Higher doses of cytarabine

Cytarabine is a chemotherapy medicine. Higher doses can be used on their own or with other medicines to treat some people with acute myeloid leukaemia (AML).

Summary

- Higher doses of cytarabine are used to treat some people with acute myeloid leukaemia (AML). Your doctor might recommend it for other types of leukaemia.
- Higher doses of cytarabine are a type of chemotherapy. You have it through a drip into a vein (or a central line, if you have one).
- You will have regular blood tests to check how well the treatment is working and how your body is coping with it.
- You may get some side effects while you are having higher doses of cytarabine. Some people have very few side effects, whereas other people experience more serious side effects.
- Tell your doctor or nurse if you have any side effects.

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About higher doses of cytarabine

This webpage is about higher doses of cytarabine used on their own. We have separate information about:

- Daunorubicin + cytarabine
- Daunorubicin + cytarabine + gemtuzumab ozogamicin
- Liposomal daunorubicin + cytarabine
- Venetoclax + cytarabine
- Low-dose cytarabine

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Higher dose cytarabine is an intensive chemotherapy medicine. It stops your cancer cells from making and repairing DNA. This can stop cancer cells from growing and dividing.

There is no brand name for cytarabine. You might hear some people call it Ara-C.

Your medical team might recommend higher doses of cytarabine for you if:

- You can have intensive chemotherapy **AND**
    - You have newly diagnosed AML **OR**
    - You have AML that did not respond to your first treatment or came back after treatment

Your haematology team might recommend it for other types of leukaemia.

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Before having higher doses of cytarabine

Before you start treatment, your medical team will carry out the following tests:

- Blood tests to measure your blood counts
- Blood tests to check your liver and kidney function
- Blood tests to measure the level of salts in your blood
- Bone marrow tests

Things to tell your haematology team

Before starting treatment, you should let your haematology team know if you:

- Have any problems with your liver
- Have or ever had any problems with your heart
- Have recently had cancer treatment, radiotherapy or are due to have radiotherapy
- Have any allergies or have ever had an allergic reaction
- Are or think you may be pregnant

Some medicines or drugs may interact with higher doses of cytarabine. It is important to tell your medical team about any medicines or supplements you are taking. This includes

prescribed medicines and medicines you have bought yourself without a prescription. Examples include:

- Methotrexate, a medicine used to treat some cancers and some inflammatory conditions
- Some medicines used to treat infections
- Some medicines used to treat your heart or heart conditions
- Some medicines which can affect your immune system

> **Higher doses of cytarabine may affect your fertility. If you may want to have children in the future, tell your medical team. They can give you advice on sperm or egg storage before starting treatment.**

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Having higher doses of cytarabine



Higher doses of cytarabine are an intensive treatment. You have treatment in cycles. You have higher dose cytarabine for 3 days during the first week of the cycle. You then have a break for your blood counts to recover.



You have cytarabine through a drip into a vein (or a central line, if you have one). It takes up to 4 hours to have a full dose of higher dose cytarabine. On treatment days, you usually have two doses.



You usually need to stay in hospital to have it and until your blood counts recover. Sometimes, you may be able to have it as an outpatient.

Your team will also give you treatment or suggest things to help prevent and manage side effects. This may include:

- Medicines to help stop you feeling or being sick
- Allopurinol, to protect your kidneys
- Staying hydrated, by drinking water and via a drip, to help support your kidneys

- Antiviral medicines to prevent viral infections
- Medicines to prevent bacterial infections
- Medicines to help protect your stomach lining from the effects of the drugs you may be given
- Steroid eye drops
- Mouthwashes

Dose

Your haematology team will work out the best dose of higher doses of cytarabine for you. Your dose will be based on your height, weight and how well you respond to treatment. They will tell you what dose they recommend for you.

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Precautions

There are several precautions to be aware of when you are having higher doses of cytarabine:

- Higher doses of cytarabine may cause problems with your vision. Take care if you are driving or using tools or machinery.
- Higher doses of cytarabine can affect your heart. If you have any side effects during or after treatment that affect your heart, tell your medical team.

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Pregnancy, breastfeeding and fertility

Higher doses of cytarabine may harm unborn babies.

- If you could get pregnant, it is important to use effective contraception. You need to do this while you are having higher doses of cytarabine and for 6 months after you stop.
- If you could make someone pregnant, it is important to use effective contraception. You need to do this while you are having higher doses of cytarabine and for 6 months after you stop.

- If you think you might be pregnant, tell your haematology team as soon as possible. They may recommend stopping higher doses of cytarabine for a while. They could also recommend switching to a different treatment.
- If you are planning to get pregnant, or make someone pregnant, tell your haematology team. They can discuss your treatment options with you.

Breastfeeding

Scientists are not sure if higher doses of cytarabine pass into breast milk. If it does, it could be a risk for breastfed babies or children. You should not breastfeed when having higher doses of cytarabine.

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Monitoring

During your treatment with higher doses of cytarabine you will have blood tests:

- Before you start treatment
- Before each treatment cycle
- Regularly throughout your treatment

You may also have further blood and bone marrow tests during your treatment. Your medical team will let you know what tests you need and how often.

