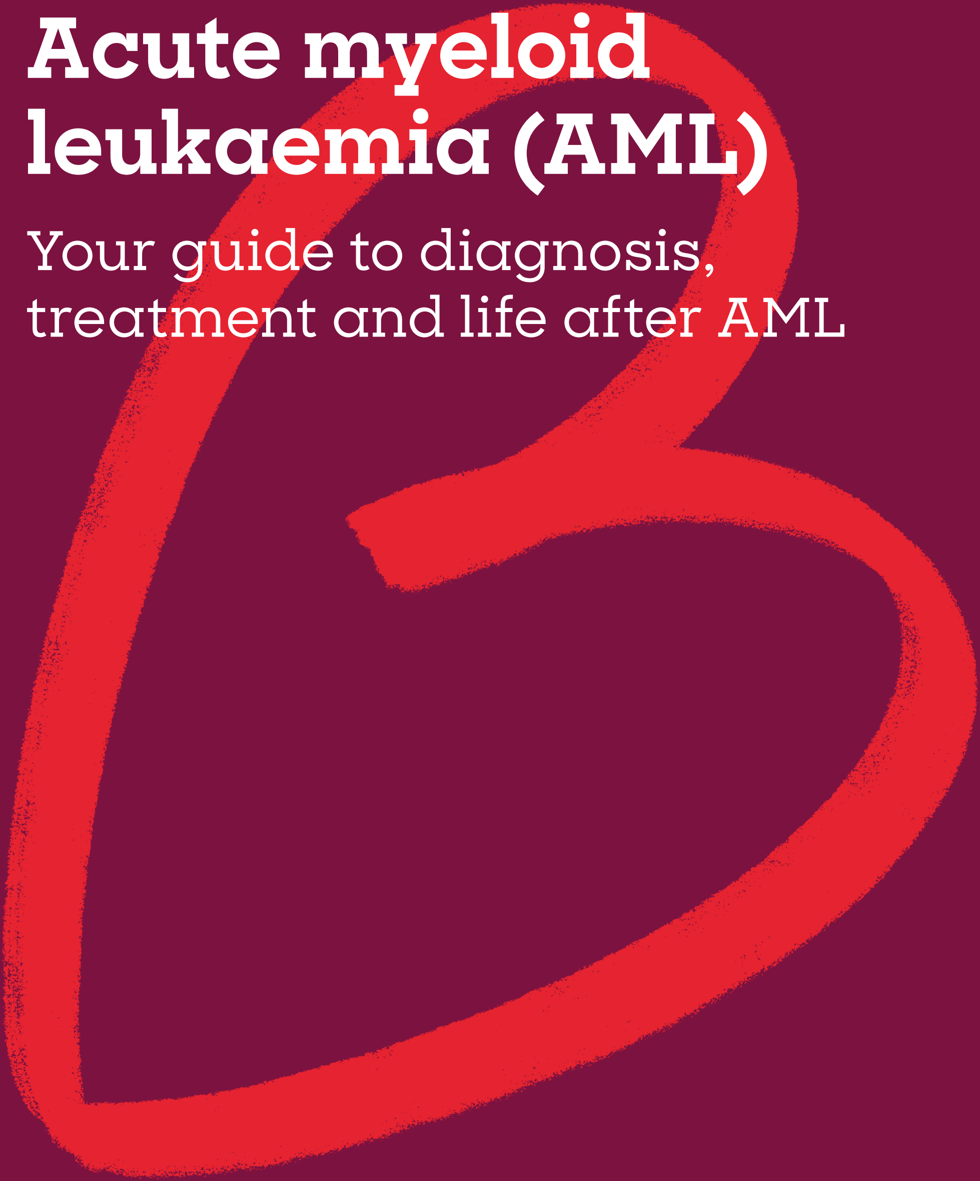
# Acute myeloid leukaemia (AML)

## Your guide to diagnosis, treatment and life after AML



Blood
cancer
UK

## Need to talk?

Contact the Blood Cancer UK Support Service with questions or worries about your diagnosis, family, work, mental health, the future.

Call free on **0808 2080 888**
(Monday: 10am to 7pm, Tuesday to Friday: 10am to 4pm and Saturday and Sunday: 10am to 1pm)
Email **support@bloodcancer.org.uk**
Visit **bloodcancer.org.uk**
Talk to others **bloodcancer.org.uk/our-forum**

We're the UK's specialist blood cancer charity, supporting anyone affected by any blood cancer. Family and friends can contact us for support too.

# My diagnosis and care

Ask your doctor or nurse to help you fill in this page about you, your diagnosis and key contacts:

## My diagnosis is:

..........................................................................................................

My hospital number is: ..........................................................................

My NHS number is: ...............................................................................

## My main point of contact (key worker) is:

Name: ..............................................................................................

Role: ................................................................................................

Phone no: .........................................................................................

Email: ..............................................................................................

You should be given a key worker. Ask if you're not sure who this is, or call us.

## My consultant's name is:

..........................................................................................................

Haematology ward/clinic: ..................................................................

Phone no: .........................................................................................

## If I need medical help outside normal hours, I can call:

Name of service: ...............................................................................

Phone no: .........................................................................................

# In this booklet

① **Finding out you have AML** 5
How you might feel 6
What happens next? 7
Telling other people 8
Questions to ask 10

② **Understanding AML** 13
What is AML? 14
What causes AML? 18
What is the prognosis for AML? 20

③ **Treatment for AML** 29
What treatment will I have? 30
  – Intensive treatment 31
  – Non-intensive treatment 40
Questions to ask about treatment 44
Key things to know about treatment 45
Side effects of treatment 46
Risk of infection 52
Treatment response and remission 56
If treatment doesn't work 62
The future of AML treatment 66

## 4 Tips for coping with treatment 69

Emotional impact of treatment 70
Tips for a better hospital stay 72
Tips for taking care at home 74
Tips for family and friends 76
How to help yourself during treatment 78

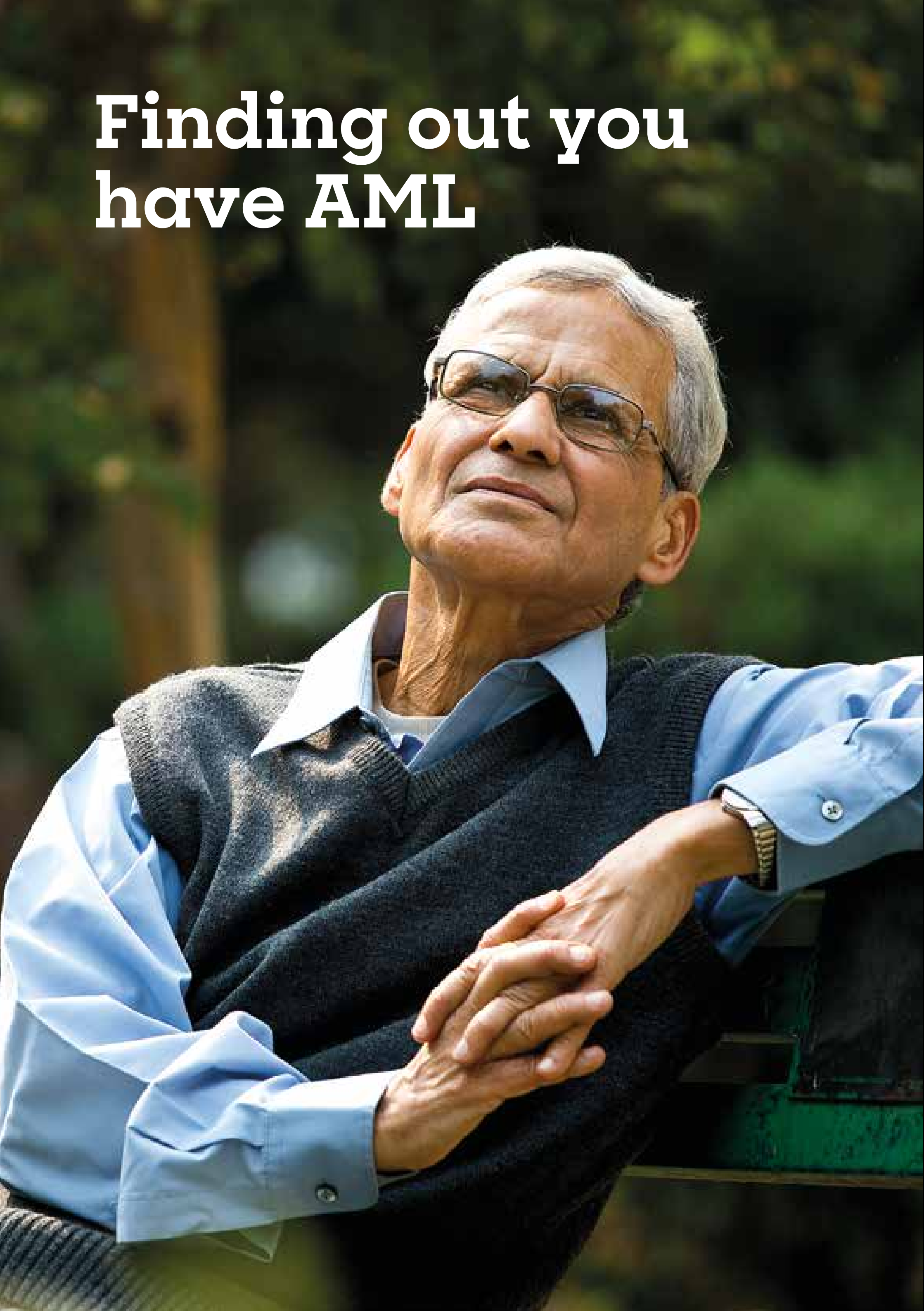
## 5 Life after AML 81

How long does it take to recover? 82
How you might feel 83
Are there any long-term side effects? 84
How to help yourself after treatment 85
Managing fatigue (tiredness) 86
Keeping active 88
Eating well 89

## 6 Getting support 91

Support for you 92
Support for family and friends 94
Support for children 96
Work, money, childcare and help at home 98
More information and support 102
Questions for your medical team 106

# Finding out you have AML



# If you’ve been diagnosed with AML, or someone you love has, this booklet is for you.

AML is a type of leukaemia, which is a type of blood cancer.

There are effective treatments for AML, but they do take several months and require time in hospital.

Being told you have AML has probably come as a big shock. There is a lot to take in, and things happen really fast.

With the help of people who've had AML, we've written this booklet to help you through it. Don't feel you have to read it all at once. Keep it handy so you can come back to it when you’re ready.

