Azacitidine injections

Azacitidine injections on their own can be used to treat some people with myelodysplastic syndromes (MDS), chronic myelomonocytic leukaemia (CMML) or acute myeloid leukaemia (AML).

Summary

- Azacitidine injections are used to treat some adults with acute myeloid leukaemia (AML), myelodysplastic syndrome (MDS) and chronic myelomonocytic leukaemia (CMML).
- Azacitidine is a type of chemotherapy medicine. You have it as an injection just under your skin, usually in your tummy, thigh or upper arm.
- Most people have azacitidine injections over 7 days, followed by 21 days without any injections.
- You will have regular blood tests to check how well the injections are working, your blood counts and how well your liver and kidneys are working.
- You may get some side effects while you are having azacitidine injections.
- Some people have very few side effects, whereas other people experience more serious side effects.
- Some side effects can be serious if not treated promptly. Contact your haematology team straight away if:
    - You have a high temperature (over 38°C), feel shivery or generally unwell
    - You feel tired, dizzy or short of breath
    - You have a cough, chest pain or wheezing
    - You get unexpected bruising or bleeding
- Tell your haematology team if you get any other side effects. They may be able to suggest things to help.

Do not stop having azacitidine injections without talking to your haematology team.

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About azacitidine injections

Azacitidine is a chemotherapy medicine that can turn on genes that have been turned off. This includes cancer-suppressing genes that are often turned off in cancer cells. Azacitidine can stop cancer cells making proteins. This can stop them growing and dividing.

Brand names for azacitidine injections include:

- Azacitidine betapharm
- Azacitidine Sandoz
- Azacitidine Seacross
- Azacitidine Tillomed
- Vidaza

Azacitidine injections are used to treat some adults with acute myeloid leukaemia (AML), myelodysplastic syndrome (MDS) and chronic myelomonocytic leukaemia (CMML).

Your haematology team might recommend azacitidine injections for you if:

- You cannot have, or do not want, a stem cell transplant **AND**
    - You have MDS that has a medium or high chance of progressing quickly **OR**
    - You have AML or CMML and your leukaemia cell count meets a certain threshold

Sometimes, your doctor might suggest azacitidine in other circumstances. They will explain what they recommend and why.

If you have AML, you might have azacitidine on its own, or with other treatments like venetoclax or ivosidenib, both of which you take by mouth.

This webpage is about azacitidine used on its own. We have separate information about azacitidine with venetoclax and azacitidine with ivosidenib.

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Before having azacitidine injections

Before starting azacitidine, your haematology team will carry out checks to make sure it's suitable for you. These might include:

- Blood tests to measure your blood counts
- Blood tests to check your liver and kidney function
- Bone marrow test

> **You should tell your doctor if you have:**
>
> - **Kidney disease or liver disease**
> - **Ever had a heart attack or heart condition**
> - **A history of lung disease**

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Having azacitidine injections

You usually have azacitidine injections in a treatment cycle of 28 days. Depending on how you cope with treatment, and how well it works, your doctor might make some changes to the length of your treatment cycle or how many days you have injections.

- You usually have azacitidine injections over 7 days at the start of each cycle. This is usually 5 days of treatment, a weekend off, then another 2 days of treatment.
- For the rest of your treatment cycle, you do not have azacitidine injections.
- You usually go to a hospital day unit to have each injection, and go home the same day.
- Your doctor will give you tablets to help stop you feeling sick or being sick. You usually take these 30 minutes before you have your azacitidine injection.
- Your doctor or nurse will give you the injection just under your skin in your tummy, thigh or upper arm.

Dose

Your doctor will work out the best dose of azacitidine for you 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 azacitidine injections.

- Azacitidine injections may make you feel tired or weak or make it difficult to concentrate. Take care if you are driving or using tools or machinery.
- Azacitidine can affect how well your kidneys work. If you stop peeing, or you're peeing less than usual, tell your doctor straight away.
- Tell your haematology team about any other medicines or herbal supplements that you are taking.

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Pregnancy, breastfeeding and fertility

Azacitidine injections may harm unborn babies, especially during the early stages of pregnancy.

- If you could get pregnant, it is important to use effective contraception while you are having azacitidine injections and for 6 months after you stop.
- If you could make someone pregnant, it is important for you to use effective contraception while you are having azacitidine injections and for 3 months after you stop.
- If you are having azacitidine and think you might be pregnant, tell your haematology team as soon as possible. They may recommend stopping treatment for a while or 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 azacitidine passes into breastmilk. If it does, it could be a risk for breastfed babies or children. You should not breastfeed when having azacitidine.

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Monitorin

During your treatment with azacitidine injections you will have blood tests before starting each cycle of treatment. You may also have further blood and bone marrow tests during your treatment cycle. Your haematology team will let you know what tests you will need and how often.

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

- Check how well azacitidine injections are working for you
- Make sure your blood counts have not dropped too low
- Check how well your liver and kidneys are working

Tumour lysis syndrome

Chemotherapy kills cancer cells. When lots of cancer cells breakdown quickly, they can release a large amount of chemicals into your blood. This is known as tumour lysis syndrome. It can affect how well your kidneys work, as well as causing changes to your heartbeat and sometimes fits (seizures).

Tumour lysis syndrome is rare. It happens to less than 1 in every 1,000 people having azacitidine injections.

If you have a very high leukaemia cell count before treatment, your haematology team might give you medicine to help prevent tumour lysis syndrome. They will monitor you closely so they can treat it quickly if it happens.

Differentiation syndrome

Very rarely, azacitidine injections might cause a serious problem called differentiation syndrome. This can happen if recovering white blood cells release too many immune chemicals, which can trigger a severe reaction.

