Newly diagnosed with acute myeloid leukaemia (AML)

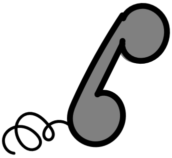
A Guide for Patients

Leukaemia Care
YOUR Blood Cancer Charity

About Leukaemia Care

Leukaemia Care is the UK's leading leukaemia charity. For over 50 years, we have been dedicated to ensuring that everyone affected receives the best possible diagnosis, information, advice, treatment and support.

Our services

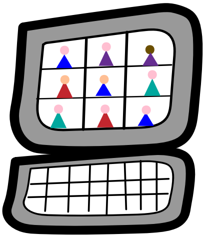


Helpline

Our helpline is available 9am to 4:30pm Monday to Friday. If you need someone to talk to, call **08088 010 444**.

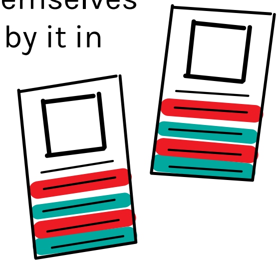
Alternatively, you can send a message via WhatsApp on **07500 068065** on weekdays 9am to 5pm.

Support Groups



Our nationwide support groups are a chance to meet and talk to other people who have been affected by an AML diagnosis. For more information, scan this QR code:

Buddy Support



We offer one-to-one phone support with volunteers who have had AML themselves or been affected by it in some way. You can speak to someone who knows what you are going through. For more information on how to get a buddy call **08088 010 444** or email support@leukaemiacare.org.uk

Counselling Service

Our counselling service helps AML patients and their loved ones access up to six sessions of counselling. To apply, scan this QR code:

Advocacy and Welfare

Our advocacy and welfare officers are here to help you find the support you need for many issues surrounding an AML diagnosis. These include insurance, benefits and clinical trials. If you would like support from our advocacy or welfare officer, email **advocacy@leukaemiacare.org.uk** or call **08088 010 444**.

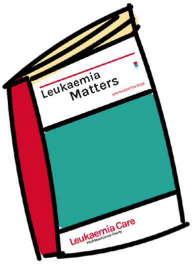
Cost of Living Fund

This fund provides grants to patients and families affected by AML, to help with essential living costs. All applications must be made via the form which can be found by scanning the QR code:

Write a Will

Using our complimentary service, you can write a simple Will so you know what happens to your estate when you die. To start writing your free Will today, scan this QR code:

Patient Magazine



Our magazine includes inspirational patient and carer stories as well as informative articles by medical professionals. To subscribe to our magazine, scan this QR code:

In this booklet

There is a lot of information about cancer on the internet. Some of it may not be reliable or up-to-date, and much of it will not be applicable to you. Your haematology team is best placed to give you information that is specific to you because they know your individual circumstances. If you want to search for information yourself, look for reputable organisations like the NHS or national charities. Look for a quality mark, such as the Patient Information Forum (PIF) tick.

Introduction

There is a lot of information in this booklet. Each chapter has a short summary at the beginning if you'd prefer a short overview.

Acute myeloid leukaemia (AML) is a fast-growing cancer that develops from a type of immature white blood cell. In this booklet, we cover what AML is, how it is diagnosed and what treatment you may have. We also include practical information about living with AML.

This booklet is only a guide of what you might experience. Your haematology team will give you a copy of your specific treatment plan.

We'd like to thank Dr Jonathan Kell and Dr Elspeth Payne, consultant haematologists, and Catherine Langton, clinical nurse specialist, for reviewing this information. We'd also like to thank our patient reviewers Dave, Janine and Judy.

Throughout this booklet, you will see QR codes and URLs that link to webpages for further support. If you are not able to access the webpages, please email information@leukaemiacare.org.uk or call 08088 010 444.

About acute myeloid leukaemia (AML)

Summary

- Acute myeloid leukaemia (AML) is a fast-growing blood cancer.
- There are different subtypes of AML based on:
  - The genetic changes in your leukaemia cells
  - What your leukaemia cells look like under a microscope
- AML can affect people of any age, but it is more common in people over 65. It is slightly more common in men than in women.
- We do not know the exact causes of AML.
- AML can cause symptoms such as:

Fatigue
Infections
Shortness of breath
Bleeding or bruising
Fever
Bone pain
Anaemia
Tummy pain or fullness

About AML

Acute myeloid leukaemia (AML) is a fast-growing blood cancer. It starts in blood-forming cells in your bone marrow called myeloid stem cells. These myeloid stem cells divide and mature uncontrollably. This increases the different types of white blood cells in your blood and bone marrow. The cells fill up your bone marrow and stop it making enough healthy red and white blood cells.

Different types of AML

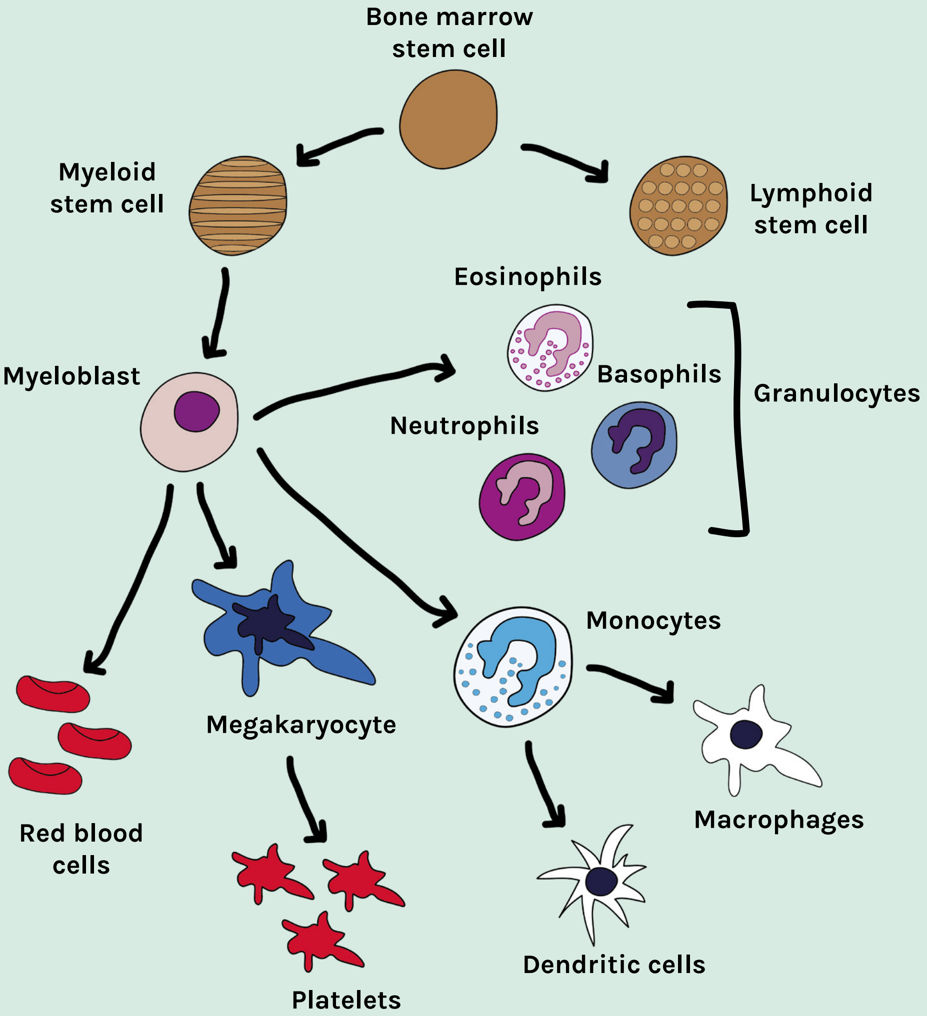
There are different subtypes of AML, which might affect what treatment you have. They are based on:

- The genetic changes in your leukaemia cells
- What your leukaemia cells look like under a microscope

We have separate information about the genetic changes in AML. Follow the link, scan the QR code or search for 'genetics in acute myeloid leukaemia' at leukaemiacare.org.uk.

More on blood cell development

There are different types of stem cells in your bone marrow. The myeloid stem cells grow into red blood cells, platelets and different types of white blood cells. In acute myeloid leukaemia your myeloid stem cells don’t mature like they usually would. This means you have a high number of immature myeloid stem cells, which stops your bone marrow from making enough healthy blood cells.



Subtypes of AML include:

- Acute myelomonocytic leukaemia (AMML)
- Acute megakaryoblastic leukaemia (AMKL)
- Acute promyelocytic leukaemia (APL)

APL does not behave the same as other types of AML so it needs different treatment. We have separate information about APL. Follow the link, scan the QR code or search for 'acute promyelocytic leukaemia' at leukaemiacare.org.uk.

AML can also develop from another type of blood cancer, or after having radiotherapy or chemotherapy. This is called secondary AML.

Your haematology team should tell you what subtype of AML you have and what it means for you.

We have separate information about AMKL, AMML and secondary AML. Follow the links, scan the QR code or search for 'acute megakaryoblastic leukaemia', 'acute myelomonocytic leukaemia' and 'secondary AML' at leukaemiacare.org.uk.

Who gets AML?

AML is one of the most common types of leukaemia. Around 2,710 people are diagnosed with it each year in the UK.

AML can affect people of any age, but it is more common in people over 65. It is slightly more common in men than in women. It can affect people of any ethnic background.

AML mainly affects adults, but rarely, children can get it. Children with Down's syndrome or other gene changes have a higher chance of getting childhood AML.

The Children's Cancer and Leukaemia Group have more information on AML in children. Follow the link, scan the QR code or search 'acute myeloid leukaemia' at www.cclg.org.uk.

Causes of AML

We do not know the exact causes of AML. People with AML have genetic changes in their leukaemia cells that stop the cells from working properly. However, in most cases, we do not know why these genetic changes occur. These changes are not because of anything you have or have not done. But there are some factors that increase your chance of getting them. These include:

- Your age – AML is more common in people over 65
- Your family history – your chance of getting AML might be higher if someone else in your family also has AML, although this is rare
- Having a genetic condition, such as Down's syndrome
- Exposure to certain chemicals, including benzene, pesticides and herbicides
- Smoking
- Exposure to radiation
- Previously having chemotherapy or radiotherapy
- Having another blood cancer such as myelodysplastic syndrome (MDS) or a myeloproliferative neoplasm (MPN)

We have separate information about MDS and MPNs. Follow the link, scan the QR code or search for 'MDS' or 'MPNs' at leukaemiacare.org.uk.

Symptoms and signs of AML

The signs and symptoms you might get vary from person to person. They also depend on how many leukaemia cells you have, and how much your normal blood cells production has been affected.

> **"I began to be too tired to go to work. I would drop my son off at school, go home and sleep on the sofa. I was having night sweats and my glands swelled. I was really ill and had not been feeling 100% for about 6 weeks at this point, so my mum and dad came to see me and told me to go the GP."**
>
> Helen, living with AML

AML can cause the following signs and symptoms:

- Infections that last a long time or keep coming back
- Feeling tired, breathless or dizzy due to a low red blood cell count (anaemia)
- Bruising or bleeding easily (for example, nose bleeds or bleeding gums when you brush your teeth)
- Tummy pain, bloating or discomfort due to a swollen spleen or liver (you may particularly notice this feeling under your ribs on the left-hand side)
- A feeling of fullness after eating, again due to a swollen spleen
- Fever
- Fatigue
- Bone pain

Diagnosis of AML

Summary

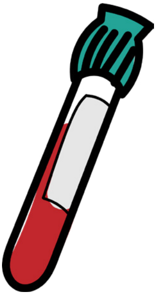
- Your haematology team will diagnose AML based on:
    - Blood tests
    - Bone marrow tests
- They will send your blood and bone marrow samples for specialised tests in the lab.
- Depending on your symptoms, you might also have other tests and scans.
- Your haematology team will use the results of your tests to work out how likely your AML is to respond well to treatment, and whether there are particular treatments that might be especially suitable for you.
- It can be difficult waiting for test results. We are here for you if you need support. You can email us at support@leukaemiacare.org.uk, message us on WhatsApp at **07500 068065** or call our freephone helpline on **08088 010 444**.

Diagnosis of AML

Tests and scans

To be diagnosed with AML your medical team will need to collect blood and bone marrow samples. They will send the samples to a lab to undergo specialist testing.

Blood tests



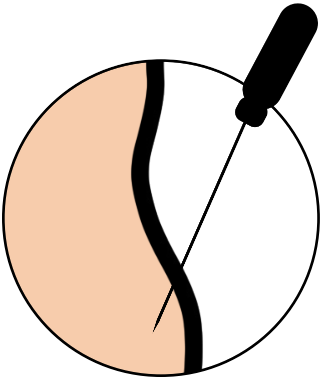
You will have blood tests to check:

- Your full blood count. This measures the number of white blood cells, red blood cells and platelets in your blood.
- Your liver and kidney function.
- If you have any viral infections that could flare up during treatment.

If you have AML your blood tests will usually show lower levels of healthy white blood cells, red blood cells and platelets. You will also have a higher number of immature white blood cells. The type of immature white blood cells that are present will depend on the subtype of AML that you have.

