MACMILLAN
CANCER SUPPORT

UNDERSTANDING ACUTE MYELOID LEUKAEMIA (AML)

> ‘I decided I still had things I wanted to do and I was with the people who could make me better and knew what they were doing. So I would work with them and tackle it head on.’

Tony, diagnosed with AML

About this booklet

This booklet is about a type of leukaemia called acute myeloid leukaemia (AML). It is for anyone who has been diagnosed with AML, or who wants to know more about it. It also has information for carers, family members and friends.

The booklet explains:

- what AML is
- symptoms and how AML is diagnosed
- how AML is treated
- coping with AML.

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

The 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.

If you find this booklet helpful, you could pass it on to your family and friends. They may also want information to help them support you.

Quotes

Throughout this booklet, we have included quotes from people who have had AML. They are from people who have chosen to share their experiences with us. This includes Tony, who is on the cover of this booklet. Some quotes are from our Online Community at **macmillan.org.uk/community**

For more information

This booklet does not have information about other types of leukaemia or leukaemia in children under 16.

For more information about leukaemia in children, contact the Children's Cancer and Leukaemia Group (CCLG). Visit **cclg.org.uk** for more information.

We have separate information about AML for teenagers and young adults. Visit **macmillan.org.uk/teens**

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**.

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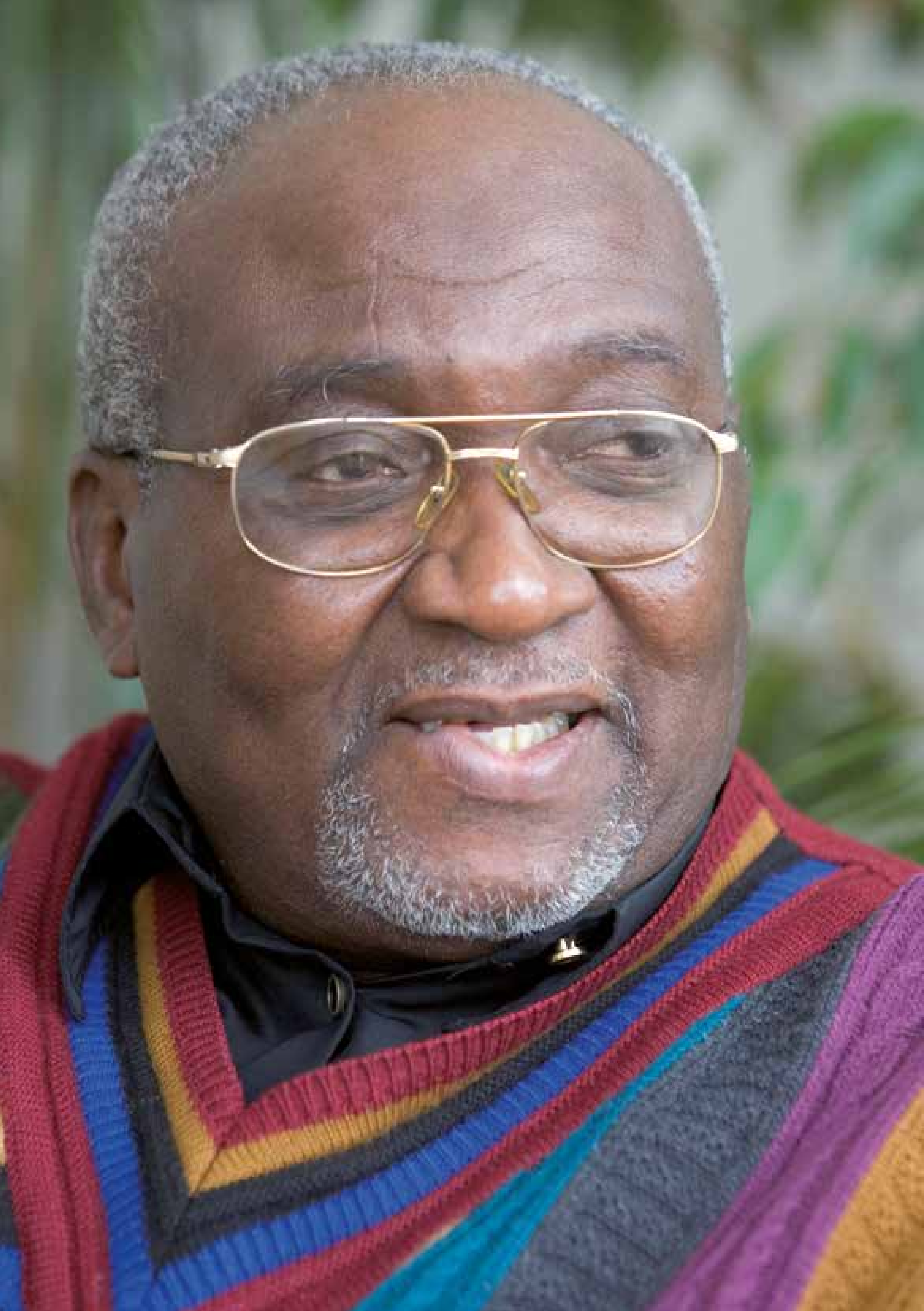

THE BLOOD AND AML

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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 myeloid leukaemia (or AML). To help you understand AML and its treatment, it is useful to know how blood cells are made and what they do.

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 our 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.

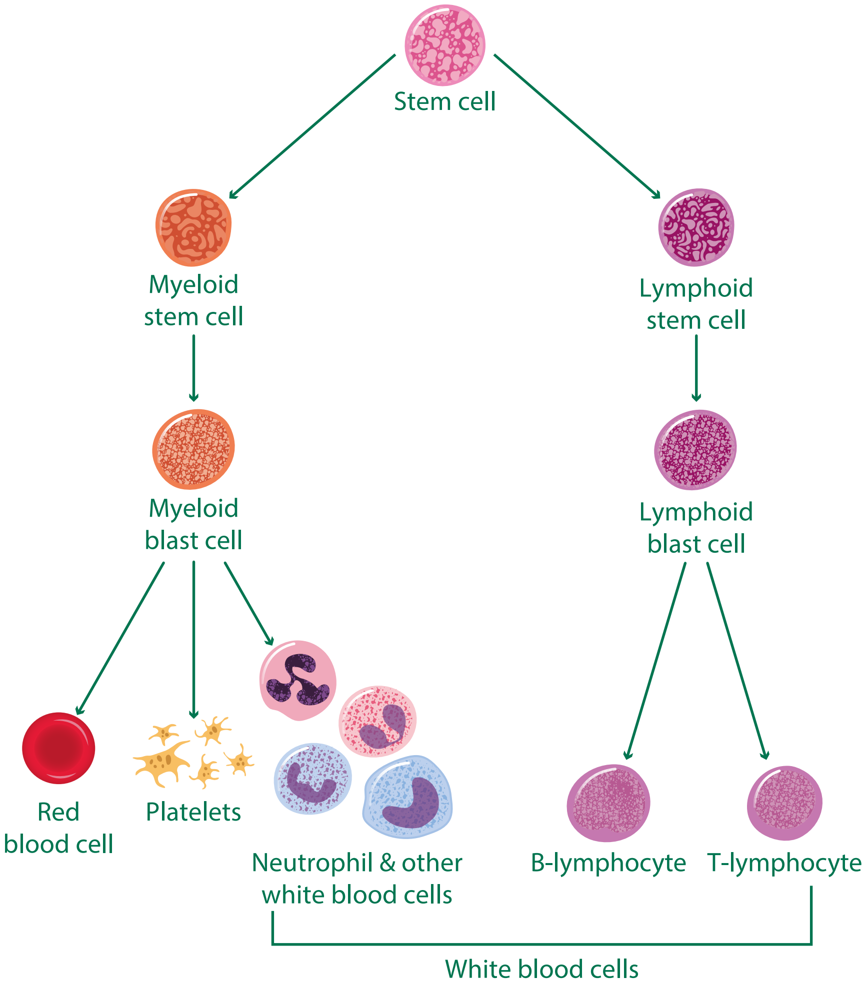
Every blood cell grows from a stem cell in the bone marrow. There are two types of blood stem cell:

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

Myeloid stem cells are the cells affected in AML.

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.

How blood cells divide



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

- 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.
- White blood cells help fight and prevent infection. There are several types of white blood cell. The two most important types are neutrophils and lymphocytes.