**I was diagnosed and started treatment so quickly, I couldn’t even process what was happening. Everyone was crying but I just didn’t react. It didn’t seem real.**
Anna, diagnosed with AML in 2015

## How you might feel

Being diagnosed with AML, or having someone you love get diagnosed, often comes as a shock. You might be feeling very overwhelmed, especially if you've never heard of AML.

Many people think of leukaemia as a children's illness, but it actually affects more adults than children. It can affect people of any age, gender or ethnicity.

People talk about feeling stunned, sad, angry, numb… and it can change from minute to minute. But you're not alone.

There are around 40,000 people diagnosed with blood cancer every year in the UK, and many of them have AML.

This booklet offers lots of support and personal stories about living with AML.

When you're ready, you can contact our Support Service if you have any questions. Family and friends can contact us too, and we're here even if you just need a chat. Contact us on **0808 2080 888** or **support@bloodcancer.org.uk**

# What happens next?

After diagnosis, lots of things can happen quite quickly. Here are the main things that happen next:

- **You'll probably start treatment straight away** – this is to get the leukaemia under control. You might also need other treatments like blood transfusions.
- **You'll have more tests** – blood tests and genetic tests will tell doctors more about your type of AML and which treatments would work best for you.
- **Your medical team will work out your future treatment plan** – they will look at your test results and your general health, and recommend the best treatment plan for you.
- **You should be given a main point of contact in your medical team** – this is usually a clinical nurse specialist (CNS). They are there to answer any questions that you or your family have.

> **At first I couldn't take information in. But my family, they wanted lots of information straight away. The facts, what to expect, and how to help me. This booklet can give them that.**
>
> Bav, diagnosed with AML in 1999

## Telling other people

Telling people you love that you've got AML can be really hard. If you have to tell children, it can feel heartbreaking.

There is no right or wrong way to tell people, and there is no perfect set of words. How you do it (and who does it) will depend on your individual situation.

Remember, even if it doesn't go how you thought it would, it's a conversation you'll come back to again. Giving people copies of this booklet might help – you can order more from **bloodcancer.org.uk/our-booklets** or call us.

### Telling children

Telling children or grandchildren can be the hardest part for many people.

There are resources available that can help teach children about cancer, and help them start to ask questions. Contact our Support Service and we can recommend some resources and help you prepare for talking to your children.

There's also a story on our website from Simone, about how she told her family, including children, that she had blood cancer: **bloodcancer.org.uk/simone**

You can find other parents and guardians on our online community forum talking about how they did it at **bloodcancer.org.uk/our-forum**

## Marie

### How did you feel when you were first diagnosed?

"I was so shocked, it was surreal. It was like I was watching a movie and this was all happening to someone else. The way I coped was to just focus on the next 24 hours – I could only take it one day at a time."

Read Marie's story at **bloodcancer.org.uk/marie** or call us and we'll post it to you.

## Questions to ask

If your medical team ask whether you have any questions, it might be hard to think of any when everything is happening so fast.

You don't have to ask anything straight away, but when you're ready, these questions might help:

- What is blood cancer?
- Why have I got AML?
- Can it be cured?
- What will happen next?
- How long will I be in hospital?
- Who can support my family?

> **They said to me, have you got any questions? And I just thought, I have no idea what to ask! So I think it's helpful to have a list of questions to get you started.**
>
> Yvonne, diagnosed with AML in 2018

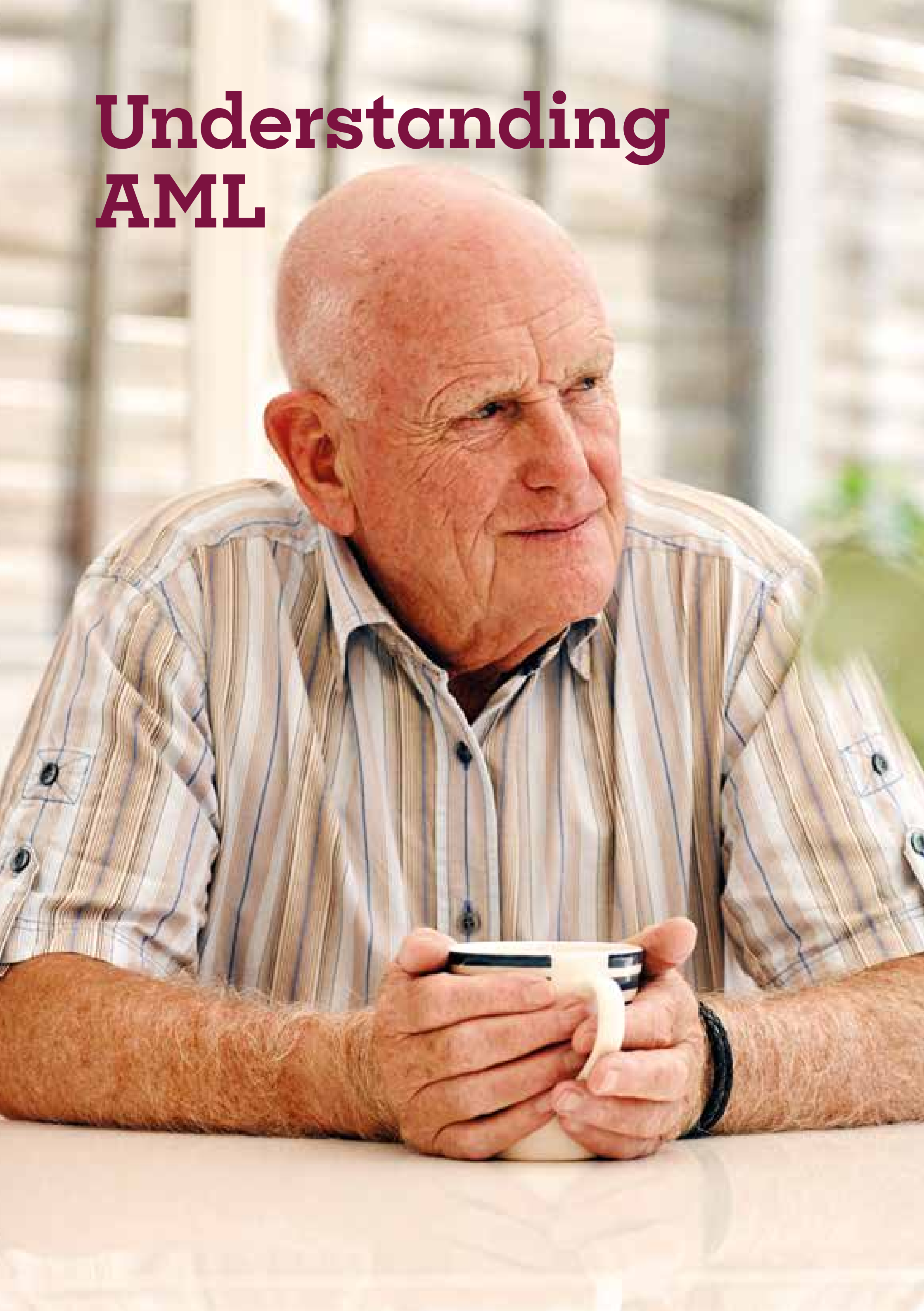
# Support for family and friends

If someone you love has been diagnosed with AML, we're here for you too. We can tell you more about AML and talk about how you are feeling.

Visit **bloodcancer.org.uk/friends-family**

Or contact our Support Service
on **0808 2080 888** or
**support@bloodcancer.org.uk**

# Understanding AML



## As the news of your diagnosis starts to sink in, you might want to know more about AML.

AML is a fast-growing type of blood cancer. In AML, some of your blood cells aren't working properly.

This stops your blood doing the things it normally does to keep you healthy, like fighting off infections or carrying oxygen around the body.

We don't know why AML happens to some people and not others. AML can happen to anyone, and it's not because of anything you have done.

> **Don't Google! That will add to the fear. Use trustworthy sources like this booklet or charities, and write down any questions you still have for your doctor.**
> Josh, diagnosed with AML in 2015

# What is AML?

Acute myeloid leukaemia (AML) is a fast-growing type of blood cancer. It's called "acute" because it develops very quickly and needs fast treatment. In AML, your blood and immune system are not working properly.

## How does AML develop?

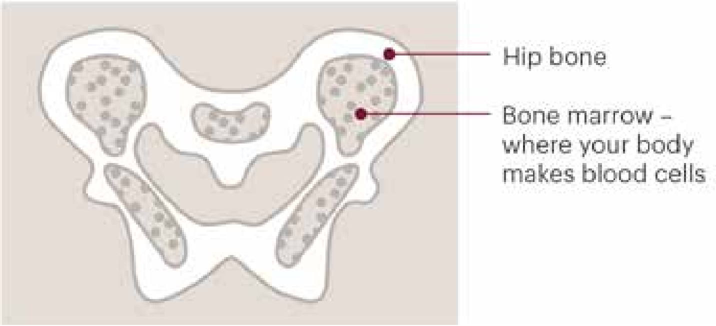
Your whole body is made up of cells. And inside every cell is DNA, which tells the cell what to do and how to grow.

The main types of cells in the blood and immune system are red blood cells, white blood cells and platelets. They all do different important jobs in the body.

In AML, something goes wrong in the DNA inside some of your blood cells. This means the blood cells don't grow or work properly.

AML starts in the bone marrow, which is a soft, spongy tissue in the centre of some bones. This is where your body grows its blood cells.

The bone marrow:



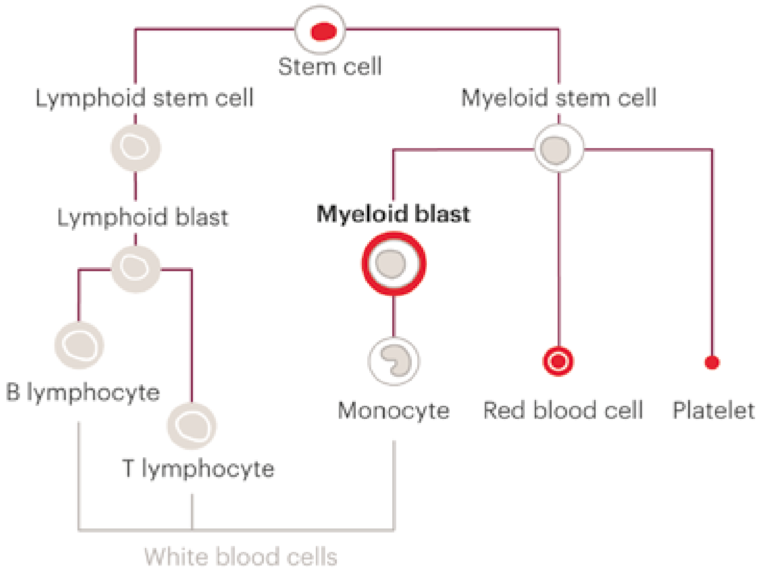
All blood cells start off as 'stem cells' (very young blood cells). Inside the bone marrow, stem cells grow into all different types of blood cells.