> **"I waited all day for the blood results to come back. By the evening, a doctor came to tell me that there was an anomaly in my blood – blast cells had shown up in the tests and it was likely that I had leukaemia. The next day, I was transferred to a specialist unit for a bone marrow biopsy to determine what type of leukaemia this was. I was told I could go home for a week to sort out a few bits and then I would need to return for my first round of chemo."**
>
> Michael, living with AML

Bone marrow tests

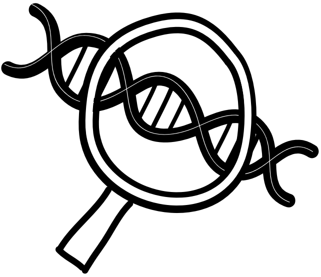


If your haematology team think you might have AML, they will also do a bone marrow test. This involves taking a sample of your bone marrow, usually from the back of your pelvis, under local anaesthetic. They send the sample to the lab for testing.

A bone marrow test helps your haematology team make an accurate diagnosis. It also helps them work out the subtype of AML you have.

Cancer Research UK have more information on having a bone marrow test. Follow the link, scan the QR code, or search 'bone marrow test' at cancerresearchuk.org

Lab tests



Your team will send your samples for specialised tests in the lab.

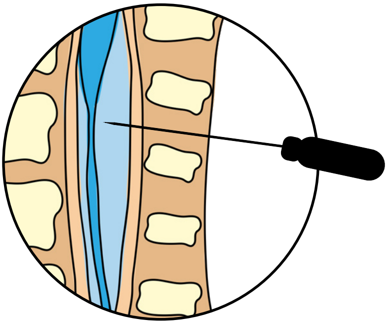
- They look at the samples under a microscope to check for abnormal cells.
- They do tests to find out what proteins are on the surface of your cells. This helps doctors make an accurate diagnosis.
- They also do tests to look for genetic changes in your cells. You might hear your doctor call these PCR tests, cytogenetic tests, molecular, genetic or DNA tests. Some people might have whole genome sequencing.

We have separate information about the genetic changes in AML. Follow the link, scan the QR code or search for 'genetics in acute myeloid leukaemia' at leukaemiacare.org.uk.

Other tests you might have

You might have an X-ray, CT scan, ECG or other heart scans to help work out which treatment options are best for you.

Lumbar puncture



Depending on your symptoms, your haematology team might recommend a lumbar puncture to check if you have AML cells in your central nervous system. A lumbar puncture is a test to collect a sample of the fluid that surrounds your brain and spinal cord.

You have an injection to numb a small area of your lower back first. Then your doctor puts a needle between the bones in your spine to collect a sample of fluid. It may be uncomfortable during and afterwards, and you might get a headache. Ask your doctor or nurse what painkillers you can use if you need them.

Your test results may take a little while, which may be a worrying time for you. It is important for your haematology team to have all the results so they can make an accurate diagnosis. It can also help them work out the most suitable treatment options for you.

We are here for you if you need support while you are waiting for your results. Email us at support@leukaemiacare.org.uk, message us on WhatsApp at **07500 068065** or call our freephone helpline on **08088 010 444**.

Risk grouping

Your haematology team will use the results of your tests to work out how likely your AML is to respond well to treatment, and whether there are particular treatments that might be especially suitable for you. They sometimes call this ‘risk grouping’.

Treatment of AML

Summary

- Your haematology team will recommend either intensive or non-intensive treatment, depending on your individual needs.
- Intensive treatment happens in phases. These are usually induction, consolidation and sometimes maintenance.
  - Induction therapy usually involves having chemotherapy, sometimes with a targeted medicine too. It aims to kills as many leukaemia cells as possible. You usually stay in hospital for a few weeks to have it.
  - Consolidation therapy aims to kill any leukaemia cells that may be left. This improves the chance that your AML will stay in remission. It often involves chemotherapy, sometimes alongside a targeted treatment. Some people might have a stem cell transplant.
  - Maintenance therapy aims to reduce the risk of your AML coming back. Not everyone will need maintenance treatment, but your haematology team might recommend it if you have a higher chance of relapse.
- Non-intensive treatment is gentler. It aims to control your AML as much as possible rather than cure it. It usually involves low-dose chemotherapy. You might also have a targeted therapy as well.
- You might start non-intensive treatment while you are in hospital, but you can usually have most of it as an outpatient.
- You will also have treatment to prevent or treat symptoms or side effects.

Treatment of AML

Overview of treatment options

Your medical team will recommend treatment for you based on many factors, including:

- Your age
- Your subtype of AML
- Whether or not you have any other medical conditions
- Your overall fitness
- The genetic changes in your leukaemia cells
- Your preference on how you wish to be treated

They will recommend either intensive or non-intensive treatment based on these factors.

Intensive treatment happens in phases. These are usually induction, consolidation and sometimes maintenance.

Non-intensive treatment is gentler. It aims to control your AML as much as possible rather than cure it.

Your haematology team are best placed to discuss your treatment options as they know your individual circumstances.

We have separate information on different treatments used in AML. Scan the QR code to order or download the leaflets or visit leukaemiacare.org.uk and search for the treatment that has been recommended for you.

Your medical team may ask if you'd like to take part in a clinical trial, if there is one suitable for you. This is where new treatments, or different ways of using existing treatments are tested to find out which is better.

Macmillan have more information about clinical trials. Follow the link, scan the QR code or search for 'clinical trials' at macmillan.org.uk.

Some treatments for AML can affect your fertility. If you think you might want to have children in the future, tell your haematology team. They can talk to you about options to preserve your fertility.

Intensive therapy

If your team recommend intensive treatment, you will have it in phases.

Before starting intensive therapy

Your treatment will involve a lot of medicines that have to be given as an injection or a drip. Your treatment will also involve having regular blood tests. Your haematology team will fit a central line to make this easier.

You have a local anaesthetic to numb the skin first so it does not hurt when the line goes in. You might have a sedative too, if you need one.

You might have an ultrasound before your nurse or doctor puts the tube in, and a chest X-ray afterwards. This is to make sure that the tube has been inserted properly, and in the right place.

More about central lines

A central line is a long, thin plastic tube that enters the skin in your arm or your chest. It runs underneath your skin and ends in a large vein near your heart. It can be used to give treatments straight into your veins, and to take blood samples.

A central line can stay in place for weeks or months. Having one fitted means:

- You don't have to have a tube put into a vein every time you go for treatment
- You don't need to have a needle put into your arm when you have blood tests
- Your treatment goes into larger, sturdier veins that are less likely to leak or be damaged

You'll need to keep your central line clean and dry to reduce the chance of it getting infected. It needs to be flushed with sterile fluid once a week to stop it getting blocked. Your team will arrange for someone to do this for you.