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 figures below are 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	130–180g/l (men)
	115–165g/l (women)
Platelets	150–400 x 109/l
White blood cells (WBC)	4.0–11.0 x 109/l
Neutrophils	2.0–7.5 x 109/l
Lymphocytes	1.5–4.5 x 109/l

These numbers can vary depending on:

- your age
- whether you are male or female
- your ethnic background.

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

The numbers might look complicated when they are written down, but doctors and nurses often use them in a simple way. For example, you may hear them saying things like, ‘your haemoglobin is 140’ or ‘your neutrophils are 4’.

Most people with leukaemia soon get used to these numbers and what they mean. But you can always ask your medical team to explain in more detail.

Acute myeloid leukaemia (AML)

Acute myeloid leukaemia (AML) is a cancer that affects myeloid cells.

Normally, myeloid stem cells make blasts that develop into healthy blood cells. But in AML, some blasts are abnormal and do not develop fully. These abnormal blasts are called leukaemia cells. In most types of AML, blasts that should become white blood cells are affected. In less common types of AML, blasts that should become platelets or red blood cells are affected.

The abnormal blasts cannot do the job of a normal cell. They also fill up the bone marrow. This means there is not enough space to make the usual numbers of healthy white blood cells, red blood cells and platelets your body needs.

AML is rare. Around 3,100 people in the UK are diagnosed with AML each year. It can develop in people of any age, but is more common in people aged 60 and over.

Types of AML

AML can be grouped into different types. This depends on:

- the type of blood cells affected
- gene changes inside the leukaemia cells
- whether you had a blood disorder called myelodysplasia before developing AML
- whether the AML is linked to previous chemotherapy treatment (called treatment-related AML or t-AML).

Treatment for most types of AML is usually the same. A type called acute promyelocytic leukaemia (APL) is treated differently (see pages 55 to 56). APL affects about 6 in 100 (6%) adults with AML.

Causes and risk factors

The cause of AML is not known. But research is going on all the time to find out more about it. Like other cancers, AML is not infectious and cannot be passed on to other people.

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

Age

AML is more common in people aged 60 and over.

Radiation

Exposure to very high radiation levels increases the risk of developing AML. For example, there might be high levels of radiation after a nuclear accident. Very few people in the UK will be exposed to radiation levels high enough to increase their risk.

Radon is a naturally occurring radioactive gas. Research has shown that a person's risk of developing AML is not significantly increased by exposure to radon gas.

Exposure to chemicals

Rarely, AML is diagnosed in people who have been exposed to certain chemicals over many years. This includes people who have worked in jobs using benzene and other solvents.

Smoking

Smoking increases the risk of developing AML. Researchers think this may be because there is benzene in cigarette smoke.

Chemotherapy and radiotherapy

Rarely, people who have had certain types of chemotherapy or radiotherapy develop AML a few years later. This is called secondary leukaemia or treatment-related AML.

Blood disorders

People with certain blood disorders, such as myelodysplasia or myeloproliferative disorders, have a higher risk of developing AML.

Genetic conditions

People with certain genetic conditions have a higher risk of developing leukaemia. This includes Down's syndrome and Fanconi's anaemia.

Family history

Sometimes AML or another blood cancer affects several relatives in a family. If you are worried about leukaemia in your family, talk to your GP or specialist doctor.

Symptoms of AML

Most symptoms of acute leukaemia are caused by leukaemia cells filling the bone marrow. This means healthy blood cells do not move into the blood as normal.

Low numbers of red blood cells

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 lightheaded.

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 in women.

Other symptoms

Other symptoms may include:

- having a fever and sweats
- unexplained weight loss
- swollen lymph nodes.

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

If you have any of these symptoms, you should always tell your doctor and have them checked. But remember, these symptoms can also be caused by many other illnesses.

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How AML is diagnosed

Some people are diagnosed with AML after being taken to hospital with symptoms (see pages 16 to 17) 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. Pregnant women can often still have tests and some treatment 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:

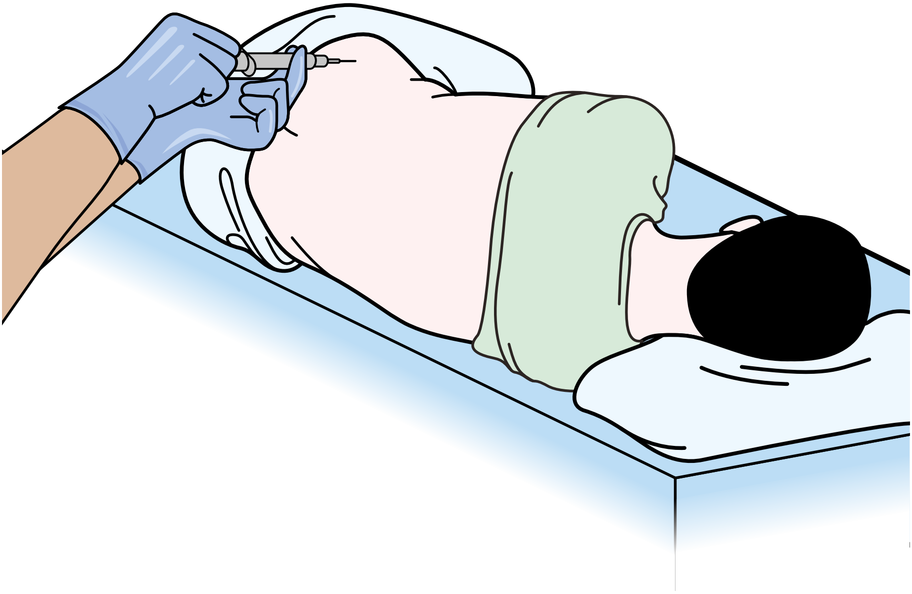
- check the numbers of the different types of blood cell – called a full blood count (see pages 10 to 11)
- look for leukaemia cells.

If the haematologist thinks you might have leukaemia, they will arrange to take a sample of your bone marrow.

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.

Having a 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 be given gas and air (Entonox®) to breathe in through a mouth piece 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 tests are used to find out more about any abnormal cells. Tests may include the following.

Immunophenotyping

This test looks for specific proteins on the surface of leukaemia cells. It helps identify the type of leukaemia and the type of blood cell that has become abnormal. This test can also be used to look for very small amounts of leukaemia during, and at the end of, treatment.

Cytogenetics and molecular tests

These tests look for gene changes inside the leukaemia cells. Tests may include:

- G-banding – this is where the genetic material from a leukaemia cell is examined using a special microscope.
- FISH (fluorescence in situ hybridisation) – this looks for specific gene changes that may not be seen with G-banding.
- PCR (polymerase chain reaction) – this is a very sensitive test that looks for specific gene changes that cannot be seen under a microscope. 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 team more information about the exact type of AML 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, close friend or your specialist nurse. Or you can call the Macmillan Support Line on **0808 808 00 00**.

> ‘I was alone and it was a hard thing to process. I was shocked but also comforted by the fact that they found out what was wrong with me, so they could get to work on making me better.’
>
> **Tony**

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 health
- other heart tests
- 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 page 57) as part of your treatment. Your healthcare team use information about your tissue type to find a possible stem cell donor for you.

Lumbar puncture

A lumbar puncture is a test that checks for leukaemia cells in the fluid around the brain and spinal cord. You may have this test but it is not always needed. 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 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 two 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.

A lumbar puncture can also be used to inject chemotherapy (see pages 47 to 52) into the CSF. This is called intrathecal chemotherapy. It may be done to treat leukaemia in the CNS.

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. 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 can find more information at **macmillan.org.uk/cancerregistry**

‘I was telling myself it had to get worse to get better. That got me through it.’

Tony

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Treatment overview

Treatment for AML usually starts as soon as possible after diagnosis. You may have different treatments, such as:

- chemotherapy
- targeted therapy
- ATRA or arsenic trioxide for APL
- stem cell transplant.

The main 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.

Most people in the UK have treatment for acute leukaemia as part of research called clinical trials.

Intensive treatment

The aim of intensive treatment is to cure AML. It is usually given in two main phases.

- Induction phase – treatment is given to get rid of the leukaemia cells in your blood and bone marrow.
- Consolidation phase – treatment is given to get rid of any remaining leukaemia cells to prevent the leukaemia coming back.

