemotherapy through a thin needle into your back. You will have this done at different times during treatment for ALL.

The most common chemotherapy drugs used are:

- methotrexate
- cytarabine.

You will also have a steroid drug into the spine along with the chemotherapy drugs.

Maintenance

Unless you have a donor stem cell transplant (see page 60), you will have maintenance treatment after consolidation treatment. The aim is to prevent the leukaemia coming back and to keep you in remission. You have it for up to 2 to 3 years as an outpatient. The most common chemotherapy combination for maintenance treatment for ALL is methotrexate and mercaptopurine. You take these as tablets. You may also have vincristine into a vein and a steroid called prednisolone.

Side effects of chemotherapy

Chemotherapy can cause side effects. Your doctor, nurse or pharmacist will explain what to expect. Different drugs cause different side effects.

The main side effects are described here, as well as some ways to reduce or control them. You may get some of these side effects but are very unlikely to get them all. Always tell your doctor or nurse about any side effects you have so they can help.

> **‘Chemo was definitely a shock to the system. For the first few rounds I was absolutely fine. But then when I did get sick, it was really bad.’**
>
> **Matt, diagnosed with ALL**

Risk of infection

Chemotherapy usually reduces the number of white blood cells in your blood. These cells normally fight infection. If the number of white blood cells is low, you are more likely to get an infection. A low white blood cell count is called neutropenia.

Your doctor may give you the following:

- antibiotics to help prevent an infection
- injections of a drug called G-CSF under the skin.

This may help your bone marrow make a type of white blood cell called neutrophils.

When you are in hospital, your nurse will check your temperature regularly and monitor you for signs of infection. Always let them know if you feel unwell or cold and shivery.

When you are at home, contact the hospital straight away on the 24-hour contact number you have if:

- your temperature goes over 37.5°C (99.5F)
- you suddenly feel unwell, even with a normal or low temperature
- you have symptoms of an infection.

Symptoms of an infection include:

- feeling shivery
- a sore throat
- a cough
- diarrhoea
- needing to pass urine (pee) often
- pain when passing urine.

It is important to follow any specific advice your healthcare team gives you.

You will have regular blood tests to check the levels of all your blood cells. Your treatment may need to be delayed if the number of white blood cells is too low or you develop an infection.

Bruising and bleeding

Chemotherapy can reduce the number of platelets in your blood. Platelets are cells that help the blood to clot.

If the number of platelets is low, you may bruise or bleed easily. You may have:

- nosebleeds
- bleeding gums
- heavy periods
- blood in your urine (pee) or stools (poo)
- tiny red or purple spots on your skin that may look like a rash.

Tell your doctor if you have any unexplained bruising or bleeding. You may need a drip to give you extra platelets. This is called a platelet transfusion.

Anaemia (low number of red blood cells)

Chemotherapy can reduce the number of red blood cells in your blood. Red blood cells carry oxygen around the body. If the number of red cells is low, this is called anaemia. You may have symptoms such as:

- pale skin
- lack of energy
- feeling breathless
- feeling dizzy and light-headed.

Tell your doctor or nurse if you have these symptoms.

If you are very anaemic, you may need a drip to give you extra red blood cells. This is called a blood transfusion.

Tumour lysis syndrome

When you first have chemotherapy, large numbers of leukaemia cells die and break down quite quickly. This releases large amounts of a waste chemical called uric acid into your blood. The kidneys usually get rid of uric acid but may not be able to cope with large amounts. This can cause a side effect called tumour lysis syndrome (TLS).

TLS can cause swelling and pain in the joints (gout). It may also cause more serious effects. This can include kidney problems, an abnormal heartbeat, or in rare cases, seizures.

To prevent or manage TLS, you may be given a tablet called allopurinol or a drip (infusion) called rasburicase. Your doctor or nurse may also ask you to drink plenty of fluids. Or they may give you extra fluids as a drip.

Feeling sick

Some chemotherapy drugs can make you feel sick (nauseated) or be sick (vomit). Your doctor will prescribe anti-sickness (anti-emetic) drugs to prevent this. Let your doctor or nurse know if your anti-sickness drugs are not helping, as there are several different types you can take. We have more information about nausea and vomiting on our website (see page 102).

Sore mouth

This treatment may cause a sore mouth and throat. You may also get mouth ulcers. This can make you more likely to get a mouth or throat infection. Use a soft toothbrush to clean your teeth or dentures in the morning, at night and after meals.

If your mouth or throat is sore:

- tell your nurse or doctor – they can give you a mouthwash or medicines to help
- try to drink plenty of fluids

We have more information about mouthcare during chemotherapy on our website (see page 102).

Constipation

Some chemotherapy drugs and also anti-sickness drugs and pain killers can cause constipation. Let your nurse or doctor know if this happens so they can prescribe drugs to prevent or treat this. Drink plenty of liquids. Gentle exercise, such as short walks, can help to improve constipation.

Diarrhoea

Rarely, some chemotherapy drugs may cause diarrhoea. Tell your doctor if this happens. They will check whether you need treatment for an infection. They may also give you drugs to control diarrhoea. Always tell them if it is severe or does not get better. It is important to drink plenty of fluids if you have diarrhoea.

Tiredness (fatigue)

This treatment will make you feel very tired and you will need a lot of rest. You will get tired easily for some months after treatment has finished. Gentle exercise, like short walks, can give you more energy. The tiredness will slowly get better.

If you feel sleepy, do not drive or use machinery.

We have more information in our booklet **Coping with fatigue (tiredness)** and on our website (see page 102).

> **‘Fatigue was a big thing for me, but just walking around the garden helped me feel good. Exercise helped my recovery so much.’**
>
> **Ellis**

Hair loss

Most people lose all the hair on their head during treatment. Eyebrows, eyelashes and other body hair may also thin or fall out. Hair loss usually starts about 2 weeks into the induction phase of treatment (see page 46). It is almost always temporary. Your hair will usually grow back over a few months after your treatment has finished or during maintenance (if you have this) – see page 48.

We have more information in our booklet **Coping with hair loss** and on our website (see page 102).

Skin changes

If your skin feels dry, try using an unperfumed moisturiser every day. During treatment, and for several months afterwards, you will be more sensitive to the sun. Your skin may burn more easily than usual. You can still go out in the sun. But use a suncream with a sun protection factor (SPF) of at least 50. Cover up with clothing and a hat.

