

# Acute myeloid leukaemia (AML)

**Blood  
cancer  
UK**

# About this booklet

We have produced this booklet in collaboration with expert medical professionals and people affected by blood cancer. Thank you to Consultant Haematologists Professor Paresh Vyas and Dr Mike Dennis, and Clinical Nurse Specialist Kirsty Crozier, for their support checking the content of this booklet.

We're a community dedicated to beating blood cancer by funding research and supporting those affected. Since 1960, we've invested over £500 million in blood cancer research, transforming treatments and saving lives. To find out more about what we do, see page 117.

**bloodcancer.org.uk**

**0808 2080 888**

**(Mon, Tue, Thu, Fri, 10am–4pm, Wed, 10am–1pm)**

**support@bloodcancer.org.uk**

A list of references used in this booklet is available on request. Please email us at **information@bloodcancer.org.uk**

## **Disclaimer**

We make every effort to make sure that the information in this booklet is accurate, but you shouldn't rely on it instead of a fully trained clinician. It's important to always listen to your specialist and seek advice if you have any concerns or questions about your health. Blood Cancer UK can't accept any loss or damage resulting from any inaccuracy in this information, or from external information that we link to.

The information in this booklet is correct at the time it was printed (March 2015). In January 2019, we made some changes to the 'At a glance', 'Treatment' and 'Outlook' chapters to reflect the introduction of three new treatments.

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# Introduction

This is a booklet for people with AML, and for people who know someone with AML.

Being told that you, or a loved one, have any type of cancer can be one of the hardest things you'll ever have to hear.

There's sure to be a lot of information to take in right now.

We hope this booklet will help you to understand your condition and feel in control throughout this time. We'll try to answer as many of the questions you might have along the way – from symptoms through to tests, treatment and living with AML, and where you can get support.

Every person is different, with a different medical history. So when you're deciding what's right for you, discuss your situation with your specialist as well as getting information from this booklet and other places.



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Our Support Services Team are here for anyone affected by blood cancer. Contact us on **0808 2080 888** or **[support@bloodcancer.org.uk](mailto:support@bloodcancer.org.uk)**

We have more information and personal stories about living with and beyond blood cancer on our website: **[bloodcancer.org.uk/living-well](https://www.bloodcancer.org.uk/living-well)**

# Acute myeloid leukaemia (AML) at a glance

Anyone can get AML, but it's more common in older people. The type of treatment you have will depend on lots of different factors, which means that everyone's outlook will be different.

## **What is AML?**

AML is a form of cancer which affects a type of blood cell called myeloid cells. Myeloid cells include red blood cells, platelets and certain types of white blood cells. As blood cells are made in the bone marrow, the cancer will be present in your bone marrow and in your blood.

## **Who gets AML?**

Anyone can get AML, but it's more common in people over 60. Children can also get AML.

## **What's the outlook?**

Each patient will have a different outlook. Your outlook will depend on a range of factors, like your age, medical fitness (the health of your vital organs) and the specific type of AML you have developed. The type of AML you have can also be important. The outlook can also change depending on what treatment you've had previously for AML or another cancer or illness. If you do want to find out more about your individual outlook, your specialist is the best person to talk to.

## **What are the treatments for AML?**

The treatment you have for AML will depend on your age, medical fitness and the specific type of AML you have.

Treatment is divided into intensive and non-intensive approaches. Intensive treatment is aimed at curing the disease and involves two phases of chemotherapy, sometimes with targeted therapy. These phases are called remission induction therapy and consolidation therapy. For some people, intensive treatment may also involve a stem cell transplant.

Non-intensive treatment is given to patients who might not be able to tolerate the stronger treatment in intensive therapy. Non-intensive treatment involves gentler chemotherapy, given either in hospital or at home. This option is not aimed at curing the disease – instead it aims to control the disease and give patients an excellent quality of life for as long as possible.

## **Can AML lead to any other conditions?**

Combination chemotherapy for AML can give rise to side effects; the most serious is a second leukaemia. However, this is very uncommon: we know that only around 2–5% of people get a second leukaemia, usually within five to ten years after the initial treatment.

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We have information about childhood AML on our website.  
Go to **[bloodcancer.org.uk/childhood-aml](https://bloodcancer.org.uk/childhood-aml)**





**Stick to trustworthy  
information from cancer  
charities or the NHS.  
Your healthcare team  
will tell you the best  
place to find it.**

Wendy, diagnosed with blood cancer aged 46

**Knowing the basics about  
blood, bone marrow and  
your immune system  
is useful.**

If you're worried, get in touch on **0808 2080 888**  
or email **[support@bloodcancer.org.uk](mailto:support@bloodcancer.org.uk)**

# Blood, bone marrow and your immune system

It's a good idea to know a bit about blood, bone marrow and your immune system, as your healthcare team will talk to you about them.

## **Blood**

Blood is composed of two parts: a part called plasma, and your blood cells, which are made in the bone marrow. You could think of your bone marrow as being like a factory. This factory needs to make fresh blood cells every day so you can survive, because some blood cells only live for a day or two.

The blood has many important functions:

### Transport system

Red blood cells (erythrocytes) transport oxygen around the body. Inside these red cells is a pigment called haemoglobin that carries the oxygen.

Blood transports other things in plasma, such as food, water and proteins to different parts of your body. Blood also carries waste chemicals to the kidneys and lungs so they can get rid of them.

### Defence system

Defence is a very important function of blood. The defence system is controlled by the white cells, called leukocytes, which are also made in the bone marrow (the soft spongy material inside your bones). The white cells are a part of your immune system and fight infections. There are different types of white cells; the important white cells that you need on a daily basis are called neutrophils, which fight bacteria and fungi.

If you don't have enough white blood cells in your body, or if they don't work correctly, as happens with many types of blood cancer including AML, this can mean your defence system doesn't work as well as it should and you may be more likely to pick up infections.

## Clotting system

Whenever you damage or break one of your blood vessels, there are ways your body will stop you from bruising and bleeding. The initial protection against bruising and bleeding is managed by blood cells called platelets, made by your bone marrow. These live for one or two days, and proteins known as clotting factors help support platelets in stopping bruising and bleeding.

## Communication system

Organs in the body release hormones into the blood which send messages to other organs. This isn't affected by AML.

## How many of each type of blood cell should you have?

Everyone has slightly different numbers of each type of blood cell. If you're healthy, the amount you have of each normally stays within a range, as set out in the table below. This table shows how many of each type a healthy person has:

<b>Blood cell or substance</b>	<b>Levels found in a healthy person</b>
Haemoglobin (Hb) level (for red blood cells)	130–180 g/l (men) 115–165 g/l (women)
Platelets	150–400 x 10 <sup>9</sup> /l
White blood cells (WBC)	4.0–11.0 x 10 <sup>9</sup> /l
Neutrophils	2.0–7.5 x 10 <sup>9</sup> /l
Lymphocytes	1.5–4.5 x 10 <sup>9</sup> /l

Your blood values depend on a number of different things, including sex, age, and ethnicity. Also, different laboratories will use different equipment and testing methods, so normal values can vary slightly from hospital to hospital. So this table should only be used as a rough guide. Your healthcare team can explain what your results mean for you.

## **Bone marrow and how blood cells are made**

All blood cells are made in the soft material inside your bones (called the bone marrow). All blood cells are made from a group of parent cells called blood stem cells.

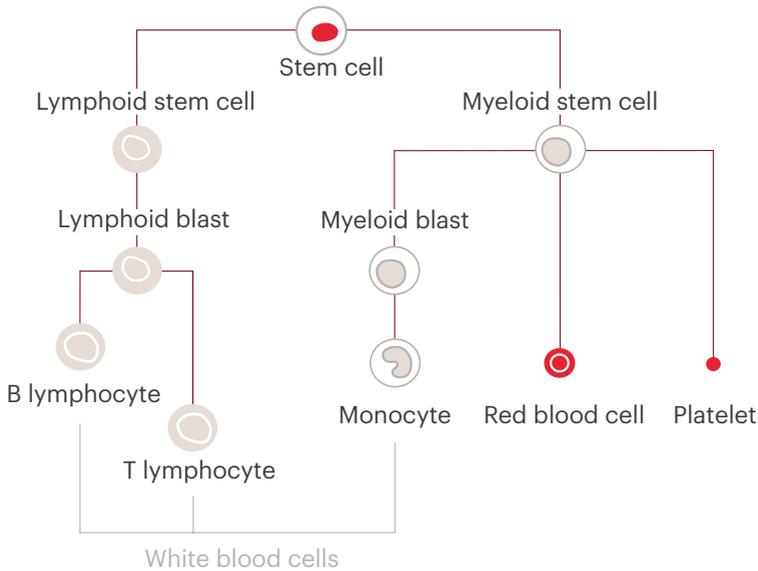
All of us have around 10,000 stem cells. Most of the time these stem cells are asleep. Stem cells live with you for your whole life and are unique because they can make all blood cells. Occasionally they will divide and make cells that are called progenitor cells.

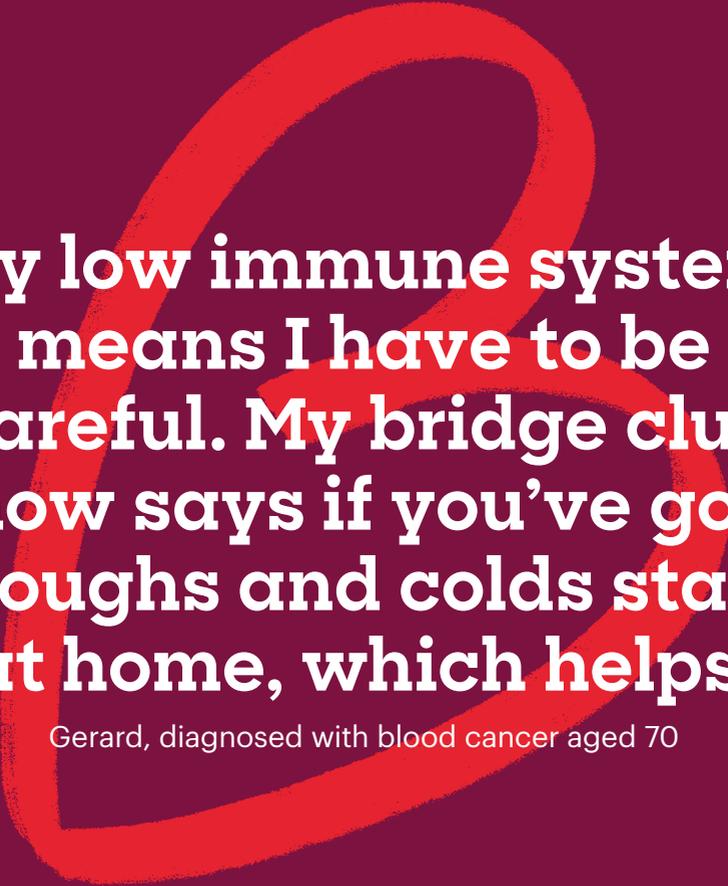
The progenitor cells don't live as long, but they grow a lot and make sure you can make enough blood cells for everyday life.

There are two types of progenitor cells: myeloid and lymphoid. They give rise to immature cells called blasts. These blast cells steadily grow up into mature cells: red cells, platelets and white blood cells, which are then released by your bone marrow into your blood.

We group together some of these blood cells into what are called myeloid cells. Myeloid cells are red blood cells, platelets and all white blood cells, except one type of white blood cell called lymphocytes. It's these myeloid cells that are affected in AML.