In each phase, you may have different treatments. You will have some treatment as an inpatient in hospital. You will stay in hospital for a few weeks at a time. You may stay in for longer if you need treatment to manage side effects, or if you have a stem cell transplant. Your doctor and nurse will explain your exact treatment plan and what to expect in each phase.

> ‘To make the hospital more homely, take some personal items in, such as photos, cushions, a special pillow and ornaments. All these things help.’
>
> **Karen**

During treatment, your healthcare team will take blood and bone marrow samples (see pages 21 to 24) to check for leukaemia cells. The results of these tests help doctors:

- see how well your treatment has worked
- make decisions about your next treatment
- see if the leukaemia is more likely to come back.

If the tests show very small numbers of leukaemia cells, or none at all, 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). It can affect the treatment you need to have.

Sometimes leukaemia comes back after a remission. This is called a relapse. If you relapse, it may be possible to have more treatment and get into a second remission. A long-term remission or cure is the aim of this type of treatment.

Non-intensive treatment

Non-intensive treatment uses lower doses of chemotherapy or other drugs to control AML for as long as possible. You may be able to have some treatments as an outpatient and go home the same day.

You may have non-intensive treatment if you have other medical conditions or health problems. Non-intensive treatment has less risk of serious side effects and may be easier to cope with.

Your doctors will take regular blood and bone marrow samples to see how treatment is working. This helps them decide on any further treatment you may need.

Supportive care

Leukaemia and treatment for leukaemia can cause symptoms and side effects. Your doctor will monitor these and give you supportive treatment to prevent or manage them. This may include having:

- red blood cells or platelets given into a vein if you have low numbers of these cells – called a blood or platelet transfusion
- drugs to prevent infections if you have low numbers of healthy white blood cells
- drugs to prevent or manage side effects of treatment.

Sometimes leukaemia treatment does not get rid of the leukaemia or cannot control it any longer. You may have supportive or palliative care to help control any symptoms. If you would like more information about palliative care, or would like to talk to someone, call us on **0808 808 00 00**.

> ‘I found I felt so much better after each transfusion. They certainly got me through some very difficult times. I am so grateful to all those magnificent blood donors out there.’
>
> **Gail**

Before treatment starts

Planning your treatment

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

- one or more haematologists – doctors who specialise in blood cancers and disorders
- specialist haematology nurses – who give information and support
- a transplant consultant – an expert in managing and arranging stem cell transplants
- radiologists – who specialise in scans and x-rays
- pharmacists – who specialise in chemotherapy and other drugs.

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

Your treatment plan may depend on:

- the type of AML you have (see page 13)
- your general health.

During your treatment, someone from the MDT will be your main contact. Often this is a specialist haematology nurse. Their name and contact details should be recorded in your case notes and given to you. If you have questions or need advice about your treatment, they will be able to help.

Where treatment is given

You will 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.

Teenagers and young adults

Some hospitals have cancer units for teenagers and young adults. These are sometimes called TYA units. Other hospitals may have a ward or area for teenagers. Not every hospital offers this. You may have to travel further from home to have treatment at one.

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 and understand what you are going through.

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. Overall, your treatment and care will be the same.

> ‘I found that the nurses and healthcare assistants were great through my stay and treatment. With having plenty of people around making each other laugh, I didn’t have time to think about my condition.’
>
> **David**

Giving your consent

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. 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 advantages 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 normal to need something explained again. It is a good idea to have a family member or friend with you when the treatment is explained, to help you remember the discussion.

Most doctors will give you written information about your treatment, including a treatment schedule. This can help you understand your treatment and plan when you may be at home or staying in hospital. If you are not given a schedule, you can always ask for one.

You may sometimes feel that hospital staff are too busy to answer your questions, but it is important for you to know how the treatment is likely to affect you. The staff should be willing to make time for your questions.

Treatment for acute leukaemia often has to start very 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 any treatment, acute leukaemia is life-threatening. You are free to choose not to have treatment you are offered, but this can be a serious decision. It is important to tell your doctor or nurse. You do not have to explain why you do not want treatment, but if your team understands your reasons they can give you better advice and support. They will also record your decision in your medical notes.

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 make a decision about your treatment plan.

You may be offered treatment that aims to cure the leukaemia. This may involve some disadvantages such as:

- some longer stays in hospital – often 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 40).

Many people decide to have this treatment because the chance of curing the leukaemia outweighs these disadvantages. However, 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 involves lower doses of chemotherapy and a lower risk of side effects. It may also mean less time in hospital. These benefits make this treatment suitable for people who:

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

However, this treatment is less effective. The leukaemia is less likely to go into remission or to stay in remission.

There is no right or wrong way to feel about the benefits and disadvantages of treatment. Everyone has different things that are important to them. Your doctor or nurse is the best person to talk to for clear and detailed information about your treatment.

Second opinion

Your multidisciplinary team (MDT) uses national treatment guidelines to decide the most suitable treatment for you. Even so, you may want another medical opinion. If you feel it will be helpful, you can ask either your specialist or GP to refer you to another specialist for a second opinion.

Getting a second opinion may delay the start of your treatment, so you and your doctor need to be confident that it will give you useful information. If you do go for a second opinion, it may be a good idea to take a relative or friend with you, and have a list of questions ready, so that you can make sure your concerns are covered during the discussion.

Fertility

Some of the drugs used to treat leukaemia can affect your fertility. Fertility is the ability to get pregnant or make someone pregnant. Your doctor or nurse will talk to you about this before you start your treatment. If you have a partner, you may want them to be involved too.

This is a lot to think about when you are already dealing with leukaemia. Your team may not be able to tell you exactly what will happen. But they will explain how your fertility is most likely to be affected. Some treatments such as stem cell transplants have a high risk of causing permanent infertility.

You may be able to have fertility preservation before treatment for leukaemia. But it is important to remember that treatment usually needs to start quickly, so fertility preservation is not always possible. Women may also be able to have fertility preservation when they are in remission.

We have more information about fertility in our booklets **Cancer treatment and fertility – information for women** and **Cancer treatment and fertility – information for men** (see page 94).

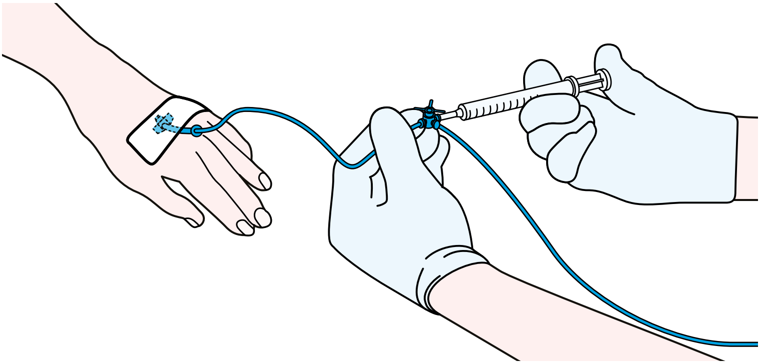
Starting treatment

Many treatments for acute leukaemia are given into your bloodstream. These are given through a line put into a vein.

Cannulas

During induction treatment (see page 31), you may have a short thin tube called a cannula. This is put into a vein in the back of your hand or lower arm. Your nurse will place a clear dressing over it to make sure it stays in place. Having a cannula put in can be a bit uncomfortable or painful, but it should not take long and any pain soon gets better. A cannula can stay in place for several days if needed.

A cannula



Central lines, PICC lines and ports

By the start of your consolidation treatment (see page 31), you will have a central line, PICC line or port put in. These are used to give treatments into your bloodstream. They can also be used to take blood samples. They can stay in place for several months and you can go home with it.