Your skin may darken during treatment. It will return to its normal colour after you finish treatment. Always tell your doctor or nurse about any skin changes. They can give you advice and may prescribe creams or medicines to help.

Effects on the heart

Some of the drugs used to treat leukaemia can affect the way the heart works. Your doctors plan your treatment carefully to reduce the risk of this happening. You may have tests to check how well your heart is working before, during and after treatment.

Steroids

You almost always have steroids during treatment for ALL. You usually start having steroids a few days before you start chemotherapy. Steroids can:

- destroy leukaemia cells
- make chemotherapy more effective
- reduce allergic reactions caused by some chemotherapy drugs
- prevent side effects such as feeling sick (nausea).

Steroids can be given into a vein or as tablets. Prednisolone and dexamethasone are 2 steroids often used to treat ALL.

Side effects of steroids

Steroids can cause side effects. But these will gradually disappear as the steroid dose is reduced. Your doctor, nurse or pharmacist may give you a card that explains you are taking steroids. You should carry the card with you at all times so that a doctor will know you are having steroid treatment in an emergency.

Mood and behaviour changes

Steroids can affect your mood. You may feel anxious or restless, or have mood swings. Talk to your doctor or nurse if you are worried about this.

Problems sleeping

You may also have problems sleeping. Tell your doctor or nurse if you do. Taking your steroids early in the morning may help you sleep better.

Tummy pain or indigestion

Steroids can irritate the stomach and may cause tummy (abdominal) pain or indigestion. Tell your nurse or doctor if you have these. It can help to take your steroid tablets with food. Your doctor may also give you medicines to protect your stomach.

Increased appetite

Steroids can make you feel much hungrier than usual and you may gain weight. Your appetite will go back to normal when you stop taking steroids. If you are worried about gaining weight, talk to your doctor or nurse.

Raised blood sugar levels

Steroids can raise your blood sugar levels. You will need to check your blood sugar every day. Your nurse can show you how to do this. Symptoms of raised blood sugar levels include:

- feeling thirsty
- needing to pass urine more often
- feeling tired.

Tell your doctor or nurse if you have these symptoms.

If you have diabetes, your blood sugar levels may be higher than usual. Your doctor will talk to you about how to manage this. You may need to adjust the dose of your insulin or tablets.

Build-up of fluid

You may put on weight, or your ankles and legs may swell because of fluid building up. This is more common if you are taking steroids for a long time. Tell your doctor or nurse if you have any swelling. If your ankles and legs swell, it can help to put your legs up on a foot stool or cushion. The swelling gets better after your treatment ends.

Stem cell transplants

Some people with ALL have a treatment called a donor or allogeneic stem cell transplant.

You have this treatment when you are in remission (see pages 30 to 33). It depends on:

- the risk of ALL coming back
- whether a donor is available.

If ALL comes back (relapses), some people have a stem cell transplant when they are in remission again.

Stem cell transplants may increase the chances of curing the leukaemia or may keep it in remission for longer. But this treatment is not suitable or necessary for everyone. It can have serious risks.

If your doctor thinks you need a donor transplant, they will arrange for you to talk to the transplant team.

Having a donor stem cell transplant

There are different stages to a donor stem cell transplant:

You have high doses of chemotherapy, sometimes with a type of radiotherapy called total body irradiation (TBI). This is called conditioning treatment. The intensity of the treatment will depend on your age and your general health. Your donor's stem cells are collected from their blood or bone marrow.

After the conditioning treatment, you are given the donor's stem cells into your line as a drip (see page 43). They replace the cells that have been destroyed by the conditioning treatment.

The donor stem cells start making new healthy red blood cells, white blood cells and platelets in your bone marrow. The new white blood cells help your immune system find and destroy any remaining leukaemia cells.

A stem cell transplant can cause side effects. Some of these can be serious. It is only done in specialist transplant units. You may need to stay in hospital for 4 to 6 weeks, or sometimes longer. Recovery may take many months. There are likely to be times when you feel very unwell.

We have more information about having a donor stem cell transplant in our booklet **Understanding stem cell transplants using donor cells (allogeneic)** – see page 102.

Targeted and immunotherapy drugs for ALL

You may have a targeted therapy or immunotherapy drug, depending on the type of ALL you have (see page 12.) These drugs target something in or around the leukaemia cell that is helping it to grow. Some targeted drugs are also immunotherapy drugs. They use the immune system to find and attack cancer cells.

Your doctor or nurse will explain which type of drug is suitable for you.

Some of these drugs may only be available in certain situations. If a drug is not available to you on the NHS, there may be different ways you can still have it. Your cancer doctor can give you advice. We have more information about what to do if a treatment is not available on our website (see page 102).

Tyrosine kinase inhibitors (TKIs)

TKIs are a type of targeted therapy drug used to treat Ph+ ALL (see page 12). Tyrosine kinase (TK) is a chemical messenger that tells the leukaemia cells when to develop and divide. In Ph+ ALL, the leukaemia cells make high levels of tyrosine kinase. This makes them grow in an uncontrolled way. TKI drugs block (inhibit) the TK signal, which causes the leukaemia cells to die. You have a TKI with chemotherapy (see page 45) as your first treatment. They are also used if the leukaemia does not respond to treatment or comes back. You take them as tablets or capsules every day.

Types of TKIs

- imatinib
- dasatinib
- ponatinib
- nilotinib.

Imatinib is the most often used TKI. You usually have it first.

We have more information on these drugs on our website (see page 102).

Side effects

Side effects of TKIs are usually mild. They include:

- feeling sick
- diarrhoea
- tiredness
- leg aches or cramps
- an itchy rash.

These are usually more noticeable in the first 4 weeks of treatment. After that, they begin to get better. Tell your nurse or doctor if you have any side effects. There is usually something they can do to treat them.

Monoclonal antibodies

These are targeted therapy drugs that work on the immune system. They target certain proteins on the leukaemia cells and use the immune system to attack them.

You have these drugs with chemotherapy or on their own. You have them as a drip into a vein.

Rituximab is used to treat B cell ALL (see page 12) if the leukaemia cells have a protein called CD20 on their surface. This is sometimes called CD20 positive leukaemia. You may be able to have rituximab as an injection under the skin after you have had some treatments as a drip.

Other monoclonal antibodies may also be used to treat B cell ALL. They target different proteins found on the leukaemia cells:

Blinatumomab (Blincyto®) may be used if the leukaemia cells are CD19 positive. You may have it if you are in remission (see page 47) but have very small numbers of leukaemia cells (minimal residual disease) – see page 47.