### Blood cell production





**My low immune system means I have to be careful. My bridge club now says if you've got coughs and colds stay at home, which helps.**

Gerard, diagnosed with blood cancer aged 70

**Acute myeloid  
leukaemia (AML) is a  
blood cancer which  
affects myeloid cells.**

If you're worried, get in touch on **0808 2080 888**  
or email **[support@bloodcancer.org.uk](mailto:support@bloodcancer.org.uk)**

# What is AML?

Acute myeloid leukaemia (AML) is a type of blood cancer. In AML, the cells in the bone marrow that produce myeloid cells become cancerous.

AML is a form of cancer which affects a type of blood cell called myeloid cells, which include red blood cells, platelets and certain types of white blood cells. When you have AML, it stops you making enough of these blood cells, which makes you unwell. The symptoms you get will depend on the type of blood cell your body isn't making enough of.

As blood cells are made in the bone marrow, the cancer will be present in the bone marrow and in the blood.

## How AML develops

All leukaemias start in stem cells or progenitor cells. This happens when the cells don't mature properly and remain immature. These cells have a distinctive appearance when a specialist looks at your bone marrow cells under a microscope.

Every day we make around 10 billion new blood cells, and the information which controls how these blood cells grow up is held within our DNA. Every time a cell divides, the entire DNA code has to be copied exactly, and mistakes are made by chance.

AML develops when there are errors in the information that controls how blood cells grow up. It usually takes mistakes in several key genes that control blood production to cause AML.

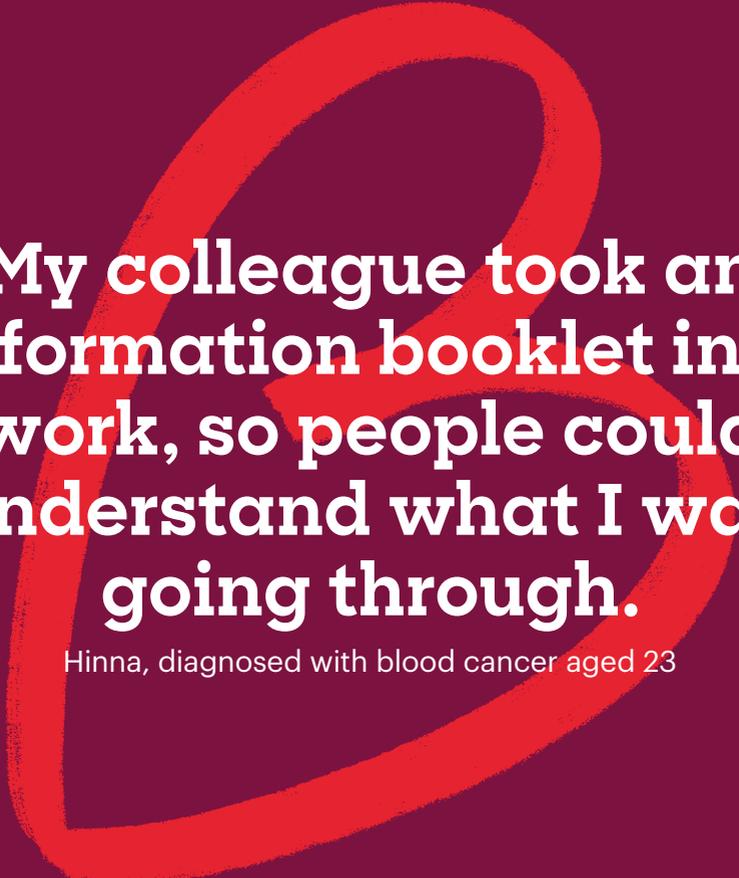
## Types of AML

AML is one of several different types of acute leukaemia. Acute promyelocytic leukaemia (APL, also known as APML) is a type of AML. About 15% of all cases of AML are part of this specific type.

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We have a separate booklet **Acute promyelocytic leukaemia (APL)**. See **page 115** for how to order.





**My colleague took an  
information booklet into  
work, so people could  
understand what I was  
going through.**

Hinna, diagnosed with blood cancer aged 23

**AML can affect anyone.  
There are several factors  
which can lead to AML,  
many of which you  
can't control.**

If you're worried, get in touch on **0808 2080 888**  
or email **[support@bloodcancer.org.uk](mailto:support@bloodcancer.org.uk)**

# Who gets AML?

When you're diagnosed with any cancer, one of the first things you might think is: 'why me?'

In many cases, we still don't know what causes AML. We know that some things that we can't change have an impact on AML, like age and sex. We also know that there are some rare external factors which can have an impact, like exposure to radiation or chemicals. Sometimes, you can also be at an increased risk of getting AML if you've got a related blood condition, or if you've been treated for a different cancer in the past.

## Age

We're now beginning to understand why age is important. As you get older, you have more time to acquire the errors in your DNA which can cause AML. People of all ages can develop AML, but you're more likely to get AML above the age of 60. Around a quarter of people who are diagnosed are under 65.

In some very rare cases, children can develop AML – this is called childhood AML.

## Sex

Slightly more men than women develop AML. We don't know why.

## Family history

In most cases, AML doesn't run in families. However, rarely, in some families there are more cases of AML than we'd expect to occur by chance.

If you're concerned about this, do discuss it with your doctor.

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You can find out more about childhood AML on our website. Go to **[bloodcancer.org.uk/childhood-aml](http://bloodcancer.org.uk/childhood-aml)**



The age you are when you develop AML can have an impact on your treatment – see **page 52** for more information.

## **Radiation and chemical exposure**

Exposure to very high radiation levels increases the risk of developing AML. Hardly anyone is exposed to these levels of radiation in normal everyday life.

Exposure to certain other chemicals could also increase the risk of getting AML. One of these chemicals is called benzene, which is found in cigarette smoke and exhaust fumes. Whilst smoking cigarettes has been reported to increase the risk of getting AML, exhaust fumes don't have enough benzene to pose a risk.

## **Previous treatment**

Some patients can develop AML after being treated for another illness with either chemotherapy and/or radiotherapy.

This type of AML is called treatment-related AML (tAML). Certain types of chemotherapy and radiotherapy are more likely to cause this than others.

Your chance of developing tAML is based on the type of treatment you originally had for the other illness or cancer. The risk of getting tAML is highest between five and eight years after receiving treatment for the other cancer, but some patients can develop it earlier.

## Other conditions

If you have another condition which affects the production of myeloid cells, you can be at higher risk of getting AML. In these cases, the cancer is called secondary AML. This is especially true if you're over the age of 60. Between 25–40% of AML cases in over 60s can be linked to a previous condition. These conditions are called antecedent haematological disorders.

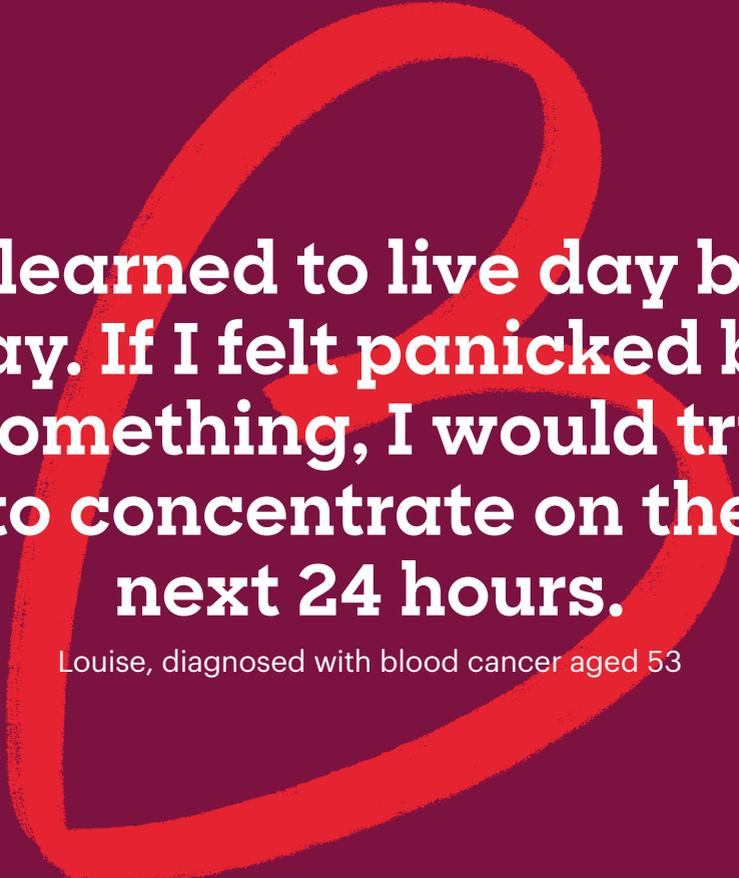
If you feel these disorders are relevant to you or a member of your family, please read our other booklets on myelodysplastic syndromes (MDS) and myeloproliferative neoplasms (MPN).

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We have the separate booklets **Myelodysplastic syndromes (MDS)** and **Myeloproliferative neoplasms (MPN)**.

See **page 115** for how to order.





**I learned to live day by day. If I felt panicked by something, I would try to concentrate on the next 24 hours.**

Louise, diagnosed with blood cancer aged 53

**It's important to remember  
that not everyone will get  
all of the symptoms listed  
- each person is different.**

If you're worried, get in touch on **0808 2080 888**  
or email **[support@bloodcancer.org.uk](mailto:support@bloodcancer.org.uk)**

# Symptoms

If you're diagnosed with AML, there are some symptoms which you might see before your diagnosis. It's important to remember that not everyone will get all of these symptoms. Each individual is different, and will have a different experience.

The most common set of symptoms seen in people who have AML are listed below. These symptoms can happen because the cancer cells are stopping your normal blood cell production.

## **Tiredness**

This is caused by a lack of red blood cells, which results in a lack of haemoglobin (the protein which carries oxygen). This is called anaemia.

This causes:

- tiredness or lack of energy, which you feel much more than usual
- breathlessness, which you might notice when you try to do something like walking, shopping or housework
- chest pain, although this is a rarer symptom.

## **Bruising and bleeding**

This is caused by a low platelet count in your blood.

This can result in:

- being more prone to bruising, which may occur without experiencing any bumps or knocks
- bleeding from your gums – we can all bleed sometimes when we brush our teeth, but this is bleeding more than you'd usually get.

Sometimes, you might not notice bleeding in other body parts because it's somewhere you can't see, like inside your gut. In this case, you may not notice blood in your stool – your stools could just be very black and tarry.

## **Infections**

Infections are caused by a low white blood cell count. This can result in:

- fever
- infections such as pneumonia, urinary tract infections or gastroenteritis
- chest pain, although this is a rarer symptom.