Induction therapy

Induction therapy aims to kill as many leukaemia cells as possible to achieve complete remission. This is when less than 5 in every 100 cells in your bone marrow are immature white blood cells when a specialist looks at them through a microscope.

Induction therapy usually involves having chemotherapy. You usually stay in hospital for a few weeks to have it. The combination of chemotherapy drugs that you might have include:

- Daunorubicin and cytarabine (sometimes known as DA)
- Liposomal daunorubicin and cytarabine (sometimes known as CPX-351 or Vyxeos)
- Fludarabine, cytarabine, granulocyte-colony stimulating factor and idarubicin (FLAG-Ida)
- Chemotherapy combinations containing mitoxantrone

Your haematology team might suggest a different combination of chemotherapy. If so, they will tell you what they recommend and why.

You might also have targeted treatment depending on what genetic changes you have in your leukaemia cells. Targeted therapies are drugs designed to block specific proteins in leukaemia cells. This means they kill leukaemia cells with as few effects on healthy cells as possible.

Targeted therapies that you might have include:

- Midostaurin – you might have this alongside chemotherapy if your leukaemia cells have a gene change called *FLT3*
- Gemtuzumab ozogamicin – you might have this alongside chemotherapy if your leukaemia cells make a protein called CD33
- Quizartinib - you might have this alongside chemotherapy if your leukaemia cells have a gene change called *FLT3-ITD*

Your haematology team will let you know what they recommend for you and why.

At the end of your induction therapy, you will have a bone marrow test to check how well your leukaemia has responded to treatment.

- If your leukaemia has responded, you will move onto consolidation therapy.
- If not, you may have another cycle of induction therapy.

Consolidation therapy

Consolidation therapy aims to kill any leukaemia cells that may be left. This improves the chance that your AML will stay in remission.

Your haematology team will recommend consolidation therapy based on:

- How well you are likely to cope with treatment
- How you responded to induction therapy
- Whether or not a suitable stem cell donor is available
- The risk of your AML coming back
- The genetic changes in your leukaemia cells

Consolidation therapies that you might have include:

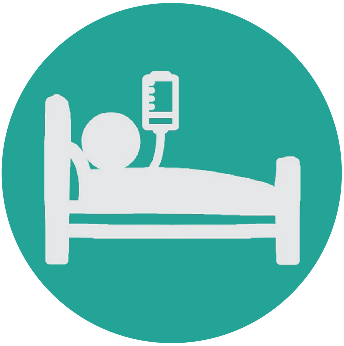
- Liposomal daunorubicin and cytarabine
- High-dose cytarabine (also known as HiDAC)
- Chemotherapy combinations containing mitoxantrone

You might also have a targeted medicine, depending on the gene changes in your leukaemia cells.

You usually stay in hospital to have consolidation treatment. In some hospitals, you may be able to stay in a hotel next to the hospital and have your treatment as an outpatient every day.

There may be some times when you need to stay in hospital for longer. Your haematology team will let you know what they recommend for you and why.

Stem cell transplantation



If your AML has a medium or high risk of coming back, your haematology team might suggest a stem cell transplant.

A stem cell transplant involves having high-dose chemotherapy and sometimes radiotherapy. This kills the blood-forming cells in your bone marrow, called stem cells. These are then replaced by healthy stem cells. For most people with AML, the healthy stem cells come from a brother or a sister, or from a matched unrelated donor. Rarely, they might be your own stem cells, collected before you have chemotherapy.

A stem cell transplant is very intensive. It is only suitable for people who are fit enough to have it. Your team will let you know if it is an option for you. They will discuss it with you and give you a chance to ask questions.

We have separate information on stem cell transplants. Scan the QR code to order or download the booklet or visit leukaemiacare.org.uk and search ‘stem cell transplants.’

Anthony Nolan is a UK charity that has further information on stem cell transplants. Follow the link, scan the QR code or visit www.anthonynolan.org.

Maintenance therapy

Maintenance therapy aims to reduce the risk of your AML coming back. Not everyone will need maintenance treatment, but your haematology team might recommend it if you have a higher chance of relapse. Relapse is when your AML comes back after you had achieved remission.

You might have chemotherapy, or a targeted drug. The treatment you get depends on:

- The type of AML that you have
- The genetic changes in your leukaemia cells
- How well you are likely to cope with the treatment

These treatments are usually given as tablets or capsules to take at home. You may need to take these long-term, usually for a year or longer.

Maintenance therapies that you might receive include:

- Azacitidine tablets
- Midostaurin
- Quizartinib

Your haematology team will let you know what they recommend for you and why.

Non-intensive therapy

If your haematology team think you might not cope well with intensive treatment, they might recommend other, gentler options. This can be because of:

- Your age
- Your physical fitness
- Other health conditions you have

The aim of non-intensive treatment is to keep your AML under control as much as possible with as few side effects as possible. This aims to reduce your symptoms and improve your quality of life. But it does not cure your AML.

Usually, you will be treated with gentler or low-dose chemotherapy. You might also have a targeted medicine.

Non-intensive treatments that you might have include:

- Azacitidine injections
- Venetoclax and azacitidine
- Venetoclax and low-dose cytarabine
- Ivosidenib and azacitidine
- Hydroxycarbamide
- Low-dose cytarabine

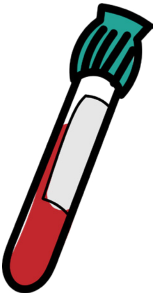
Supportive treatment

You might also need medicine to prevent or treat symptoms or side effects. This is called supportive care. It might include:

- Blood transfusions or medicines called growth factors, if your blood counts are low
- Anti-sickness or anti-diarrhoeal medicines
- Pain relief, if you need it
- Medicine to prevent or treat infections
- Mouth washes to help with mouth ulcers, oral thrush or a sore mouth
- Food or drink supplements, if you are not able to eat or drink enough
- Steroids, which reduce inflammation in your body and can help with many different symptoms
- Physiotherapy
- Emotional and social support

Measuring your response to treatment

You will have regular tests during your treatment to check how well your AML is responding.



The tests will measure:

- Your blood cell counts. This is sometimes called your **haematological response**.
- The level of leukaemia markers or leukaemia genetic changes in your white blood cells. This is called your **molecular response**.

Most people will need a repeat bone marrow test during treatment. Sometimes, depending on the genetic changes in your leukaemia cells, your haematology team may be able to check your molecular response from a blood test instead.