Once blood cells are fully grown, they are released into the bloodstream to do their jobs in the body.

But... in AML, some blood cells get stuck at an early stage of growth. These immature cells are called "**myeloid blasts**". These are the leukaemia cells.

This means you don't have all the healthy blood cells that you need.

## How stem cells grow into blood cells:



## How does AML affect your body?

When you have AML, some of your white blood cells do not develop properly. These faulty blood cells (called blasts) can't do the jobs that normal white blood cells do, like fighting off infections in your body.

Blasts also build up in the body, making it harder for your body to grow other normal blood cells like healthy red blood cells and platelets.

This means that as well as having faulty white blood cells that can't fight off infections, your body might also not have enough red blood cells (which carry oxygen around the body) or platelets (which prevent bleeding). This lack of healthy blood cells is what causes the symptoms of AML.

## Other types of AML

In very rare cases, it's the red blood cells or platelets that are faulty. These are very rare types of AML called **acute erythroid leukaemia** and **acute megakaryoblastic leukaemia**. The treatments for these types of AML are the same and this booklet is about all these types of AML.

There is one particular type of AML called **acute promyelocytic leukaemia (APL)** which is different. If you have APL, you need our APL booklet instead – call us or visit **bloodcancer.org.uk/our-booklets**

## Who gets AML?

About 3,100 people are diagnosed with AML each year in the UK. Three quarters of these (75%) are aged 60 or over, but AML can happen at any age.

## What are the symptoms?

Some of the symptoms you might have when you are diagnosed with AML include:

- fatigue (tiredness)
- breathlessness
- infections
- weight loss
- bruising
- bleeding (for example from your gums, nose bleeds, more prolonged bleeding from a cut, having heavier periods than normal, or blood in your urine or poo).

> **I thought leukaemia was something that only children got. I didn't realise there were different types of leukaemia, and even different types of AML.**
> Anna, diagnosed with AML in 2015

# What causes AML?

We don't know exactly why some people get AML and others don't. AML can happen to anyone, and it's not because of anything you have done.

There are some things that make a person slightly more likely to get AML – these are called risk factors. But most people with these risk factors never develop AML.

## Age

Like most cancers, AML is more common in older people. This is because the longer we live, the more chance there is for accidental errors to happen in the DNA inside cells.

People of all ages can develop AML, but you're more likely to get AML over the age of 60. The most common age to develop AML is between 85 and 89 years old. Around a quarter of people who are diagnosed are under 60.

## Sex at birth

People who are born male are slightly more likely to get AML than people born female, but we don't know why. Around 44% of AML cases are in females, with 56% in males.

## Family history

In most cases, AML doesn't run in families. In some families, there are more cases of AML than we'd expect to occur by chance. AML can sometimes be linked to an inherited genetic mutation, but this is extremely rare. If you're worried about leukaemia in your family, talk to your doctor.

## Smoking

Long-term exposure to certain chemicals could increase the risk of getting AML. One of these chemicals is called benzene, which is found in cigarette smoke. This could explain why people who smoke have a slightly higher risk of AML, although most people who smoke never get AML.

## Other conditions

If you have another condition which affects the production of myeloid blood cells, such as myelofibrosis or MDS, you can be at higher risk of getting AML. There are specific treatments for AML that has developed from another blood condition.

## Previous medical treatment

Some people develop AML after having chemotherapy, radiotherapy or other specific drugs in the past for another illness. The AML can develop a number of years later. This type of AML is called treatment-related or therapy-related AML (tAML).

## Genetic disorders

Children with Down's syndrome are at an increased risk of developing any type of acute leukaemia. There are also some rare inherited genetic mutations that can increase the risk of AML, such as RUNX1 and DDX41. If you're worried about any of these genetic risks, talk to your doctor.

**While these things do slightly increase the risk, AML can happen to anyone and it's not because of anything you have done.**

## What is the prognosis for AML?

Prognosis means what is likely to happen in the future. It is a way of saying what the most likely outcome will be, or the most likely range of options, based on what has happened to other people with AML.

Prognosis information can give you a rough picture of what happens to large groups of people with AML, but it can't say exactly what will happen to you, as nobody can know that.

There are some things that we know affect prognosis, like:

- your age
- your general level of fitness
- the type of AML you have.

But even after taking these things into account, people can still have quite different experiences.

Everyone's prognosis is individual to them.

When you are diagnosed, and any time during your treatment, your doctor can tell you what the aim of your treatment is:

- For many people, the aim is to get rid of the leukaemia completely. This requires strong treatment and takes some time, but for many people the treatment is successful and they are cured.

- For other people, the treatment doesn't manage to completely get rid of the leukaemia. The aim of treatment might then become to control the AML and your symptoms for as long as possible.

- People who are older, who have other serious underlying heath issues, or who are generally frail may not be able to have treatment that could cure the AML.

If you aren't clear what the aim of your treatment is, ask your doctor.

Whatever stage you are at, we are here to support you through it. We hope the information in this booklet will help you cope with AML, and talk openly with your medical team.

The next few pages explain things that can affect your prognosis.

## Your general fitness and ability to have intensive treatment

Your general health and fitness affects prognosis. If you are generally quite well, then you are more likely to be able to have intensive treatment, which gives the best chance of a cure. If you are more frail, or have other health conditions, you might not be able to have intensive treatment.

Often (but not always) people who are younger are generally fitter and more able to cope with intensive treatment, and therefore have better outcomes. But this doesn't mean that someone older can't have a good outcome – it depends on your personal level of fitness and how you respond to treatment.

## How well the AML responds to treatment

If your first set of treatments for AML are successful at getting you into a remission, then this suggests a better prognosis in the long-term. Also, the quicker you reach a remission, the better the long-term prognosis.

If your treatment doesn't work, or it works at first but then the AML comes back later, then this is harder to treat. But there are still options, and some people do still manage to get rid of the AML with more treatment.

## Genetic mutations in the AML cells

There are many different genetic changes that can happen inside AML cells. Some of these are linked with less good outcomes, and others are linked with better outcomes.

Genetic mutations are also helpful markers that can be monitored by your doctors to see how treatment is working.

Examples of genetic mutations include: FLT3, NPM1, TP53, ASXL1, RUNX1, IDH1, IDH2, CEBPA, t(8;21) and inv(16). We explain all of these, and how they affect prognosis, at **bloodcancer.org.uk/aml-prognosis**

If you've been told you have a genetic mutation, remember:

- It’s very common to have one or more genetic mutations.
- Your prognosis depends on many other factors too, not just on the genetic mutations.
- The genetics of AML is complex, so ask your doctor if you want to know more, as they know your personal situation.

If a genetic mutation is linked to a less good prognosis, this is mainly because of the increased risk of relapse in the future (the AML coming back). But this helps guide treatment decisions, because there are treatments that can be used to reduce the risk of relapse.

There are also some treatments that are more effective in people with certain mutations.

## AML risk groups

Your medical team might talk about your risk level being **favourable** (low), **intermediate** (medium) or **adverse** (high). These risk groups are based on the genetic mutations in your AML cells and the chance of relapse. Knowing the risk group helps doctors plan treatment, but your overall prognosis depends on other things too, like your general health.

## Secondary AML (s-AML)

Secondary AML is AML that has developed because of previous medical treatment or a previous blood disorder. It's usually linked with a worse prognosis, but there are specific treatments for it. There are different types:

- **Therapy-related AML (t-AML)** – AML that has happened as a result of other medical treatment you've had in the past

- **AML with myelodysplasia-related changes (AML-MRC)** – AML that has developed from another blood cancer called MDS

- **AML that develops from other blood cancers** such as MPN, CMML and CML.

## Asking about your prognosis

Some people want to know about their prognosis because it helps them feel more able to plan ahead.

If you want to know about your individual prognosis, your medical team are the best people to ask. They know you and your individual situation. You could ask questions like:

- What is the aim of my current treatment?
- What are the most likely possible outcomes for me?

Sometimes a family member might want to know more than you do about prognosis. Your healthcare team can talk to your family about prognosis, but only if you give them permission to.

If you look up statistics, be aware these are often not explained fully and can be misleading. Many people find statistics unhelpful, but if you do want to look at them, you should always discuss them with your doctor, who can explain what they really mean for you.

If you hear or read something about your prognosis that you don’t understand or that worries you, speak to our Support Service on **0808 2080 888** or **support@bloodcancer.org.uk**

# Understanding your type of AML

You can find more detailed information about AML, symptoms, tests and genetic mutations at **bloodcancer.org.uk/aml**

If you don’t use the internet,
call us free on **0808 2080 888.**

## Rebecca

### How did you deal with having a higher risk genetic mutation?

"I was devastated, as I had been hoping for good news. I had to shift my mindset, to realise that a transplant would give me the best chance of remission, and that the mutation was a passport to the best treatment there is. Through AML, I've had to learn ways of finding hope when I really need it."

Read Rebecca's story at **bloodcancer.org.uk/rebecca** or call us and we'll post it to you.

# Treatment for AML

## Treatment for AML usually starts quickly after diagnosis, to get the leukaemia under control. After this, treatment continues for several months.

For many people, the aim of treatment is to get rid of the leukaemia completely. This requires intensive treatment.

For others, the main aim may be to keep the AML and symptoms under control for as long as possible.

This chapter tells you about the different treatment options and the medical side of things. The next chapter (Coping with treatment) talks more about the emotional and practical impact of treatment, and tips for coping.

> **At first I had no emotional response, I just wanted to get on with it. But once I was facing the treatment plan, I was full of fear. I was scared of the chemotherapy, but also scared it wouldn't work.**
> Yvonne, diagnosed with AML in 2018

# What treatment will I have?

There are two main groups of treatments for AML.

**If you're not sure which treatment you are having, ask your doctor, so you can read the right pages in this chapter:**

- ● **Intensive treatment – pages 31–39**
- ● **Non-intensive treatment – pages 40–43**

Intensive treatment gives the best chance of getting rid of the AML completely, but it means having very strong treatment that can cause severe side effects.

Non-intensive treatments are gentler. They can't usually get rid of AML completely, but they aim to keep the leukaemia and symptoms under control for as long as possible.

## Intensive treatment

There are two stages to intensive treatment:

- Induction (to get rid of the AML) – takes around one month
- Consolidation (to stop AML returning) – takes up to 6 months

### Stage 1 – Induction with chemotherapy

Induction therapy aims to kill as many leukaemia cells in your blood and bone marrow as possible.