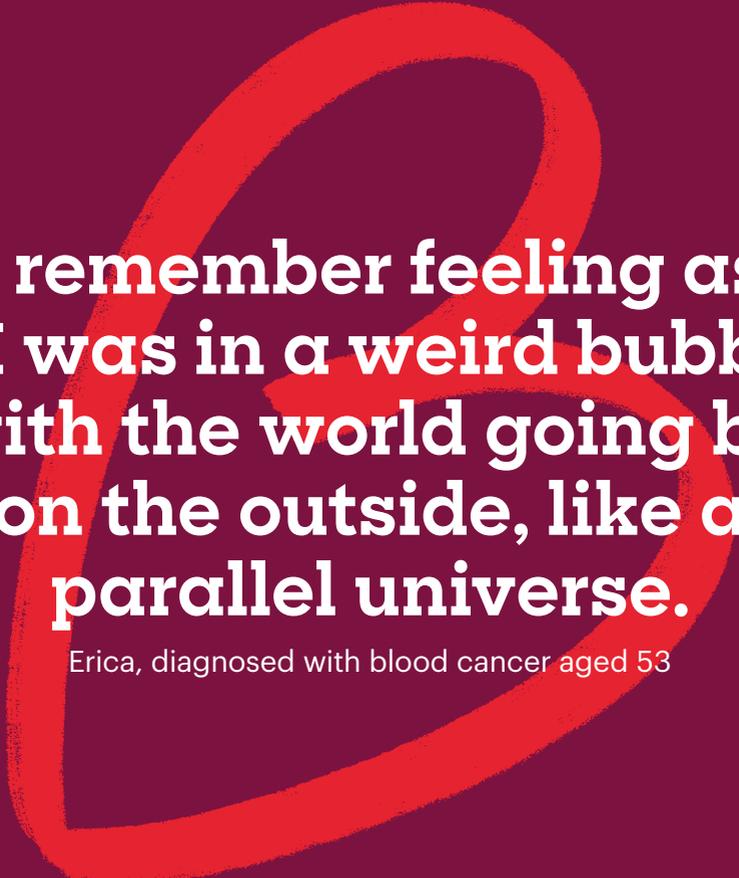
## **Weight loss**

We don't fully understand the link between AML and weight loss, although we do know it's caused by a high metabolism (when your body is quick at changing the food you eat into energy). Sometimes, you can lose weight without changing your diet.

## **Other symptoms**

There are some other, less common, symptoms of AML. These other symptoms include lumps and bumps on your body, known as swollen lymph nodes. Your lymph nodes are bean-shaped organs in several places in the body, including your neck, armpit and groin, that act as filters to catch viruses, bacteria and other foreign materials.

Sometimes patients can also develop chloromas. These happen when a lump of leukaemia cells, known as a nodule, collect within the skin to form a tumour. This is a rare symptom – only 2–3% of patients are affected by chloromas. If you have a chloroma, your doctor will seek a specialist opinion.



**I remember feeling as if I was in a weird bubble with the world going by on the outside, like a parallel universe.**

Erica, diagnosed with blood cancer aged 53

**It's important that you know and understand your diagnosis. You could ask your team to write it in this booklet, so you have it to hand.**

If you're worried, get in touch on **0808 2080 888** or email **[support@bloodcancer.org.uk](mailto:support@bloodcancer.org.uk)**

# Diagnosis

You'll have a set of tests to confirm whether you have AML or not. It's important that you know and understand your diagnosis. It might be a good idea to get your consultant to write it down so you can use it if you're looking for more information or support, or you need to tell other people about it.

If you're diagnosed with AML, you'll have some further tests to determine the right treatment for you. At any time, you can ask your healthcare team to tell you why you're having a certain test and what the results mean.

## Tests for AML

AML can usually be diagnosed with a series of simple and accurate laboratory tests. You'll have several tests to confirm whether you have AML.

Sometimes it can take a few weeks before you get your diagnosis. You may feel anxious whilst waiting for your test results, but it's very important that your doctor takes this time to understand your illness, so that you have the right treatment.

### Full blood count and blood film

A full blood count (FBC) measures the number of each type of cell in the blood: red cells, white cells and platelets. You might be sent for this test by your GP as part of a routine check-up. Other patients might have one when they're in hospital for something else.

If your FBC shows that you might have AML, you'll need to go to hospital for more tests. If you're diagnosed with AML, you'll have regular FBCs to monitor your condition.

A blood film is also taken from a sample of your blood, which your doctor or hospital team use to look at your blood cells under a microscope. This allows them to see if you have any leukaemia cells in your blood.

## Bone marrow aspirate and trephine

In most cases, your doctor will also take a bone marrow sample to see how your blood is working inside your bone marrow.

There's two parts to your bone marrow test. You'll have a bone marrow aspirate, which is where a sample of bone marrow is sucked out from your hip bone using a fine needle. Sometimes this is followed by taking a core of the marrow, using a different type of needle; this sample is also taken from the hip. This test is known as a bone marrow trephine. These tests can be done under local anaesthetic or with mild sedation.

Bone marrow tests provide information about the structure of the marrow and the number and distribution of the different blood cell types – and cancer cells, if present.

You might not have these tests if active treatment isn't appropriate for you. Your doctor will talk to you about this if it's the case.



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You can find more information on tests and scans for blood cancer on our website at [bloodcancer.org.uk/tests](https://www.bloodcancer.org.uk/tests)

## Immunophenotyping and cytogenetics

You'll have tests called immunophenotyping and cytogenetics. These are important because they prove whether you have an acute leukaemia. This genetic information helps your healthcare team decide on suitable treatment options, which they'll discuss with you. Sometimes you might have more genetic tests, but not all people have them.

### Immunophenotyping

Several laboratory tests are done on your blood and bone marrow samples that you've given. The hospital team will look at the cells under a microscope. They'll test whether the cells are leukaemia cells by a technique called immunophenotyping, which counts the number of leukaemia cells and determines whether these cells are myeloid or lymphoid cells. This test can tell your doctors the type of acute leukaemia you have – so if you have AML, acute lymphoblastic leukaemia (ALL), or acute promyelocytic leukaemia (APL).

## Cytogenetics

Leukaemia is caused by genetic errors. Sometimes this happens on a greater scale, which is easy to see under the microscope.

Genes are arranged into structures called chromosomes. We have 46 chromosomes, which can sometimes be broken or rearranged. The hospital team will look to see if this has happened. The study of this is called cytogenetics.



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We have separate booklets **Acute promyelocytic leukaemia (APL)** and **Acute lymphoblastic leukaemia (ALL)**.

See **page 115** for how to order.

## Further tests

Once you've had the results of your diagnostic tests back from the laboratory, you and your healthcare team will have lots of information about your condition. But before and after diagnosis, you might have some other tests.

These tests will give your doctors additional information, and help to measure your medical fitness – which may influence decisions about your treatment.

## Blood clotting system tests

If your doctors suspect you may have AML, you'll have your blood clotting system tested. You need this test because the leukaemia cells may change how your clotting system works, which can affect your body's ability to properly stop bleeding and bruising. This will be one of the first basic tests carried out when you're first admitted to hospital. If the tests show that your clotting system isn't acting normally, you might have acute promyelocytic leukaemia (APL).

If you're diagnosed with APL, your treatment will be different from the treatment for AML.



## General health tests and infection screening

When you're diagnosed with AML, you'll have a general health assessment. This will help work out if you'll be particularly vulnerable to side effects from treatment.

You'll have a range of tests to check your general health, including your heart, liver and kidney function, and tests for HIV and hepatitis B and hepatitis C.

Your healthcare team will talk to you about what the results of these tests mean for your treatment.

## **Classifying AML and risk grouping**

The information from your tests will help to determine which type of AML you have. There's a classification system used by doctors which was created by the World Health Organization (WHO). This divides AML into different groups based on which cells have become abnormal, but you won't hear doctors using this classification with you on a day-to-day basis.

The most important part of classifying AML is risk grouping. This classification is based on the amount of damage to your DNA (also called genetic abnormalities) and the number of leukaemia cells that are still in your bone marrow after your first course of treatment.

### **Risk groups**

In some cases, especially for people having intensive treatment, healthcare teams often try to stratify, rather than classify your condition. Classification means dividing disease into different categories or types, whereas stratifying means defining how severe the leukaemia is. Stratifying helps your healthcare team to understand how the leukaemia might affect you and how easy or difficult it will be to treat.

Stratifying also gives doctors an idea about which treatments will be best for you.

There are three risk groups in AML. Risk often refers to how likely a relapse is (the cancer coming back).

- **Low risk** describes people with a good chance of being cured and a low risk of relapse. Low risk patients won't usually need a stem cell transplant. Occasionally, these patients may have a transplant later, if they do relapse.
- **Intermediate risk** describes people who are neither high nor low risk. Intermediate risk patients may or may not need a stem cell transplant.
- **High risk** describes people who have a high risk of relapse. They'll have the most intensive treatment. High risk patients will often have a stem cell transplant early in their treatment, if it's suitable for them.

Your risk group can change while you're being treated – you can ask your healthcare team for any updates about your condition.



## **Your healthcare team**

If you're diagnosed with AML, your hospital should give you the names and contact details of your consultant, clinical nurse specialist and other members of your healthcare team – there's space to write them at the back of this booklet if you want to.

You can then use these details to contact your team if you have any questions you want to ask when you're not in the hospital.

## Your consultant

All patients with AML are treated by a haematologist – a doctor who specialises in treating patients with blood diseases.

## Your clinical nurse specialist

All cancer patients will be given a key worker, usually a clinical nurse specialist. They'll become important to you as they'll be your key point of contact with the rest of your healthcare team. You may like to have a meeting with your clinical nurse specialist when you're first diagnosed, to discuss your condition. Really make use of your clinical nurse specialist as they'll be with you right through your treatment.

## Your day unit team

There'll be a team of doctors in training and nurses on the ward in the hospital and the day unit. They'll work together with your consultant and clinical nurse specialist to look after you.

## Your multidisciplinary team

When you're diagnosed with something like AML, your condition is discussed at a multidisciplinary team (MDT) meeting. An MDT brings together doctors, nurses and any other specialist staff who will be looking after you.

A senior consultant usually leads the meetings, which are held regularly. They'll discuss the best treatment for you and every aspect of your care, including any changes in your condition.

## Talking to other patients

You might want to ask your consultant or key worker if you can talk to someone who's had the same diagnosis and treatment as you. If you do this, remember that someone else's experience won't always be the same as yours. For example, some patients have side effects from a drug and other patients don't.

You may also want to contact a support organisation – many provide patient meetings or further online support. Your clinical nurse specialist may be able to provide you with details.

## Your other healthcare professionals

It's definitely worth telling other healthcare professionals you see, like your dentist or optician, about your diagnosis and any medication you take.

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You can talk to other people with blood cancer or read their experiences on our forum: **[forum.bloodcancer.org.uk](https://forum.bloodcancer.org.uk)**  
Please see **page 95** for a list of support organisations you can contact.



## Finding out more

After you've been diagnosed, it's worth taking some time to think about what information you want to know, when and how. For some people, this is a way to have some control over what's happening.

- Let your consultant and clinical nurse specialist know how much information you'd like, and in what form. You can always ask for more information later.
- Write down any questions you have and keep them handy for when you see your consultant or key worker. If they can't answer your questions, they'll be able to tell you who to speak to.
- You might prefer to ask your clinical nurse specialist questions rather than your consultant, but do whatever works for you.
- Most patients say they find it useful taking someone with them to consultations. If you'd find it helpful, you could ask them to take notes while you listen. You can choose who to take; it doesn't have to be a family member.

- If you're staying in hospital it might be harder to have someone with you when you speak to your consultant. It might be useful to ask in advance what time the consultant is likely to speak to you, so you can try to arrange for someone to be with you at that time.
- When you're in the clinic or staying in hospital, you may be looked after by a more junior doctor, a senior house officer or a registrar. These doctors have left medical school but are still training to be consultants. They'll be able to answer many of your questions, but if they can't then they'll ask the consultant. All doctors in training are supervised closely by more senior colleagues.
- Some people find that joining a patient support group is helpful. It may be easier to talk to someone outside of your family about your situation and being able to share similar experiences might also help you.