Coping with treatment for AML

Summary

- It can be hard dealing with treatment and its side effects. Some things that people with AML told us helped them include bringing home comforts to the hospital, talking to people who understand what they're going through, and keeping a sense of humour.
- You might experience fatigue. Planning, pacing yourself and saving energy for things that are important to you can help.
- You may have a higher chance of getting infections, and any infections you do get may be more serious. Let your haematology team know straight away if you think you have an infection. Try to take steps to reduce your chance of getting an infection.
- Some treatments can lead to hair loss. This can be distressing, but there are lots of options to help you cope with it. Do what feels best for you and allows you to feel the most confident.
- Mouth problems are a common side effect of many cancer treatments. Your medical team may be able to give you mouthwashes, gels or painkillers, as well as medicines to prevent mouth infections.

Coping with treatment

Preparing for each round of treatment, having the treatment and dealing with the side effects can all take a toll on you. It is hard, but it does get better. Some things that people with AML told us helped them include:

- Bringing some home comforts with you to the hospital, like your own mug, pillows and photos. This can help the room feel less clinical and more your own.
- Being matched in our Buddy service, so you can speak to someone who understands what you are going through.
- Being well informed so you can understand why your body is feeling or doing certain things.
- Using social media to connect with others who are going through the same treatment at the same time, reading patient stories or engaging with charities.
- Music. It can be difficult to focus on TV or reading, but music can be calming. Some people have found playing the guitar or singing helped.
- Downloading your favourite films and games to play, especially if you are isolating.
- Keeping a sense of humour. Some people use dark humour to be able to make light of certain things.
- Applying aloe vera gel from the fridge around where you have injections. It can help soothe your skin and relieve itching.

> **"One of the doctors warned me this would be the hardest year of my life. But my medical team has thrown everything at me to get well and for this I am hugely grateful."**
>
> Michael, living with AML

We're here for you if you need support. Scan the QR code, follow the link or search 'support for you' at leukaemiacare.org.uk to find out how we can help you. Our support services include:

- Helpline and advocacy services to provide information and support
- Support groups and a buddy service, where you can connect with people who understand your experience
- A counselling service where you can apply for a grant for up to six sessions of counselling

If you'd like to talk to someone who understands what you're going through:

- Call our freephone helpline on **08088 010 444**
- Message us through WhatsApp on **07500 068065**
- Email support@leukaemiacare.org.uk

"For anyone who is going through this: keep positive, stay focused on short-term goals, try not to set your sights on when you might be discharged (it is never when you want it to be), don't google, save your questions for the professionals, don't be too hard on yourself, chemotherapy fog is real, but it does fade, and I know it sounds weird, but maintain a sense of humour! Remember life outside the hospital is waiting for you and will embrace you when you step out into the sunshine."

Charlotte, living with AML

Coping with side effects

The treatment you have kills your leukaemia cells but it may also damage some of your healthy cells. This can cause side effects, like fatigue, infections that last a long time or keep coming back, hair loss and mouth ulcers or a sore mouth. These can be hard to cope with but your haematology team are there to help you. It's important to let them know if you're struggling as they may be able to offer treatments to help.

Fatigue

AML, and treatments for AML, can cause fatigue. This is a feeling of mental or physical exhaustion that doesn't get better with sleep or rest.

Fatigue can be frustrating as it cannot be treated with medicines. It is common for fatigue to continue after treatment, but it does often get better over time.

> **"I had never experienced any health problems before, so when I started feeling tired all the time, I assumed it was due to my new job - I had just started my nursing cadetship. It got to the point where I would come home from work at 5pm and then fall asleep in the bath. Then get out the bath and need to go straight to bed."**
>
> Beth, living with AML

Tips for coping with fatigue

- Make plans and pace yourself
  - Prioritise things that are important to you and reserve energy for these
  - Build time to rest around planned busy periods
  - Allow yourself to rest as and when you need
- Keep to a regular sleep schedule
  - Try to go to bed and wake up at around the same time each day
  - Keep your bedroom quiet and a comfortable temperature
  - Avoid eating or drinking alcohol, coffee, tea or chocolate before bedtime
  - Avoid using laptops, tablets or mobile phones before going to bed
- Do regular, gentle exercise to maintain your fitness levels
- Accept help with household tasks

Spotting and preventing infections

AML and its treatment can lower your white blood cell count. This is called neutropenia. Having a low white blood cell count means your body can’t fight infections as well as usual. So, you have a higher chance of getting infections, and any infections you do get may be more serious.

Contact your medical team straight away if you think you have an infection. Signs include:

- A high temperature (38°C or higher)
- Aching muscles, shivering or chills
- Sore throat, blocked or runny nose or cough
- Burning or stinging when you pee, or peeing more often than usual
- Diarrhoea, being sick or tummy pain
- Headache or stiff neck
- Pain or redness around any cuts, wounds or drips
- Feeling very tired or generally unwell

Infections can get worse quickly if you have a weakened immune system, so it is important to get treatment as soon as possible. Your medical team should tell you who to contact if you think you have an infection.

If your white blood cell count is low, there are things you can do to lower your risk of getting an infection. These include:

- Washing your hands frequently
- Avoiding crowded spaces
- Avoiding people who are unwell
- Storing and preparing food correctly to reduce the risk of food poisoning
- Making sure your kitchen is clean
- Regularly cleaning surfaces that you touch a lot, like light switches and door handles
- Having any vaccinations that you are eligible for

Your medical team may also prescribe antibiotics or antiviral medicines to help prevent infections.

> **"I went home for Christmas, and it was very special with the family. I had to be careful as I didn't have many neutrophils, but luckily, I didn't get sick."**
>
> Helen, living with AML

Hair loss

Some treatments can lead to hair loss. It can be very emotional, as for most people, your hair can feel like an important part of you. It can be distressing at first, but this feeling usually passes.

It can help to be prepared, and to inform your loved ones that you may lose your hair. This can help them cope better and support you, as they know what's going on. If you have children, it can help to get them to touch your head and ask questions so they feel like it is normal and not something bad.

You may wish to cut your hair short or shave it when the hair loss starts. This can also help reduce itching and help with not having to wash your hair. Some people may choose to cover their hair loss with wigs, headscarves, hats or bandanas. Do what feels best for you and allows you to feel the most confident.

Cancer Hair Care UK has more information on hair loss, including how to care for Afro-textured hair during chemotherapy. Follow the link, scan the QR code or search for 'hair loss' on cancerhaircare.co.uk

Mouth ulcers, oral thrush and sore mouth

Mouth problems are a common side effect of many cancer treatments. You may get mouth ulcers, sores or oral infections, which can be painful.

It's important to let your medical team know if your mouth is sore. They may be able to give you mouthwashes, gels or painkillers, as well as medicines to prevent mouth infections.