Your medical team will use the results of these tests to:

- Check how well higher doses of cytarabine are working for you
- Make sure your blood counts have not dropped too low
- Check how well your liver and kidneys are working
- Check the level of salts in your blood

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How long to have higher doses of cytarabine

The number of cycles you have depends on how you respond to treatment and how well your body is coping with it. You usually have two to four cycles of treatment.

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Side effects

Like all medicines, higher doses of cytarabine can cause side effects. Some of these may be serious. Side effects are different for everyone, and we cannot predict what side effects you may or may not get.

Tell your haematology team about any side effects you have. They may be able to suggest things you can do or give you medicines to help.

Talking to your haematology team about side effects

- Higher doses of cytarabine can make it difficult for your body to fight off infections. If you have an infection, or feel unwell before or during treatment, tell your medical team. They can then treat the infection.
- Higher doses of cytarabine can cause nerve damage. If you have pain, numbness, weakness, tingling or loss of balance, tell your medical team.
- Higher doses of cytarabine can cause lung damage. If you have shortness of breath, rapid breathing, or bluish skin (this may look different on black or brown skin) tell your team.

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Serious side effects

> **The following side effects can happen at higher doses of cytarabine. These side effects could be serious and require urgent treatment. Contact your doctor or nurse straight away if you have any of these side effects.**

Your medical team will closely monitor you for serious side effects. This means they can treat them promptly if they happen. The most important serious side effects for people having higher doses of cytarabine are:

- Low levels of all your blood cells (red blood cells, white blood cells and platelets)
- Changes in your personality, feeling less alert or confused
- Difficulty speaking, problems with your balance and coordination
- Uncontrolled shaking or trembling, uncontrolled eye movements, fits (seizures)
- Headaches, drowsiness, dizziness, coma
- Cloudy vision or sore, red, itchy or irritated eyes
- Tummy pain, bloating, feeling sick or being sick, or other problems with your gut
- A swollen liver or other problems with your liver
- Fluid on your lungs
- Periods stopping (if you usually have them)
- Sore, weak, stiff, achy or swollen muscles, feeling generally exhausted
- A fast and irregular heartrate, shortness of breath and swelling of your legs, due to problems with your heart

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Common side effects

You may experience some of the following side effects when having higher doses of cytarabine. Tell your medical team if you get any side effects. They may be able to suggest things to help.

Common side effects affect more than 1 but less than 10 out of every 100 people who are having higher doses of cytarabine.

Common side effects include:

- Feeling tired, dizzy or short of breath. This can be due to a low red blood cell count (anaemia) or red blood cells that don't work properly.
- Frequent or long-lasting infections due to a low white blood cell count.
- Unexpected bruising or bleeding like nosebleeds, bleeding gums, blood spots or rashes. This is due to a low platelet count.
- Loss of appetite.
- Sore, inflamed eyes (you'll have eye drops to try to prevent this).

- Difficulty swallowing.
- Tummy pain.
- Feeling sick or being sick (you'll have medicine to try to prevent this).
- Diarrhoea.
- Inflammation or ulcers in or around your mouth or bottom.
- Changes in your liver or kidney function (as seen on a blood test).
- Increased levels of uric acid in your blood, which can lead to gout (you'll have medicine to try to prevent this).
- Red, itchy skin, a rash, or swelling and redness where you had the injection (this may look different on black or brown skin).
- Hair loss.
- Difficulty peeing.
- Fever.

Cytarabine syndrome

This is a type of allergic reaction that can happen, usually 6 to 12 hours after you have had a cytarabine injection. You may get symptoms like:

- Fever
- Muscle aches and pains
- Bone pain
- Chest pain
- Reddish skin covered in bumps (this may look different on black and brown skin)
- Red and sore eyes
- Feeling sick
- Feeling generally unwell

If you experience these symptoms, tell your medical team. They may give you treatment, such as steroids, to help.

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What to do if you get side effects

Tell your medical team if you get any side effects. They may be able to suggest things to help. This could include:

- Lowering your dose of cytarabine or temporarily stopping treatment

- Medicines like antibiotics, antifungals or antivirals to treat and prevent infections
- Blood or platelet transfusions if you have low levels of blood cells
- Mouthwashes, rinses and gels to help with sore mouth
- Steroid eye drops to help with sore, itchy or irritated eyes
- Medicines to prevent and treat sickness and diarrhoea
- Medicines to reduce your uric acid level to prevent gout
- A drip if you're not getting enough fluid

You may need to stay in hospital to manage some of these side effects.

Hair loss

Higher doses of cytarabine can cause hair loss. This can include hair on your head, facial hair, body hair and pubic hair. It is usually reversible and starts to grow back 2 to 3 months after finishing treatment.

Hair loss happens gradually. Some people prefer to shave their hair or cut it short. This can give you a feeling of control and reduce the emotional impact of it falling out. You could also cover your hair loss, if you choose to. There are lots of options like hats, headscarves, wraps, turbans or wigs.

Cancer Hair Care UK has more information on hair loss, including how to care for Afro-textured hair during chemotherapy.

Blood Cancer UK and Macmillan have more information on coping with side effects and treatment.

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If this treatment does not work

If higher doses of cytarabine are not working well, there are a number of different options. Your haematology team will explain what they recommend for you.

If your AML does not respond to treatment, this is known as refractory AML. We have more information about relapsed and refractory AML.

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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.

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