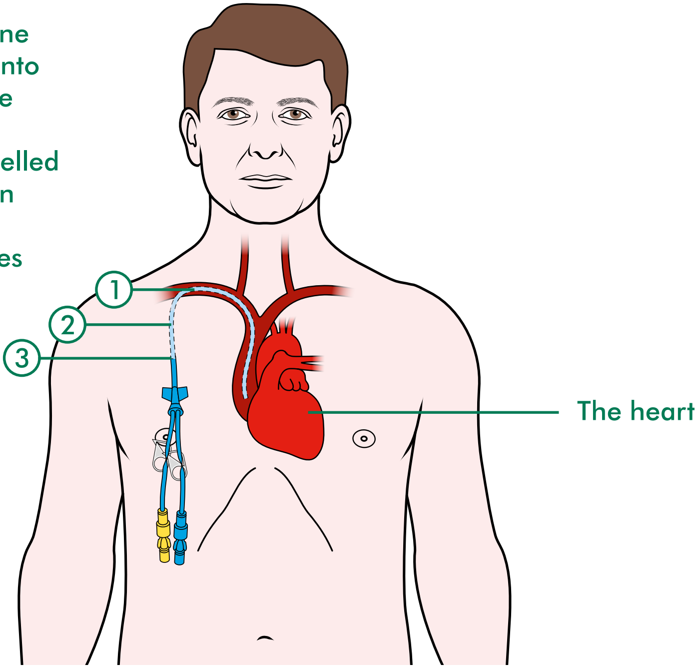
Most people get used to having a line or port. Your nurse will explain how to look after your line or port so that it does not get blocked or cause infection. They will arrange any support you need. If you are worried about your line or port, contact your team in the chemotherapy clinic or on the ward.

Central line

A central line is a long, thin, hollow tube that is put into a vein in your chest. It is sometimes called a Hickman® line or a Groshong® line.

A central line is put in under the skin of your chest and into a vein close by. You will be given a local anaesthetic to numb the area before the line is put in. One end of the line goes into a large vein just above your heart. The other end comes out of your chest. Once the line is in place, it is taped or stitched to your skin. This is to stop the line being pulled out of the vein.

A central line



① Central line inserted into chest here

② Line tunnelled under skin

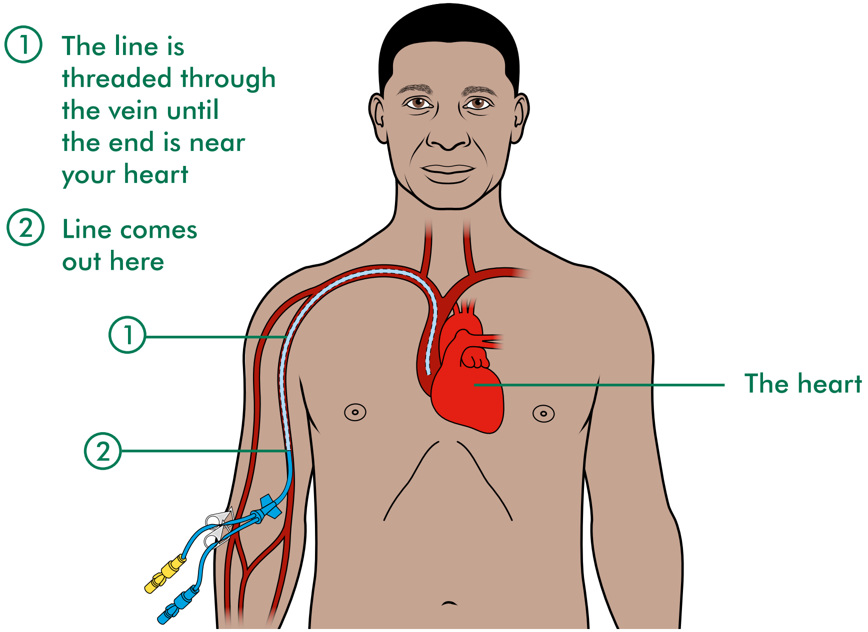
③ Line comes out here

PICC line

A PICC line is a long, thin, hollow tube that your doctor puts into a vein near the bend in your elbow.

You will be given a local anaesthetic to numb the area before the line is put in. The specialist nurse or doctor gently threads it along the vein until the tip sits in a large vein in your chest. The end of the line comes out just below the crook of your elbow. Once it's in place, the PICC line is taped firmly to your arm to prevent it being pulled out of the vein.

A PICC line



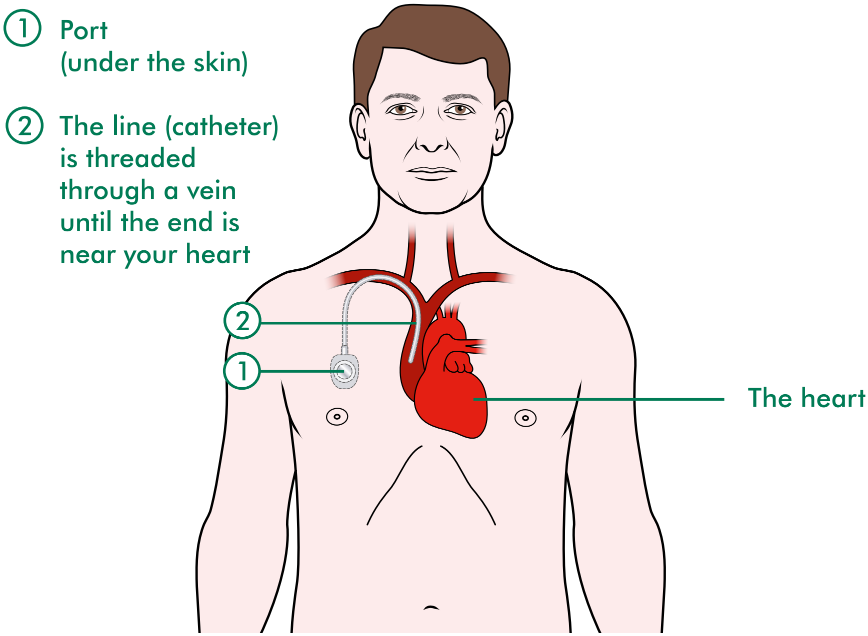
Implantable port

An implantable port is a thin, soft, plastic tube with a rubber disc (port) at the end. It is put in using a general or local anaesthetic. The doctor places the tube in a vein so its tip sits just above your heart. They place the disc under the skin on your upper chest.

After the procedure, you can feel and see the port as a small bump under the skin on your chest. But it is completely inside the body. There are no tubes outside of your body.

To use the port, a nurse passes a short needle through your skin into the disc. When they have finished taking blood samples or giving treatment, they take the needle out again.

An implantable port



Having chemotherapy

Chemotherapy

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

You will have several different chemotherapy drugs during treatment. Most of these drugs will be given through your line or port into a vein (intravenously). Some people may also have chemotherapy as a small injection under the skin.Rarely, chemotherapy is given into the fluid around the spine using a lumbar puncture (see page 26). This is called intrathecal chemotherapy.

We have a booklet called **Understanding chemotherapy** that you may find useful (page 94).

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 you are very unlikely to get them all. Always tell your doctor or nurse about any side effects you have so they can help.

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 often
- pain when passing urine.

It is important to follow any specific advice your 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 your 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. Contact the hospital straight away if you injure yourself or develop any unexplained bruising or bleeding. This includes:

- nosebleeds
- bleeding gums
- blood spots or rashes on the skin.

If your platelets are low, try to avoid injuries. Here are some tips that might help:

- wear protective gloves when doing housework
- be careful not to bump into things or trip
- use a soft toothbrush to protect your gums and do not floss.

You will probably need platelet transfusions at times during your treatment. These are given by a drip (infusion).

Anaemia (reduced number of red blood cells)

Chemotherapy may reduce the number of red bloods cells (haemoglobin) in your blood. A low level of red blood cells is known as anaemia, which can make you feel very tired and lethargic. You may also become breathless.

Anaemia can be treated with blood transfusions. This should help you to feel more energetic and ease the breathlessness.

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) and 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 possibly 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 (see page 94).

Sore mouth

Your mouth may become sore or dry, or you may notice small ulcers during treatment. Drinking plenty of fluids, and cleaning your teeth regularly and gently with a soft toothbrush, can help to reduce the risk of this happening. Tell your nurse or doctor if you have any of these problems, as they can prescribe mouthwashes and medicine to prevent or clear mouth infections.

We have more information about:

- mouth care during chemotherapy
- coping with eating problems if your mouth is sore.

See page 94 for more information.

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.

Try to eat more fibre, raw fruits, cereals and vegetables and drink plenty of liquid. 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 if you need treatment for an infection and give you drugs to control diarrhoea if needed. Always tell them if it is severe or it if does not get better.
It is important to drink plenty of fluids if you have diarrhoea.