You'll be in hospital for this treatment and will have repeated infusions of chemotherapy spread over about 5–10 days. The chemotherapy will damage your healthy blood cells as well as the leukaemia cells. After treatment, it will take about three weeks for your healthy blood cells to grow back. You'll probably stay in hospital during this time.

Once your healthy blood cells have recovered, you'll have more tests to check for leukaemia cells. If no leukaemia cells can be seen under the microscope, then you are in remission and can move to consolidation therapy (next page).

Some people go into remission after just one round of chemotherapy, whereas others need two rounds.

If after two rounds of chemotherapy, you aren't in remission, this is called refractory AML. There are different treatment options if this happens, explained on pages 62–63.

## Stage 2 – Consolidation with chemotherapy

If you reach remission from your induction therapy, then you'll have consolidation therapy to give you the best chance of staying in remission. Consolidation aims to stop the AML coming back, by killing any final leukaemia cells that may remain.

Consolidation involves having more cycles (rounds) of chemotherapy, usually with similar drugs to your induction treatment. This stage lasts several months.

Each cycle of treatment lasts about one month – the chemotherapy is given over roughly one week, followed by about three weeks of recovery time. You'll be in hospital for a lot of this, but you may be able to go home for breaks in between the cycles of treatment.

If your leukaemia has a lower risk of coming back, doctors may recommend chemotherapy only. If there is a higher risk of your leukaemia coming back, they might recommend chemotherapy and a stem cell transplant (see pages 38–39).

## Which drugs will I have for intensive treatment?

Not everyone's AML is the same. There are different types of AML, and different drugs work for different types. You'll have tests to find out which type of AML you have.

Some people have their treatment as part of a clinical trial, giving the chance to have one of the latest treatments. You can ask your doctor about this.

Most people have intensive treatment with a combination of chemotherapy drugs. There are also other types of drugs (called targeted drugs) which can be added to the chemotherapy to make it more effective.

Your treatment plan will be personal to you, and which drugs you have will depend on your particular type of AML.

Research into new AML treatments is happening now, so information about treatments can change. For the most up-to-date information on AML treatment, visit **bloodcancer.org.uk/aml-intensive-treatment** or call us.

## How are intensive drugs given?

Most high intensity treatments for AML involve having chemotherapy drugs given directly into your bloodstream. This is called intravenous (IV) chemotherapy, or an infusion.

It can take around two hours to deliver the treatment into your bloodstream, using a tube that goes into a vein. This will be done several times, on different days, over about a week. Other drugs can be taken as tablets alongside the IV treatment. You'll do this several times, as you'll need several cycles of treatment.

### PICC lines and central lines (Hickman lines)

To make it easier to give you treatment over several months, you'll have a long, thin tube inserted into one of your veins. This can stay in for the whole treatment plan, so you won't need to keep having injections for treatment or blood tests.

The line can be inserted under a local anaesthetic (so the area is numbed and you won't feel anything) or a general anaesthetic (so you are put to sleep to have it inserted). This is a very common procedure.

A PICC line goes into a vein in your arm. A central line (Hickman line) goes into a vein in your chest. The line will come out of your arm or chest, and there will be a cap on the end of it.

When it's not being used, it will be covered with a bandage. It won't stop you doing anything, except you'll need to avoid getting it wet.

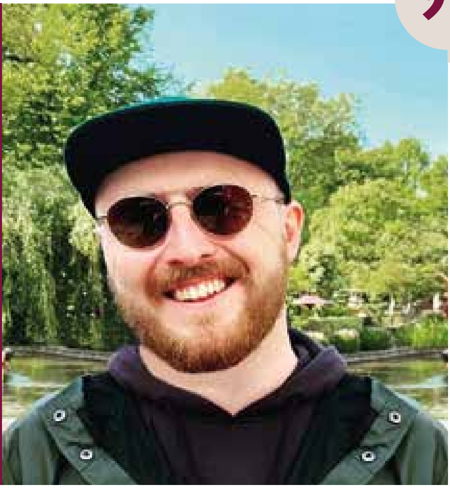
## What other treatments might I need?

As well as the treatment you have for the leukaemia, you'll need other treatments to deal with symptoms and side effects. This is sometimes called 'supportive care'.

AML and its treatment affects your healthy blood cells and immune system. You might need antibiotics to reduce your risk of getting an infection during treatment. You will probably also need to have transfusions of red blood cells and platelets. These are taken from healthy blood donors and used to replace the cells that your body cannot make.

You may also have anti-sickness medicines, to help prevent nausea (feeling sick).

> **Chemotherapy is such a scary word. Even the consent forms made me feel like I was signing my life away. But now I feel proud that I did all this. If you're in treatment now, just know you have the strength within you too.**
> Graeme, diagnosed with AML in 2017



## How will intensive treatment affect my daily life?

Intensive treatment for AML lasts many months. You'll be in hospital for a lot of it, and you might feel ill, from the AML or from the treatment. You'll be at a higher risk from infections during treatment too, so there might be times when you can't have many visitors.

Most people are able to spend some time at home though, in between cycles of chemotherapy. This can be a welcome break from hospital and treatment, although you might still need regular blood transfusions or tests while at home.

Many people with blood cancer describe AML treatment as a rollercoaster, both for them and their family, with lots of ups and downs. Things can be hard to predict and sometimes your treatment plan might have to change.

Other people with AML and their families have lots of tips about how they got through treatment. You can find these in the next section of the booklet – Coping with treatment.

You can also talk to other people who've had AML, or other relatives of AML patients, at **bloodcancer.org.uk/our-forum**

## What are the side effects?

Treatment for AML can cause several side effects, but everyone reacts to treatment differently. Side effects and things you can do to reduce them, including managing the risk of infection, are explained on pages 46–54.

## Graeme

### How did you find intensive treatment?

"It's really tough, the side effects and the mental impact. I found watching positive videos and reading success stories of other people with AML would spur me on. The other big thing for me was to change this narrative in my head that the chemo was some sort of poison. It's cancer that's the enemy, and chemo is your medicine."

Read Graeme's story at **bloodcancer.org.uk/graeme** or call us and we'll post it to you.

## Stem cell transplant

If your doctor thinks there is a high risk of the AML coming back, they might advise you to have a stem cell transplant as part of your consolidation therapy. This might be needed to give you the best chance of staying in remission.

If your AML has returned after treatment, or your first treatment didn't work, a stem cell transplant can also be used to try to get you into remission.

A stem cell transplant involves having cancer treatment to get rid of the leukaemia, before having new stem cells put into your body, which come from somebody else (a donor). Stem cells are very young blood cells, which can grow into new healthy blood cells in your body. This type of transplant is called an allogeneic (donor) stem cell transplant.

In effect, a stem cell transplant aims to completely replace your immune system and your bone marrow, so they can function normally again.

A transplant is an intensive treatment that can have serious complications. This is why transplants are only recommended for people who are fit enough, and when the possible benefits outweigh the risks.

Although a transplant carries lots of risks, it is also one of the most effective ways to cure AML. For more information about stem cell transplants, visit **bloodcancer.org.uk/treatment-types** or call our Support Service.

## Marie

### What was the process of preparing for a transplant like?

"I wanted to know the whole plan upfront, but it just doesn't work like that. Even at the start, my plan moved in a whole new direction because we didn't find a match. As a patient, you can't know the endpoint, you just have to put your trust in your medical team and focus on what you can control."

Read Marie's story at **bloodcancer.org.uk/marie-treatment** or call us and we'll post it to you.

## Non-intensive treatment

If you are not fit or well enough to have intensive treatment, there are non-intensive treatments available.

These treatments aim to control the AML as much as possible, without causing as many side effects that could harm you more. This may be a better option for people who are more frail, or whose general level of fitness would make it difficult to tolerate strong treatment.

For most people, non-intensive treatments can't cure the AML, but they can often get the disease into remission, allowing it to be controlled for as long as possible.

These treatments are gentler than intensive treatments, and aim to give you the best possible quality of life. Many of them can be taken at home rather than hospital.

Most treatment can be taken at home or as an outpatient, but you'll have regular checks with your hospital team. You'll also have blood tests to monitor how the treatment is working.

You might also need other treatments to keep you as well as possible, like antibiotics or blood transfusions (when healthy blood cells from a donor are transferred into your bloodstream).

## Which drugs will I have for non-intensive treatment?

Not everyone's AML is the same. There are different types of AML, and different drugs work for different types.

Some people have their treatment as part of a clinical trial, which offers the chance to try newer treatments being looked at for AML – see page 66.

Most people have low-dose chemotherapy, which is usually given by injections or tablets. Other types of drugs (called targeted drugs) are sometimes added too, which can also be taken as tablets.

Your treatment will be tailored to your personal situation, usually with the aim that you can spend as much time outside of the hospital as possible.

Research into new AML treatments is happening now, so information about treatments can change. For the most up-to-date information on AML treatment, visit **bloodcancer.org.uk/aml-non-intensive-treatment** or call us.

# Coping with non-intensive treatment

If you are having non-intensive treatment, or a loved one is, contact our Support Service. We are here for you, if you have questions or worries, or if you just need to talk: **0808 2080 888**
**support@bloodcancer.org.uk**

## How will non-intensive treatment affect my daily life?

Low intensity treatment for AML is mainly done as an outpatient. You might be able to take the treatment at home, and just visit hospital for check-ups.

The treatments do have side effects, but they are not as severe as the ones caused by strong chemotherapy. An increased risk of infections is one side effect it's important to know about. There's more about this on pages 52–54.

If you're having low intensity treatment, it might be hard for you or your family to accept that the AML probably can't be cured.

It can be hard to think about the future in this situation, although it's often helpful if you can talk openly and honestly with your medical team about things. There are some suggested questions you could ask them on the next page.

Talking to other people with AML can help too. It might also help your family to connect with other relatives of people with AML. Visit **bloodcancer.org.uk/our-forum**

You can find some more sources of support if the AML can't be cured on page 65.

## Questions to ask about treatment

Whether you have intensive or non-intensive treatment, here are some questions you could ask your medical team.

Anna also shares her tips on talking to your medical team and being your own advocate at **bloodcancer.org.uk/anna**

- What treatment am I having and why?
- What is the aim of my treatment?
- How will the treatment affect my daily life?
- Are there any long-term effects of the treatment?
- What’s the best outcome I can hope for?
- Is there a clinical trial I can join?
- When I'm at home, how can I look after myself?

You might want to give the doctors and nurses permission to answer these questions if your family ask them too.