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You can find a list of questions you might want to ask on **page 102**.





**A large part of my job is listening and talking to patients about their fears and other emotions. It's as important as the clinical care.**

Darren, Clinical Nurse Specialist

## **Telling people**

Many patients tell us that keeping in touch with loved ones throughout their illness keeps them going. However, some people may find it stressful having to discuss their condition lots of times with family, friends and colleagues.

You might find it easier to ask a trusted family member or friend to be your 'information person' and ask them to keep people updated on your behalf. Another idea is setting up a blog or Facebook page, so you or different people can post information on it that everyone can read.

## **Telling children and teenagers**

Talking to children and teenagers about your cancer diagnosis can be difficult. There are lots of organisations that are able to support you and offer you advice about how to explain cancer to children of different ages.

Your CNS should also be able to help or refer you to someone else who can help. They'll be able to advise you on things like picking a good time, planning what to say, being honest and tailoring what you say to your child's age.

## Telling your GP

Your team at the hospital will keep your GP informed about your condition and any treatment you're having. They'll usually send your GP a letter with this information. As the patient, you'll often be sent a copy too. These letters can have a lot of medical terms in them which you might not have heard before, or there might be something in it which worries you. If this is the case, let your hospital or GP know – a quick chat with them might help to reassure you.

## Cancer and work

If you have your treatment as an inpatient in the hospital, you should tell your employer about your diagnosis, as you'll need time off work. It can be hard asking for time off at short notice if no one knows about your illness, and your colleagues and human resources department might be able to offer support and information about benefits you might be entitled to.



There's more information about cancer and how it can affect your work or study on **page 89**.

Macmillan Cancer Support also has information on talking to children about cancer. Go to **macmillan.org.uk** then search for 'talking to children and teenagers'.

**The type of treatment  
you have for AML will  
depend on your age,  
medical fitness and  
your risk of relapse.**

If you're worried, get in touch on **0808 2080 888**  
or email **[support@bloodcancer.org.uk](mailto:support@bloodcancer.org.uk)**

# Treatment

Throughout your treatment, your healthcare team will always discuss your treatment options with you. You'll be able to give your opinions and preferences and ask questions.

If at any point you're feeling anxious, or you have questions but don't feel confident about approaching your healthcare team, speak to our Support Services Team. They're here to listen and help you through your diagnosis, treatment and beyond.



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We have general information managing your treatment at **[bloodcancer.org.uk/treatment](https://bloodcancer.org.uk/treatment)**

## Treatment planning

Treatment planning looks at whether a certain treatment would cause you more harm than good. The most important factors in treatment planning are:

- whether you're fit and well enough to receive intensive chemotherapy and whether you'd benefit from this
- whether doctors think there's a high risk that the AML will return (a relapse) following standard treatment
- whether there is targeted therapy available for your specific type of AML
- your opinion on which treatments you want to receive.

Everyone is different, so your doctor will consider these factors – factors which determine your 'fitness for treatment' – on an individual basis.

## Age and fitness

The biggest factor in determining your fitness for treatment is your age. If you're over 60, some extra factors might affect how the AML is treated.

Doctors are more cautious about giving more intensive treatment to people over 60 because your age can affect how well your body responds to

treatment or deals with toxic drugs. As each person is different, doctors can't always say how age will affect your fitness for treatment. For example, a younger person with other medical problems might be less suitable for intensive treatment than a very fit but much older patient. Your healthcare team will bear all of this in mind when discussing your treatment options with you.

## **Risk of relapse**

Your healthcare team will monitor your risk of relapse carefully throughout your treatment. The likelihood of you relapsing might change depending on which treatments you have.

A relapse is when the leukaemia comes back. This happens when the amount of leukaemia is reduced through treatment but not completely removed. Patients with a higher chance of relapse at diagnosis are more likely to have a stem cell transplant earlier in their treatment.

Many factors determine the risk of relapse. This will be assessed by your healthcare team initially when you're diagnosed, and it's often reassessed after each course of treatment.



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There's more information on relapse on **pages 75-76**.

## Clinical trials

It's really important that doctors keep trying to find the best way to treat AML. One way that cancer treatments have improved is by testing drugs. This involves comparing the best current drugs used, against those that are at least as good, and may be better. This is done through a clinical trial.

The UK has the largest AML clinical trials in the world and this has allowed the UK to lead in finding better treatments for AML. These trials are run by the NHS, and most patients in the UK with AML are asked to join a clinical trial (90% of patients under the age of 60 enter one). The trials are designed by senior clinicians who are specialists in AML.

Thanks to clinical trials, there's been a big improvement in outlook and treatment over the last 40 years. To decide what the next trial will be, clinicians look at the studies that have taken place in the UK over the last few years. AML studies currently have three main aims:

- to increase the number of patients who are cured
- to introduce safer and more effective treatments for people with AML
- to minimise the side effects of treatment.

Being in a clinical trial means you'll have the opportunity to have the newest available treatment, which may not be given outside of the trial. You'll still receive the normal care that the NHS provides whilst you're taking part in the trial. Your safety and wellbeing is always the first priority – you'll be very closely monitored and have detailed follow-up.

If you're eligible for a clinical trial, you'll be asked if you'd like to consider taking part at the start of your treatment. Your clinician will know which trial is appropriate for you and give you more detailed information.

Taking part in a clinical trial does come with uncertainties, and you may prefer not to take part in one. If you don't want to take part in a trial, you'll be offered the best treatment available at that time, which is suitable for your individual condition.



You can find out more about clinical trials at  
**[bepartofresearch.nihr.ac.uk](http://bepartofresearch.nihr.ac.uk)**

## **Reviewing treatment planning**

Throughout your treatment, decisions will be continuously reviewed with you. Your healthcare team will make sure they give you as much information as you want and need about the advantages and disadvantages of all available treatments and how long-term side effects can be treated.

## **Types and phases of treatment**

The most important decision about your treatment is whether you have intensive treatment or non-intensive treatment.

Intensive treatment involves strong chemotherapy drugs (which kill leukaemia cells), sometimes given with targeted therapy drugs (which interfere with the way leukaemia cells grow). The aim of intensive treatment is to cure the AML. This approach is split into two parts called remission induction therapy and consolidation therapy.

Non-intensive treatment usually involves gentler chemotherapy. The aim of non-intensive treatment is not to cure the patient but to give them the best quality of life for as long as possible.

## Supportive care

As well as the active treatment you'll receive to reduce the leukaemia, all patients receiving both intensive and non-intensive therapy will have a type of treatment called supportive care.

Supportive care is treatment to reduce infections, provide blood and platelet transfusions, and, in some cases, medicines to reduce bruising and bleeding.

Some people offered non-intensive treatment might decide not to go ahead with chemotherapy. This would mean you'd only receive supportive care, which will focus on helping your body to deal with the difficulties it's having in making functioning blood cells.



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We have fact sheets **Understanding infection** and **Blood transfusions** – see **page 115**.

## Intensive treatment

Although each patient is treated on an individual basis, intensive chemotherapy is normally appropriate if you're under 75 years of age and you have good medical fitness.

You'll have intensive treatment in two phases called remission induction therapy and consolidation therapy. This treatment involves strong chemotherapy, sometimes with targeted therapy drugs. The treatment often successfully kills the leukaemia cells, but it's associated with more severe side effects.

You'll usually have three to four courses (sometimes called blocks or cycles) of treatment over four to six months. Each course lasts a few days, and you'll normally recover from each course in about three to six weeks.

You'll have most of your remission induction and consolidation treatment as an inpatient in hospital, but nearly all patients will get some time at home, even if it's just for a few days.

Most patients get to go home for a week or so in between courses, usually just after chemotherapy has finished. During this time you'll be monitored closely a couple of times a week. If you need them, you'll be given blood and platelet transfusions, to support your body and reduce some of your symptoms.

### Remission induction therapy

The remission induction phase aims to clear leukaemia cells from your blood and bone marrow and quickly get your bone marrow working normally again. This treatment involves a combination of chemotherapy drugs and sometimes targeted therapy drugs.

You'll usually have two courses of chemotherapy in this phase of your treatment. The chemotherapy will be given to you by intravenous (IV) infusion, into a large vein in your arm via a long, flexible tube. There are two types of line that may be used for the infusion:

- a PICC (peripherally inserted central catheter) line, which will go through a vein in your arm at the end of your elbow
- a tunnelled central venous line (also known as a Hickman line), which will go into a vein under your skin in the upper part of your chest.

## Consolidation therapy

After you've finished remission induction therapy, you'll start on consolidation therapy. The aim of this phase of treatment is to reduce your risk of relapse. Without consolidation therapy, there's a higher risk of relapse in the year after your initial treatment.

During consolidation therapy, you'll have more chemotherapy – usually one or two courses. You may also continue to have targeted therapy.

Some patients will also have a stem cell transplant. If you do have a transplant, you might not have any more chemotherapy after your remission induction treatment, or you might just have one more course.

There are lots of different options for consolidation therapy, which are chosen on an individual basis. You'll get to discuss this with your consultant.

## Targeted therapy

You may also be given targeted therapy drugs as part of your induction and consolidation therapy. There are two types of targeted therapy drug offered to people with AML: gemtuzumab and ozogamicin (Mylotarg®) and midostaurin (Rydapt®).

If the immunophenotyping tests you have at diagnosis detect a protein called 'CD33' on the surface of your leukaemia cells (most people with AML have this), your doctors may recommend that

you also have gemtuzumab ozogamicin alongside chemotherapy. Gemtuzumab ozogamicin is given through an intravenous (IV) infusion on specific days of your induction therapy and consolidation therapy.

If you have a mutation called 'FLT3' (between 25% and 30% – just under a third – of people with AML have this) your doctors may recommend that you have midostaurin with chemotherapy. You'll have tests to check for this mutation during the first week following your diagnosis. Midostaurin is a tablet that you take twice a day for two weeks just after each course of induction and consolidation therapy.

### Liposomal chemotherapy

If you have AML caused by treatment you've had for another cancer or related condition, or your doctor has identified changes in your bone marrow known as myelodysplasia-related changes, you may be offered a different type of chemotherapy to the one that's usually used for induction and consolidation therapy, called 'liposomal chemotherapy'. It's given in the same way as standard chemotherapy – by intravenous (IV) infusion, into a large vein in your arm.



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For more information on stem cell transplants, see **page 65**.

Liposomal chemotherapy is given over three days during your first course of induction therapy. Some patients will then have a few more days of treatment during subsequent courses of induction and consolidation therapy.

### Remission after intensive treatment

Your doctors will measure how well you've responded to treatment. During treatment you'll have blood tests to see if your blood looks normal and if your blood cell count is normal. You'll then have another bone marrow sample taken, to see if this looks normal too. You'll have other genetic tests, similar to the ones you had when you were diagnosed, to look for any changes treatment has caused.

If your intensive treatment is a success, this is called remission. In remission, your bone marrow produces blood cells normally and you'll have fewer than 5% of blast cells in your bone marrow. The DNA in your cells will also be back to normal.

If you have the FLT3 mutation, after achieving remission you'll continue to take midostaurin on its own to help stop the cancer coming back.

## Non-intensive treatment

Non-intensive treatment involves low doses of chemotherapy. Non-intensive treatment can be less effective in guaranteeing long term remission but it's much less toxic. This may be a better option if you're older or have other medical problems.

There are a number of different options for non-intensive treatment which vary from person to person, and no one treatment is better or worse than any other. A number of different drugs can be used and most people will be offered the chance to take part in a clinical trial.

