

Relapsed and refractory acute myeloid leukaemia (AML)

This leaflet is about AML that hasn't responded to treatment (refractory) or has come back after successful treatment (relapsed). We cover what relapsed or refractory AML is, what your treatment options are, and where to get support if you need it. We also cover supportive and end of life care.

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Throughout this leaflet, you will see 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 01905 755977.

Summary

- Relapsed AML is when AML comes back after successful treatment.
- Refractory AML is when AML does not respond to your first treatment.
- You may experience the same, similar or different symptoms compared to when you were first diagnosed.
- You will need blood and bone marrow tests. Your haematology team will use the results to work out what treatment options are best for you.
- They might recommend:
 - Treatment as part of a clinical trial, if there is one suitable for you
 - Intensive chemotherapy
 - A stem cell transplant
 - Targeted treatment
 - Non-intensive treatment
- You will also have supportive care to help with side effects and symptoms, as well as looking after your physical, emotional and mental health.
- If there are no suitable treatment options left, your haematology team might suggest end of life care. This aims to relieve your symptoms and give you a good quality of life.

Finding out your AML has come back or not responded to treatment can be difficult. We're here if you need support:

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

What is relapsed or refractory AML?

There are many treatment options for acute myeloid leukaemia (AML). They can be very successful. But not everyone responds to treatment. And sometimes, AML comes back after treatment. This is called relapsed or refractory AML.

- Relapsed AML is when AML comes back after successful treatment.
- Refractory AML is when AML does not respond to your first treatment.

Finding out your AML hasn't responded to treatment, or has come back, can be distressing. We're here to support you. You can email us at support@leukaemiacare.org.uk, message us on WhatsApp at **07500 068065** or call our freephone helpline at **08088 010 444**.

If you have relapsed or refractory AML, there are different treatment options. Your haematology team will recommend the most suitable one for you based on your individual case and your test results. They will explain your treatment plan and discuss your next steps with you.

Signs and symptoms of relapsed or refractory AML

The signs and symptoms you might have vary from person to person. You may get the same, similar or different symptoms compared to when you were first diagnosed. Some common signs and symptoms of AML include:



Feeling exhausted for no reason (fatigue)



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 easily or bleeding when you wouldn't usually (for example, nose bleeds or bleeding gums when you brush your teeth)



Joint or bone pain



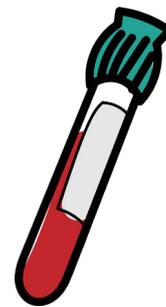
Tummy pain, bloating or fullness after eating

Diagnosing relapsed or refractory AML

You will have blood and bone marrow tests to confirm if your AML has come back or not responded to treatment. These will be similar to when you were first diagnosed.

Your haematology team will send your samples to a lab to look for any new genetic changes in your leukaemia cells. Some genetic changes respond well to targeted treatments. Some genetic changes mean that certain treatments are less likely to be successful.

Your haematology team will use the results of your tests to help decide on the most suitable treatment for you.



Treatment for relapsed or refractory AML

Treatment of relapsed or refractory AML is based on your individual circumstances. There are many options. Your medical team will recommend the most suitable treatment for you based on:

- What treatment you've already had and how you responded to it
- Any side effects you had
- Your age and overall fitness
- Your subtype of AML
- The genetic changes in your leukaemia cells
- Whether or not you have any other medical conditions
- Your preference on how you wish to be treated

Here, we cover some of the treatment options they might suggest.

Treatment as part of a clinical trial

Your medical team might suggest treatment as part of a clinical trial, if there is one suitable for you. This could let you access treatments that would not otherwise be available.

Clinical trials are research studies that aim to find out which treatments work best. They might look at using treatments that are already available for other conditions, or at completely new treatments.

If there is a clinical trial that may be suitable, your medical team should explain what it would involve, and the risks and benefits of taking part. They will give you the information you need to decide if it's something you'd like to do. It is your choice whether or not to take part.