- Inotuzumab ozogamicin (Besponsa®) may be used if the leukaemia cells are CD22 positive. You may have it if ALL does not go into remission with chemotherapy or if it has come back (relapsed).

Your doctor or specialist nurse can tell you more about these drugs and their side effects.

CAR-T therapy

CAR-T stands for chimeric antigen receptor T-cell. This is an immunotherapy treatment. It involves collecting your own immune cells and changing them so they become better at fighting the leukaemia cells. These cells then target the leukaemia cells.

The type of CAR-T therapy used to treat ALL is called tisagenlecleucel (Kymriah®). It may be used to treat young people under 25 with B cell ALL if other treatment has not worked, or if ALL comes back.

CAR-T therapy is complicated and can have serious side effects. It is only suitable for a very small number of people. Currently, it is only available in a few specialist hospitals.

We have more information about CAR-T therapy on our website (see page 102).

Supportive care

Leukaemia and its treatment can have symptoms and side effects which may cause some complications. Your doctor and nurse will monitor you for these. They will give you supportive treatments to prevent or manage them.

Possible complications may be caused by infection, bleeding and low blood cell counts. Supportive care is an important part of treatment for leukaemia.

Blood products

If your red blood cells or platelets are low, you can have a blood or platelet transfusion to increase the number of these cells in your blood. The blood or platelets you are given are from carefully screened blood donors. You have the blood or platelets through a drip into a vein.

Having a blood transfusion will increase your energy levels and reduce breathlessness. If your blood count goes down again, you may need another blood transfusion.

A platelet transfusion will reduce your risk of problems with bleeding.

Drugs to prevent or treat infections

You will have drugs to treat or prevent infections. You may get an infection because you have low numbers of healthy white blood cells. This can be because of the leukaemia or its treatments. Different types of drugs are used to treat or prevent different types of infections. They include antibiotics, antiviral and antifungal drugs.

Drugs to help make more white cells (growth factors)

Drugs called growth factors can be used to encourage the bone marrow to make white bloods cells. These drugs include granulocyte-colony stimulating factors (G-CSFs), such as filgrastim (Neupogen®) and pegfilgrastim (Neulasta®).
These drugs:

- shorten the length of time you have a low white blood cell count
- lower your risk of infection

Growth factors are also used before and after a stem cell transplant (see pages 59 to 60).

Removing extra cells from the blood (leukapheresis)

Very rarely, some people with an extremely high number of white blood cells have a process called leukapheresis. Doctors remove the blast cells (see pages 7 to 9) from the blood to prevent them clogging up blood vessels. They use a machine called a cell separator to do this. This process is rarely done. We have more information about leukapheresis on our website (see page 102).

Clinical trials

Clinical trials are medical research studies involving people. Doctors may use cancer clinical trials to:

- test new treatments to see if they work better than current treatments
- find which treatments have fewer side effects
- find new ways to combine treatments to see if they work better
- test new cancer drugs to find out more about them and their side effects
- improve the way treatments are given to try to reduce side effects.

Results from clinical trials can improve cancer treatments and help people live longer. Trials can also look at improving things like diagnosis and symptom management.

Taking part in a trial

Your cancer doctor or specialist nurse may talk to you about taking part in a clinical trial. Or you could ask them if there are any trials suitable for you.

Usually, cancer clinical trials happen in several hospitals around the country. You may have to travel to take part in a trial.

A research nurse or doctor will give you information about the trial. It is important to understand what is involved before you agree (consent) to take part. You can ask the research nurse or doctor any questions you have.

They will also explain the possible benefits and any possible risks of the trial. Clinical trials are designed to be as safe as possible. The researchers will monitor you closely during and after the trial.

If you decide not to take part in a trial, your cancer doctor and specialist nurse will respect your decision. You do not have to give a reason for not taking part. Your decision will not change your care. Your cancer doctor will give you the standard treatment for the type and stage of cancer you have.

We have more information about cancer clinical trials on our website. Visit **macmillan.org.uk/information-and-support/treating/clinical-trials**

Giving blood and tissue samples

During your diagnosis and treatment doctors often take blood samples. They may also take a small piece of tissue or a sample of cells. These tissue samples are called biopsies. The samples can be looked at under a microscope. Your cancer doctor may ask your permission to store and use these blood or tissue samples for cancer research. This will only happen after they have done all the tests you need.

Your samples can only be stored for research if you give your consent. Your cancer doctor can answer any questions you have.

Your name is removed from the samples before they are stored. This means you cannot be identified.

The samples may be used to:

- find out more about the causes of certain cancers
- develop new cancer drugs or treatments.

This type of research takes a long time. The results may not be available for many years.

AFTER TREATMENT FOR ALL

Follow-up

After your treatment, you will have regular check-ups. Your doctor or specialist nurse will tell you what to expect. These follow-up appointments will continue for several years. They are a good time to talk about any questions or worries you have.

If you had a stem cell transplant (see page 60) , we have more detail on follow-up and aftercare on our website (see page 102).

Your doctor will ask you how you have been feeling. They will also ask whether you have any new or ongong side effects.

You will have regular blood tests to check:

- the number of normal cells in your blood, to make sure the leukaemia is still in remission
- your general health – for example, how well organs like your kidneys and liver are working.

Depending on the treatment you had, you may also have bone marrow samples taken to check for signs of leukaemia (see page 23) . Sometimes you may need other tests, such as x-rays or scans.

Many people find that they get very anxious before these appointments. This is normal. It may help to get support from family and friends.

If you have any problems, or notice any new symptoms between appointments, talk to your doctor or specialist nurse as soon as possible. Do not wait for your next appointment.

What if the leukaemia comes back?

For some people, leukaemia comes back after treatment. This is called a relapse. If this happens, you may have further treatment. Some people have the same chemotherapy drugs they had during their induction treatment (see page 46). Others are offered different types of chemotherapy. With further treatment, a second remission may be possible. Some people may be able to have a stem cell transplant from a donor.

Targeted or immunotherapy drugs may also be used. If you have Ph+ ALL (see page 12), you will be offered a different TKI (see pages 61 to 62). Occasionally, CAR-T therapy is a possible treatment option (see page 64).

Sometimes treatment can control the leukaemia but not cure it. The aim of treatment in this case is to reduce any symptoms and improve quality of life for as long as possible.

Possible long-term effects of treatment

Unfortunately, treatment for leukaemia can sometimes cause side effects that are permanent or happen months or years later.