There's space on pages 106–107 to write down more questions and notes.

## Key things to know about treatment

Your treatment will be managed by a medical team who are specialists in blood cancer.

- **You should be given a named key contact, usually a clinical nurse specialist (CNS)**, and a phone number or email in case you have any questions or worries. If you don’t know yours, ask your team.
- **Your doctor and the rest of your medical team are there to answer your questions.** Don't be afraid to ask them whatever you want to know. It's their job to make sure you understand what's happening. We have suggestions for questions to ask on pages 10 and 44.
- **You can contact us for help preparing for appointments or talking to your medical team** – this is something we talk to people about a lot. If you don't feel confident talking to your medical team, contact our Support Service.

> **You can feel powerless going through treatment. But knowing some self-care tips, or having questions to ask the doctor – these things become hugely important when you’ve lost all other control.**
>
> Marie, diagnosed with AML in 2016

# Side effects of treatment

Intensive and non-intensive treatments for AML do cause side effects, but everyone reacts to treatment differently.

Most side effects will gradually go away after treatment ends. Some side effects can last longer, or appear years later. We explain long-term side effects on page 84.

Side effects include:

- breathlessness
- bruising and bleeding (nosebleeds or bleeding gums)
- changes in taste or smell
- diarrhoea or constipation
- extreme tiredness (fatigue)
- feeling sick or being sick
- hair loss
- infections or fever
- nerve damage (causing pain, numbness or weakness)
- skin changes
- sore mouth or gut.

**The most important thing to do is tell your doctor or nurse if you notice any changes in your body. You can stop many side effects from getting worse if you deal with them early.**

We have more information, tips and stories about these side effects on our website at **bloodcancer.org.uk/side-effects**

Next we cover some side effects in more detail and tell you where to get support.

## Fertility

AML treatments can cause reduced fertility or infertility. This means it may be more difficult or impossible to get pregnant or father a child naturally in the future.

The main treatment that causes permanent infertility is having very high doses of chemotherapy before a stem cell transplant, or total body irradiation. Most other intensive chemotherapy treatments cause temporary infertility, rather than permanent infertility, although it's impossible to know for sure until you start trying for a child.

It's often possible to collect and freeze sperm before starting treatment, so you can use it in the future.

Collecting eggs or ovarian tissue is often not possible before treatment, because of the need to start treatment quickly.

There is no right or wrong way to feel if you're told the treatment could cause infertility. Some people feel completely devastated. For others it might feel less important.

If it's something that worries you, tell your doctor or nurse. They can talk to you about your options.

You can talk to us if you prefer. We talk to people every day about the impact that AML has on your body and your future. Contact our Support Service and we'll help you get the support and information you need.

## Hair loss

Hair loss is a temporary side effect, but often quite an emotional one. It's worth being aware that you might find it difficult or shocking at first, but this will likely pass.

Telling people that you might lose your hair before it happens can help. When people are prepared, they often react in a better way.

Telling children about hair loss in advance makes it easier for them to adjust. Letting them touch your head or ask about the hair loss might also help, as they realise it's normal and not something to feel bad about.

Your medical team can tell you about where to get a wig, if you want one. You can get a free synthetic wig from the NHS. If you want a real (human hair) wig, you'll normally have to pay for this yourself.

Wigs are not the only option. Many people prefer headwear like a hat, scarf, head wrap or bandana. You might want to choose these in advance so you are ready, and you don't need to rush to find one when the hair loss starts.

Just allowing your hair to fall out and being bald is another option. Many people find this the most comfortable option. Cutting your hair short before it falls out can also help you adjust. Some people shave their heads, rather than waiting for hair to fall out. However you choose to handle it, there are lots of people sharing tips in our online forum.

## Yvonne

### How did you cope with changes to your appearance?

"As my body and appearance continued to change, I felt less and less like myself. Hair can be part of our identity, so to lose it, you lose so much – your control and choices over how you look. But you ultimately have to accept it, and remember it won't last forever."

Find more about hair loss, including caring for Afro-textured hair, at **bloodcancer.org.uk/hair-loss** or call us.

## Nausea and vomiting

Nausea (feeling sick) and vomiting (being sick) are common side effects of intensive AML treatments. You'll be given anti-sickness medicines to try to prevent this, and in most cases these are very effective. There are many options, so tell your doctor or nurse if you still feel sick.

As well as taking anti-sickness medicines, there are self-help tips that other people with blood cancer find helpful:

- Peppermint tea, peppermints, a fizzy drink, ginger beer and ginger biscuits can help with nausea.
- Avoid fried, spicy and very sweet foods. Plain, bland foods may be easier to eat.
- Eat little amounts more often, rather than trying to eat whole meals.
- Chew your food well and sip drinks slowly.

We have lots more information about this side effect at **bloodcancer.org.uk/sickness-and-vomiting**

## Sore mouth

Chemotherapy can cause ulcers or sores in your mouth. This can be very painful for some people. There are medicines that can help, including mouthwashes, gels, tablets and sprays. You might need painkillers as well. Make sure you tell your medical team if your mouth is sore.

As well as taking any medicines your doctor prescribes you, there are also self-help tips from other people with blood cancer:

- Suck on ice cubes or crushed ice. Ice creams or ice lollies can also help.
- Avoid rough or hard foods like crusty bread or crisps.
- Avoid hot drinks, spicy foods, or acidic foods like tomatoes, oranges and lemons.

We have lots more information about this side effect at **bloodcancer.org.uk/sore-mouth**

We can't list every possible side effect in this booklet. But you can talk to us about any side effect by contacting our Support Service.

Our website has more information about side effects, including brain fog, nerve damage, sleep problems, hair loss and body image changes: **bloodcancer.org.uk/side-effects**

## Risk of infection

Having AML makes it more likely you'll get infections, because the condition and the treatment affect your immune system.

If you do get an infection, it can become serious, because your body might not be able to fight it off. In some cases it can turn into sepsis, which is life-threatening.

It's important to be aware of this, because if you act fast when you have an infection, it can be treated before it gets worse.

There are simple things you can do to lower your risk of infection such as washing your hands often, staying away from anyone who is unwell and avoiding crowds and busy places.

There are two important things to do from the start:

- **Find out who you can contact urgently (and out of hours)** if you think you have an infection, and write it at the front of this booklet or somewhere you can easily find it.

- **Make sure you know the symptoms of infection** (see the next page), and call your emergency contact number straight away if you have any of these symptoms.

## Symptoms of an infection

These are common symptoms of an infection, but tell your medical team straight away if you just don't feel quite right.

- fever (temperature higher than 37.5°C)
- low temperature (less than 36°C)
- shivering and sweating
- feeling confused
- sore throat or cough
- rashes or swelling
- frequent watery poos (diarrhoea)
- a burning or stinging sensation when weeing
- unusual stiffness of the neck
- achy, flu-like symptoms
- generally not feeling well.

Make sure you get any vaccinations you need too – see the next page.

> **If you get a temperature or any symptoms of infection when you're at home, please contact the hospital straight away! Getting an infection when you have AML is common, but if you don't get antibiotics quickly, things can quickly turn.**
> Rebecca, diagnosed with AML in 2020

## Vaccines and covid-19

People with AML are at higher risk of serious illness from covid-19 (coronavirus) and other viruses like flu.

Your doctor will usually recommend a flu jab, a covid jab and possibly a pneumonia jab. If you have AML, you shouldn't have live vaccines, but the flu, covid and pneumonia vaccines aren't live and so they're safe for you.

They will give you some protection, although probably not as much protection as for someone who doesn't have AML.

There's lots more information about coronavirus and blood cancer on our website at **bloodcancer.org.uk/coronavirus** Find out more about other infections and managing your risk at **bloodcancer.org.uk/infection**

We have fact sheets about different side effects, which you can order from **bloodcancer.org.uk/our-booklets** or by calling us.

# Finding other people who’ve had treatment

Our online forum has over 1,500 members. Some have blood cancer themselves and some are family members and friends.

It's moderated by the Blood Cancer UK team so it's a safe place to share and get advice. Visit **bloodcancer.org.uk/our-forum**

# Treatment response and remission

During treatment, you'll have tests to monitor your AML and how you are responding to treatment.

## Blood tests

You'll have regular blood tests to check if the leukaemia, or the treatment, is affecting your healthy blood cells. If this happens, you might need a red blood cell or platelet transfusion. We explain what the blood counts mean on pages 60–61.

You'll also have regular blood tests to check that your liver and kidneys are working well, as these can be affected by leukaemia treatment.

## Bone marrow biopsy

AML starts in the bone marrow, so checking the bone marrow for leukaemia cells (blasts) is an important test. A bone marrow test will almost always be done as part of the initial process of diagnosing AML. You are also likely to have further bone marrow tests done during and after treatment. Comparing the results at different times will show how well the treatment is working.

# What do the results mean?

## What are blasts?

Blasts are very young blood cells. They are normally found in the bone marrow, where they grow into fully functioning blood cells, before moving into the bloodstream to do their jobs in the body – see page 15.

If you have AML, your body makes too many blasts (also called myeloid blasts or myeloblasts), and they don't develop fully. This means there are lots of immature blasts in your bone marrow and blood. These are the leukaemia cells.

In someone healthy, the bone marrow contains less than 5% blasts and there wouldn't be any in the blood. In AML, there can be high numbers of blasts in the bone marrow and the blood.

Your doctors will use blood tests and bone marrow biopsies to measure how many blasts you have. AML is usually diagnosed if the number of blasts is 20% or more. When treatment is working, this number will go back down.

## Complete remission (CR)

Complete remission means you have less than 5% blasts in your bone marrow, and all your other blood cell counts have recovered to normal levels. This indicates that the bone marrow is working normally again.

## Complete remission with incomplete recovery (CRi)

Complete remission with incomplete recovery (CRi) means you have less than 5% blasts in your bone marrow, but your healthy blood cell counts like neutrophils (white blood cells) and platelets haven't all fully recovered.

If you have complete remission with incomplete recovery, you are still in remission.

> **My top piece of advice is: if you don't understand something, ask and ask again. Don't be afraid to ask what something means. You're not expected to understand everything, and no question is too silly!**
>
> Anna, diagnosed with AML in 2015

## Measurable/minimal residual disease

Measurable residual disease (previously called minimal residual disease) means there is still a small number of leukaemia cells left in the body after treatment. You can have MRD even when you are in remission.

Because of the very small number of cells, these aren't picked up when looking at samples down the microscope.

So you might be in remission, and an MRD test might be positive, showing that you still have a very small number of leukaemia cells. This means you might need some more treatment, to give you the best chance of staying in remission.