To help cope with sore mouth or other oral problems you could try:

- Brushing your teeth with a soft toothbrush at least twice a day, as well as flossing gently.
- Using an antimicrobial mouthwash. Alcohol mouthwashes can dry your mouth, so it is best to avoid these.
- Sucking on ice chips and drinking water often.
- Chewing food slowly and drinking plenty of fluid with meals to help taste.
- Avoiding hot, spicy, acidic or hard foods, like crusty breads, pineapple or lemons.

Early menopause

Sometimes, chemotherapy can stop your ovaries working properly, which can lead to an early menopause. This can cause a wide range of symptoms.

Going through the menopause earlier than expected can be distressing. Let your haematology team know if you are struggling and they can discuss your options with you.

If you are experiencing the menopause, there is support and treatment to help. This includes hormone replacement therapy as well as treatments and tips to manage your symptoms.

The Menopause Charity has information on the menopause, including support and treatments available. Follow the link, scan the QR code or visit themenopausecharity.org

Outcomes of AML

Summary

- The outcome of AML depends on your individual situation, your health history and the way you respond to treatment. As with most cancers, outcomes vary from person to person.
- There are many treatment options for AML. But not everyone responds to treatment. If your AML does not respond to your first treatment, your haematology team will talk to you about your options.

What can impact your outcome?

Your outcome can vary depending on your individual situation, your health history and the way you respond to treatment. As with most cancers, outcomes vary from person to person. They depend on lots of different factors, including:

- Your age
- Your AML subtype
- The genetic changes in your leukaemia cells
- Your overall fitness
- Your blood cell counts
- If you have any leukaemia cells left after treatment

We have separate information about the genetic changes in AML. Follow the link, scan the QR code or search for 'genetics in acute myeloid leukaemia' at leukaemiacare.org.uk.

Your haematology team are best placed to discuss what they expect for you because they know your individual circumstances.

If you are interested in general survival numbers for AML, we include some figures on the next page. You may prefer not to look at these.

It’s important to remember that survival numbers cannot tell you what will happen in individual situations. They look at what happened to groups of people with a similar diagnosis in the past. They are based on data collected over many years, when people may not have received treatments that are available now.

5-year survival rates are commonly quoted. This is the proportion of people with a particular condition who are still alive 5 years after diagnosis.

Survival rates do not tell us anything about what people who are not alive 5 years after diagnosis died from. It may have been the condition, or it may have been another cause.

On average, around 55 in every 100 people with AML under 40 are still alive 5 years after their diagnosis.

Outcomes are generally poorer in older people, especially in people over 60 to 70, when treatment often aims to control AML rather than cure it.

What happens if AML does not respond to treatment?

There are many treatment options for AML. But not everyone responds to treatment. This is called refractory AML.

- Between 8 to 9 in every 10 young people with AML achieve remission. This means that 1 to 2 in every 10 young people do not.
- Around 5 in every 10 older people with AML achieve remission. This means that 5 in every 10 older people do not.

If your AML does not respond to your first treatment, your haematology team will talk to you about your treatment options.

Depending on your individual circumstances, they might recommend chemotherapy, a targeted drug, a stem cell transplant or supportive care.

We have separate information on relapsed and refractory AML. Scan the QR code, follow the link or visit leukaemiacare.org.uk and search 'Relapsed and refractory acute myeloid leukaemia.'

Living with AML

Summary

- Being diagnosed with AML can be overwhelming. There's a lot to take in, and you probably have a lot of questions and concerns.
- You may experience a variety of emotions. There is no right or wrong way to feel. But if you think you may be depressed, contact your GP.
- If you are struggling, don't be afraid to ask for help from friends, family, your haematology team or Leukaemia Care.
- You might want to talk to your friends and family about your condition. Remember, this is your choice. You can choose when to tell them and how much.
- During your treatment for AML, you may need to stay in hospital for a few weeks. You might need to arrange for someone to look after things at home while you are away.
- You probably have a lot of questions. Make a list of them so you don't forget to ask them when you see your medical team.
- Trying to eat a well-balanced diet and staying active can help improve both your physical and mental health.
- Having AML can affect your work or finances. You are entitled to reasonable adjustments to help you cope with work. You may also be eligible for financial support.

Living with AML

Being diagnosed with AML can be overwhelming. There's a lot to take in, and you probably have a lot of questions and concerns. Here, we cover some of the things you may want to know.

You might find our newly-diagnosed checklist helpful. Follow the link, scan the QR code or search 'just diagnosed' at leukaemiacare.org.uk.

Managing your emotions

Finding out you have AML is difficult. You may need emotional and practical support. It is likely you will experience a range of complex thoughts and emotions, like:

- Shock or disbelief
- Uncertainty, anxiety or fear about the future
- Sadness or depression
- A sense of loss of the person you used to be, and how safe you felt
- Worry about other people's reactions
- Isolation, or a feeling that other people don't understand what you're going through
- Guilt, anger, frustration or irritability
- A loss of self-confidence

Everybody reacts differently. You may experience some of these emotions but not others. You might have different feelings at different times. There is no right or wrong way to feel.

Let your medical team know how you're feeling. They can help you access support and may be able to refer you for counselling if you need it.

Sadness and depression

You might be feeling low, which is a natural effect of your diagnosis and treatment. However, you may have depression if:

- Your low mood persists for several weeks
- You feel hopeless
- You lose interest and pleasure in life

If you think you may be depressed, it is important to contact your GP. They can help you access the support and treatment that you need.

If you are in crisis, the NHS has urgent mental health helplines that offer 24-hour advice and support. Follow the link or scan the QR code for details or or go to the 'mental health' section at www.nhs.uk

Where to seek support and how to cope

Talking to other people can help. It can be difficult to talk to loved ones, so you might prefer to speak to someone independent. It can also help to talk to other people who have gone through a similar experience.

We're here for you if you need support. Scan the QR code, follow the link or search 'support for you' at leukaemiacare.org.uk to find out how we can help you. Our support services include:

- Helpline and advocacy services to provide information and support
- Support groups and a buddy service, where you can connect with people who understand your experience
- A counselling service where you can apply for a grant for up to six sessions of counselling

If you'd like to talk to someone who understands what you're going through:

- Call our freephone helpline on **08088 010 444**
- Message us through WhatsApp on **07500 068065**
- Email support@leukaemiacare.org.uk

Some people find relaxation techniques help them cope with difficult emotions, or use complementary therapies like acupuncture, massage or yoga. Some people find faith or spirituality helpful.

Macmillan have information on complementary therapies, including mindfulness. Follow the link or search 'complementary therapies' at macmillan.org.uk

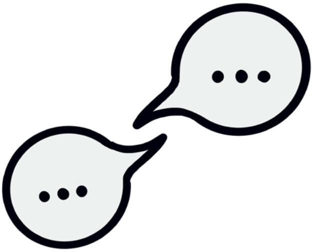
Telling other people

When you are first diagnosed with AML, there is a lot to take in. You may need to give yourself time to adjust before you decide when and how to tell others about it. People may be anxious to know what's happening, which can make you feel under pressure to tell them. Let them know you need time to process the information yourself before you are ready to talk about it.