These will not happen to everyone. Your doctor or specialist nurse can explain how likely they are to affect you. They may give you advice about ways to prevent or manage long-term effects. This may include:

- telling them about certain symptoms
- having regular tests or check-ups with your GP or at a hospital clinic
- having treatments or medicines
- making lifestyle changes.

Changes to heart health

Some leukaemia treatments can increase your risk of heart problems later in life. After these treatments, your doctor may arrange tests to check your heart every few years. They may also advise you to have regular blood pressure checks and blood tests to check your cholesterol levels. Your GP can arrange this for you.

We have more information about cancer treatment and your heart in our booklet **Heart health and cancer treatment** (see page 102).

Second cancers

People who have had intensive chemotherapy (see page 45) or a stem cell transplant (see pages 59 to 60) have a slightly higher risk of developing a different cancer years later.
It is important to go for any cancer screening tests when you are invited. Screening tests:

- look for early changes that can be treated to prevent cancer
- find cancer at an early stage when it is easier to treat.

We have more information about breast, bowel and cervical screening on our website (see page 102). Ask your doctor or specialist nurse what screening you should have and when you should have it.

Fertility

Treatment for leukaemia can affect your fertility. If you are thinking about getting pregnant or trying to make someone pregnant, talk to your doctor. They can give you advice based on the leukaemia treatment you had and your age. You may be able to have tests to check whether your fertility has been affected. Your doctor or nurse can arrange for you to see a fertility specialist for more advice if needed.

We have more information about fertility after treatment in our booklets **Cancer and fertility – information for women** and **Cancer and fertility – information for men** (see page 102).

Early menopause

The menopause usually happens between the ages of 47 and 53. But treatment for leukaemia can cause an earlier menopause. Your doctor can tell you whether this is likely.

Symptoms of the menopause can include:

- hot flushes
- night sweats
- joint pain
- reduced sex drive
- vaginal dryness
- disturbed sleep
- mood swings and anxiety.

Tell your doctor if you have any of these symptoms. You may have blood tests to check for signs of the menopause. If you are younger, you may have hormone replacement therapy (HRT) or the contraceptive pill to reduce menopausal symptoms. Your doctor will explain the possible benefits and risks of HRT.

Changes to bone health

Having high-dose steroid treatment (see pages 57 to 58), or taking steroids for 3 months or more, may affect your bone health later in life. You may develop bone thinning (osteoporosis) and have a higher risk of bone fractures.

Your doctor may advise you to take vitamin D and calcium supplements to help look after your bones. There are also things you can do to look after your bones. These include:

- eating a balanced diet with foods high in calcium and vitamin D
- doing regular weight-bearing exercise, such as walking
- not smoking
- keeping to the recommended alcohol guidelines.

We have more information about bone health after cancer treatments in our booklet **Bone health** (see page 102).

If you had treatment for ALL as a teenager or young adult, you also have a risk of developing a condition called avascular necrosis. This affects the blood supply in the bones. Symptoms include painful joints or problems moving joints. If you have these symptoms at any time after your treatment, tell your GP, doctor or specialist nurse so they can help.

Changes to your bone health do not always cause symptoms. Your doctor may arrange a scan every few years so any changes can be found and treated early.

Looking after yourself

It is important to look after yourself during treatment and while you recover. Some side effects may take weeks or months to improve, especially after intensive treatment. There are things you can do to manage some side effects and to improve your well-being.

If you had a stem cell transplant (see pages 59 to 60), we have separate advice on recovery on our website (see page 102).

Sex

Usually, there is no medical reason to stop having sex during treatment for leukaemia. But if your platelets are low, your doctor may advise you to avoid penetrative sex until they recover. You are more likely to bleed if your platelets are low or to get an infection if your neutrophils are low. Your doctor or nurse can give you more information about this.

Leukaemia and its treatment cause physical and emotional changes that can affect your sex life. Side effects may mean you feel too unwell or tired for sex. You may also have changes such as hair loss that affect your body image and self-esteem. We have more information in our booklet **Body image and cancer** (see page 102).

Usually, difficulties slowly improve after treatment. If you have a partner, it can help to talk openly with them about how you feel. You may both need some time to adjust. If changes to your sex life do not improve, your specialist nurse can give you advice or arrange expert support if needed. We have more information in our booklet **Cancer and your sex life** (see page 102).

Contraception

Even if your treatment is likely to damage your fertility (see page 75), you may still be able to get pregnant or make someone pregnant. Drugs used to treat leukaemia can be harmful to an unborn baby. You should use contraception during your treatment and for several months after. Ask your doctor or specialist nurse for more information.

Protecting a partner

Leukaemia cannot be passed on during sex. But small amounts of chemotherapy or other drugs may get into your bodily fluids. This includes vaginal fluid and the fluid that carries sperm (semen). To protect your partner, your doctor may advise that during treatment and for a time after you:

- use a condom for vaginal or anal sex
- use a condom or a latex barrier such as a dental dam for oral sex.

This also helps protect you from sexually transmitted infections (STIs). This is important because your treatment can affect how your body fights infections.

Your diet

Having treatment can weaken your immune system. This means you are more likely to get an infection. Try to avoid possible risks of infection from food. Your hospital may also give you further advice. Here are some tips that might help:

- eat freshly cooked food
- avoid reheating food
- make sure frozen foods are completely defrosted in the fridge, then cook them straight away, following cooking instructions
- wash salads, fruit and vegetables well.

Ask your doctor or specialist nurse for advice. They may give you a list of foods to avoid, such as raw meat and fish, undercooked eggs and unpasteurised cheese.

When your blood counts recover (see page 10), you can usually eat a normal diet. Eating a healthy, balanced diet and keeping to a healthy weight may help to:

- increase your energy levels
- improve your sense of well-being
- reduce the risk of new cancers, heart disease, strokes and diabetes.

We have more information in our booklet **Healthy eating and cancer** (see page 102).

Alcohol

If you drink alcohol, drinking a lot can slow your recovery. It can increase the risk of bleeding, especially if your platelet count is low. It can also affect how some drugs work. Ask your doctor if it is okay for you to drink alcohol.

Smoking

If you smoke, giving up is one of the healthiest decisions you can make. Smoking increases the risk of bone thinning (osteoporosis). It is also a major risk factor for smoking-related cancers and heart disease. Ask your doctor or nurse for advice.

The NHS has a lot of information and support to help you give up smoking. Look on the NHS website for the country where you live (see page 110).