MRD tests are much more sensitive than conventional bone marrow biopsies and blood tests, and have hugely improved our ability to spot when AML might relapse.

## Complete molecular remission (MRD negative)

Complete molecular remission means you are in complete remission and there is no sign of leukaemia in your blood or bone marrow, even after using the very sensitive MRD tests explained above.

## Blood counts

AML and its treatment can reduce the number of healthy blood cells you have.

There are three main types of blood cell – red blood cells, white blood cells and platelets. There are different types of white blood cell, including neutrophils, lymphocytes and monocytes – see page 15.

Your doctors will measure the levels of key blood cells. If your counts are too low for one or more types of blood cell, your doctor may adjust your treatment or give you a red blood cell or platelet transfusion.

Everyone has slightly different numbers of each type of blood cell. If you’re healthy, your blood counts will normally fall within the ranges we mention below. But blood counts can vary depending on your sex, age and ethnicity. For example, people from African Caribbean heritage have slightly lower blood counts than those who are white.

Ask your medical team what your blood test results and numbers mean, because they know what's normal for you.

- **Red blood cells and haemoglobin (Hb)** – Red blood cells deliver oxygen around the body, carrying it in a substance called haemoglobin. Your doctors will look at your levels of haemoglobin. In someone healthy, this level can range from 115 to 180 (measured in grams per litre). You will usually need a blood transfusion if this goes below 80.

- **Platelets** – These cells help the blood to clot, to prevent uncontrolled bleeding. In someone healthy, the level of platelets can range from 150 to 400 (measured in billion cells per litre). If this level goes below 10, you might need a platelet transfusion.

- **White blood cells** – These cells protect you from infection. In someone healthy, this level can range from 4 to 11 (measured in billion cells per litre). Leukaemia cells are a type of white blood cell, so when you are first diagnosed this level can be very high.

- **Neutrophils** – Neutrophils are an important type of white blood cell that protect you against infection. For a healthy person, the level can range from 2 to 7.5 (measured in billion cells per litre). If this number is lower than 2, you might be neutropenic and at high risk of infection.

  Most leukaemia treatments make the number of neutrophils go down, and intensive treatments can reduce it almost to zero. During this time you are at high risk from infections and need strong antibiotics if this happens. When the neutrophil count goes back up, your body is more able to fight infections by itself again. See pages 52–54 for more about avoiding infections.

- **Lymphocytes** – For this other type of white blood cell, the level can range from 1.5 to 4.5 (measured in billion cells per litre). Lymphocyte levels are usually less affected by AML treatment than other blood cell types.

## If treatment doesn’t work

If your treatment isn't working, or if AML comes back later, there are other treatment options available.

If your first treatment for AML doesn't get you into remission, this is called refractory AML.

If you do get into remission, but the AML comes back at a later time, this is called a relapse.

Most relapses happen in the first two years after finishing induction treatment. After this, they become less common as time passes, and after five years the chance of relapse is extremely small.

### What are the treatments for relapsed or refractory AML?

Refractory or relapsed AML is harder to treat, but there are still options and people can still be cured.

Your doctor will do some more tests to check for any new genetic mutations that have developed in your AML cells. This will help them plan the best treatment, as different drugs work against different genetic mutations.

The treatment you have will also depend on whether you are fit and well enough to physically cope with intensive chemotherapy or not. There are both intensive and non-intensive treatment options.

## Intensive treatments for relapsed/refractory AML

In general, people who are able to have intensive chemotherapy and a stem cell transplant have a higher chance of being cured. If your first remission lasted a long time, this also increases the chance of getting another remission.

Intensive treatments give the best chance of getting another remission. Options include chemotherapy (also called salvage chemotherapy) and stem cell transplant. These are explained more on pages 31–39.

## Clinical trials

There are many clinical trials and studies looking at improving treatment for relapsed or refractory AML. Trials offer the chance to try a new treatment that could be better than existing treatments. Your hospital might be taking part in one, or know of one nearby. Ask your doctor if there are any clinical trials that might be suitable for you.

## Non-intensive options for relapsed/refractory AML

For people who are more frail, or whose general level of fitness would make it difficult for them to tolerate strong treatment, non-intensive treatment might be a better option. Options include low-dose chemotherapy and other types of cancer drugs. These are explained more on pages 40–43.

# Clinical trials for AML

For more information about clinical trials or help searching for trials, visit **bloodcancer.org.uk/clinical-trials**

Find out more about the AML research we're funding at **bloodcancer.org.uk/research**

If you don't use the internet, call us free on **0808 2080 888.**

## If you’re told the AML can’t be cured

Hearing that your treatment, or the treatment of someone you love, has stopped working, is understandably extremely difficult.

You can feel shocked, scared, or devastated. You might also feel angry, or very sad. Emotions can be overwhelming.

When treatment hasn't worked, it's common to have feelings similar to grief. If it's someone you love who has AML, you might feel completely helpless.

Many people say they can only take one day at a time, and that trying hard to focus on happy memories and telling each other how you feel is important.

Sue talks about how she dealt with the news that her husband's blood cancer might not be cured here:
**bloodcancer.org.uk/sue**

If you've been told there might not be many treatment options left, we are here for you, for emotional support or to talk about how you're coping. Contact our Support Service on **0808 2080 888**.

## The future of AML treatment

Over the years, treatment for AML has improved thanks to clinical trials finding new and better drugs.

The discovery of certain genetic changes (mutations) that happen in AML cells means that newer treatments are much better at targeting and destroying leukaemia cells.

Clinical trials are key to treating AML, especially for people who can't have a stem cell transplant, or whose AML comes back or doesn't respond to treatment. Trials are looking at new drugs in these situations, which may be better than existing treatments.

We can help you find out if there are any clinical trials you might be eligible for, through our Clinical Trials Support Service: **bloodcancer.org.uk/clinical-trials**

## Bav

### What was it like having AML as a young person?

"It was quite lonely. In hospital, everyone around me was a lot older. I felt so different and like I didn't fit in. It took me a while to find someone like me – another young Indian girl – but when I did, it made me feel so much less alone."

Read Bav's story at **bloodcancer.org.uk/bav** or call us and we'll post it to you.

# Tips for coping with treatment

# Treatment for AML can be hard, but other people with AML and their families have lots of tips from experience.

This chapter gives lots of practical tips about things you can do to help yourself.

Treatment can have a big emotional impact too, on you and your family. If you need to talk, contact our Support Service. Family and friends can contact us too.

> **Having goals during treatment is important. You need some purpose. Mine were things like standing up in my hospital room 10 times a day, or doing all my recommended doses of mouthwash.**
>
> Graeme, diagnosed with AML in 2017

## Emotional impact of treatment

Many people with blood cancer say that at first, they were in shock from the diagnosis, or that things happened so fast, there wasn't time to think. You might be too unwell or tired to react, or there might be too much to take in.

People with AML and their loved ones describe trying to stay strong for each other, and not wanting to break down. But most people do feel scared, lonely or isolated at times. Family and friends can also feel very helpless.

Everyone reacts in their own way. However you are feeling is normal, and you're not alone.

Yvonne talks about the emotional impact of AML treatment in her story here: **bloodcancer.org.uk/yvonne**

Going through treatment can be traumatic for many people. If you need someone to talk to, contact our Support Service on **0808 2080 888** – we're here to help you through it.

## Josh

### What strategies did you use to cope?

"I couldn't escape the expectations I was placing on myself to be strong. Compartmentalising things was my coping strategy and it worked for a time, but it's not a lasting strategy. We need to admit that we can't beat this on our own, and we do need emotional support. Visualising my life after cancer, I realised I should take the help that's on offer."

Read Josh's story at **bloodcancer.org.uk/josh** or call us and we'll post it to you.

# Tips for a better hospital stay

If you're in hospital for several weeks, you might at times feel lonely, vulnerable, frustrated or even bored. Other people with AML find these things helpful.

If you're a family member or friend, you could help with some of these.

- Moving around your hospital room each day if you can. Even just walking and standing will be good for you.
- Notepad and pen, to write down any questions for your doctor, or to plan your visitors.
- Drawings or cards from children – they brighten up your room, but they also give children something positive to do.
- Being honest about whether you want visitors – sometimes you might not feel like it, and that’s fine.
- Home-cooked food – but check with your medical team.
- Keeping a diary to track your progress.
- Photographs of happy memories, family or friends.
- Eye mask and ear plugs – helpful for sleeping at hospital.
- Chosen person to get medical updates – give your medical team permission to give updates to a close family member or friend. Sometimes you might not remember everything.

## Things to bring to hospital

Having your personal things with you makes you feel better. If your medical team say it's OK, you could bring your own:

- pillow
- clothes
- wash bag/toiletries
- colourful blanket to brighten the room
- photo frames
- mug
- tea or hot chocolate
- snacks
- hand cream or moisturiser
- picture-based or easy books and magazines
- adult colouring book
- headphones or music.

Remember, flowers carry bacteria so probably aren't allowed – it might be worth telling people this.

> **Take things one day at a time and accept there might be setbacks – this is normal so don't worry. I found I had less visitors as treatment went on, so be prepared for that and take things to occupy you.**
>
> Bav, diagnosed with AML in 1999

## Tips for taking care at home

You or your family might want to know how to prepare for you coming home from hospital.

Here are some things you can do to look after yourself at home:

- Have contact details for your medical team, including who you can contact on evenings and weekends, and keep them somewhere easy to find.

- Keep the house generally clean and warm – if you're worried about being able to do this, tell your medical team.

- Have food that's quick and easy to make ready at home. If friends or neighbours want to help, ask them to make something for your freezer. Ready-made meals or snacks are fine too – the important thing is that you eat.

- Try to move around each day. Even just walking around the house will be good physical activity that can help improve your strength.

- Going outside for a walk or visiting somewhere you like in the car will be good for your mental health and safe as long as you avoid crowded places.

- You can have visitors or see friends if you feel up to it. Avoid big groups and anyone who is sick, but having contact with people you are close to is important.

- Take time to rest. Your body needs a chance to recover from treatment, so don't push yourself too hard.
- Do things you enjoy too. Plan things that make you happy, and plan some rest in between activities.
- Know how to reduce the risk of catching an infection – this is important for you and anyone who looks after you to know – see pages 52–54.