There will be some people you want to tell and others you prefer not to. It is up to you who you tell and how much you tell them. It can help to make a list and plan what you want to say beforehand. In the conversation with your loved ones, you might want to:

- Explain that you have a type of blood cancer.
- Explain what symptoms you get (maybe you feel tired or get infections a lot).
- Explain your needs. Your family and friends may be happy to know they can help support you by helping around the house or doing the food shop.
- Be open and honest about how you feel. People who care about you will help you as best as they can.
- Have a print-out or factsheet with you. This means you don't have to remember everything that your friends and family might want to know. Or you could give them a copy of this booklet.

If you can, choose somewhere you can hear each other clearly and where you're not likely to be interrupted. Try to speak slowly and calmly to give the other person time to take in the information. If you're struggling to know what to say, you could try:



- "This is going to be difficult, but I need to tell you something."
- "You know I've been feeling unwell for a while. I've had some tests and they've found out what is wrong."
- "I've had some bad news, but now I've got a diagnosis, there's a plan for me to start treatment."

Repeating yourself to different people can be draining. You could ask your family or friends to let other people know, so you don't have to tell everybody yourself.

Staying in hospital

During your treatment for AML, you may need to stay in hospital for a few weeks.

You might need to arrange for someone to look after your home while you are away. You also may need someone to look after your children, pets or water any plants you may have. If you work, and you know that you will be staying in hospital, you will need to let your employer know.

You can also take some things with you that will make your hospital stay more comfortable like:

- Comfortable clothes, underwear and nightwear – loose clothes work well because they can fit over a drip if you need one
- Socks and slippers
- Toiletries, including period products if you need them
- Essential items like glasses, contact lenses, or a hearing aid
- Things to do like your phone, tablet or laptop (plus a charger), books, puzzles or crafts
- Photos, cards or other things to cheer you up
- A sleep mask and ear plugs
- Your own pillow, towels and bedding, if your hospital allows them
- A list of all the medicines you usually take

Going to appointments

As a person with AML, you will often need to attend appointments with your haematologist, clinical nurse specialist (if you have one) or sometimes your GP. Once you're in your appointment, it can be hard to take in everything your doctor or nurse tells you. It can help to take a family member or friend with you for support.

Ask any questions you may have. If you don't understand something, ask your medical team to explain. They will be used to this. You could take notes on your phone or on paper to help you remember. Or you could ask your doctor or nurse to write things down or ask if they're happy for you to record the conversation.

Questions you might want to ask include:

- What tests will I need?
- What might the tests show?
- How long will it take to get the results back?
- What treatment will I need?
- How long will my treatment last?
- How will I know if my treatment has worked?
- What might the side effects be?
- Are there any foods or medicines that I need to avoid?
- Will I be able to go back to work?
- Where can I get help claiming benefits and grants?
- Where can I get help dealing with my feelings?

Looking after yourself

It's important to look after yourself as well as you can. This can help you feel better physically and emotionally. If you're able to, try to eat a well-balanced diet. This will help you:

- Feel stronger
- Have more energy
- Cope better with your treatment

Some treatments for AML may affect your appetite or have side effects like feeling sick. This can make it difficult to eat a healthy diet. Try to eat what you can. If you're struggling, ask your medical team for advice.

The NHS website has information and guidance on eating a healthy, balanced diet. Follow the link, scan the QR code or search 'eat well' at nhs.uk.

Staying active is also helpful. Exercise can improve your wellbeing, quality of life and physical health. It can also help you cope with your emotions. It doesn't have to be strenuous – even a gentle walk can help. Choose a level of exercise that works for you and how you are feeling.

If your blood counts are very low, ask your haematology team if you need to take any precautions.

Work, education and money

Treatment for AML can be intensive. You may need to stay in hospital for some time, so you will need to take time off work, school or education. Even if you are not in hospital, you are likely to need time off when you're feeling unwell and to attend appointments.

You'll need to keep your employer or education provider informed. Depending on your employment contract, you may be entitled to sick pay. If you are at university, you may want to consider deferring your attendance for a while.

If you are well enough to go to work or university, you are entitled to reasonable adjustments to help you cope. You may wish to have an open conversation with your employer or education provider about how they can support you.

Having AML may affect your finances, whether or not you are working. Being diagnosed with leukaemia can come with extra costs such as extra heating costs, travel to and from hospital and childcare costs. You may be eligible for financial support.

If you have AML, you are entitled to free prescriptions. Your haematology team or GP can tell you how to apply for this.

Charities and financial support

We have a range of services that can help you when living with AML, including a welfare service and cost of living hub. Follow the link, scan the QR code or search 'support for you' at leukaemiacare.org.uk

Macmillan have information on benefits and financial support you might be able to access. Follow the link, scan the QR code or search for 'benefits and financial support' on www.macmillan.org.uk for more information.

Glossary of medical terms

Acupuncture: a type of complementary therapy where fine needles are inserted into certain areas of your body.

Acute megakaryoblastic leukaemia (AMKL): a rare subtype of acute myeloid leukaemia.

Acute myeloid leukaemia (AML): a fast-growing type of blood cancer that starts in blood-forming cells called myeloid stem cells.

Acute myelomonocytic leukaemia (AMML): a rare subtype of acute myeloid leukaemia.

Acute promyelocytic leukaemia (APL): a rare subtype of acute myeloid leukaemia.

Anaemia: a low red blood cell count.

Bone marrow: the spongy centre of some of your larger bones where blood cells are made.

Central nervous system: your brain and spinal cord.

Chemotherapy: medicine that kills cancer cells or stops them dividing and multiplying.

Consolidation treatment: treatment that aims to kill any leukaemia cells that may be left after induction therapy.

CT scan: a scan that uses X-rays and a computer to make detailed pictures of the inside of your body.

Down's syndrome: a condition when a person is born with an extra copy of chromosome 21.

ECG: a test to check the electrical signals in your heart.

Fatigue: extreme tiredness or lack of energy that can interfere with your usual activities and doesn't get better when you rest.

Genetic: relating to genes.

Growth factor: a type of medicine that boosts your blood cell counts.

Haematological response: how well leukaemia is responding to treatment based on your blood cell counts.

Haematologist: a doctor who specialises in diseases of the blood.

Haematology: the branch of medicine that deals with diseases of the blood.

Induction treatment: treatment that aims to kills as many leukaemia cells as possible.