Keeping physically active

Regular gentle activity, such as walking, is a good way to build up energy levels. It can also help reduce stress and anxiety.

But you will need to build it up gradually and be careful about exercising while your blood count is recovering. If your red blood cells are low (anaemia), you will feel very tired and will need to take things slowly. You will need to avoid swimming and high-impact or contact sports until you are no longer at risk of infection and bleeding. Ask your doctor or nurse about what kind of exercise is suitable for you when your blood count is recovering.

Vaccinations

Your doctor may advise you to have vaccinations against illnesses such as flu and coronavirus. If you live with other people, your doctor may suggest they also have these vaccinations and keep up with other regular vaccinations. If you had a donor stem cell transplant (see pages 59 to 60), you will lose the effect of any vaccinations you had as a child. You will need to have these vaccinations again. Your doctor will advise you about this.

There are some types of vaccines that are not safe to have until your immune system recovers. These are called live vaccines. They include flu vaccines that are given as a spray up the nose. If you have young children, they should not have this type of flu vaccine. This is because it may affect you too. Ask your doctor or specialist nurse for more advice about this or before you have any vaccinations yourself. It is important to get advice from your doctor if you are planning any travel abroad.

Social life

While your white blood cell levels are low, try to avoid crowded places such as cinemas, pubs and public transport. This may help reduce your risk of infections.

How quickly you get back to your full social life may depend on the treatment you had and how your blood cell levels recover. Your doctor or specialist nurse can give you advice and tell you what your full blood count is.

Avoid contact with people who have an infection such as chickenpox, shingles or measles. If you are worried you have had contact with someone with an infectious disease, contact your doctor or specialist nurse.

Holidays and travel

If you are planning to go on holiday, talk to your doctor. For the first few months after treatment, you may still have regular check-ups or clinic appointments at the hospital. You may sometimes need blood or platelet transfusions.

If you had a stem cell transplant, it is best not to plan any holidays until at least 6 months after treatment has finished. Your doctor will usually advise you not to travel abroad in the first year after a transplant, unless there is a cancer treatment centre nearby.

Ask your doctor for advice about travel and any vaccinations you might need. We have more information about travel and cancer, including information about travel insurance in our booklet **Travel and cancer** (see page 102).

Going back to work or study

Your doctor or nurse can give you advice about when to start work or study again. It may depend on the treatment you had and how well you are recovering. If you had a stem cell transplant, your doctor or specialist nurse may advise you to wait until your blood count has gone back to normal or almost normal.

When you are ready to go back to work or study, you may want to start part-time and build up gradually. Talk to your employer, occupational health department, teacher or tutor about your plans for returning to work or study. There may be ways they can help.

You can also ask them to talk to the people you work or study with about your illness and treatment before you return. Check that you feel comfortable about the way they plan to do this. We have more information about returning to work on our website and our booklet **Work and cancer** (see page 102).

Finding ways to cope

Leukaemia and its treatment can have a big impact on your life. There may be times when it is all you think about. It can also feel like you have little control over many of the things that are happening.

You may find you want things to be as normal as possible. This can involve staying in contact with friends and doing your usual activities. Or you may decide different things are important to you now and want to make changes. There are some things you can do that may help you cope.

Find more support

Talk to your doctor, specialist nurse or one of our cancer support specialists about other support that may be available. They may help you find more practical advice, medical information, emotional support or spiritual comfort. Call the Macmillan Support Line free on **0808 808 00 00**, 7 days a week, 8am to 8pm, or visit **macmillan.org.uk**

Talk to someone

It can help to share how you are feeling and what is on your mind. There may be a few people you can talk openly to and ask anything. They could be family, friends or colleagues, or someone from a local carers' or cancer support group.

Find ways to relax

Different things work for different people. Taking time to relax can help you cope with stress and anxiety. We have information in our booklet **Complementary therapies and cancer** (see page 102).

Remember some complementary therapies may not be suitable if you have leukaemia or are having treatment for leukaemia. It is important to talk to your doctor or specialist nurse before you have any complementary therapy. It is also important to tell your complementary therapist that you have leukaemia.

> **‘This experience made me realise some of the things I want to do. I want to go into social work and use my experiences to help others.’**
>
> **Matt**

YOUR FEELINGS AND RELATIONSHIPS

Your feelings

It is common to have many different feelings when you are told you have cancer. You may feel shocked, scared, depressed, guilty or angry. This can be difficult to cope with. Partners, family and friends may also have some of the same feelings.

We have more information about emotions on our website and in our booklet **How are you feeling? The emotional effects of cancer** (page 102).

Your healthcare team will usually give you support. But you may feel you need more help. Talk to your cancer doctor, GP or specialist nurse. They can refer you to a specialist doctor, psychologist or counsellor who can help. You can also call the Macmillan Support Line on **0808 808 00 00** and talk to one of our cancer support specialists.

Talking to family, friends or other people affected by cancer may help. For more information or for help finding local support groups, visit **macmillan.org.uk/supportgroups** or talk to other people on our Online Community at **macmillan.org.uk/community**

There is more information on page 102 about other ways we can help you.

Relationships

Cancer and its treatment are stressful and may affect your relationships. Your experience of cancer may strengthen your relationships with people close to you. Or it may put a strain on relationships. Any problems usually improve over time, especially if you talk openly with each other.

We have more information online about relationships and in our booklet **Talking about cancer** (page 102).

If you are a family member or friend

If you know someone with cancer, you might find it hard to talk about the cancer or your feelings. You can support the person with cancer by listening and talking with them.

We have more information about supporting someone on our website and in our booklet **Talking with someone who has cancer** (see page 102).

If you are looking after a family member or friend with cancer, you may be a carer. We have more information and practical tips for carers on our website and in our booklet **Looking after someone with cancer** (page 102).

Talking to children and teenagers

Deciding what to tell children or teenagers about cancer is difficult. It can be hard to know what to tell them, and you may be worried about upsetting them.

It may be best to start by giving them small amounts of information, and then tell them more when they are ready. Use simple, straightforward language to explain what is happening. You can encourage them to talk to someone they trust, who can support them. They may also find support online.

The website **riprap.org.uk** offers information and support for teenagers who have a parent with cancer.

We have more information in our booklet **Talking to children and teenagers when an adult has cancer** (page 102).