Your treatment, and the way it's given, will usually be tailored to your individual circumstances and aims for you to be able to spend as much quality time outside of the hospital as possible. You'll have most of your treatment as an outpatient, but you'll have regular assessments with your hospital healthcare team.



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There's more information on clinical trials on **page 54**.

## Treatment to prevent central nervous system relapse

Very rarely, patients have problems with how their nervous system is working. This happens because the leukaemia cells pass into the fluid that surrounds the brain and spinal cord (cerebrospinal fluid, or CSF). If this is the case for you, some of the symptoms you may get include loss of strength and problems with your vision or senses.

On these rare occasions, your doctors will take a sample of fluid to be tested. This is done through a procedure called a lumbar puncture.

During a lumbar puncture, the doctor will take a small sample of your CSF. A very fine needle is carefully inserted between the bones of the lower spine (backbone) under local anaesthetic.

If the tests show that you have leukaemia cells in your CSF, you'll need a series of regular lumbar punctures. The process will be very similar to the procedure for getting a sample, but instead of fluid being taken from your CSF, a chemotherapy drug will be injected into your CSF to help treat and kill the leukaemia cells. Your doctor will talk to you about this type of treatment if you need it.

## Stem cell transplants

In some people, leukaemia is best cured by having a stem cell transplant. This is where a patient receives chemotherapy to reduce the leukaemia in their bone marrow, then receives blood stem cells from another healthy individual (a donor).

### Stem cell transplants in intensive treatment

You may be offered a stem cell transplant if you're having intensive treatment, but only if the benefit of having a transplant outweighs the risk. This is usually based on your risk grouping.

- In **low risk patients**, the benefit doesn't normally outweigh the risk, so you won't usually be offered a transplant. In the small number of low risk patients that do have one, or for those who relapse, the transplant will usually happen later on in your treatment schedule.
- For **intermediate risk patients** the situation is more complex, and an individual decision will be made between you and your healthcare team.
- In **high risk patients**, the benefit often outweighs the risk, and these patients are usually considered for a transplant early on, after consolidation chemotherapy.

## Stem cell transplants as a relapse option

You may have the option of having a stem cell transplant as part of your relapse treatment.

Patients who are under 70 in second remission (the leukaemia has gone for the second time) will be considered for a stem cell transplant, but this depends on your individual fitness and the consultant you're seeing.

There are some patients over the age of 70 who may be able to have a reduced intensity transplant if they're medically fit enough. These types of transplants have been developed to make the transplant more manageable with fewer long term side effects.

If a transplant may be too risky for you, you'll be able to discuss this with your healthcare team. It might be that you could take part in a clinical trial.

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We have a booklet about stem cell transplants called **Blood stem cell and bone marrow transplants: The seven steps**. See **page 115** for how to order.



You can find more information on risk groupings on **page 40**.

## Palliative care

Throughout your treatment, you might have contact with a palliative care team – they're also known as a support care team. They're experts in managing your symptoms and improving your quality of life. They'll be able to support both you and family members.

You'll also need to take care of your general health – your palliative care team will be able to help here.

## Side effects

There are many long-term and short-term side effects of treatment. Different people have different responses to their treatment. Even if two patients are receiving the same course of treatment, they might have a different experience. So you might not get all, or even any, of these side effects – try to bear this in mind when reading about them. If you have any questions, you might like to discuss it with your healthcare team. We cannot list every possible side effect here, so if you experience any side effects, do tell your doctor or nurse.

## Short-term side effects of intensive treatment

Short-term side effects can last for a few days or weeks – for some people they last for the length of their treatment. Sometimes you may get these side effects after your treatment.

Typical side effects include:

- fatigue (see page 60)
- nausea (feeling sick) and vomiting: these symptoms can be well-managed – you’ll receive anti-sickness drugs so this isn’t usually a problem for many patients
- loss of taste – which can lower your appetite
- hair loss – some patients consider wearing a wig during this time but ask your healthcare team about different options
- diarrhoea – this symptom is common but can be well-managed with tablets

- infections – all patients with AML will at some point get infections which will require time on antibiotics in hospital
- rashes
- damage to organs – such as the kidneys, liver or lungs
- nerve damage, which may last for longer – this is a rare symptom.

As well as killing the leukaemia cells in your bloodstream, intensive treatment for AML will also reduce the number of healthy blood cells that your bone marrow produces. To combat this, you'll have regular blood and platelet transfusions to top up your blood with healthy cells.



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We have information on looking after yourself physically and emotionally at **[bloodcancer.org.uk/living-well](https://www.bloodcancer.org.uk/living-well)**.

## Long-term side effects of intensive treatment

Long-term side effects can last for months or years. Some may not even occur until years after treatment has finished – these are known as late effects.

### Infertility

You might be worried about the effect of your treatment on your fertility. It's a common concern that many patients have, and one that also impacts on their partners and families too. If you're having treatment for AML at an age when you're thinking about having children or you think you might like to have children in the future, then it's a good idea to discuss the options for protecting your fertility with your doctor.

Some chemotherapy drugs may have a temporary effect on fertility. Permanent infertility is most likely in patients who've had a stem cell transplant after high doses of chemotherapy or whole body irradiation.

It's natural to worry about the effects of treatment on any children you might have after your treatment. Lots of evidence from clinical studies has shown that any cancer treatment a parent has doesn't lead to an increased risk of cancer or other health problems in their children.

## Developing other conditions

It's possible for people to develop other cancers and blood disorders due to their treatment for AML. This can affect 2–5% of patients. This usually occurs five to eight years after treatment.

Modern treatment methods have been designed to reduce the use of drugs and radiotherapy which cause secondary conditions, meaning that the risks of developing these conditions are now much lower.

## Heart damage

Anthracyclines are a group of chemotherapy drugs used to treat AML. These drugs join with the DNA in your cells and damage the DNA's structure. They're especially effective against cells which divide quickly, like cancer cells.

Anthracyclines can cause damage to your heart. However, this side effect is uncommon because healthcare teams are careful to limit the doses you have.

## Side effects of non-intensive treatment

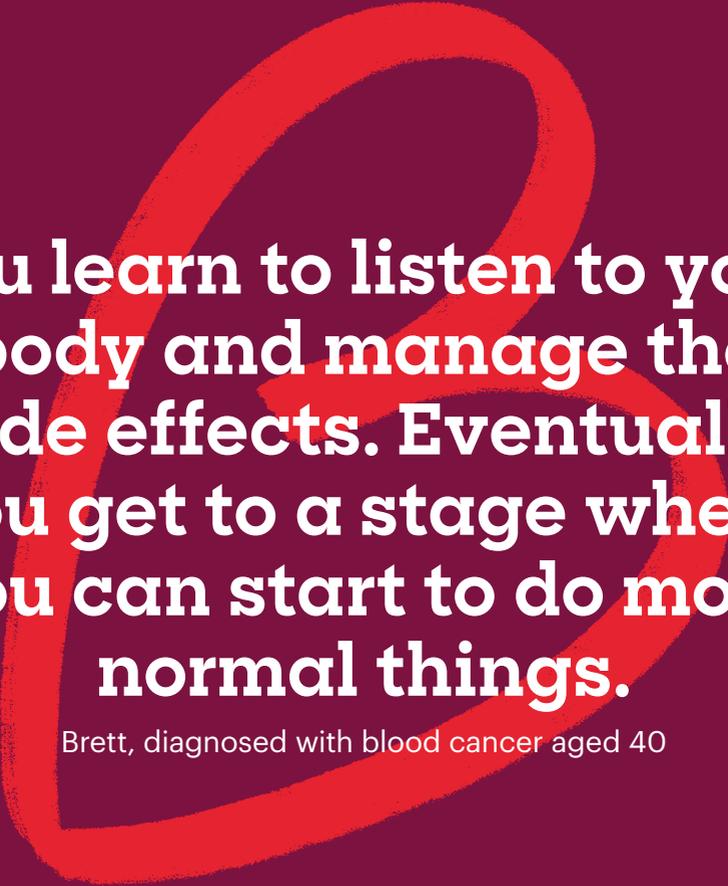
The main side effects of non-intensive treatment include:

- being more vulnerable to infections
- fatigue
- being more prone to bleeding and bruising.

Some of the other side effects of non-intensive treatment are similar to those for intensive treatment, but they'll be much milder or they may not happen at all. They include:

- milder nausea
- chance of hair loss
- problems with your gut.

You'll see your healthcare team regularly, so if you're having any side effects you should tell them, as they might be able to help you cope.



**You learn to listen to your  
body and manage the  
side effects. Eventually  
you get to a stage where  
you can start to do more  
normal things.**

Brett, diagnosed with blood cancer aged 40

## Follow-up

Your follow-up will mostly involve looking out for signs of relapse and treatment complications.

For the first year after your treatment, you'll normally have a check-up every one to two months. After one year, your check-ups will get less and less frequent, until you have them every year at five years and onwards.

It's also common for your follow-up to include tests of your bone marrow using a bone marrow aspirate test, like you had when you were diagnosed. These help doctors to monitor your levels of leukaemia cells.

Long term follow-up is really important if you've received treatments that may affect the function of your vital organs. Your doctor will discuss this with you, if this is the case for you.

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For more information on bone marrow aspirate tests, see **page 35**.





## Relapse

For some patients having intensive treatments, and for all having non-intensive treatment, there's a risk of relapse.

Relapse means the cancer comes back. On average, this may affect around half of all patients who achieve a remission after their initial treatment, but every patient has different risk factors. The chance of relapse depends on the initial risk group you are in at diagnosis (see page 29). Unfortunately not all patients who relapse will always respond well to more treatment.

Specialists can predict how successful more treatment will be by looking closely at the leukaemia cells. Using this information, you and your healthcare team can decide on the best way forward for your treatment.

## Relapse treatment

The treatment for relapsed AML varies from patient to patient. Before you have any treatment, you'll discuss your options with your healthcare team to find the best treatment for you. Lots of different factors can influence which treatment you have, including your age, your medical fitness, and how long you were in remission for.

The main decision you and your healthcare team will have to make when you decide on your treatment is whether you'd like to use intensive treatment, which aims to cure the disease, or non-intensive treatment, which aims to give the best quality of life for as long as possible. Treatment might involve more chemotherapy or a stem cell transplant.

Achieving a cure is more common in patients whose first remission lasted a long time, who are medically fit, and who can have a stem cell transplant.

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For more information on stem cell transplants in relapse see **page 66**.



## Palliative care in relapse

If the doctors feel that more treatment isn't likely to succeed, you may be advised that palliative care is more appropriate than intensive treatment. Your doctor will discuss the options with you in detail before you decide on a treatment plan.

Palliative care will lessen your symptoms and control the disease rather than looking for a cure. It's really important to note that palliative care is not the same as terminal care. Palliative care aims to extend survival as well as controlling your symptoms.

**Every person is individual,  
so your consultant and  
healthcare team are the  
best people to ask about  
your likely outlook  
(your prognosis).**

If you're worried, get in touch on **0808 2080 888**  
or email **[support@bloodcancer.org.uk](mailto:support@bloodcancer.org.uk)**

# The outlook

Each patient with AML will have a different outlook, which depends on a range of factors. These include your age and medical fitness, whether your disease is low or high risk, and whether the cancer is primary or secondary.

## **Your prognosis**

Patients in the low risk group who are treated without a stem cell transplant have about a 70–90% chance of long term survival (surviving to five years after remission). High risk patients tend to have a poorer prognosis, although some of these patients do particularly well with a stem cell transplant. For people who aren't medically able to have intensive treatment, the goal is not to achieve a cure, but to improve the length and quality of life.

