

---

# Azacitidine for Acute Myeloid Leukaemia

**A Guide for  
Patients**

**Leukaemia Care**  
YOUR Blood Cancer Charity

# Introduction

**Azacitidine is a chemotherapy drug, which is used for the treatment of adult patients who are not eligible for stem cell transplant, with acute myeloid leukaemia (AML), high risk myelodysplastic syndrome (MDS) or with chronic myelomonocytic leukaemia.**

This patient information booklet is for patients, family or friends of the patient or a carer who like to know more about this drug.

Booklet compiled by one of our medical writers Saloua Najjam, PhD., and Shirley Aston, nurse advisor at Leukaemia Care. This booklet has been peer reviewed by nurse advisor Fiona Heath and medical advisor Professor David Bowen. We are also grateful

to leukaemia patients Sue Chambers and Anne Taylor for their valuable contribution as patient reviewers.

However, for more information, please talk to your consultant, haematologist, clinical nurse specialist (CNS) or hospital pharmacist.

If you would like any information on the sources used for this booklet, please email [communications@leukaemiare.org.uk](mailto:communications@leukaemiare.org.uk) for a list of references.

# In this booklet

Introduction	2
In this booklet	3
About Leukaemia Care	4
What is Azacitidine?	6
Who receives Azacitidine?	7
How is Azacitidine administered?	8
What are the side effects of Azacitidine?	10
What happens if Azacitidine doesn't work for me?	17
Glossary	18
Useful contacts and further support	19

# About Leukaemia Care

**Leukaemia Care is a national charity dedicated to ensuring that people affected by blood cancer have access to the right information, advice and support.**

## Our services

### Helpline

Our helpline is available 9.00am - 10.00pm on weekdays and 9.00am - 12.30pm on Saturdays. If you need someone to talk to, call **08088 010 444**

### Nurse service

We have two trained nurses on hand to answer your questions and offer advice and support, whether it be through emailing **nurse@leukaemicare.org.uk**, over the phone on **08088 010 444** or via LiveChat.

### Patient Information Booklets

We have a number of patient information booklets like this available to anyone who has been affected by a blood cancer. A full list of titles – both disease specific and general information titles – can be found on our

website at **www.leukaemicare.org.uk/resources/filter-by-resource-type/information-booklets**

### Support Groups

Our nationwide support groups are a chance to meet and talk to other people who are going through a similar experience. For more information about a support group local to your area, go to **www.leukaemicare.org.uk/our-support-groups**

### Buddy Support

We offer one-to-one phone support with volunteers who have had blood cancer themselves or been affected by it in some way. You can speak to someone who knows what you are going through. For more information on how to get a buddy call **08088 010 444** or email **support@leukaemicare.org.uk**

### Online Forum

Our online forum, [www.healthunlocked.com/leukaemia-care](http://www.healthunlocked.com/leukaemia-care), is a place for people to ask questions anonymously or to join in the discussion with other people in a similar situation.

### Patient and carer conferences

Our nationwide conferences provide an opportunity to ask questions and listen to patient speakers and medical professionals who can provide valuable information and support.

### Website

You can access up-to-date information on our website, [www.leukaemicare.org.uk](http://www.leukaemicare.org.uk), as well as speak to one of our care advisers on our online support service, LiveChat (9am-5pm weekdays).

### Campaigning and Advocacy

Leukaemia Care is involved in campaigning for patient well-being, NHS funding and drug and treatment availability. If you would like an update on any of the work we are currently doing or want to know how to get involved, email [advocacy@leukaemicare.org.uk](mailto:advocacy@leukaemicare.org.uk)

### Patient magazine

Our free quarterly magazine includes inspirational patient and carer stories as well as informative articles by medical professionals. To subscribe go to [www.leukaemicare.org.uk/resources/subscribe-to-journey-magazine](http://www.leukaemicare.org.uk/resources/subscribe-to-journey-magazine)

# What is Azacitidine?

**Azacitidine may also be known as Vidaza.**

Azacitidine is a cytotoxic drug. Cytotoxic drugs (sometimes known as antineoplastics) describe a group of medicines that contain chemicals which are toxic to cells, preventing their replication or growth, and so are used to treat cancer.

Azacitidine is usually given as an injection underneath the skin (subcutaneously). This can be in your upper arm, leg or stomach.

If you wish to have further information on AML, MDS or CMML, please view our collection of patient information booklets that are available on our website at [www.leukaemiacare.org.uk](http://www.leukaemiacare.org.uk)

# Who receives Azacitidine?

Azacitidine is used for the treatment of adults who are not eligible for stem cell transplant, with:

- Acute Myeloid Leukaemia.
- Intermediate-2 and high-risk myelodysplastic syndromes (MDS).
- Chronic Myelomonocytic Leukaemia

Leukaemia Care offers nationwide support groups for people affected by a diagnosis of a blood or lymphatic cancer. Visit [www.leukaemiacare.org.uk](http://www.leukaemiacare.org.uk), or call **08088 010 444**, to find out more and to find a group near you.