WORK AND FINANCIAL SUPPORT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Help with money and benefits

When you are affected by cancer, you may need help with extra costs. Or you may need support with money if you have to stop working. We have more information online about Statutory Sick Pay and benefits you may be entitled to. We also have information for carers (page 102).

Benefits are payments from the government to people who need help with money. You can find out more about benefits and apply for them online. Go to:

- **gov.uk** if you live in England or Wales
- **socialsecurity.gov.scot** if you live in Scotland
- **nidirect.gov.uk** if you live in Northern Ireland.

The benefits system and other types of financial support can be hard to understand. Macmillan has experienced welfare rights advisers and financial guides. You can speak to them by calling the Macmillan Support Line on **0808 808 00 00**.

You can also get information about benefits and other types of financial help from Citizens Advice if you live in England, Scotland or Wales, or Advice NI if you live in Northern Ireland (see page 112).

Our booklet **Help with the cost of cancer** has lots more information (page 102).

Macmillan Grants

Macmillan Grants are small, mostly one-off payments to help people with the extra costs that cancer can cause. They are for people who have a low level of income and savings.

If you need things like extra clothing or help paying heating bills, you may be able to get a Macmillan Grant. A grant from Macmillan does not usually affect the benefits you are entitled to. It is an extra bit of help, not a replacement for other support.

To find out more, or to apply, call on **0808 808 00 00** or visit **macmillan.org.uk/grants**

Insurance

If you have, or have had, cancer, you may find it hard to get certain types of insurance.

If you are thinking about buying insurance or making a claim, one of our financial guides can help. You can call them on **0808 808 00 00**.

We have more information in our booklet **Travel and cancer** (see page 102). Our Online Community forum on Travel insurance may also be helpful, visit **macmillan.org.uk/community**

Work

You may not know how cancer will affect your work, now or in the future.

It is a good idea to talk to your manager or human resources (HR) department soon after you are diagnosed. This will help them to support you better.

Your cancer doctor, GP or specialist nurse can help you decide whether you should go back to work, and when.

Our booklets **Work and cancer**, **Working while caring for someone with cancer** and **Self-employment and cancer** have more information that may be helpful. You can also find out more about your employment rights in our booklet **Your rights at work when you are affected by cancer** (see page 102).

There is also lots more information online at **macmillan.org.uk/work**

FURTHER INFORMATION

About our information

We provide expert, up-to-date information about cancer. And all our information is free for everyone.

Order what you need

You may want to order more booklets or leaflets like this one. Visit **be.macmillan.org.uk** or call us on **0808 808 00 00**.

We have booklets about different cancer types, treatments and side effects. We also have information about work, financial issues, diet, life after cancer treatment and information for carers, family and friends.

Online information

All our information is also available online at **macmillan.org.uk/information-and-support** You can also find videos featuring stories from people affected by cancer, and information from health and social care professionals.

Other formats

We also provide information in different languages and formats, including:

- audiobooks
- Braille
- British Sign Language
- easy read booklets
- eBooks
- large print
- translations.

Find out more at **macmillan.org.uk/otherformats**
If you would like us to produce information in a different format for you, email us at **cancerinformationteam@macmillan.org.uk** or call us on **0808 808 00 00**.

The language we use

We want everyone affected by cancer to feel our information is written for them.

We try to make sure our information is as clear as possible. We use plain English, avoid jargon, explain any medical words, use illustrations to explain text, and make sure important points are highlighted clearly.

We use gender-inclusive language and talk to our readers as ‘you’ so that everyone feels included. Where clinically necessary we use the terms ‘men’ and ‘women’ or ‘male’ and ‘female’. For example, we do so when talking about parts of the body or mentioning statistics or research about who is affected. Our aims are for our information to be as clear and relevant as possible for everyone.

You can read more about how we produce our information at **macmillan.org.uk/ourinfo**

Other ways we can help you

At Macmillan, we know how a cancer diagnosis can affect everything, and we are here to support you.

Talk to us

If you or someone you know is affected by cancer, talking about how you feel and sharing your concerns can really help.

Macmillan Support Line

Our free, confidential phone line is open 7 days a week, 8am to 8pm. Our cancer support specialists can:

- help with any medical questions you have about cancer or your treatment
- help you access benefits and give you financial guidance
- be there to listen if you need someone to talk to
- tell you about services that can help you in your area.

Call us on **0808 808 00 00** or email us via our website, **macmillan.org.uk/talktous**

Information centres

Our information and support centres are based in hospitals, libraries and mobile centres. There, you can speak with someone face to face. Visit one to get the information you need, or if you would like a private chat, most centres have a room where you can speak with someone alone and in confidence.

Find your nearest centre at **macmillan.org.uk/informationcentres** or call us on **0808 808 00 00**.

Talk to others

No one knows more about the impact cancer can have on your life than those who have been through it themselves. That is why we help to bring people together in their communities and online.

Support groups

Whether you are someone living with cancer or a carer, we can help you find support in your local area, so you can speak face to face with people who understand. Find out about support groups in your area by calling us or by visiting **macmillan.org.uk/selfhelpandsupport**

Online Community

Thousands of people use our Online Community to make friends, blog about their experiences and join groups to meet other people going through the same things. You can access it any time of day or night. Share your experiences, ask questions, or just read through people's posts at **macmillan.org.uk/community**

The Macmillan healthcare team

Our nurses, doctors and other health and social care professionals give expert care and support to individuals and their families. Call us or ask your GP, consultant, district nurse or hospital ward sister if there are any Macmillan professionals near you.

Help with money worries

Having cancer can bring extra costs such as hospital parking, travel fares and higher heating bills. If you have been affected in this way, we can help.

Financial guidance

Our financial team can give you guidance on mortgages, pensions, insurance, borrowing and savings.

Help accessing benefits

Our benefits advisers can offer advice and information on benefits, tax credits, grants and loans. They can help you work out what financial help you could be entitled to. They can also help you complete your forms and apply for benefits.

Macmillan Grants

Macmillan offers one-off payments to people with cancer. A grant can be for anything from heating bills or extra clothing to a much-needed break. Call us on **0808 808 00 00** to speak to a financial guide or benefits adviser, or to find out more about Macmillan Grants.

We can also tell you about benefits advisers in your area. Visit **macmillan.org.uk/financialsupport** to find out more about how we can help you with your finances.

Help with work and cancer

Whether you are an employee, a carer, an employer or are self-employed, we can provide support and information to help you manage cancer at work. Visit **macmillan.org.uk/work**

Work support

Our dedicated team of work support advisers can help you understand your rights at work. Call us on **0808 808 00 00** to speak to a work support adviser (Monday to Friday, 8am to 6pm).