Intensive treatment: strong treatment that aims to cure your AML. It usually happens in phases, known as induction, consolidation and sometimes maintenance.

Leukaemia: a group of cancers that usually start in the bone marrow and lead to high numbers of abnormal blood cells.

Lumbar puncture: a test to collect a sample of the fluid that surrounds your brain and spinal cord through a needle in your back.

Maintenance treatment: treatment that aims to reduce the risk of your AML coming back.

Molecular response: how well leukaemia is responding to treatment based on the level of changed genes in your blood or bone marrow.

Myelodysplastic syndrome (MDS): a type of cancer where your bone marrow produces immature, abnormal blood cells that do not work properly.

Myeloid stem cells: blood-forming cells.

Myeloproliferative neoplasm (MPN): blood cancers that develop when cells in your bone marrow grow out of control and make too many blood cells.

Neutropenia: a low white blood cell count.

Non-intensive treatment: gentler treatment that aims to control your AML rather than cure it.

Platelet: a type of blood cell that helps your blood clot and stops bleeding.

Radiotherapy: treatment that uses high doses of radiation to kill cancer cells.

Red blood cell: a type of cell in your blood that carries oxygen around your body.

Refractory: cancer that does not respond well to your first treatment.

Relapse: when cancer comes back after successful treatment.

Remission: when tests or scans after treatment can find little or no cancer left in your body.

Stem cell transplant: treatment that kills abnormal blood-forming cells in your bone marrow and replaces them with healthy ones.

Supportive treatment: medicine to prevent or treat symptoms or side effects.

Targeted drugs: medicines designed to block specific proteins on cancer cells.

White blood cells: cells in your blood that help your body fight infections.

X-ray: a scan that uses low doses of radiation to take images of the inside of your body.

Useful contacts and further support

There are a number of helpful sources to support you during your diagnosis, treatment and beyond, including:

- Your haematologist and healthcare team
- Your family and friends
- Your psychologist (ask your haematologist or CNS for a referral)
- Reliable online sources, such as Leukaemia Care
- Charitable organisations

Leukaemia Care

Helpline: 08088 010 444 (Monday to Friday, 9am to 4:30pm)

WhatsApp: 07500 068065 (Monday to Friday, 9am to 5pm)

www.leukaemiacare.org.uk
support@leukaemiacare.org.uk

Blood Cancer UK

Blood Cancer UK is the leading charity into the research of blood cancers. They offer support to patients, their family and friends through patient services.

0808 2080 888 (Option 1) (Monday to Saturday, times vary)

www.bloodcancer.org.uk

support@bloodcancer.org.uk

Cancer Research UK

Cancer Research UK is a leading charity dedicated to cancer research.

0808 800 4040 (Monday to Friday, 9am to 5pm)

www.cancerresearchuk.org

Macmillan

Macmillan provides free practical, medical and financial support for people with cancer.

0808 808 00 00 (Monday to Sunday, 8am to 8pm)
www.macmillan.org.uk

Maggie's Centres

Maggie's offers free practical, emotional and social support to people with cancer and their families and friends.

0300 123 1801

www.maggiescentres.org

Citizens Advice

Offers advice on benefits and financial assistance.

0800 144 8848 (England)

0800 702 2020 (Wales)

0800 028 1456 (Scotland)

www.citizensadvice.org.uk

The Citizens Advice service does not cover Northern Ireland but their website lists contact details for local community advice agencies, depending on where you live.

How you can help us

If you've been affected by AML, sharing your story can help others going through a similar situation and help the public to better understand.

Scan the QR to share your story:

Alternatively, you can email our Communications team at communications@leukaemiacare.org.uk.

Tell us what you think of this booklet

We aim to provide information that's reliable, up-to-date, and covers what matters to you. We want you to feel supported and able to be involved in decisions about your care. Please follow the link or scan the QR code to complete our short survey to help us improve our information and make sure it meets your needs. Or get in touch with us by email, phone or post.

You can also contact us if you'd like a list of the references we used to compile this booklet.

- Email our Information team at information@leukaemiacare.org.uk
- Call our Head Office on **01905 755 977**
- Write to us at Leukaemia Care, One Birch Court, Blackpole East, Worcester, WR3 8SG
- Leave us a review if you've ordered a booklet online

If we've helped you - here's how you can give back

Fundraising is at the core of what we do here at Leukaemia Care, and without it we wouldn't be able to provide the support we do.

Fundraising isn't all about running a marathon, and there are plenty of ways to give thanks and show your support.

You could:

- Ask your local shop or workplace to host a collection tin
- Ask your place of work about charity of the year partnerships or grants
- Take on one of our more accessible walking challenges
- Host a quiz night or get your friends together for a catch-up and a meal
- Host a bake sale at work or school, or even a coffee morning with friends
- Share information about the activities we have going on to get friends and family joining in
- Stream online from the comfort of your own home

However, if you can run a marathon or want to do a thrilling skydive, we've got you covered!

Whatever you want to do, we can support you to raise money for Leukaemia Care. Get in touch with the fundraising team by email fundraising@leukaemiacare.org.uk or calling **08088 010 444**.

You can also find out more about how to get involved by scanning the QR code.

Plenty of ways to give

There are so many ways you can give in support of those affected by a leukaemia diagnosis, the possibilities are endless - find one that fits you and let's get giving!

By bank transfer

You can transfer your donation straight from your account to ours. Our bank details are:

Sort code: **20-98-61**

Account number: **80823805**

Account name: **Leukaemia Care**

By cheque

Please make your cheque payable to Leukaemia Care, and then pop it in the post to: **Leukaemia Care, One Birch Court, Blackpole East, Worcester, WR3 8SG**

Online

Simply pop onto our website at www.leukaemiacare.org.uk/donate or scan the QR code to donate.

By phone

You can call us to pay by debit or credit card over the phone. Simply call **01905 755977**.

Leukaemia Care is the UK’s leading leukaemia charity. For over 50 years, we have been dedicated to ensuring that everyone affected receives the best possible diagnosis, information, advice, treatment and support.

Every year, 10,000 people are diagnosed with leukaemia in the UK. We are here to support you, whether you’re a patient, carer or family member.

Want to talk?

Helpline: **08088 010 444**
(free from landlines and all major mobile networks)

WhatsApp: **07500 068065**

Office Line: **01905 755977**

www.leukaemiacare.org.uk

support@leukaemiacare.org.uk

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

Leukaemia Care is registered as a charity in England and Wales (no. 1183890) and Scotland (no. SC049802).

Company number: 11911752 (England and Wales).

Registered office address: One Birch Court, Blackpole East, Worcester, WR3 8SG

Leukaemia Care
YOUR Blood Cancer Charity

Trusted Information Creator
Patient Information Forum

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