Tiredness (fatigue)

You will probably feel very tired and need a lot of rest. Try to balance this with some gentle exercise, such as short walks, which will help. You'll probably tire easily for some months after your treatment, but this will gradually get better. We have a booklet called **Coping with fatigue** that you may find helpful.

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. 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).

We have a booklet called **Coping with hair loss** that you may find helpful (see page 94).

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, and 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.

Targeted therapy

Targeted therapy uses drugs or other substances to find and attack leukaemia cells. There are different types of targeted therapy for AML. Each type targets something that is helping leukaemia cells grow and survive.

This type of treatment is sometimes given with chemotherapy to treat AML. It may only be available as part of a research trial. Some targeted therapy drugs are only effective in treating certain types of AML. Your doctor or nurse will explain if they are suitable for you. They will give you information about the drug, how it is taken and possible side effects.

Drugs used to treat APL

If you have a type of AML called acute promyelocytic leukaemia (APL), your treatment may also include the following drugs.

ATRA (All Trans-Retinoic Acid)

ATRA is also known as tretinoin (Vesanoid®). This drug makes the leukaemia cells develop fully. This can reduce leukaemia symptoms very quickly.

You take every day as capsules with food. It is usually given with chemotherapy or the drug arsenic trioxide (see next page).

Side effects can include:

- headaches
- dry skin and mouth
- feeling sick (nausea)
- bone pain
- dry eyes.

Arsenic trioxide (ATO, Trisenox®)

This drug damages the leukaemia cells. It is given into a vein through a drip.

Side effects can include:

- heart changes
- diarrhoea
- tiredness
- muscle and bone pain
- a high temperature
- raised blood sugar.

Stem cell transplants

Some people with AML will have a treatment called a donor or allogeneic stem cell transplant. During this treatment, you are given the following:

- High doses of chemotherapy and sometimes a type of radiotherapy called total body irradiation or TBI. This is called conditioning treatment.
- Healthy stem cells from another person (a donor) into your line or port as a drip. These replace the cells that have been destroyed by the conditioning treatment.

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

A stem cell transplant causes 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. There are likely to be times when you feel very unwell.

Rarely, people with AML will have a stem cell transplant using their own stem cells. This is called an autologous stem cell transplant or high dose treatment with stem cell support.

Stem cell transplants may help in your situation. It may increase the chances of curing the leukaemia or keep it in remission for longer. But, this is an intensive treatment and it is not suitable or needed for everyone.

We have more information about having a donor stem cell transplant or high dose treatment with stem cell support (see page 94).

Research – clinical trials

Most people in the UK have treatment for acute leukaemia as part of research called clinical trials. These are usually large national and international studies that aim to find out more about leukaemia and treatment. They use drugs and treatments for leukaemia that are known to work well. But they may give them:

- in different combinations
- with newer types of drugs.

Clinical trials may:

- test new treatments, such as new chemotherapy drugs
- look at new combinations of existing treatments, or change the way they are given to make them more effective or reduce side effects
- compare the effectiveness of drugs used to control symptoms
- find out how cancer treatments work
- find out which treatments are the most cost-effective.

Trials are the only reliable way to find out if a different type of chemotherapy, radiotherapy, or other treatment is better than what is already available.

Taking part in a trial

Usually, several hospitals around the country take part in these trials. It’s important to remember that some treatments look promising at first but later are shown to be less effective or have side effects that outweigh the benefits.

Your doctor or nurse will explain this and what is involved in a trial before you make any treatment decisions.

If you decide not to take part in a trial or change your mind at any time, your doctor will respect your decision and you do not have to give a reason. However, it can help to let them know your concerns so that they can give you the best advice. There will be no change in the way that you are treated by the hospital staff, and you will be offered the standard treatment for your situation.

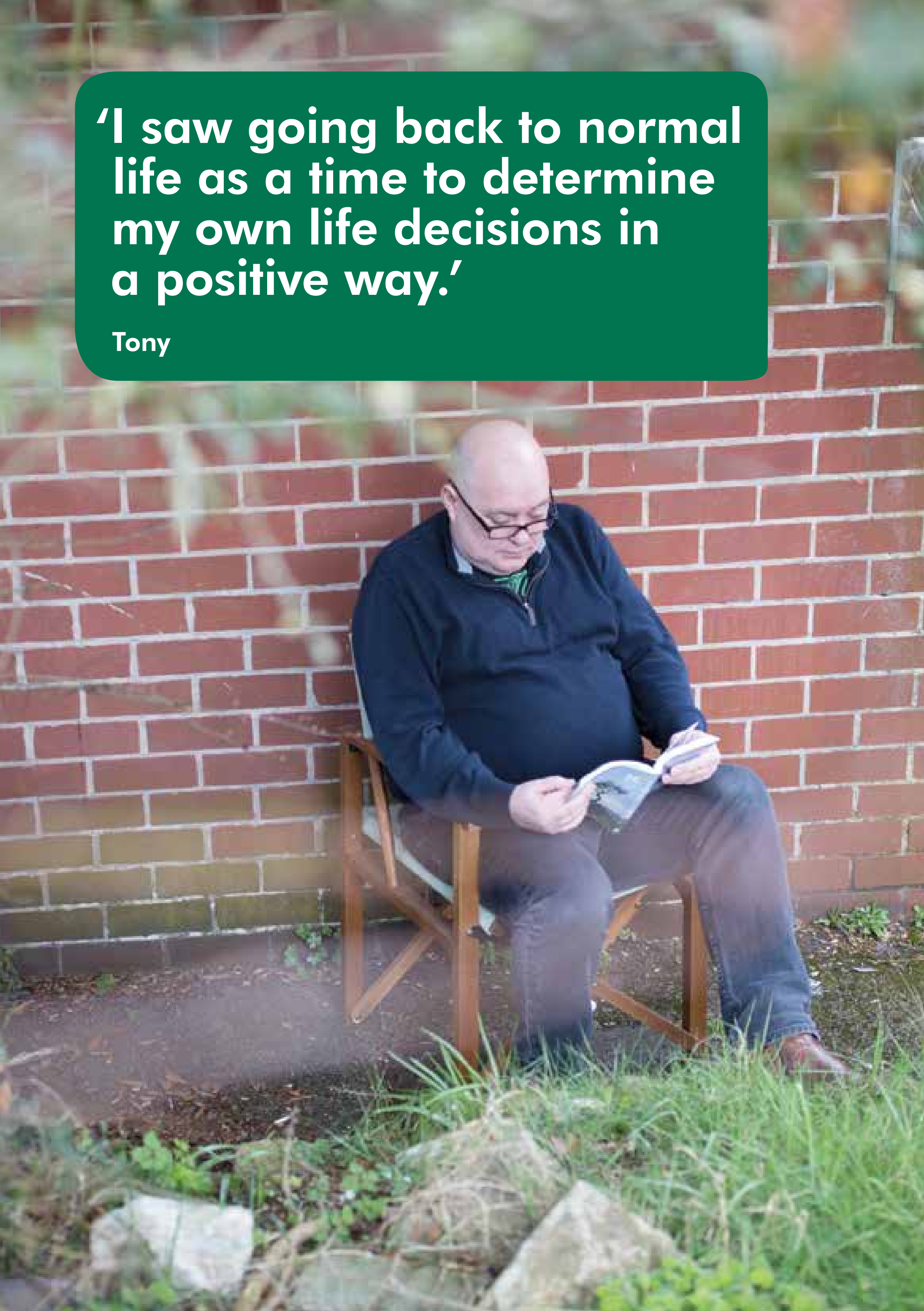
We have a booklet called **Understanding cancer research trials (clinical trials)** that you may find helpful (see page 94).

Blood and bone marrow samples

Blood and bone marrow samples are taken to help make the right diagnosis. You may be asked for your permission to use some of your samples for research into cancer. If you take part in a trial, you may also give other samples. These may be frozen and stored for future use when new research techniques become available. Your name will be removed from the samples so you cannot be identified.

The research may be done at the hospital where you are treated, or at another one. This type of research takes a long time, and results may not be available for many years. The samples will be used to increase knowledge about the causes of leukaemia and its treatment. This will hopefully improve the outlook for future patients.

> ‘I saw going back to normal life as a time to determine my own life decisions in a positive way.’
>
> **Tony**



AFTER TREATMENT FOR AML

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Looking after yourself

It is important to look after yourself during treatment and while you recover. Remember, you may have some side effects that take weeks or months to improve, especially after intensive treatment. Here are some things you may want to think about.