Other useful organisations

There are lots of other organisations that can give you information or support. Details correct at time of printing.

Acute leukaemia support organisations

ACLT (African Caribbean Leukaemia Trust)

Tel **020 3757 7700**
www.aclt.org
Support for people from ethnic minorities affected by blood cancers. Helping to improve the number of potential stem cell donors, particularly from the African and Caribbean communities.

Anthony Nolan

Tel **0303 303 0303**
www.anthonynolan.org
The UK's largest stem cell and bone marrow register.

Blood Cancer UK

Tel **0808 208 0888**
www.bloodcancer.org.uk
Supports research into the causes, treatment and cure of leukaemia, lymphoma and myeloma. Provides information about blood cancers and treatments.

The British Bone Marrow Registry (BBMR)

Tel **0300 123 23 23**
www.bbmr.co.uk
Part of NHS Blood and Transplant (NHSBT). Register of stem cell donors and cord blood donations from England, Scotland, Wales and Northern Ireland. Recruits, tests and registers blood donors who volunteer to become stem cell donors.

Leukaemia CARE

Freephone helpline **08088 010 444**
www.leukaemiacare.org.uk
Provides care and support to patients, their families and carers whose lives have been affected by blood cancer.

Teenage Cancer Trust

Tel **020 7612 0370**
www.teenagecancertrust.org.uk
A charity devoted to improving the lives of teenagers and young adults with cancer. Runs a support network for young people with cancer and their friends and families.

General cancer support organisations

Cancer Black Care

Tel **020 8961 4151**
www.cancerblackcare.org.uk
Offers UK-wide information and support for people from Black and ethnic minority communities who have cancer. Also supports their friends, carers and families.

Cancer Focus Northern Ireland

Helpline **0800 783 3339**
www.cancerfocusni.org
Offers a variety of services to people affected by cancer in Northern Ireland.

Cancer Research UK

Helpline **0808 800 4040**
www.cancerresearchuk.org
A UK-wide organisation that has patient information on all types of cancer. Also has a clinical trials database.

Cancer Support Scotland

Tel **0800 652 4531**
www.cancersupportscotland.org
Runs cancer support groups throughout Scotland. Also offers free complementary therapies and counselling to anyone affected by cancer.

Macmillan Cancer Voices

www.macmillan.org.uk/cancervoices
A UK-wide network that enables people who have or have had cancer, and those close to them such as family and carers, to speak out about their experience of cancer.

Maggie's

Tel **0300 123 1801**
www.maggies.org
Has a network of centres in many locations throughout the UK. Provides free information about cancer and financial benefits. Also offers emotional and social support to people with cancer, their family, and friends.

Penny Brohn UK

Helpline **0303 300 0118**
www.pennybrohn.org.uk
Offers physical, emotional and spiritual support across the UK, using complementary therapies and self-help techniques.

Riprap

www.riprap.org.uk
Developed especially for teenagers in the UK who have a parent with cancer. Has an online forum where teenagers going through similar experiences can talk to each other for support.

Tenovus

Helpline **0808 808 1010**
www.tenovuscancercare.org.uk
Aims to help everyone in the UK get equal access to cancer treatment and support. Funds research and provides support such as mobile cancer support units, a free helpline, benefits advice and an online ‘Ask the nurse’ service.

General health information

Health and Social Care in Northern Ireland

online.hscni.net
Provides information about health and social care services in Northern Ireland.

NHS.UK

www.nhs.uk
The UK’s biggest health information website. Has service information for England.

NHS Inform

Helpline **0800 22 44 88**
www.nhsinform.scot
NHS health information site for Scotland.

NHS 111 Wales

www.111.wales.nhs.uk
NHS health information site for Wales.

Patient UK

www.patient.info
Provides people in the UK with information about health and disease. Includes evidence-based information leaflets on a wide variety of medical and health topics. Also reviews and links to many health- and illness-related websites.

Counselling

British Association for Counselling and Psychotherapy (BACP)

Tel **0145 588 3300**
www.bacp.co.uk
Promotes awareness of counselling and signposts people to appropriate services across the UK. You can also search for a qualified counsellor on their ‘How to find a therapist’ page.

UK Council for Psychotherapy (UKCP)

Tel **020 7014 9955**
www.psychotherapy.org.uk
Holds the national register of psychotherapists and psychotherapeutic counsellors, listing practitioners who meet exacting standards and training requirements.

Emotional and mental health support

Mind

Tel **0300 123 3393**
www.mind.org.uk
Provides information, advice and support to anyone with a mental health problem through its helpline and website.

Samaritans

Helpline **116 123**
www.samaritans.org
Provides confidential and non-judgemental emotional support, 24 hours a day, 365 days a year, for people experiencing feelings of distress or despair.

Financial support or legal advice and information

Advice NI

Helpline **0800 915 4604**
Email advice@adviceni.net
Provides advice on a variety of issues including financial, legal, housing and employment issues.

Benefit Enquiry Line Northern Ireland

Helpline **0800 232 1271**
Textphone **028 9031 1092**
www.nidirect.gov.uk/money-tax-and-benefits
Provides information and advice about disability benefits and carers' benefits in Northern Ireland.

Citizens Advice

Provides advice on a variety of issues including financial, legal, housing and employment issues. Use their online webchat or find details for your local office by contacting:

England

Helpline **0800 144 8848**
www.citizensadvice.org.uk

Scotland

Helpline **0800 028 1456**
www.cas.org.uk

Wales

Helpline **0800 702 2020**
www.citizensadvice.org.uk/wales

GOV.UK

www.gov.uk
Has information about social security benefits and public services in England, Scotland and Wales.

Jobs and Benefits Office Enquiry Line Northern Ireland

Helpline **0800 022 4250**
Textphone **0800 587 1297**
www.nidirect.gov.uk/money-tax-and-benefits
Provides information and advice about disability benefits and carers' benefits in Northern Ireland.

LGBT-specific support

LGBT Foundation

Tel **0345 330 3030**
www.lgbt.foundation
Provides a range of services to the LGBT community, including a helpline, email advice and counselling. The website has information on various topics including sexual health, relationships, mental health, community groups and events.

Live Through This

www.livethroughthis.co.uk
A safe space for anybody who identifies as part of the queer spectrum and has had an experience with any kind of cancer at any stage. Also produces resources about LGBT cancer experiences. LTT runs a peer support group with Maggie's Barts.