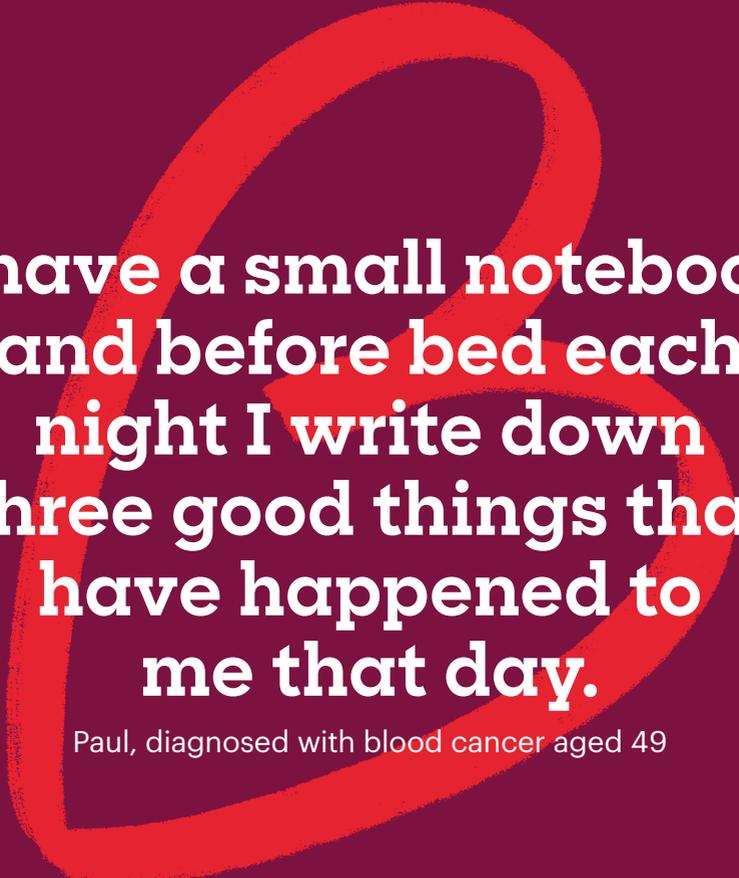
AML that's developed because of previous treatment for another cancer and other forms of secondary AML (see page 17) are usually more difficult to treat with standard chemotherapy. This means that they have a poorer overall prognosis compared with primary AML, which is why stem cell transplants are usually considered as a treatment option.

## Talking about your prognosis

You may find it hard to ask or talk about your prognosis. Sometimes those close to you might want to know your prognosis even if you don't. However, your healthcare team aren't allowed to give this or any other information to anyone – not even family members – without your permission. Try to decide early on who you want to know about your condition, then tell your healthcare team – you can change your mind any time.

Remember that your outlook might change, for example, if you respond well to treatment. If there's a change in your condition, or if you've finished all or part of your treatment, you might want to consider asking if your prognosis is still the same.

Our Support Services Team can talk to you about any questions you have about outlook. Contact us on **0808 2080 888** or **support@bloodcancer.org.uk**



**I have a small notebook  
and before bed each  
night I write down  
three good things that  
have happened to  
me that day.**

Paul, diagnosed with blood cancer aged 49

**Your healthcare team  
should look after your  
emotional needs, as well  
as your physical ones.**

If you're worried, get in touch on **0808 2080 888**  
or email **[support@bloodcancer.org.uk](mailto:support@bloodcancer.org.uk)**

# Everyday life and AML

If you've been diagnosed with AML you might experience a range of emotions at different times. There can be a physical impact on your day-to-day life too. This section will guide you through both aspects.

## **Looking after yourself emotionally**

Being told that you have cancer can be very upsetting and will almost certainly bring many different emotions. Friends and family may be able to offer support, but it may be harder for them to understand the long term emotional impact that you might experience.

Your healthcare team should consider your emotional, as well as physical, needs – this is called a holistic needs assessment. You'll have one a few times throughout the course of your treatment and beyond, as your emotional needs might change

## **Looking after yourself physically**

### **Changes in your condition**

Your condition might change over time – your healthcare team will be able to talk to you about this and offer advice. Always keep your healthcare team updated about any new or changed symptoms you have after you're diagnosed.

### **Keeping active**

You might feel tired (fatigued) a lot. This is caused by your AML and isn't the same as normal tiredness which improves with rest and sleep.

While even the idea of doing something can be tiring if you've got fatigue, try to keep as active as you can because evidence shows that this could help to make your symptoms less severe.

Although staying active may help, there's no evidence that any particular exercise programme can improve your condition or how you respond to treatment.

## Diet

Similarly, there's no evidence that any special diet will improve your condition or how you respond to treatment. However, you're likely to feel fitter and healthier if you follow general advice on good diet from your hospital or GP.

Because your immune system may not be working as normal, you'll need to take extra care to avoid infections that you might get from food. Your body won't be able to destroy germs and resist infection as easily, so be careful about handling food safely and cooking things thoroughly.

Your healthcare team will usually include a dietician. Your dietician may ask you to go on a neutropenic diet. This is a diet for people with a weakened immune system, which can minimise your risk of infection from food. Those who will be receiving a stem cell transplant will usually be advised about following a stricter diet than those who are receiving non-intensive treatment or palliative care.



Our booklet **Eating well with neutropenia** is for people who've been advised to follow a neutropenic diet. See **page 115** for how to order.

## Vaccination

It's a good idea for all AML patients to have the flu vaccine each year – your GP might contact you about this but if they don't then you can request the vaccine yourself. It might not work as well for people with AML, but will still offer some protection.

If you have AML, avoid having any live vaccines during your active treatment. Fortunately only a few vaccines used in the UK are live. The most commonly used ones are MMR (measles, mumps and rubella) and shingles. The yellow fever vaccine, occasionally needed for travel to certain areas, is also a live vaccine.

## Shingles

Shingles is the infection of a nerve and the skin around it. It can affect you if you've had chickenpox, even if you had it a long time ago, as it's caused by the same virus which can lie dormant in your body for years. You're more likely to get shingles if your immune system isn't working well – for example, if you have AML.

Shingles has some quite obvious symptoms. If you think you have it, let your GP or specialist know as quickly as possible (within 24 hours of the rash appearing is best). If it's treated early, the symptoms won't be as bad. Symptoms include:

- a rash, normally on one side of your body
- an itching, tingling or burning feeling
- pain where the rash is
- blisters filled with fluid which burst and form sores which then crust over.

You can't catch shingles from someone who has it, but you can catch chickenpox from someone with an open shingles sore, if you haven't had chickenpox already.



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You can read about the experiences of other people who are going through similar experiences on our online community forum at **[forum.bloodcancer.org.uk](https://forum.bloodcancer.org.uk)**

## **Alternative and complementary therapies**

There's an important difference between alternative therapies, which are offered in place of medical treatment, and complementary therapies, which are used alongside standard treatment.

We don't recommend that you use any alternative therapy in place of proven medical care.

Always let your healthcare team know about any complementary treatments you're using or thinking of using. They might advise you to avoid certain therapies because of specific risks to do with your AML or the treatments you're receiving. In other cases they might say a therapy is OK as long as you take specific precautions.

### **Herbal medicines**

Herbal preparations might be safe for a healthy person but they could be dangerous when combined with your chemotherapy.

### **Acupuncture**

If you're considering acupuncture, remember that you're at a heightened risk of bleeding and bruising. This may make acupuncture inadvisable. Before having any type of acupuncture, it's a good idea to discuss this with your doctor.

## Practical support

### Work, education and home life

If you work or are studying you will need to contact your employer or college, or ask someone to do it for you. Most will do everything they can to help.

You might need to make appropriate arrangements with your employer or college at the time when you're diagnosed so you can have time off when you need to be at the hospital. If you have to stay in hospital for your treatment, or you're not well enough to go to work or college, you'll need to make a more formal agreement.

You might also need to make appropriate domestic arrangements too. This might include things like having a family member, friend or another person who can make sure you get sick pay, start investigating any benefits you might be entitled to, or make sure your bills keep being paid whilst you're being treated.

You might need to bring in written proof of your diagnosis from your healthcare team, which makes clear the effect AML could have on your ability to work or study.

If you're a parent or a carer, you may need support during your treatment. You might have unplanned stays in hospital so it's helpful to have plans in place just in case.

## Cancer and the law

People with cancer, or any other serious disease, are covered by a law called the Equality Act – for the purposes of the Act, cancer is considered a disability. This means that employers and places of study are required by law to make reasonable arrangements for 'people with disabilities' and can't discriminate against you. An example of a reasonable arrangement would be if you need time off to go to hospital for treatment. Your employer or college has to allow this and isn't allowed to reduce your pay or make you take the time as unpaid leave.

## Getting to hospital

If you're being treated as an outpatient (not staying in overnight) you might need to be at the hospital a lot over a long period of time. If you find this hard because of transport or any other reason, you can ask your consultant if you can have any of your treatment nearer to where you live. It might not always be possible but sometimes it is – it depends on the healthcare facilities close to your home and the type of treatment you're having.

If this isn't possible and transport is a problem, you can ask about hospital transport. Hospital transport can be restricted, but you should ask your doctor about their hospital policy. You might also be able to claim a refund from the hospital for what it costs you to travel to your appointments. If you'd like to find out more about this support, you can speak to your team at the hospital or a benefits advisor.

## Financial support

Your finances might be the last thing on your mind if you've just been diagnosed with cancer, but there are lots of places you can get help and advice.

Your hospital will normally have medical social workers or welfare rights (benefits) advisors who can advise on which benefits you might be able to receive. These might be especially useful if you're on a low income or you're unemployed. If you're worried you can ask to speak with an advisor as soon as possible after your diagnosis. Alternatively, your hospital might be able to arrange for an advisor from somewhere else to visit you.

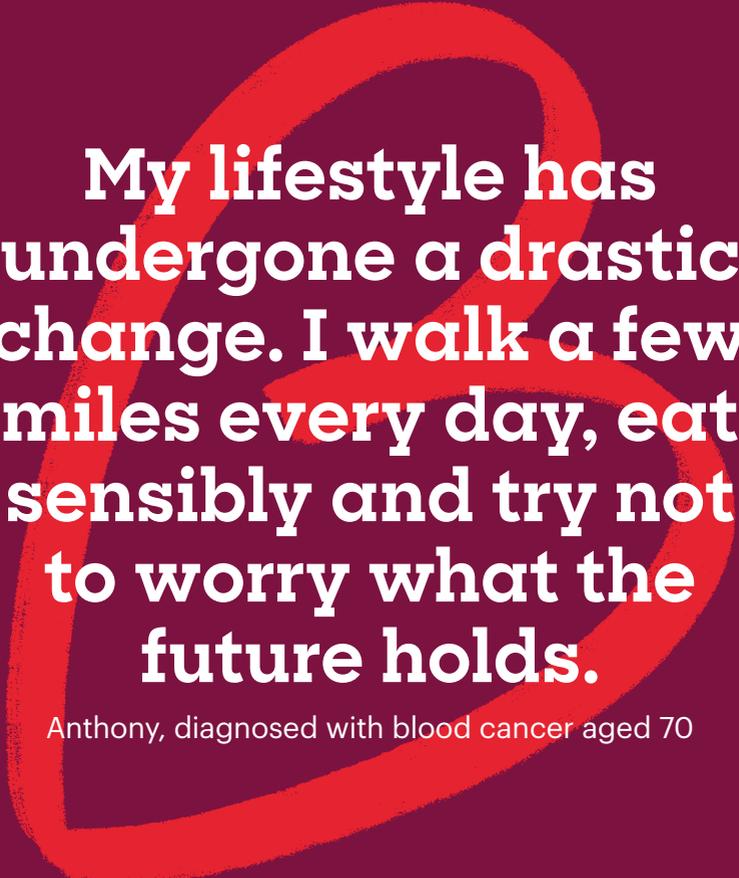
There are many organisations who can help and advise you about benefits and can offer other practical advice about work, as well as providing emotional and social support.

