Relapsed or refractory acute myeloid leukaemia (AML)

Relapsed acute myeloid leukaemia (AML) is when AML comes back after successful treatment. Refractory AML is when AML does not respond to your first treatment. Find out what your treatment options are, and where to get support if you need it.

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 similar or different symptoms 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.

Download our leaflet about relapsed or refractory AML

Download our factsheet about relapsed or refractory AML

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What is relapsed or refractory AML?

Acute myeloid leukaemia (AML) is a fast-growing blood cancer.

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

Finding out AML hasn't responded to treatment, or has come back, can be distressing. We're here to support you.

If you have relapsed or refractory AML, there are different options. Your medical team will discuss your treatment plan and next steps with you.

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Signs and symptoms of relapsed or refractory AML

You may have the same, similar or different symptoms to when you were first diagnosed. Some common signs and symptoms 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)
- Unexpected bruising or bleeding (like nosebleeds or bleeding gums)
- Joint or bone pain
- Tummy pain, bloating or fullness after eating

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Diagnosis of 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 medical team will send your samples to look for any new genetic changes in your leukaemia cells. These help your medical team work out the most suitable treatment for you.

Your medical team will use the results of your tests to decide which treatment is the most suitable option for you.

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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

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.

If there is a clinical trial that might 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.

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 medical 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.

Stem cell transplant

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A stem cell transplant involves having high-dose chemotherapy and sometimes radiotherapy. It is very intensive and is only suitable for people who are fit enough to have it.

Your medical 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 it, and it can take many months to recover.

Targeted treatments

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.

Targeted treatments your team might suggest include:

- Gilteritinib
- Ivosidenib
    - This medicine is approved as a first treatment for AML, but is sometimes used in relapsed or refractory AML. This is called 'off-label' treatment. It's when a doctor prescribes a medicine that's approved for one condition to treat a different condition.

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

Non-intensive treatment

If your haematology team think you might not cope well with intensive treatment, they might recommend other, gentler options.

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

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- Low-dose cytarabine
- Hydroxycarbamide

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

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

Supportive care

You might also need medicine to prevent or treat symptoms or side effects. This is called supportive care. It aims to reduce your symptoms, extend your survival, and give you and your loved ones the best quality of life possible. It might include:

- Blood transfusions or medicines called growth factors. They can help 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, infections or a sore mouth.
- Food or drink supplements, if you are not able to eat or drink enough.
- Steroids, which help with many different symptoms and side effects.
- Physiotherapy.
- Emotional and social support.

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. Call our freephone helpline on 08088 010 444, message us on WhatsApp at 07500 068 065 or email us at support@leukaemiacare.org.uk.

The following charities also provide support and information for people dealing with end of life care:

- Compassion in Dying
- Hospice UK
- Marie Curie

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Sources we used to develop this information

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Need support?

You are not alone. We're here for you whether you have a diagnosis yourself or know someone who has. If you'd like advice, support, or a listening ear, call our freephone helpline on 08088 010 444 or send a WhatsApp message to 07500 068 065.

Helpline and WhatsApp →

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