Your diet

When your blood counts recover, you can usually eat and drink 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, stroke and diabetes.

Having treatment can lower your immune system. This means that you are more likely to get an infection. Try to avoid possible risks of infection from food. Here are some tips that might help:

- eat freshly cooked food
- avoid reheating food
- make sure that frozen foods are completely defrosted before cooking
- wash salads and fruit 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.

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

We have a booklet called **Healthy eating and cancer** that you may find helpful (see page 94).

Sex

Usually there is no medical reason to stop having sex during treatment for leukaemia. You may feel less interested in sex if you feel tired or sick. These side effects will gradually improve when your treatment is finished.

Your doctor may advise you to avoid having sex when your platelets are low. If you have a higher risk of bleeding, your doctor may advise you to avoid penetrative sex.

You may also be advised to not have sex after having a stem cell transplant. You may not be able to have any close physical contact with anyone for a while. This is because you are more likely to get an infection, which can be dangerous. Your doctor can give you more information about this.

Contraception

Drugs used to treat leukaemia can be harmful to an unborn baby. You should use contraception to prevent a pregnancy during your treatment and for at least 4 months after. Even if your treatment is likely to damage your fertility (see page 40), you may still be able to get pregnant or make someone pregnant. Ask your doctor or specialist nurse for more information.

Leukaemia cannot be passed on during sex. However, 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 your treatment you:

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

Using condoms and dental dams also helps protect you from sexually transmitted infections (STIs). This is important because your treatment may affect how your body fights infections.

Vaccinations

Your doctor may advise you to have vaccinations against common illnesses such as flu. If you live with other people, you doctor may also suggest that they have the flu vaccine and keep up with other regular vaccinations.

If you had a donor stem cell transplant (see page 57), you will lose the effect of any vaccinations you had as a child. You will need to have these vaccinations again.

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 advice about this or before you have any vaccinations yourself.

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 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 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 a booklet called **Travel and cancer** which includes information about travel insurance (see page 94).

Keeping physically active

Regular gentle activity is a good way to help build up energy levels. Walking is a good example of this. Exercise has also been shown to help reduce stress and anxiety.

You will have to be careful about exercising if your platelets are low. If you have low numbers of red blood cells (anaemia), you may feel very tired and sometimes breathless. Ask your doctor or nurse about what kind of exercise is suitable for you when your blood count is still recovering.

> ‘I started walking to make myself better. It started as 100 yards, then got a bit longer. Then I reached 6 mile walks. The exercise really helped how I felt’
>
> **Tony**

Smoking

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

Ask your doctor or nurse for advice if you are thinking about quitting. We have a booklet called **Giving up smoking** that you may find helpful (see page 94).

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, 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 a booklet called **Work and cancer** which has information about returning to work (see page 94).

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.

Get the most out of meetings with your medical team

Before you meet, think about questions you want to ask or things that are worrying you. Write your questions down when you think of them, so that you can bring the list to your meeting. Some people find it helps to have a friend or family member in the meeting with them. Your doctor or specialist nurse will usually be able to answer your questions.

Take medications as prescribed

This might be treatment for the leukaemia, or medicines that prevent or reduce symptoms and side effects of treatment.

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. 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.

We have information about complementary therapies in our booklet **Cancer and complementary therapies** if you find these useful (see page 94).

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.

Your doctor will examine you. They will ask you how you have been feeling and about any new or ongoing side effects.

You will have regular blood tests to check your general health and the number of normal cells in the blood. Depending on the treatment you had, you may also have bone marrow samples (see pages 21 to 22) taken to check for signs of leukaemia. 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.

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.

Second cancers

People who have had intensive chemotherapy (see pages 31 to 32) or a stem cell transplant (see page 57) 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 (see page 94). Ask your doctor or specialist nurse what screening you should have and when you should have this.

Fertility

If you are thinking about trying to get pregnant, talk to your doctor. They can give you advice based on the leukaemia treatment you had and your age. They can help you arrange tests to check if your fertility has been affected by treatment. They can arrange for you to see a fertility specialist for more advice if needed.

We have more information about fertility after treatment for men, women and teenagers and young adults (see page 94).

Early menopause

Most women reach the menopause between the ages of 47 and 53. But treatment for leukaemia can cause some women to have an earlier menopause. Your doctor can tell you if this is likely.

Symptoms of the menopause can include:

- hot flushes
- night sweats
- joint pain
- reduced sex drive
- vaginal dryness
- disturbed sleep.

It can also cause mood swings and feelings of anxiety. Tell your doctor if you have any of these symptoms.

You may have blood tests to check for signs of the menopause. Some women have hormone replacement therapy (HRT) to reduce menopausal symptoms. Your doctor will explain any possible benefits and risks of HRT.

What if the leukaemia comes back?

For some people, leukaemia comes back after treatment. This is called a relapse. If this happens, further treatment can be given. Some people have the same chemotherapy drugs that were used during their induction phase again. Others are offered different types of chemotherapy or newer drugs. With further treatment, a second remission may be possible.

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

Who can help?

Sometimes it is difficult to know who can help. There is lots of support to help you and the people close to you. This may include the following:

- District nurses, who visit patients and their families at home if nursing support is needed.
- Hospital social workers, who can give you information about social services and benefits you may be able to claim. This may include meals on wheels, a home helper, help with hospital travel costs or childcare.
- Palliative care nurses, who are experts in assessing and treating symptoms of advanced leukaemia. They may support people in hospital or at home. If you need this support, your GP or specialist nurse can usually arrange it.

Many people find it helps to talk about what they are going through. You may want to talk to someone you know well. This could be a parent, sibling, partner or friend. Or you may decide to talk to someone outside your family and friends. This could be your GP or specialist nurse, or a religious leader.

If you would like to talk to other people affected by leukaemia, there are several ways to do this.

Self-help or support groups offer a chance to talk to other people in a similar situation. Joining a group can be helpful if you live alone, or do not feel able to talk about your feelings with people you know. Not everyone finds talking in a group easy, so it might not be for you. Try going along to see what the group is like before you decide whether to join.

Many people now get support on the internet through:

- online support groups
- social networking sites
- forums
- chatrooms
- blogs for people affected by leukaemia.

You can use these to ask questions and share your experience. Our Online Community is a social networking site where you can talk to people in our forums, blog your journey, make friends and join support groups. Visit **macmillan.org.uk/community**

Call us on **0808 808 00 00** if you have questions about getting more support.

YOUR FEELINGS AND RELATIONSHIPS

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Your feelings

It is common to feel overwhelmed by different feelings when you are told you have leukaemia. We talk about some of these here. Partners, family and friends may also have some of the same feelings.

You might have different reactions to the ones we describe here. There is no right or wrong way to feel. You will cope with things in your own way. Talking to people close to you or other people affected by leukaemia can often help.

Shock and disbelief

You may find it hard to believe it when your doctor tells you that you have leukaemia. It is common to feel shocked and numb. You may not be able to take in much information and might keep asking the same questions. At first, you might find it hard to talk to family and friends about the leukaemia. This usually gets easier as the shock wears off and it becomes more real to you. You may find you cannot think or talk about anything but the leukaemia. This is because your mind is trying to process what you are going through.

Fear and anxiety

You might feel very anxious or frightened about whether treatment will work and what will happen in the future. This uncertainty can be one of the hardest things to cope with. It can help to try to focus on what you can control. You may want to find out more about the leukaemia, its treatment and how to manage side effects. It can also help to talk about your feelings and to take time to do things that are important to you and that you enjoy.

Doctors often know roughly how effective a type of treatment could be. But they cannot be sure what will happen to an individual person. Although they may not be able to answer your questions fully, they can usually talk through any problems with you and give you some guidance.

Avoidance

You might cope by not finding out very much about the leukaemia and by not talking about it. If you feel like this, let your family and friends know that you do not want to talk about it right now. You can also tell your doctor if there are things you do not want to know or talk about yet.

Sometimes, this avoidance can be extreme. Some people may not believe that they have leukaemia. This is sometimes called being in denial. It may stop them making decisions about treatment. If this happens, it is very important for them to get help from their doctor.