Macmillan has [more information on clinical trials](#). Follow the link, or search 'clinical trials' at www.macmillan.org.uk

Intensive chemotherapy

Intensive chemotherapy options used to treat relapsed or refractory AML include:

- FLAG-Ida
- High-dose cytarabine
- Mitoxantrone-based chemotherapy



If intensive chemotherapy is suitable for you, your haematology team will tell you what they recommend. They will explain how you have it and what you can expect from treatment.

You usually stay in hospital to have intensive chemotherapy.

We have [separate information on different treatments used in AML](#). Follow the link, or visit leukaemiacare.org.uk and search for the treatment that has been recommended for you.

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 matched donor, such as from a brother or sister, or from an unrelated donor. Rarely, they might be your own stem cells, collected before you have chemotherapy.

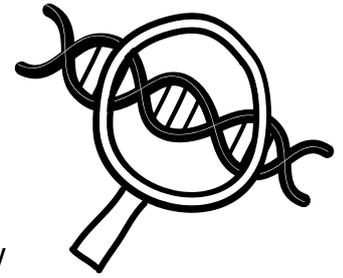
A stem cell transplant is very intensive. It is only suitable for people who are fit enough to have it. Your team will let you know if it is an option for you. They will discuss it with you and give you a chance to ask questions.

You usually stay in hospital for several weeks to have a stem cell transplant. It can take many months to recover.

We have [separate information on stem cell transplants](#). Follow the link 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, or visit www.anthonynolan.org

Targeted treatment

You might have a targeted treatment based on the genetic changes in your leukaemia cells. This affects what proteins the cells make.



Targeted treatments are designed to block specific proteins in leukaemia cells. This means they kill leukaemia cells with as few effects on healthy cells as possible.

Gilteritinib is the only targeted treatment currently approved on the NHS for relapsed or refractory AML. It blocks a protein called FLT3. Your doctor might recommend it for you if your leukaemia cells have a change in the *FLT3* gene.

Other targeted treatments might be available:

- Off-label. This is when a doctor prescribes a medicine that's approved for one condition to treat a different condition. For example, they might prescribe a medicine that's approved as a first treatment for AML to treat relapsed or refractory AML. This could include ivosidenib, a targeted treatment for people whose leukaemia cells have a genetic change in a gene called *IDH1*.
- Through a compassionate access scheme. This is when you have a treatment that is not approved in the UK yet but is available early due to promising clinical trial results.
- As part of a clinical trial.



You have targeted treatment as tablets to take at home. You usually carry on taking them as long as they are helping you.

We have [separate information on different treatments used in AML](#). Follow the link, or visit leukaemiacare.org.uk and search for the treatment that has been recommended for you.

Non-intensive treatment

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. It aims to reduce your symptoms and improve your quality of life. But it does not cure your AML.

Usually, you will be treated with a gentler or low-dose chemotherapy. Non-intensive chemotherapy you might have for relapsed or refractory AML includes:

- Azacitidine
- Low-dose cytarabine
- Hydroxycarbamide

Your haematology team will tell you what they recommend and what you can expect from treatment.

You usually have non-intensive treatment at home or as a hospital outpatient.



We have [separate information on different treatments used in AML](#). Follow the link, or visit leukaemiacare.org.uk and search for the treatment that has been recommended for you.

Your emotions

Finding out your treatment is not working or hasn't worked can be upsetting. You may need emotional and practical support. It is likely you will experience a range of complex thoughts and emotions. You may feel a range of emotions like:



- Uncertainty, anxiety, or fear about the future
- Shock, anger, guilt or frustration
- Sadness or depression

If you are struggling with your emotions, tell your medical team or GP. They can help you access the support and treatment you need.

If you are in crisis, the NHS has urgent mental health helplines that offer 24-hour advice and support. Search 'mental health' on www.nhs.uk to find out more.