> **When I went home in between chemo cycles, I spent lots of quality time with my family, but my other goal was to do more on my feet, to build myself up and get stronger for the next cycle.**
> Rebecca, diagnosed with AML in 2020

## Tips for family and friends

As well as everything on the last few pages, here are some other tips from people who've been where you are:

- It can be draining keeping so many people updated on how the person with AML is doing. Setting up a WhatsApp group makes it easier to send updates to everyone quickly.
- If friends or neighbours want to help, ask them to drop over some food for your freezer. This can make a big difference when you're too tired or busy to cook.
- Make a list of the practical things you still need to do – like doing laundry or feeding a pet. Then when people ask how they can help – ask them about these things. Often people really want to help, and are happy to be given a job. You could give someone you trust a key to make things easier.
- It might feel wrong or impossible to prioritise your needs as well, but you do need to sometimes. Even 15 minutes of doing something for you, whether that's having a walk, calling a friend or taking a shower, will help you reset.

We've written this booklet with family and friends in mind, so there are more tips on other pages that you might find helpful too.

# Supporting someone through treatment

Find more information, practical tips and stories about supporting someone through blood cancer treatment on our website at **bloodcancer.org.uk/friends-family**

If you don’t use the internet, call us and we'll post what you need.

## How to help yourself during treatment

Looking after your physical and mental health is important and will help you cope with treatment.

Here are some tips from other people who’ve been through AML:

1. **Take things one day at a time** – Focusing just on today, rather than thinking about the future, can help you get through treatment. Many people keep a diary, to help them realise the progress they've made.

2. **Celebrate small wins** – AML can bring lots of ups and downs, and focussing on the ups can help your mindset. If your latest blood result was slightly better, if you're able to spend some time out of hospital, or if you enjoyed having a visitor, these are all achievements.

3. **Give yourself time to absorb and ask questions** – You don't have to learn everything at once. Take time to read information, write down your questions, and then take them to your medical team or our Support Service.

4. **Remember, it's normal to feel down sometimes too** – A positive mindset does help, but it's not easy. Having a low mood and struggling to cope is normal. But if you are continuing to struggle, you might need more support – tell your nurse.

**5. Have a goal or focus** – Goals can keep you going, provide motivation, and help you feel positive. While there is a lot you can't control, try to think about things you can control. You might have mini goals for each day, or simply keep a photograph of someone special to look at – find something that can motivate you through this.

**6. Try to keep moving** – Being physically active improves your strength and your mood. Even in hospital, standing or walking in your room if you can will help.

**7. Talk to someone** – Keeping things to yourself can add extra pressure and make things harder. Be open with close friends and family if you can – many people say this is their biggest support. Or contact our Support Service and talk to us – we are here to talk about anything, even just for a chat.

**8. Complementary therapies can reduce side effects** – they can’t treat the cancer, but they can make you feel better. Therapies include massage, reiki, reflexology, aromatherapy, meditation and acupuncture. Speak to your medical team first though, as some therapies may not be safe for you.

**9. Mindfulness can help** – Many people with blood cancer say that mindful exercises help, even people who've never tried them before. They reduce stress, relax you, and help you sleep better. Anyone can do it – you don't need any special skills. There are some short videos to help you try it at **bloodcancer.org.uk/mind-emotions**

# Life after AML

## Finishing treatment for AML is a big achievement worth celebrating, although it can take time for your body to recover.

Don't feel bad if you don't bounce back quickly after AML. Your body has been through a lot. You can build your fitness back up, but it will take time.

Most people are relieved that treatment is over, but you might also feel very vulnerable or not yourself.

You might find finishing treatment harder than expected – this is natural, and this chapter will help you find ways to adjust.

> **The end of treatment doesn't mean it's all over – other patients understand this. After treatment, I needed someone to hear and validate the realities of what I'd been through.**
> Yvonne, diagnosed with AML in 2018

## How long does it take to recover?

People with AML say it's important to know that after finishing treatment, there is another stage to the journey.

Recovering from AML isn't the same as recovering from other illnesses. It can take several months to rebuild your fitness. Trying to increase your physical activity will help.

You will have check-ups with your medical team regularly after treatment. This could be several times a week at first, to make sure you are OK. Eventually the check-ups will be monthly, and later every few months.

Follow-up appointments last several years, although they get more spaced out as time goes on. Your medical team will be checking your blood and helping you manage any side effects after treatment.

> **I want other people with AML to know that if you've got through treatment, you are doing great! If you're still really tired or weak, you aren't failing, it's normal and you are making progress.**
> Anna, diagnosed with AML in 2015

## How you might feel

Finishing treatment can bring mixed feelings. Many people feel relieved and happy that it's over. But it's also common to feel vulnerable, alone or worried about the future.

If you are coping with lasting side effects, like changes to your heart or lungs, or infertility, it can be hard to accept that the treatment has changed your body more permanently.

For many people, the emotional impact of what they've been through can hit them harder after treatment ends. You might start to process everything that's happened.

There's no right or wrong way to feel after treatment. There's more on our website about adjusting to life after blood cancer: **bloodcancer.org.uk/after-treatment**

Many people find counselling helpful (see page 104).

You can also talk to us – we often talk to people about adjusting to life in remission.

## Are there any long-term side effects?

Long-term side effects can last for months or years after treatment ends, but usually get better with time. Some side effects can happen years later, called late effects.

### Fatigue (tiredness) and brain fog

Many people continue to have some level of fatigue for a while after having AML. Some people find they have changes to their memory or concentration too. There is more information at **bloodcancer.org.uk/fatigue** and **bloodcancer.org.uk/brain-fog**

### Risk of infection

You might be at a higher risk of infection for a while after AML treatment, as your immune system recovers. It's really important to know if there's anything in particular you should avoid like crowded places, people who are ill, gardening or housework – check with your medical team.

### Second cancer

Research shows that people under 60 have a slightly higher risk of getting cancer again after AML treatment. If this happens, it's normally five to ten years later. If you are over 60, your risk of cancer is similar to anyone else's. Treatment today is designed to reduce this risk as much as possible.

### Heart damage

Certain types of chemotherapy drugs called anthracyclines, and sometimes radiotherapy, can cause damage to your heart. This side effect is uncommon now because treatment doses are planned to reduce the risk as much as possible.

## How to help yourself after treatment

It takes time to recover from AML, but there are things you can do to help move things along.

**1. Report any new symptoms to your medical team** – Ask what symptoms you should look out for, and don't hesitate to contact your team if you get any – don't wait until your next appointment if you have any worries.

**2. Keep a positive mindset** – Many people with AML say that this is one of their main coping strategies. This doesn't mean being fine all the time – everyone has bad days and it's important to accept these. But paying more attention to things that have gone well, however big or small, does help.

**3. Listen to your body** – If you're tired, the housework can wait. If you're having a good day, going on a walk or doing some exercise can help. Do what feels right for you, do things that make you happy, and don't put too much pressure on yourself.

**4. Keep moving** – Physical activity will help you recover from AML. It also helps you sleep better and reduces stress, anxiety and depression. Even a five minute walk can help – see page 88.

**5. Get emotional support** – It's common for the emotional impact of everything to be felt once treatment ends. Many people find counselling helps them adjust to this big change in your life. You can talk to our Support Service too – we often talk to people about coping in remission.

## Managing fatigue (tiredness)

Fatigue is a type of tiredness that many people with blood cancer get. It's different from normal tiredness.

It can affect you mentally and physically, and it can come on suddenly. You might feel like you are totally drained.

It's important to know:

- **You're not alone –** Fatigue is a common symptom of blood cancer and a side effect of treatment.
- **There are lots of things that can help –** It might seem strange, but being physically active reduces fatigue.

People with blood cancer say these things help:

- **Balance activity and rest –** You need both to fight fatigue. Light exercise can actually help.
- **Learn what's doable for you –** Plan time to rest in between activities or days out.
- **Go easy on yourself –** If you need a rest day, have one. You're not being lazy.
- **Tell your medical team –** They need to know about any symptoms you are having.

Visit **bloodcancer.org.uk/fatigue** for more tips.

## Anna

### How did you cope with remission?

"It's not really talked about, how what you've gone through can really impact you afterwards. I spent time mourning my past self and fighting to get back to who I was, when it would have been healthier to accept that this huge experience did change me, and that something new could be created out of it."

Read Anna's story at **bloodcancer.org.uk/anna-life-after-treatment** or call us and we'll post it to you.

## Keeping active

Being physically active can improve your fitness and strength, reduce fatigue and improve your mood. That's not just what the research says – many people with blood cancer have found it to be true.

- **Walking is good exercise –** If you don't normally walk far, start with five or 10 minutes a day and slowly build up.
- **Goals are motivating –** Set yourself goals and tick them off when you've done them. Order an activity planner from us, or use an app like Habit Tracker or Done.
- **Do something you enjoy –** If you choose an activity you like, you’re more likely to keep it up. If you're not sure what to do, ask other people for recommendations and try something new.
- **Make it social –** This usually helps people stick to their plans. Find an exercise buddy (your partner, a friend, a neighbour) and follow a plan together.
- **Get tips from other people with blood cancer –** Join our online community forum and find out how others are staying active after AML.

Find exercise videos for people with blood cancer at **bloodcancer.org.uk/keeping-active**

## Eating well

Eating well is important, as it will give you the nutrients and energy you need to stay healthy. Here are some general tips to bear in mind:

- **No diet, supplement or 'super food' can cure cancer –** in fact, cutting out too many foods could mean you're not getting everything you need.
- **It's best to follow a healthy, balanced diet –** Ask your medical team or GP if there's anything specific you need to eat more or less of.
- **You need carbohydrates –** Wholewheat pasta, wholegrain bread or potatoes with skin on will release energy through the day. Carbs should make up around a third of a meal.
- **Eat lots of fruit and veg –** They're packed with vitamins, minerals, and are a good source of fibre. Boost your intake by adding extra vegetables into sauces.
- **Protein helps your body grow and repair –** Try beans, peas, lentils, fish, meat, dairy, eggs and vegetarian and vegan alternatives such as Quorn or tofu.
- **Iron is vital for energy –** As well as meat, you can get iron from beans, nuts, dried fruit, wholegrains, and dark-green leafy vegetables.

We have more tips for making cooking and eating easier if you're tired at **bloodcancer.org.uk/eating-well**

# Getting support

## An AML diagnosis has a big effect on you and those close to you. But there is lots of information and support out there.

It's really important that both you, and your family and friends, get the support you need. For you, this will help you get through treatment and the day-to-day. For your family, it will help them cope with what's happening.

> **We need to remember what the goal is – not just to survive, but to live our lives after cancer. That's why I decided to find the right support for me – so I could really enjoy the main prize, having my life back!**
>
> Josh, diagnosed with AML in 2015

## Support for you

When you are first diagnosed with AML, you might simply feel shocked or stunned.

Many people describe staying strong for their family or not wanting to break down. But most people also feel scared, lonely or isolated at other times.

We are here if you want to talk or have any questions or worries.