Sometimes, avoidance is the other way around. Family and friends may seem to avoid you and the fact that you have leukaemia. They may not want to talk about it or they might change the subject. This is usually because they are also finding the leukaemia difficult to cope with, and they may need support too. Try to let them know how this makes you feel and that talking openly with them about your illness will help you.

Anger

You may feel angry about your illness and sometimes resent other people for being well. These are normal reactions, especially when you feel frightened, stressed, out of control or unwell. You may get angry with the people close to you. Let them know that you are angry at your illness and not at them. Finding ways to help you relax and reduce stress can help with anger. This can include:

- talking about or writing down how you feel
- gentle exercise
- breathing or relaxation therapy
- yoga or meditation.

Guilt and blame

You may feel guilty or blame yourself or others for the leukaemia. You may try to find reasons for why it has happened to you. Most of the time, it is impossible to know exactly what has caused a person's leukaemia. Over time, several different factors may act together to cause leukaemia. Doctors do not fully understand all of these factors yet. Try to focus on looking after yourself and getting the help and support you need.

Feeling alone

You might feel alone if you do not have enough support. Family and friends may live far away, have other commitments or feel uncomfortable because of their own fears about cancer. Try to let your family and friends know how you feel and how they could support you more.

If you need more support, you can call the Macmillan Support Line free on **0808 808 00 00** and talk to one of our cancer support specialists. Our website **macmillan.org.uk/supportgroups** can help you find out about local support groups. You can also talk to other people going through the same thing on our Online Community at **macmillan.org.uk/community**

It is normal to have times when you want to be left alone to sort out your feelings. But if you find you are avoiding people a lot of the time, then try to talk to your doctor or specialist nurse.

If you need more help

If you feel anxious, panicky or sad a lot of the time, or think you may be depressed, talk to your doctor or specialist nurse. They can refer you to a doctor or counsellor who can help. They may also prescribe medicine to help with anxiety, or an antidepressant drug.

These feelings can be very difficult to deal with, and sometimes people need more help. This happens to lots of people and does not mean you are not coping. We have a booklet called **How are you feeling? The emotional effects of cancer** which you may find useful (see page 94).

If you are a relative or friend

Some people find it hard to talk about leukaemia or share their feelings. You might think it is best to pretend everything is fine, and carry on as normal. You might not want to worry the person, or you might feel you are letting them down if you admit to being afraid. But not telling them how you feel can make it even harder to talk, and may make them feel very isolated.

You can help by listening carefully to what the person with leukaemia wants to say. It may be best not to rush into talking about the illness. Often it is enough just to listen and let them talk when they are ready.

You may find some of the courses on our Learn Zone website helpful. There are courses to help with listening and talking to help friends and family support their loved ones affected by cancer. Visit **macmillan.org.uk/learnzone** to find out more.

We have more information that has suggestions if you have a friend or relative with leukaemia. If you are looking after a family member or friend with leukaemia, we have information about this that can help. We also have more information about supporting someone with leukaemia at **macmillan.org.uk/carers**

Talking to children

Deciding what to tell your children or grandchildren about your leukaemia is difficult. An open, honest approach is usually best. Even very young children can sense when something is wrong, and their fears can sometimes be worse than the reality.

How much you tell your children will depend on their age and how mature they are. It may be best to start by giving only small amounts of information, and gradually tell them more to build up a picture of your illness.

Teenagers

Teenagers can have an especially hard time. At a stage when they want more freedom, they may be asked to take on new responsibilities and they may feel over-burdened. It's important that they can go on with their normal lives as much as possible and still get the support they need.

If they find it hard to talk to you, you could encourage them to talk to someone close who can support and listen to them, such as a grandparent, family friend, teacher or counsellor. They may also find it useful to look at the website **riprap.org.uk** which has been developed especially for teenagers who have a parent with cancer.

We have a booklet called **Talking to children and teenagers when an adult has cancer** that you may find helpful (see page 94).

WORK AND FINANCIAL SUPPORT

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Financial help and benefits

When you are affected by cancer, you might need help with extra costs. Or you might need financial support if you have to stop working.

Statutory Sick Pay

If you work for an employer and take time off sick, you may be able to get Statutory Sick Pay. Your employer will pay this for up to 28 weeks.

Benefits

Benefits are payments from the government to people who need financial help. You can find out more about benefits and apply for them online. Go to **gov.uk** if you live in England, Wales and Scotland or **nidirect.gov.uk** if you live in Northern Ireland.

Here are some benefits that you might be able to get if you are affected by cancer.

Employment and Support Allowance (ESA)

This benefit is for people under State Pension age who cannot work because of illness or disability. There are different types of ESA:

- Contribution-based ESA may be available if you have paid enough National Insurance.
- Income-related ESA may be available if your income and savings are low, or if you cannot get contribution-based ESA. Income-related ESA is gradually being replaced by a new benefit called Universal Credit.

Personal Independence Payment

This benefit is for people aged between 16 and 64 who have problems moving around and looking after themselves. You must have had these difficulties for at least 3 months and expect them to last for at least 9 months.

> ‘Macmillan helped me get my PIP. They were the only people that actually felt like they were trying to help me and see things from my point of view. It was fantastic to have that support.’
>
> **Tony**

Attendance Allowance

This benefit is for people aged 65 or over who have problems looking after themselves because of an illness or disability. This could mean getting out of bed, having a bath or getting dressed. You must have had these problems for at least 6 months.

Special rules

If you are terminally ill, and your doctor thinks you may be expected to live for less than 6 months, you can apply for some benefits using a fast-track process called special rules. Your claim will be dealt with quickly and you will get the benefit you applied for at the highest rate. It does not matter if you live longer than 6 months. Your doctor or specialist nurse will need to fill out a form for you.

Help for carers

Carer's Allowance is a weekly benefit that helps people who look after someone with a lot of care needs. If you do not qualify for it, you can apply for Carer's Credit.

Carer's Credit helps prevent gaps in your National Insurance record if you have to stop working while you are caring for someone else. You do not get money, but it protects your right to a State Pension later in life.

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, help paying heating bills or even a relaxing holiday, you may be able to get a Macmillan Grant.

How much you get will depend on your situation and needs. The average grant is around £380, but this may change from time to time. A grant from Macmillan would not normally affect the benefits you are entitled to. It is an extra bit of help, not a replacement for other support.

Insurance

If you have, or have had, cancer, you may find it hard to get certain types of insurance. This includes life and travel insurance. A cancer diagnosis might also mean that you can get a payout from an insurance scheme that you already have.

If you are looking into buying insurance or making a claim, one of our financial advisers can help. Call **0808 808 00 00**.

We have more information about insurance, and travel and cancer. Our Online Community forum Travel insurance may also be helpful. Visit **macmillan.org.uk/travelinsurancegroup**

More information

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 one 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.

Our booklet **Help with the cost of cancer** has lots more information (see page 94).

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 early on. If your workplace has a human resources (HR) or personnel department, contact them as soon as you can. If they know how the cancer or treatment may affect your ability to work, they can support you better.

Some people stop working during cancer treatment and for a while after, until they feel ready to go back. Others carry on working, perhaps with reduced hours or other changes to their job.

Some people may decide not to go back to work. Or they may choose to do something different. Others may not be able to go back to work because of the effects of cancer on their health. Going back to work may depend on the type of work you do or how much your income is affected.

It is important not to take on too much, too soon. Your cancer doctor, GP or specialist nurse can help you decide when and if you should go back to work.

Our booklets about **Work and cancer**, **Working while caring for someone with cancer** and **Self-employment and cancer** may be helpful (see page 94). There is also lots more information at **macmillan.org.uk/work**

Employment rights

If you have, or have ever had cancer, the law considers you to be disabled. This means you cannot be treated differently (less favourably) than other people at work because of cancer. If you are treated less favourably because of cancer, this is called discrimination.

The law also says your employer has to make reasonable adjustments (changes) to your workplace and their work practices.

If you live in England, Scotland or Wales, you are protected by the Equality Act 2010. If you live in Northern Ireland, you are protected by the Disability Discrimination Act 1995.

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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 leaflets or booklets like this one. Visit **be.macmillan.org.uk** or call us on **0808 808 00 00**.

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

Online information

All of our information is also available at **macmillan.org.uk/information-and-support** There you'll also find videos featuring real-life 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'd 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**.