Talking to other people can help. It can be difficult to talk to your 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.](#) 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 Buddy Service, where you can connect with people who understand your experience
- Counselling Service where you can apply for a grant of 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 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

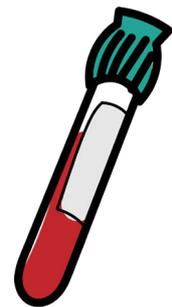
Supportive care

You might also need medicine to prevent or treat symptoms or side effects. This is called supportive care. It does not treat your AML itself, but it helps you feel better. It aims to reduce your symptoms, extend your survival, and give you and your loved ones the best quality of life possible.

Supportive care is sometimes called palliative care. You might be offered it alongside other treatment for AML. Or you might be offered it if no other treatment options are suitable for you.

Supportive care 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
- Mouthwashes 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 can help with many different symptoms



Supportive care also includes:

- Psychological support
- Support with exercise or physiotherapy
- Social support
- Spiritual wellbeing such as mindfulness

Your medical team should talk to you about what support they can offer you. They may refer you to a palliative care team. Let them know if you have any symptoms or side effects that you are finding hard to cope with.

End of life care

If your AML does not respond to treatment, or comes back after treatment, your medical team will talk to you about your options. They may suggest trying a different treatment. But if there are no suitable treatment options left, they might suggest end of life care.

End of life care means you do not have any more treatment that aims to control or cure your AML. But you still have treatment to relieve your symptoms and improve your quality of life. End of life care begins when you need it, and may last a few days, months or years.

End of life care helps you live as well as possible until you die. The aim is to help you have a good quality of life and die with dignity.

We are here for you if you need support with end of life care. Email us at support@leukaemiacare.org.uk, message us on WhatsApp at **07500 068065** or call the freephone helpline at **08088 010 444**.

The following charities also provide support and information for people dealing with end of life care. Follow the links or search for the charity name online.

- [Compassion in Dying](#)
- [Hospice UK](#)
- [Marie Curie](#)

What happens next?

Your medical team should talk to you about your wishes. They will also talk to you about where you'd like to receive end of life care, and where you want to die. This could be:

- At home
- In a hospital
- In a hospice
- In a care home

They will organise your care to suit your individual needs and preferences, if they can. Wherever you receive end of life care, you should have support from a palliative care team. They can also provide support for your family, friends or other loved ones.

Who provides end of life care?

End of life care involves a team of health and social care professionals. The people involved in your care depend on your individual needs. It could include doctors, nurses, your GP, counsellors, physiotherapists, occupational therapists, complementary therapists or religious leaders, if you would like this.

Planning for end of life care

Going through end of life care may be easier if you have made plans, and let people know what they are.

- You may want to make a Will.
- You could think about writing down how you would like to be cared for in the future. This is called an advance statement. It can help your family members make decisions about your care if you're not able to express yourself.
- Some people also make an advanced decision, sometimes called a living Will. This is a record of your decision to refuse particular treatments in the future.

The NHS has more [information about end of life care](#), including information on advance statements and advance decisions. Follow the link or search 'end of life' at www.nhs.uk

We offer a [free Will-writing service](#) to anyone who has been affected by leukaemia. Follow the link or search 'Wills service' at www.leukaemiacare.org.uk

Further information

We have more [information about AML](#) including booklets and factsheets to download. Follow the link, scan the QR code or search 'AML' at leukaemiacare.org.uk



We also have [booklets you can order in print free of charge](#). Follow the link or search 'AML' at shop.leukaemiacare.org.uk or scan the QR code.



We are grateful to Jonathan Kell, haematologist, and Joanne Preston, clinical nurse specialist and Dave and Joyce, patient reviewers, for reviewing this information.

If you have any feedback on this information, or you'd like a list of the references we used to develop it:

- Email information@leukaemiacare.org.uk
- Complete our [short survey](#) to help us improve our information
- Call **01905 755 977**
- Write to **Leukaemia Care, One Birch Court, Blackpole East, Worcester, WR3 8SG**

If you need support

[We're here for you if you need support](#). Follow the link or search 'support for you' at leukaemiacare.org.uk to find out how we can help you.

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