Support for carers

Carers Trust

Tel **0300 772 9600**
www.carers.org
Provides support, information, advice and services for people caring at home for a family member or friend. You can find details for UK offices and search for local support on the website.

Carers UK

Helpline (England, Scotland, Wales) **0808 808 7777**
Helpline (Northern Ireland) **028 9043 9843**
www.carersuk.org
Offers information and support to carers across the UK. Has an online forum and can put people in contact with local support groups for carers.

Cancer registries

The cancer registry

A national database that collects information on cancer diagnoses and treatment. This information helps the NHS and other organisations plan and improve health and care services. There is one in each country in the UK:

National Cancer Registration and Analysis Service

Tel **0207 654 8000**
Email **enquiries@phe.gov.uk**
www.ndrs.nhs.uk
Tel (Ireland) **0214 318 014**
www.ncri.ie (Ireland)

Scottish Cancer Registry

www.ndrs.nhs.uk/cancer-registration-your-rights-and-privacy

Welsh Cancer Intelligence and Surveillance Unit (WCISU)

Tel **0292 010 4278**
phw.nhs.wales/services-and-teams/welsh-cancer-intelligence-and-surveillance-unit-wcisu/

Northern Ireland Cancer Registry

Tel **0289 097 6028**
Email nicr@qub.ac.uk
www.qub.ac.uk/nicr

Your notes and questions

Disclaimer

We make every effort to ensure that the information we provide is accurate and up to date but it should not be relied upon as a substitute for specialist professional advice tailored to your situation. So far as is permitted by law, Macmillan does not accept liability in relation to the use of any information contained in this publication, or third-party information or websites included or referred to in it. Some photos are of models.

Thanks

This booklet has been written, revised and edited by Macmillan Cancer Support's Cancer Information Development team. It has been approved by Dr Anne Parker, Consultant Haematologist.

With thanks to: Dr Katherine Clesham, Consultant Haematologist; Caroline Kerr, Macmillan Haematology Clinical Nurse Specialist; and Dr Clare Rowntree, Consultant Haematologist.

Thanks also to the people affected by cancer who reviewed this edition, and those who shared their stories.

We welcome feedback on our information. If you have any, please contact **cancerinformationteam@macmillan.org.uk**

Sources

Below is a sample of the sources used in our acute lymphoblastic leukaemia information. If you would like more information about the sources we use, please contact us at **cancerinformationteam@macmillan.org.uk**

Hoelzer D et al. Acute lymphoblastic leukaemia in adult patients: ESMO clinical practice guidelines for diagnosis, treatment and follow-up. ESMO Guidelines Committee. 2016.

NICE (National Institute for Health and Care Excellence). Blood and bone marrow cancers. Available from https://pathways.nice.org.uk/pathways/blood-and-bone-marrow-cancers [accessed August 2021].

Phelan K and Advani A. Novel therapies in acute lymphoblastic leukemia. Current Hematologic Malignancy Reports. 2018.

Can you do something to help?

We hope this booklet has been useful to you. It is just one of our many publications that are available free to anyone affected by cancer. They are produced by our cancer information specialists who, along with our nurses, benefits advisers, campaigners and volunteers, are part of the Macmillan team. When people are facing the toughest fight of their lives, we are here to support them every step of the way.

We want to make sure no one has to go through cancer alone, so we need more people to help us. When the time is right for you, here are some ways in which you can become a part of our team.

5 ways you can help someone with cancer

Share your cancer experience
Support people living with cancer by telling your story, online, in the media or face to face.

Campaign for change
We need your help to make sure everyone gets the right support. Take an action, big or small, for better cancer care.

Help someone in your community
A lift to an appointment. Help with the shopping. Or just a cup of tea and a chat. Could you lend a hand?

Raise money
Whatever you like doing you can raise money to help. Take part in one of our events or create your own.

Give money
Big or small, every penny helps. To make a one-off donation see over.

Call us to find out more 0300 1000 200
macmillan.org.uk/getinvolved

Please fill in your personal details

Mr/Mrs/Miss/Other

Name

Surname

Address

Postcode

Phone

Email

Please accept my gift of £
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I enclose a cheque / postal order / Charity Voucher made payable to Macmillan Cancer Support
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Do you pay tax? If so, your gift will be worth 25% more to us – at no extra cost to you. All you have to do is tick the box below, and the tax office will give 25p for every pound you give.

☐ I am a UK tax payer and I would like Macmillan Cancer Support to treat all donations I make or have made to Macmillan Cancer Support in the last 4 years as Gift Aid donations, until I notify you otherwise.

I understand that if I pay less Income Tax and/or Capital Gains Tax than the amount of Gift Aid claimed on all my donations in that tax year it is my responsibility to pay any difference. I understand Macmillan Cancer Support will reclaim 25p of tax on every £1 that I give.

Macmillan Cancer Support and our trading companies would like to hold your details in order to contact you about our fundraising, campaigning and services for people affected by cancer. If you would prefer us not to use your details in this way please tick this box. ☐

In order to carry out our work we may need to pass your details to agents or partners who act on our behalf.

If you would rather donate online go to **macmillan.org.uk/donate**

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FR FUNDRAISING REGULATOR

Please cut out this form and return it in an envelope (no stamp required) to: Supporter Donations, Macmillan Cancer Support, FREEPOST LON15851, 89 Albert Embankment, London SE1 7UQ

This booklet is about acute lymphoblastic leukaemia (ALL). It is for anyone who has been diagnosed with ALL. There is also information for carers, family members and friends.

The booklet talks about the signs and symptoms of ALL. It explains how it is diagnosed and how it may be treated. It also has information about emotional, practical and financial issues.

We're here to help everyone with cancer live life as fully as they can, providing physical, financial and emotional support. So whatever cancer throws your way, we're right there with you. For information, support or just someone to talk to,
call **0808 808 00 00** (7 days a week, 8am to 8pm)
or visit **macmillan.org.uk**.

Would you prefer to speak to us in another language? Interpreters are available. Please tell us in English the language you would like to use. Are you deaf or hard of hearing? Call us using NGT (Text Relay) on **18001 0808 808 00 00**, or use the NGT Lite app.

Need information in different languages or formats? We produce information in audio, eBooks, easy read, Braille, large print and translations. To order these, visit **macmillan.org.uk/otherformats** or call our support line.

MACMILLAN
CANCER SUPPORT

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