If you normally pay for your prescriptions but you're being treated for cancer (including the effects of cancer or the treatment) you can apply for a medical exemption certificate (valid for five years) for any drugs you need for these reasons. Application forms are available from your GP surgery or hospital clinic.



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Our Support Services Team offers emotional and practical support to anyone affected by blood cancer. Contact us on **0808 2080 888** or **support@bloodcancer.org.uk**



**My lifestyle has  
undergone a drastic  
change. I walk a few  
miles every day, eat  
sensibly and try not  
to worry what the  
future holds.**

Anthony, diagnosed with blood cancer aged 70

**Blood Cancer UK offers information and support to anyone affected by blood cancer. You'll find other useful organisations listed here as well.**

If you're worried, get in touch on 0808 2080888 or email **[support@bloodcancer.org.uk](mailto:support@bloodcancer.org.uk)**

# Places you can get help and support

## Blood Cancer UK

We are here for anyone affected by blood cancer, whether it's you who's been diagnosed or someone you know.

We offer free and confidential support by phone or email. We provide information about blood cancer and life after a diagnosis. And we have an online forum where you can talk to others affected by blood cancer.

- [bloodcancer.org.uk](http://bloodcancer.org.uk)
- 0808 2080 888
- (Mon, Tue, Thu, Fri, 10am–4pm, Wed, 10am–1pm)
- [support@bloodcancer.org.uk](mailto:support@bloodcancer.org.uk)
- [forum.bloodcancer.org.uk](http://forum.bloodcancer.org.uk)

## General information and support

### Macmillan Cancer Support

Offers practical, medical, financial advice and emotional support.

- 0808 808 0000
- [macmillan.org.uk](http://macmillan.org.uk)

### Cancer Research UK

Offers information about different conditions, current research and practical support.

- 0808 800 4040
- [cancerresearchuk.org](http://cancerresearchuk.org)

### Leukaemia Care

Offers information, a support line and support groups for people affected by leukaemia and other types of blood cancer.

- 08088 010 444
- [support@leukaemicare.org.uk](mailto:support@leukaemicare.org.uk)
- [leukaemicare.org.uk](http://leukaemicare.org.uk)

## African Caribbean Leukaemia Trust (ACLT)

The ACLT aims to increase the number of black, mixed race and ethnic minority people on the UK Bone Marrow Register by raising awareness and running donor recruitment drives.

- 020 3757 7700
- [info@aclt.org](mailto:info@aclt.org)
- [aclt.org](http://aclt.org)

## Anthony Nolan

Runs the UK's largest stem cell register, matching donors to patients with leukaemia and other blood related disorders who need a stem cell transplant.

- 0303 303 0303
- [anthohnolan.org](http://anthohnolan.org)

## Maggie's

Centres across the UK, run by specialist staff who provide information, benefits advice and psychological support.

- 0300 123 1801
- [enquiries@maggies.org](mailto:enquiries@maggies.org)
- [maggies.org](http://maggies.org)

## Marie Curie

Runs nine hospices throughout the UK and offers end-of-life support to terminally-ill patients in their own homes, free of charge.

- 0800 090 2309
- [mariecurie.org.uk](http://mariecurie.org.uk)

## MedicAlert

Offers personalised jewellery that provides vital medical information to emergency professionals.

- 01908 951045
- [info@medicalert.org.uk](mailto:info@medicalert.org.uk)
- [medicalert.org.uk](http://medicalert.org.uk)

## Teenage Cancer Trust

Offers a range of information, advice and practical support to younger people diagnosed with cancer.

- 020 7612 0370
- [hello@teenagecancertrust.org](mailto:hello@teenagecancertrust.org)
- [teenagecancertrust.org](http://teenagecancertrust.org)

## Financial advice

### Citizens Advice

Offers advice on benefits and help with filling out benefits forms.

- 03444 111 444 (England)
- 03444 77 2020 (Wales)
- in Scotland and Northern Ireland, contact your local Citizens Advice
- [citizensadvice.org.uk](http://citizensadvice.org.uk)

### Department for Work & Pensions (DWP)

Responsible for social security benefits. Provides information and advice about financial support, rights and employment.

- [gov.uk/government/organisations/department-for-work-pensions](http://gov.uk/government/organisations/department-for-work-pensions)

## **Travel insurance**

### **Macmillan Cancer Support**

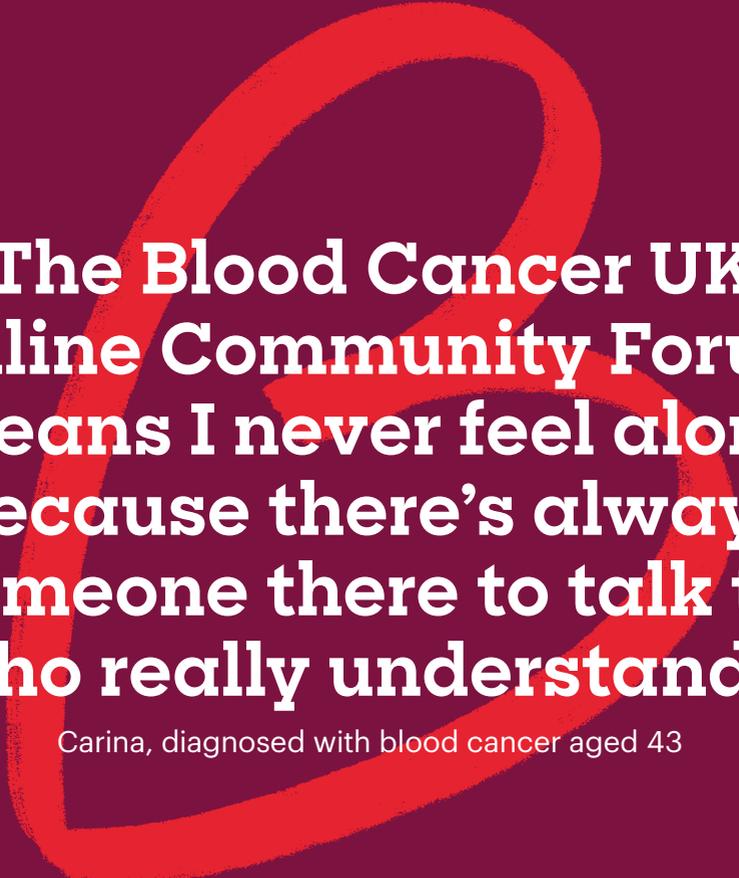
Provides information about what to consider when looking for travel insurance. It also has a list of insurance companies recommended by people affected by cancer.

- 0808 808 0000
- [macmillan.org.uk](http://macmillan.org.uk)

### **British Insurance Broker's Association (BIBA)**

Offers advice on finding an appropriate BIBA-registered insurance broker.

- 0370 950 1790
- [enquiries@biba.org.uk](mailto:enquiries@biba.org.uk)
- [biba.org.uk](http://biba.org.uk)



**The Blood Cancer UK  
Online Community Forum  
means I never feel alone  
because there's always  
someone there to talk to,  
who really understands.**

Carina, diagnosed with blood cancer aged 43

## Questions for your healthcare team

It can be a good idea to write down any questions you have before your next appointment. Here are some things you might want to ask while you're waiting to receive your diagnosis, or once you've been diagnosed.

### Tests

What tests will I have?

What will they show?

Where will I have them done?

Are there any risks associated with the tests?

Will any of the tests be painful?

Do I need to know anything about preparing for the tests, for example not eating beforehand?

How long will it take to get the results?

### Treatment - general

Will I need to have treatment?

What does the treatment do?

Is there a choice of treatments?

Is there a clinical trial that I could join?

What's likely to happen if I decide not to have the treatment my healthcare team recommended?

If I don't need to start treatment straight away, how will I know when I need to start it?

Who do I contact if I take a turn for the worse?

Who can I contact if I have any questions?

## Chemotherapy and chemo-immunotherapy

What type of chemotherapy will I have?

Will I have to stay in hospital?

If not, how often will I need to go to hospital as an outpatient?

What chemotherapy regimen will I be given? Will I be given it by mouth, injection or drip (into a vein)?

Will my treatment be continuous or in blocks of treatment (with a break in between)?

How long will my treatment last?

What side effects could I get from my treatment?

Can side effects be treated or prevented?

Will they affect me all the time or only while I'm taking certain drugs?

What are the fertility risks with treatment and what options are available to me to protect my fertility?

What effect is the treatment likely to have on my daily life?

Will I be able to carry on working or studying?

Will I need to take special precautions, for example against infection?

Will I need to change my meal times or work my drugs around these?

## Stem cell transplant

Is a transplant an option for me?

How long will I be in hospital for?

Do I have to be in isolation?

How long will it be before I get back to normal?

## Choosing the right treatment for you

If you're asked to choose between treatments, you might like to ask your consultant these questions about each one:

What's the best outcome I can hope for?

How might the treatment affect my quality of life?

## Follow-up

How will the cancer be monitored after my treatment?

How often will I need to have follow-up appointments?

Is there anything I need to watch out for after my treatment?

Who can I contact if I have any questions or worries?

## Relapse

How will doctors know if the cancer has relapsed?  
What are the options for more treatment?

What will the treatment involve? Will it be different from my initial treatment?

Will there be any side effects from more treatment?

Is my prognosis likely to change with more treatment?



**Listen to your body and  
take time out when  
you need it. Don't set a  
time limit on when you  
should feel better.**

Nichola, diagnosed with blood cancer aged 41

# Glossary

## Anæmia

A condition where you either have fewer red blood cells than normal, or you have less haemoglobin (a protein in your red blood cells which carries oxygen) than normal. In either case, this means less oxygen is carried around in your bloodstream.

## Blood count, full blood count or FBC

A blood test that counts the different types of cells in your blood.

## Bone marrow

A spongy material inside long bones, which produces your blood cells.

## Central nervous system (CNS)

The system of nerve tissues which control your body's responses. The CNS includes the brain and the spinal cord. Your peripheral nervous system is related to your CNS; this includes all of the nerves outside of your brain and spinal cord that carry messages to the CNS.

## Chemotherapy

Treatment using anti-cancer drugs; it can be a single drug or a combination of drugs. Chemotherapy is used to kill cells or stop them growing and dividing. Although it's aimed at the cancer cells, the treatment also affects normal cells which divide quickly, such as those in your hair and your gut.

## Clinical nurse specialist

A qualified nurse who specialises in a particular clinical area. Some deal with all blood cancers while others may specialise in leukaemia, myeloma, lymphoma or another specific area. Your nurse specialist can provide information and expert advice about your condition and treatment.

## Clinical trial

A planned medical research study involving patients. They can be small trials involving only a few patients or large national trials. Clinical trials are always aimed at improving treatments and reducing any side effects they cause. You'll always be told if your treatment is part of a trial.

## Chromosome

Structures in all of your cells which carry your genetic information and contain your genes.