Your haematology team will monitor you for signs of differentiation syndrome. If it happens, it can be treated with steroids.

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How long to have azacitidine injections

Most people have at least three to six cycles of treatment. After this, you usually carry on having azacitidine injections unless:

- It has not worked well enough
- It stops working well
- You are having side effects that are difficult to cope with

If this happens, your haematology team might stop azacitidine, adjust your dose, or recommend a different treatment.

Do not stop having azacitidine injections without talking to your haematology team.

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Side effects

You may get some side effects while you are having azacitidine injections. Some people may have very few side effects, whereas other people experience more serious side effects.

Here we cover side effects you might experience. Tell your haematology team if you get any side effects. They may be able to suggest things to help.

If you are getting side effects that are difficult to cope with, they might suggest:

- Temporarily stopping treatment
- Lowering your dose of azacitidine
- Delaying your next treatment cycle

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Serious side effects

> **The following side effects may be serious and require urgent treatment. Contact your doctor or nurse straight away if you have any of these side effects.**

Serious side effects that happen to less than 10 in every 100 people having azacitidine injections:

- A high temperature (higher than 38°C) with a low white blood cell count (febrile neutropenia). You might also feel shivery or generally unwell.
- A low red blood cell count (anaemia), which can make you feel tired, dizzy or short of breath.
- Pneumonia (a lung infection). You may get symptoms like:
    - A cough, chest pain
    - A high temperature
    - Shortness of breath, wheezing when you breathe
    - An aching body, feeling very tired
    - Loss of appetite
- A low platelet count, which might lead to unexpected bruising or bleeding like nosebleeds, bleeding gums, blood spots or rashes.

Serious side effects that happen to less than 1 in every 100 people having azacitidine injections:

- Difficulty breathing, swelling of your lips, itching or rash due to an allergic reaction to the medicine
- Bleeding in your brain or gut
- Urine infection, which could cause darker or smellier pee, stinging when going for a pee or needing to pee more than usual
- Sepsis which can cause symptoms like:
    - Chills, fever
    - Rapid heartbeat
    - Acting confused, slurring your words and not making sense

- Blue, grey or pale blotchy skin (this may look different on black or brown skin)
- Difficulty breathing, shortness of breath

Azacitidine can lower your blood cell counts. This can mean you may be more likely to get infections, fever, bruising, bleeding, shortness of breath or feeling very tired. If you get any of these symptoms tell your doctor or nurse straight away.

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Very common side effects

Very common side effects affect more than 10 in every 100 people who are having azacitidine injections. Very common side effects include:

- A cold, blocked or runny nose, sore throat or coughing
- A low white blood cell count, which makes you more likely to get infections, and can mean that any infections you do get are more serious
- Loss of appetite or losing weight
- Low potassium levels which can cause muscle weakness, muscle cramps and a fast and irregular heartbeat
- Finding it hard to get to sleep or stay asleep
- Dizziness, headaches
- Shortness of breath
- Nosebleeds
- Feeling sick or being sick
- Tummy pain
- Reddish or purple spots, bruising or discolouration of your skin caused by bleeding (this may look different on black or brown skin)
- Itching
- Rash
- Pain in your joints or muscles
- Fever
- Fatigue

- Feeling weak
- Chest pain
- Redness, pain or another type of reaction around where you had the injection
    - Evening primrose oil or hydrocortisone cream can help to reduce the pain and redness – discuss this with your haematology team
- Diarrhoea or constipation

Constipation is also a side effect of anti-sickness medicines that you are given with your chemotherapy. If you are experiencing constipation, it is important to let your haematology team know, as they may be able to adjust your anti-sickness medication to help with this.

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Common side effects

Common side effects affect more than 1 but less than 10 out of every 100 people who are having azacitidine injections.

Common side effects include:

- Infections. Signs of infection include:
    - A high temperature (38°C or higher)
    - Sore throat, sneezing, blocked or runny nose or cough
    - Itchy nose, throat and eyes
    - Headache or pain around your eyes, nose and forehead
    - Shortness of breath
    - Burning or stinging when you pee, or peeing more often than usual
    - Painful, hot, red swollen area of skin, blisters or peeling of skin (this may look different on black or brown skin)
    - Cold sores around your lips, mouth or tongue
    - Red patches, ulcers, loss of taste or pain, burning or swelling in your mouth

- Pain in your tummy, constipation, diarrhoea, blood in your poo or bloating
- Dehydration
- Feeling confused or anxious
- Bleeding in your brain which can cause you to feel drowsy, faint, lose consciousness or feel low on energy
- Bleeding in your eyes
- A build up of fluid around your heart which can cause shortness of breath, difficulty breathing when lying down and chest pain
- High or low blood pressure
- Painful, swollen, red bruises (this may look different on black or brown skin)
- A build up of fluid around your lungs which can cause chest pain, cough and shortness of breath
- Shortness of breath when exercising or doing something physical
- Indigestion, heartburn
- Purple or reddish skin or blood spots under the skin (this may look different on black or brown skin)
- Hair loss
- Hives and itchy skin
- Muscle spasms, or muscle aches and pains
- Kidney failure
- Blood in your pee
- Thickening and hardening of your skin
- Inflammation, skin changes or bleeding where you have the injections
- Feeling generally unwell
- Chills

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If azacitidine injections do not work

If azacitidine injections are not working well, your haematology team might suggest altering your treatment cycle or stopping treatment if your blood counts drop.

If this is not suitable for you, or does not work, they will talk to you about your treatment options. These may include:

- Other low dose chemotherapy options

- A clinical trial, if there is one suitable for you
- Treatment to relieve your symptoms and improve your quality of life, rather than treat the cancer itself

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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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