Contact our Support Service on **0808 2080 888** and tell us you've been diagnosed with AML. We can talk you through what to expect, how you're coping, and help you talk to your medical team or family members.

Many people find that reading other people's stories helps them feel more hopeful or gives them ideas of things they could try for themselves. Visit **bloodcancer.org.uk/blood-cancer-stories**

Asking other people with blood cancer how they are coping can also be very helpful, both practically and emotionally. You can do this at **bloodcancer.org.uk/our-forum**

## Yvonne

### How did you get support from other people with AML?

"Seeking support in the patient community lets me share all my worries and realise I’m not alone in them. Some days are just about sounding off and saying we wish we didn't have this. Others are there to remind us how great we are doing. It's a place to be honest and share the realities of AML."

Read Yvonne's story at **bloodcancer.org.uk/yvonne-finding-others** or call us and we'll post it to you.

## Support for family and friends

If someone you love has been diagnosed with AML, we are here for you. It's really important that you get support too.

You might be dealing with difficult emotions like fear, isolation or being powerless. You might also be managing lots of practical things at home.

Contact our Support Service and tell us what's happening. We can answer your questions about AML, talk about how you're feeling, or even just offer a place to offload:
**0808 2080 888.**

Sometimes the best support comes from other people who've been where you are. There are many family members of people with AML on our online forum supporting each other at **bloodcancer.org.uk/our-forum**

There are also lots of personal stories and tips you can read from other close family members of people with blood cancer at **bloodcancer.org.uk/friends-family**

You might want to order more free copies of this booklet, to give to other family members and friends to help them understand what's happening.

On the next few pages we list more sources of help with work, money, childcare and emotional support.

# Support in remission

For help adjusting to life after AML, see our web page "After blood cancer treatment ends" at **bloodcancer.org.uk/after-treatment**

If you don’t use the internet, call us to talk about life after treatment.

## Support for children

If you have children in your family, you might be very worried about how they will cope with the AML.

Children will normally know that something is wrong, and their fear can be worse if they don't know what's happening.

It's important that children feel included, and know they can ask questions and talk about the illness. You can help them by starting the conversation or asking them a question.

Telling children what to expect also helps them manage. For example, tell them if your hair will fall out, or tell them the plan if different people will be looking after them at times.

> **My son was my biggest concern, but children are so resilient – they often take what adults struggle with in their stride. Looking back, the most important thing was that he felt included, that we weren't hiding anything from him, and that he could ask questions. Finding space for fun was important too.**
>
> Rebecca, diagnosed with AML in 2020

Your nurse or doctor can be a great source of advice on how you can support children through this. They might even be able to talk to children with you, explain things and answer their questions.

It's a good idea to tell their school what's happening too, so that teachers can keep an eye on how they are.

Of course it's still important for children to have fun, to do some of their normal activities, and have family time.

If one parent is in hospital, it's important that children can still do fun activities with their other parent or other family members or friends, even if it's just a movie night at home.

Try not to hold back your emotions in front of children all the time. Getting upset in front of them shows that they are allowed to get upset too, and it's not something they have to hide. When a parent is ill, it's always difficult for children, but they will remember that you were honest and open with them.

You can talk to other parents and guardians about how they chose to handle blood cancer with their children in our online forum: **bloodcancer.org.uk/our-forum**

There are more tips for talking to children on page 8.

# Work, money, childcare and help at home

Key things to know if AML affects your daily life:

## Work

- **Your rights** – If you are working when you are diagnosed with AML, you have rights. Cancer is classed as a disability by the law, so you are protected against discrimination. If you are self-employed, you may still have legal protection if you are employed under a contract with an employer.

- **Talking to your employer** – Ask your doctor or nurse how long they think you'll be off work, then talk to your manager or HR department. It helps if you keep your employer updated. You could order them a copy of this booklet to explain AML from **bloodcancer.org.uk/our-booklets**

- **Company sick pay** – Find out about your company's sick pay policy. Many employers continue with full or half pay for a number of weeks. Even then, companies can choose to give more than what their official policy promises.

- **Statutory sick pay** – Ask your hospital team or doctor to give you a "fit note" (previously called a "sick note") for your employer. This explains your situation and gives you access to the legal minimum your employer has to pay you.

For advice about your rights at work, contact ACAS (**acas.org.uk**, **0300 123 1100**).

## Money

If you were working before you went into hospital, make sure you are getting all the sick pay you can – see the previous page. Other help:

- **Benefits** – You may be able to claim benefits like Universal Credit, Employment and Support Allowance (ESA), or Personal Independence Payment (PIP).
- **Carer's benefits** – If someone is looking after you at home, they might qualify for a benefit called Carer's Allowance.
- **Travel to hospital** – You might be able to get help with the cost of travelling to hospital and back, and free or reduced hospital parking. Ask your medical team or ward reception.
- **Help paying bills** – Talk to your suppliers about energy bills, council tax and mortgage payments. There is usually support available for people with cancer.
- **Help from charities** – Many charities offer grants that you don't have to pay back, including Leukaemia UK, Macmillan Cancer Support and Anthony Nolan.
- **Do you have insurance?** Could you make a claim on income protection insurance or critical illness cover?

For advice about financial support, contact Citizens Advice (**citizensadvice.org.uk**, **0344 411 1444**).

## Childcare

You might find that how you care for your children has to change while you have treatment.

Getting help from family and friends is often the best option. Children can adapt well to this, and learn about what it means to be a family or community.

Other organisations can also give you help or advice:

- **Carers Trust** can help with childcare and other practical support in the home (**carers.org**, **0300 772 9600**).

- **HomeStart** supports children and families through difficult times and can help you find local services (**home-start.org.uk**, **0116 464 5490**)

- **Your local council** can tell you about childcare options in your area and financial support.

## Help at home

Making your life easier at home means you can spend your energy recovering from treatment and having quality time with family, or doing things you enjoy. This is all important for your recovery and general well-being.

Contact your local council and tell them your situation. You might be able to get help from a professional carer, day care for children, help with housework or financial support.

Ask about getting a "Needs assessment" (for you) and a "Carer's assessment" (for whoever looks after you at home). You might both be able to get certain benefits or help.

# More information and support

Whether you have AML yourself, or someone you love does, these places can offer support.

## Blood Cancer UK Support Service

We can talk to you about anything that's on your mind, even if you just fancy a chat with someone.

People contact us about:
- understanding their condition
- treatment
- living with blood cancer
- impact on family and friends
- work issues
- mental health

Call our confidential support line free on **0808 2080 888** or email **support@bloodcancer.org.uk**

## Blood Cancer UK website

Our website has more information about AML and blood cancer in general, plus regular news articles and stories from people affected by blood cancer. Explore **bloodcancer.org.uk**

## Blood Cancer UK publications

If you prefer your information in printed form, browse our booklets about conditions, treatment, side effects and living with blood cancer at **bloodcancer.org.uk/our-booklets**

## Blood Cancer UK online community forum

Talking to other people and families affected by AML helps. They understand, and will have tips from their own experience. You can ask questions and get advice, or just read other people's posts. You don't have to create an account and you can remain anonymous. Visit **bloodcancer.org.uk/our-forum**

## Local groups

These give you the chance to meet other people affected by blood cancer face to face.

- Ask your hospital or GP what support groups are available in your area.

- Enter your postcode on the NHS website and find support groups near you: **www.nhs.uk/service-search/other-services/cancer-information-and-support/LocationSearch/320**

- Contact Blood Cancer UK to see if there's a branch in your area. Our branches are for fundraising and volunteering, but you might find that doing things with other people affected by blood cancer helps. Call **0808 2080 888** to find your local branch.

- Leukaemia Care also run support groups. Visit **www.leukaemiacare.org.uk/support-and-information/support-for-you/find-a-support-group** or call **08088 010 444** to find your local group.

## Counselling

Many people find talking to a trained counsellor helps them come to terms with difficult emotions or life changes.

To find a free NHS counsellor:

- Ask your hospital team how you can access counselling – some hospitals offer this themselves.
- Tell your GP you'd like to try counselling.
- You can self-refer online in England (**www.nhs.uk/counselling**) and Scotland (**www.breathingspace.scot/living-life**). In Wales and Northern Ireland, you need to go through your GP.

To find a private counsellor:

- Find a qualified counsellor anywhere in the UK on **BACP.co.uk** or call them on **01455 883300**.

## Social media

Many people find support in Facebook groups or other social media platforms.

- Find Blood Cancer UK on Facebook – many people get and give support to each other in comments on our posts. You can also find us on Instagram and Twitter.
- Search online or on Facebook for AML support groups.

## Your medical team

Your specialist doctor, nurse, or GP are there to answer your questions and help you deal with the impact on your life.

You should have been given a contact number or name for who to contact if you ever have questions. If you don't have this, contact our Support Service and we'll help you resolve this.

# Write any questions for your medical team here:

# Because we face it together

Finding out you have blood cancer can have a big impact on your life. But we hope it helps to know that there's a community of people out here ready to support you.

Everyone needs help at one time or another. And the most important thing to take away from this booklet is that you can get help from us when you need it, and in a way that suits you.

**bloodcancer.org.uk**

**0808 2080 888** (calls are free and confidential)

**support@bloodcancer.org.uk**

**bloodcancer.org.uk/our-forum**

Blood Cancer UK

@bloodcancer_uk

@bloodcancer_uk

Blood Cancer UK

# Thank you to our blood cancer community

Blood Cancer UK is the UK's specialist blood cancer charity. But we're much more than that – we're a community of people with blood cancer, friends, family, medical professionals, researchers and everyone who works for the charity.

Many thanks to everyone involved in making this booklet. To Anna, Anne, Bav, Graeme, Josh, Marie, Rebecca and Yvonne for their insights into what it's like to be diagnosed with AML, and for steering us in the right direction. To Advanced Nurse Practitioner Kirsty Crozier and Consultant Haematologists Richard Dillon and Professor Steve Knapper for checking the medical content.

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

## Who are Blood Cancer UK?

We're the UK's specialist blood cancer charity, working to beat blood cancer within a generation.

Since 1960, we've invested over £500 million in research, improving treatments for leukaemia, lymphoma, myeloma, MDS and MPNs. Thanks to generous donations from our supporters, we:

- fund ground-breaking research to improve survival and quality of life
- campaign for better access to treatments and services for people with blood cancer
- provide information and support for anyone affected by any blood cancer.

Find out more at **bloodcancer.org.uk**

Or call us free on **0808 2080 888**
Monday: 10am to 7pm, Tuesday to Friday: 10am to 4pm
and Saturday and Sunday: 10am to 1pm.

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