# How is Azacitidine administered?

## Before treatment

Before starting azacitidine treatment, your doctor will do some clinical pre-assessments such as:

- Recording your weight and height.
- Blood tests: run a full blood count (FBC), liver function tests (LFTs), coagulation and a measure of kidney function (U&Es).
- Bone marrow biopsy: to check how many cancer cells there are in your bone marrow.
- For female patients, a pregnancy test will be carried out to rule out any childbearing potential before each new chemotherapy course.
- You may have an electrocardiogram (ECG) test to check that your heart is working normally.

These tests will be performed to ensure that you are medically fit to start your treatment.

As a patient, you will need to

read and sign a consent form regarding the receipt of verbal and written information in relation to your disease, treatment and potential side effects.

You will usually be given anti-sickness medicine before your treatment starts.

## Treatment

You will usually be given azacitidine as an outpatient. This means you will be able to go home after each treatment.

You usually have azacitidine as a course of several cycles of treatment.

Azacitidine may be given Monday to Friday with the weekends off from treatment, however this may differ according to your hospital.

The injection can be given in your stomach, upper arm or thigh.

It is recommended to take azacitidine for a minimum of six cycles and to continue with the treatment for as long as you benefit from it or until disease progression takes place, which



indicates that the treatment may not be working. Much of this will depend on the leukaemia or MDS type you have. You should talk to your consultant or nurse if you have any queries about the length of treatment you are receiving.

Occasionally your doctor may adjust your dose of azacitidine, or they may delay your treatment for a short while. This may be because of the effects of the azacitidine on your body or on the cancer itself.

# What are the side effects of Azacitidine?

Azacitidine is generally well tolerated but there are a number of side effects that you may experience during the treatment.

## Common Side effects

- **Risk of Infection** - Azacitidine can reduce the number of white blood cells in your blood. These cells fight infection. If the number of white blood cells is low (neutropenia), you are more likely to get an infection. If you have any signs of infection, such as fever,

shivering, breathlessness, a sore throat, cough, needing to pass urine often, diarrhoea or a temperature of 37.8 C or above contact your nurse or doctor straight away as it is important to treat it as soon as possible.

- **Bruising or bleeding** - This treatment can reduce the production of platelets which help the blood clot. Let your doctor know if you have any unexplained bruising or bleeding such as nosebleeds,

You can try the following methods to try and minimise the risk of infection:

- Hand washing.
- Avoidance of ill people.
- Perform regular temperature checks using a thermometer. If your temperature exceeds 37.8°C please contact your Doctor and/or hospital team immediately. If you cannot contact them for any reason, go to the hospital directly.
- Place high importance on personal hygiene.

- If you have a central line (also known as Hickman line), keep the area around it clean and dry. This advice should also be followed if you have a PICC line.
- Clean your teeth every day and check for sores in the mouth or other signs of infection.
- If you get injured and have a scrape or cut, make sure you clean it well.
- Let your doctor or hospital team know if you have a sore bottom, or whether it bleeds.

bloodspots or rashes on the skin, or bleeding gums. You may need a platelet transfusion.

- **Aching or pain in joints or muscles** - After having azacitidine you may find that you get aches and pains in your joints and muscles. If you experience this, please discuss it with your doctor who can prescribe pain killers.
- **Anaemia (low number of red blood cells)** - While having this treatment you may become anaemic. This may make you feel tired and breathless. Let your doctor know if these symptoms become a problem, you may need a blood transfusion.
- **Headache** - This treatment can cause headaches. Let your nurse know if you experience headaches. Pain killers can be prescribed if necessary.
- **Loss of appetite**
- **Nausea** - you may feel sick in the first few days after chemotherapy. Your doctor will give you anti-sickness drugs to help prevent or control sickness. Take the drugs exactly as your nurse or doctor tells you. It is easier to prevent sickness than treat it after it has started.

- **Constipation, diarrhoea, abdominal pain and indigestion**

Tips for managing diarrhoea:

- Drink plenty of water, but avoid alcohol and coffee.
- Eat small frequent meals and take your time to eat.
- Eat fewer fibrous foods, such as cereals, raw fruits and raw vegetables.
- Avoid greasy, fatty food.
- Avoid spicy food.

Some diarrhoea can't be managed through diet alone, so speak to your medical team about any medication you may be able to take.

- **Fatigue** - Azacitidine may make you feel tired and lacking in energy. It is often worse towards the end of treatment and for some weeks after it has finished. If you do feel tired, take rest when necessary. Gentle exercise such as walking can be beneficial.

# What are the side effects of Azacitidine? (cont.)

- **Some redness and/or irritation may occur around the injection site** - This is normally only temporary. The nurse giving you the injections should change the administration site each time. Using a warm or cool pack may help to ease the pain and discomfort at the injection site. Your doctor can prescribe painkillers if needed.
- **Anaphylactic reaction** - some people may experience an allergic reaction when treated with azacitidine.
- **Liver changes**
- **Lung problems** - This treatment can affect your lungs. Tell your doctor or nurse straight away if you develop a cough or a wheeze or if you feel breathless.