Help us improve our information

We know that the people who use our information are the real experts. That's why we always involve them in our work. If you've been affected by cancer, you can help us improve our information.

We give you the chance to comment on a variety of information including booklets, leaflets and fact sheets.

If you'd like to hear more about becoming a reviewer, email **reviewing@macmillan.org.uk** You can get involved from home whenever you like, and we don't ask for any special skills – just an interest in our cancer information.

Other ways we can help you

At Macmillan, we know how a cancer diagnosis can affect everything, and we're 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's 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.

> 'Everyone is so supportive on the Online Community, they know exactly what you're going through. It can be fun too. It's not all just chats about cancer.'
>
> **Mal**

Help with money worries

Having cancer can bring extra costs such as hospital parking, travel fares and higher heating bills. If you've 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're 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**

My Organiser app

Our free mobile app can help you manage your treatment, from appointment times and contact details, to reminders for when to take your medication. Search 'My Organiser' on the Apple App Store or Google Play on your phone.

Other useful organisations

There are lots of other organisations that can give you information or support.

Acute leukaemias support organisations

ACLT (African Caribbean Leukaemia Trust)

Tel 020 3757 7700
Email info@aclt.org
www.aclt.org
Support for people from ethnic minorities affected by leukaemia and related illnesses.

Anthony Nolan

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

Bloodwise

Tel 0808 208 0888
Email support@bloodwise.org.uk
www.bloodwise.org.uk
Supports research into the causes, treatment and cure of blood cancers.
Has information about blood cancers and treatments.

The British Bone Marrow Registry (BBMR)

Tel 0300 123 23 23
www.nhsbt.nhs.uk/british-bone-marrow-registry
Part of NHS Blood and Transplant (NHSBT).
Register of stem cell donors and cord blood donations from England, Scotland, North Wales and Northern Ireland.
Recruits, tests and registers blood donors who volunteer to become stem cell donors.

CLIC Sargent

Tel 0300 330 0803
www.clicsargent.org.uk
Provides support to children with cancer, their families and carers.

Leukaemia CARE

Helpline 08088 010 444
(Mon to Fri, 9am to 10pm,
Sat, 9am to 12.30pm)
Email
support@leukaemiacare.org.uk
www.leukaemiacare.org.uk

Provides care and support to patients, their families and carers whose lives have been affected by leukaemia, lymphoma or a related blood disorder.

Teenage Cancer Trust

Tel 020 7612 0370
Email
hello@teenagecancertrust.org
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, their friends and families.

General cancer support organisations

Cancer Black Care

Tel 020 8961 4151
Email
info@cancerblackcare.org.uk
www.cancerblackcare.org.uk

Offers UK-wide information and support for people with cancer, as well as their friends, carers and families, with a focus on those from BME communities.

Cancer Focus Northern Ireland

Helpline 0800 783 3339
(Mon to Fri, 9am to 1pm)
Email
nurseline@cancerfocusni.org
www.cancerfocusni.org

Offers a variety of services to people affected by cancer in Northern Ireland, including a free helpline, counselling and links to local support groups.

Cancer Support Scotland

Tel 0800 652 4531
(Mon to Fri, 9am to 5pm)
Email
info@cancersupportscotland.org
www.cancersupportscotland.org

Runs cancer support groups throughout Scotland. Also offers free complementary therapies and counselling to anyone affected by cancer.

Maggie's Centres

Tel 0300 123 1801
Email
enquiries@maggiescentres.org
www.maggiescentres.org

Has a network of centres in various 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 3000 118
(Mon to Fri, 9.30am to 5pm)
Email
helpline@pennybrohn.org.uk
www.pennybrohn.org.uk

Offers a combination of physical, emotional and spiritual support across the UK, using complementary therapies and self-help techniques.

Tenovus

Helpline 0808 808 1010
(Daily, 8am to 8pm)
Email
info@tenovuscancercare.org.uk
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.

Counselling and emotional support

British Association for Counselling and Psychotherapy (BACP)

Tel 01455 883 300
Email bacp@bacp.co.uk
Promotes awareness of counselling and signposts people to appropriate services across the UK. You can search for a qualified counsellor at **itsgoodtotalk.org.uk**

Mind

Helpline 0300 123 3393
Text 86463
Email info@mind.org.uk
www.mind.org.uk
Provides information, advice and support to anyone with a mental health problem through its helpline and website.

Support for older people

Age UK

Helpline 0800 055 6112
(Daily, 8am to 7pm)
www.ageuk.org.uk
Provides information and advice for older people across the UK via the website and advice line. Also publishes impartial and informative fact sheets and advice guides.

Support for carers

Carers Trust

Tel 0300 772 9600
(Mon to Fri, 9am to 5pm)
Email info@carers.org
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.

Financial or legal advice and information

Benefit Enquiry Line Northern Ireland

Helpline 0800 022 4250
(Mon, Tue, Wed and Fri, 9am to 5pm, Thu, 10am to 5pm)
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 in the phone book or by contacting:

England

Helpline 03444 111 444
www.citizensadvice.org.uk

Wales

Helpline 03444 77 2020
www.citizensadvice.org.uk/wales

Scotland

Helpline 0808 800 9060
www.citizensadvice.org.uk/scotland

Northern Ireland

Helpline 0800 028 1181
www.citizensadvice.co.uk

Department for Work and Pensions (DWP)

Personal Independence Payment (PIP) Helpline
0345 850 3322
Textphone 0345 601 6677
(Mon to Fri, 8am to 6pm)
Carer's Allowance Unit
Tel 0345 608 4321
Textphone 0345 604 5312
(Mon to Thu, 8.30am to 5pm, Fri, 8.30am to 4.30pm)
www.gov.uk/browse/benefits
Manages state benefits in England, Scotland and Wales. You can apply for benefits and find information online or through its helplines.

GOV.UK

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

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 our Senior Medical Editor, Dr Anne Parker, Consultant Haematologist.

With thanks to: Gill Brisley, Acute Leukaemia and Lead Haematology Clinical Nurse Specialist; Dr Mike Dennis, Consultant Haematologist; Dr Jonathan Kell, Consultant Haematologist; Dr Jiri Pavlu, Consultant Haematologist; and Catherine Wardley, Macmillan Haematology Clinical Nurse Specialist.

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

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

Sources

We have listed a sample of the sources used in the publication below. If you would like further information about the sources we use, please contact us at **cancerinformationteam@macmillan.org.uk**

British Committee for Standards in Haematology. Milligan DW et al. Guidelines on the management of acute myeloid leukaemia in adults. British Journal of Haematology. 2006. 135: 450–474.
Fey MF and Buske C. Acute myeloblastic leukaemia in adult patients: ESMO clinical practice guidelines. Annals of oncology. 2013. 24(S6): vi138-vi143.
National Institute for Health and Care Excellence (NICE). Blood and bone marrow cancer. www.nice.org.uk/guidance/topic/conditions-and-diseases/blood-and-immune-system-conditions/blood-and-bone-marrow-cancers (accessed July 2018).

Can you do something to help?

We hope this booklet has been useful to you. It's just one of our many publications that are available free to anyone affected by cancer. They're 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're there 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 £

(Please delete as appropriate)
I enclose a cheque / postal order / Charity Voucher made payable to Macmillan Cancer Support

OR debit my:
Visa / MasterCard / CAF Charity Card / Switch / Maestro

Card number

☐☐☐☐ ☐☐☐☐ ☐☐☐☐ ☐☐☐☐

Valid from ☐☐/☐☐

Expiry date ☐☐/☐☐

Issue no ☐☐☐

Security number ☐☐☐

Signature

Date / /

Don't let the taxman keep your money

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.

Registered with FUNDRAISING REGULATOR

If you'd rather donate online go to macmillan.org.uk/donate

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 a type of leukaemia called acute myeloid leukaemia (AML). It is for anyone who has been diagnosed with AML or wants to know more about it. There is also information for carers, family members and friends.

The booklet explains the signs and symptoms of AML, and how it is diagnosed and treated. It also has information about coping with AML.

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
RIGHT THERE WITH YOU

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Also operating in Northern Ireland. Printed on sustainable material. Please recycle.

The Information Standard
Certified member

This organisation has been certified as a producer of reliable health and social care information.
www.theinformationstandard.org

What's this logo? Visit **macmillan.org.uk/ourinformation**