## Cytogenetics

The study of the structure of chromosomes.

Cytogenetic tests (or FISH tests) are carried out on samples of blood and bone marrow taken from leukaemia patients. They aim to find any changes which could be linked to the disease. They can also help doctors to decide on the treatment you'll have.

## Fatigue

A feeling of extreme tiredness which doesn't go away after rest or sleep. It might be caused by the AML itself or might be a side effect of treatment. It's one of the most common problems for people with cancer.

## Fitness for treatment

Factors which determine how well your body will be able to cope with different treatments. These include things like age, medical fitness and any other conditions you might have.

## Leukaemia

A type of blood cancer that's divided into many different types – some which develop faster (acute), and others which develop more slowly (chronic). People with leukaemia have large numbers of abnormal blood cells, usually types of white blood cell, which take over the bone marrow and often spill out into the blood stream. Other areas that may also be affected are lymph nodes, spleen, liver,

testes, the membranes surrounding the brain and spinal cord (meninges), gums and skin.

### Medical fitness

How healthy your vital organs are before treatment. This refers to organs such as the heart, lungs, kidney and liver. Age, along with other factors, can affect this.

### Myeloid cells

The term for the group of cells including red blood cells, platelets and all white blood cells except lymphocytes.

### Progenitor cell

An immature cell in the bone marrow that produces mature blood cells. It can only divide a certain number of times, whereas a stem cell can divide again and again.

### Secondary AML

AML which has developed as a result of you having another condition which affects your bone marrow.

### Stem cells

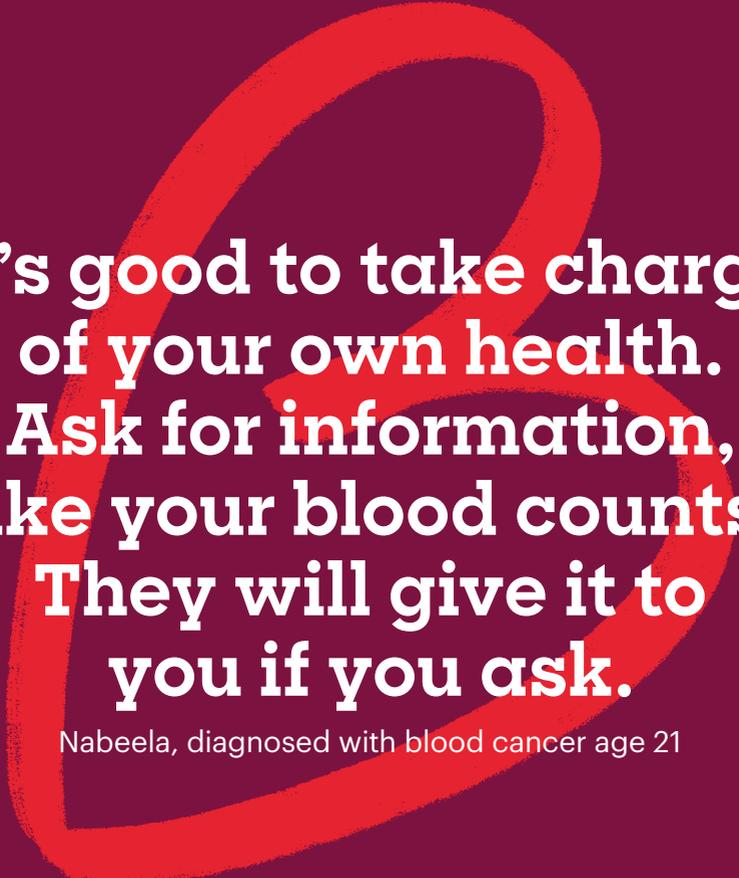
Cells that are able to develop into other cell types. Stem cells act as a repair system for your body and replenish other cells. They're found in embryos and some organs in adults.

## Treatment-related AML (tAML)

AML which develops after you've been treated for another type of disease. It can be caused by certain types of chemotherapy or radiotherapy.

## Radiotherapy

The use of radiation in treatment. Radiotherapy kills cancer cells in the area of the body being treated.



**It's good to take charge  
of your own health.  
Ask for information,  
like your blood counts.  
They will give it to  
you if you ask.**

Nabeela, diagnosed with blood cancer age 21

## Our health information

Find out more about blood cancer, its treatments and living with blood cancer. All our information is produced with expert medical professionals and people affected by blood cancer. It's available to anyone to download or order for free.

## Symptoms guide

A credit-card sized guide that folds out to explain the symptoms of blood cancer.

## Booklets

### Leukaemia

- Acute lymphoblastic leukaemia (ALL)
- Acute myeloid leukaemia (AML)
- Acute promyelocytic leukaemia (APL)
- Chronic lymphocytic leukaemia (CLL)
- Chronic myeloid leukaemia (CML)

### Lymphoma

- Hodgkin lymphoma (HL)
- High-grade non-Hodgkin lymphoma (NHL)
- Low-grade non-Hodgkin lymphoma (NHL)

### Other blood cancers

- Myeloma
- Myelodysplastic syndromes (MDS)
- Myeloproliferative neoplasms (MPN)

### Treatment and beyond

- Blood stem cell and bone marrow transplants: the seven steps
- Eating well with neutropenia
- Diary for anyone affected by blood cancer

## My information folder

An A5 folder to keep your information in.

## Fact sheets

### Conditions

- Burkitt lymphoma
- Monoclonal gammopathy of undetermined significance (MGUS)
- Waldenström macroglobulinaemia (WM)

### Treatments

- Blood transfusions
- Donating stem cells
- What is CAR-T therapy?
- Watch and wait - What you need to know
- Watch and wait - My blood counts
- Watch and wait - A quick guide for partners, carers, family and friends
- Watch and wait - A quick guide for employers
- Watch and wait - A toolkit for GPs and practice nurses

### Side effects

- Managing sickness and vomiting
- Sore mouth or gut (mucositis)
- Understanding infection

### Living with blood cancer

- If your employee or colleague has blood cancer
- My activity planner

## To order or download information

Visit **[bloodcancer.org.uk/information](https://www.bloodcancer.org.uk/information)**

Call **0808 2080 888** (Mon, Tue, Thu, Fri, 10am–4pm, Wed, 10am–1pm)

Email **[support@bloodcancer.org.uk](mailto:support@bloodcancer.org.uk)**

Or use the order form on **page 124**



**We're a  
community  
dedicated to  
beating blood  
cancer.**

# About us

We're the scientists who dedicate our careers to finding cures.

We're the nurses who find the right words in the darkest moments.

We're the campaigners and volunteers standing up for the people we love.

We're the bucket-collectors, race-runners and cake-bakers who make our research possible.

We're the friends, parents, children and grandparents affected by blood cancer.

Why?

Because we've invested over £500 million in life-saving research.

Because the finish line's in sight.

**Because it's time to beat blood cancer.**

## Because we give people the support they need

People with blood cancer and their family and friends have unique support needs.

We offer free and confidential support by phone or email, provide information about blood cancer and life after a diagnosis, and have an online forum where you can talk to others affected by blood cancer.

**bloodcancer.org.uk**  
**0808 2080 888**

(Mon, Tue, Thu, Fri, 10am–4pm, Wed, 10am–1pm)

**support@bloodcancer.org.uk**

**forum.bloodcancer.org.uk**

## Because our research is saving lives

The money raised by our community has meant we've been able to invest £500 million in research, which has changed the outlook for people with blood cancer. Our research has led to better treatments that have dramatically increased survival rates. Right now, we're funding research projects across the UK that are finding out more about blood cancer and the best way to treat it.

Find out more: **bloodcancer.org.uk/research**



## Because we campaign for better treatment and care

We work to make sure people affected by blood cancer are at the heart of Government and NHS decision-making.

We're campaigning to end delays to diagnosis, improve access to the latest treatments and help people with blood cancer get the mental health support they need.

Find out more: [bloodcancer.org.uk/campaigns](https://www.bloodcancer.org.uk/campaigns)

# Because we'll beat it together

## Donate

A quick way to help. Every pound brings us one step closer to beating blood cancer:

**[bloodcancer.org.uk/donate](https://bloodcancer.org.uk/donate)**

## Fundraise

Sign up to one of our events, or do something you enjoy with family and friends – there are lots of ways to fundraise: **[bloodcancer.org.uk/fundraise](https://bloodcancer.org.uk/fundraise)**

## Join your local community group

Local community groups raise money and awareness in their local area. Volunteer for yours to meet new people and get involved in local activities:

**[bloodcancer.org.uk/local-community-groups](https://bloodcancer.org.uk/local-community-groups)**

## Volunteer

Give your time, meet new people and experience new things by volunteering with us. There are lots of ways you can help, from your own home or in your local community: **[bloodcancer.org.uk/volunteer](https://bloodcancer.org.uk/volunteer)**

## Get your organisation involved

From funding a project, to becoming a corporate partner, find out how your organisation can help us:

**[bloodcancer.org.uk/corporate-partnerships](https://bloodcancer.org.uk/corporate-partnerships)**

Or call us on **0808 169 5155**



**I love being part of the  
Blood Cancer UK family.  
Being involved has  
helped me and my family  
cope with my diagnosis.**

Anna, diagnosed with blood cancer aged 39





## Order information from Blood Cancer UK

All of our information is free to people affected by blood cancer, but if you would like to include a donation with your order, please fill in the donation form over the page.

You can order more information by:

- visiting **bloodcancer.org.uk/information**
- Emailing **support@bloodcancer.org.uk**
- calling **0808 2080 888**
- or completing and sending this form to us freepost using the address: **FREEPOST PLUS RTSU-XAYE-XZYK, Blood Cancer UK, 111 George St, Edinburgh, EH2 4JN**

## Please send me some information

Full Name .....

Address .....

Email .....

Phone .....

Please tell us the publications you would like us to send you, free of charge (see page 114)

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## Keep in touch

We'd love to keep you updated about our exciting work and the ways you can help, including campaigns and events that you might be interested in. We promise to respect your privacy and we will never sell or swap your details.

I'm happy for Blood Cancer UK to contact me by:  Email  Phone  SMS

Don't contact me by post:

You can change how we communicate with you at any time.

Contact us on **0808 169 5155** or email **hello@bloodcancer.org.uk**



# My details

My name and hospital number

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My NHS number

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My condition

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My contacts

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My consultant

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My key worker (usually CNS)

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Haematology ward

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Haematology clinic

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Out of hours

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Other contacts

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# Because we face it together

We're a community dedicated to beating blood cancer by funding research and supporting those affected.

Get in touch for:

- Free and confidential support by phone or email
- Information about blood cancer and life after diagnosis
- An online forum for people affected by blood cancer

**[bloodcancer.org.uk](https://bloodcancer.org.uk)**

**0808 2080 888**

**(Mon, Tue, Thu, Fri, 10am–4pm, Wed, 10am–1pm)**

**[support@bloodcancer.org.uk](mailto:support@bloodcancer.org.uk)**

**[forum.bloodcancer.org.uk](https://forum.bloodcancer.org.uk)**

Your feedback on this booklet can help us improve – please send any comments to **[information@bloodcancer.org.uk](mailto:information@bloodcancer.org.uk)**



**Blood  
cancer  
UK**

Blood Cancer UK is a trading name of Bloodwise, 39-40 Eagle Street, London, WC1R 4TH. A company limited by guarantee 738089 (registered in England and Wales). Registered charity 216032 (England and Wales) SCO37529 (Scotland) © 2020 AML/0315.3