## Occasional side effects

- **Hypertension or hypotension** - High or low blood pressure.
- **Insomnia** - Difficulty sleeping or resting.
- **Haematuria** - Blood in the urine.
- **Kidney changes** - Azacitidine can affect how your kidneys work and this is monitored throughout your treatment. Kidney function usually returns to normal once treatment has stopped. It is important to drink at least two litres of water a day to help protect your kidneys.

## Rare side effects

- **Heart problems** - Azacitidine can affect the way your heart works. Tell your doctor or nurse straight away if you experience dizziness, breathlessness or chest pains.

## Sex, contraception & fertility

It is recommended that you protect yourself and your partner from the toxicity of chemotherapy drugs. You or your partner should use a condom during sexual intercourse while you are having the course of chemotherapy. Chemotherapy is dangerous to unborn babies and this will also protect you and your partner from any chemotherapy drugs that may be present in semen and/or in the vagina. You should inform your doctor immediately if you suspect that you may be pregnant.

## Fertility

This chemotherapy may affect your ability to have children and this will be discussed with you before the start of the treatment.

---

# What happens if Azacitidine doesn't work for me?

Some patients may initially improve with azacitidine and then lose the response later. Others may not respond to azacitidine.

Occasionally it may be appropriate to consider intensive chemotherapy after azacitidine. If intensive chemotherapy is not appropriate then a clinical trial may be available.

However, more commonly after azacitidine stops working, treatment will change to supportive care, which will include blood transfusions to help maintain an acceptable quality of life.

Overall, following the outcome of your treatment with azacitidine, your consultant is the best person to discuss the next steps.

# Glossary

## Acute myeloid leukaemia (AML)

It is a blood cancer which affects the myeloid cells, which include red cells, platelets and some white blood cells.

## Antineoplastic

It is a drug that inhibits or prevents the growth and spread of tumours or malignant cells.

## Bilirubin

It is an orange-yellow substance made during the normal breakdown of red blood cells

## Chemotherapy

It is a type of cancer treatment that uses one or more drugs with powerful chemical to kill growing cancer cells

## Creatinine

A chemical waste molecule that is generated from muscle metabolism.

# Useful contacts and further support

There are a number of helpful sources to support you during your diagnosis, treatment and beyond, including:

- Your haematologist and healthcare team
- Your family and friends
- Your psychologist (ask your haematologist or CNS for a referral)
- Reliable online sources, such as Leukaemia Care
- Charitable organisations

There are a number of organisations, including ourselves, who provide expert advice and information.

## Leukaemia Care

We are a charity dedicated to supporting anyone affected by the diagnosis of any blood cancer.

We provide emotional support through a range of support services including a helpline, patient and carer conferences, support group, informative website, one-to-one buddy service and high-quality patient information. We also have a nurse on our help line for any medical queries relating to your diagnosis.

Helpline: **08088 010 444**  
**[www.leukaemiacare.org.uk](http://www.leukaemiacare.org.uk)**  
**[support@leukaemiacare.org.uk](mailto:support@leukaemiacare.org.uk)**

## Bloodwise

Bloodwise is the leading charity into the research of blood cancers. They offer support to patients, their family and friends through patient services.

**020 7504 2200**  
**[www.bloodwise.org.uk](http://www.bloodwise.org.uk)**

## Cancer Research UK

Cancer Research UK is a leading charity dedicated to cancer research.

**0808 800 4040**  
**[www.cancerresearchuk.org](http://www.cancerresearchuk.org)**

## Macmillan

Macmillan provides free practical, medical and financial support for people facing cancer.

**0808 808 0000**  
**[www.macmillan.org.uk](http://www.macmillan.org.uk)**

## Maggie's Centres

Maggie's offers free practical, emotional and social support to people with cancer and their families and friends.

**0300 123 1801**  
**[www.maggiescentres.org](http://www.maggiescentres.org)**

## Citizens Advice Bureau (CAB)

Offers advice on benefits and financial assistance.

**08444 111 444**  
**[www.adviceguide.org.uk](http://www.adviceguide.org.uk)**

Leukaemia Care is a national charity dedicated to providing information, advice and support to anyone affected by a blood cancer.

Around 34,000 new cases of blood cancer are diagnosed in the UK each year. We are here to support you, whether you're a patient, carer or family member.

## Want to talk?

Helpline: **08088 010 444**

(free from landlines and all major mobile networks)

Office Line: **01905 755977**

**[www.leukaemiacare.org.uk](http://www.leukaemiacare.org.uk)**

**[support@leukaemiacare.org.uk](mailto:support@leukaemiacare.org.uk)**

Leukaemia Care,  
One Birch Court,  
Blackpole East,  
Worcester,  
WR3 8SG

Registered charity  
259483 and SC039207

**Leukaemia Care**  
YOUR Blood Cancer Charity

