
HidAC (High dose Cytarabine) for Acute Myeloid Leukaemia

A Guide for
Patients

Introduction

High dose cytarabine (referred to as HidAC) is mainly used to treat patients with Acute Myeloid Leukaemia (AML). It may also be used to treat other types of leukaemia and lymphoma.

Booklet compiled by one of our medical writers Saloua Najjam, PhD. and peer reviewed by our Nurse Advisor Fiona Heath. We are also grateful for the contribution by Louise Moreton as a valuable patient reviewer.

If you would like any information on the sources used for this booklet, please email communications@leukaemiacare.org.uk for a list of references.

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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, 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.leukaemiacare.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@leukaemiacare.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.leukaemiacare.org.uk/resources/subscribe-to-journey-magazine

What is HidAC?

Cytarabine, sometimes called cytosine arabinoside, is a chemotherapy drug and it is also known by its brand name, Ara C. It is supplied in three different doses: high, intermediate and low.

Cytarabine is a type of chemotherapy drug called an anti metabolite. Anti metabolites are similar to normal body molecules but they are slightly different in structure. They kill cancer cells by stopping them making and repairing DNA that they need to grow and multiply.

Cytarabine is one of the major drugs used in the treatment of acute myeloid leukaemia (AML) and it may also be used to treat other leukaemias and lymphomas.

If you wish to have further information on AML please view our collection of patient information booklets that are available on our website at www.leukaemicare.org.uk

Who receives HidAC?

HidAC is given to patients with acute myeloid leukaemia for:

- Induction of remission (remission means that no leukaemia cells can be found in the blood or the bone marrow.
- Consolidation (therapy that is given after induction chemotherapy to kill any remaining cancer cells that may be left in the body) following induction chemotherapy

AML patients who relapse after a stem cell transplant may be offered hidAC as a treatment option. A stem cell transplant involves infusing blood stem cells into your body to replace your damaged or unhealthy ones.

It can also be given to patients with lymphoma.

HidAC has also been used in combination with other chemotherapy drugs to treat other types of leukaemia.

More information on combination therapies can be found in the patient information booklet titled MidAC (Mitoxantrone and Cytarabine).

Your consultant may not recommend high dose cytarabine for you if, as an AML patient, you have pre-existing drug-induced bone marrow suppression. If you have any concerns, you should ask your consultant about your treatment options.

How is HidAC administered?

Before starting high dose cytarabine 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).
- They may check your glucose using a urine dipstick.
- 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.

High dose cytarabine

- Cytarabine can be given as an injection into your bloodstream (intravenously) or by injection just under the skin (subcutaneously).
- High dose cytarabine is given through a drip into your arm or you might need a central line. This is a long plastic tube that gives the drugs into a large vein, either in your chest or through a vein in your arm. It stays in while you're having treatment, which may be for a few months.
- You will receive this treatment in hospital and may have to stay in until your blood counts recover. However if you are feeling well you may be able

to go home for periods and be monitored closely as an outpatient until your blood counts recover. This usually takes about 4 weeks but will be different for everyone.

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

What are the side effects of HidAC?

This treatment can have serious or possibly life-threatening side effects. Therefore, it is very important that you report any side effects that you experience straightaway.

The side effects you may experience include:

Common side effects

- **Risk of Infection** - HidAC 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.
- **Sore eyes** - Cytarabine can commonly cause sticky or sore eyes. You will have eye drops to help prevent this. Do not wear contact lenses while you are having this treatment.
- **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, bloodspots or rashes on the skin, or bleeding gums. You may need a platelet transfusion.
- **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.
- **Gastrointestinal disorders** - Constipation, diarrhoea, stomatitis.
- **Nausea and Vomiting** - The severity of this varies from person to person. Anti-sickness medication will be given along with your chemotherapy to prevent this.
- **Fatigue** - HidAC 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.

- **Sore mouth** - Your mouth may become sore or dry, or you may notice small mouth ulcers during this treatment. Drinking plenty of fluids and cleaning your teeth regularly and gently with a soft toothbrush can help to reduce the risk of this happening.
- **Changes to kidney function** - cytarabine can cause changes to your kidney function. Your kidney function will be monitored with your routine blood tests. Drink plenty of fluids to prevent dehydration.
- **Hair loss** - Your hair may thin and you may lose your hair from your head. Hair loss is almost always temporary and your hair will grow back after chemotherapy ends.
- **Skin changes** - HidAC may affect your skin. Your skin may feel dry or itchy. Cytarabine can also cause a rash.

Uncommon side effects

- **Respiratory disorders** - Cytarabine can cause changes to the lungs. Always tell your doctor if you develop wheezing, a cough, or a fever, or if you feel breathless.
- **Effects to the nervous system** - You may feel drowsy, confused, dizzy or unsteady. Tell your nurse or doctor straight away if you notice any of these symptoms. Rarely, this treatment can cause seizures.
- **Cytarabine syndrome** - Cytarabine can sometimes cause a syndrome that can result in some or all of the following: fever, weakness and aching in your muscles and bones, a rash and pain in the chest. This will not affect everyone and will disappear soon after the cytarabine infusions stop.
- **Extravasation** - This is when chemotherapy leaks outside the vein. If you develop redness, soreness or pain at the injection site at any time please let your

What are the side effects of HidAC? (cont.)

nurse know straightaway.

- **Bowel inflammation (colitis)**
- The treatment can cause inflammation or ulcers in your bowel which may be painful and can lead to serious infection of the bowel and potentially the lining on the inside of your abdomen (peritonitis). If you notice any blood when passing stools or you develop pain in your abdomen (tummy) please let the doctor or nurse know.
- **Liver disorders** - The chemotherapy may cause changes in the way your liver works. Your medical team will monitor this closely by taking blood samples from time to time to measure your liver function. If your liver is affected, your dose of chemotherapy may need to be adjusted.

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 HidAC doesn't work for me?

Based on some previous clinical studies, it has been shown that high dose Cytarabine, when it is not working for patients with AML, was replaced by either:

- Fludarabine, cytarabine, granulocyte-colony stimulating factor (G-CSF) and amsacrine as a combination therapy.
- Fludarabine in combination with intermediate-dose of cytarabine.
- Allogeneic stem cell transplant; this is where you receive a donor stem cell transplant to replace your immune system by the donor's one.

Overall, following the outcome of your treatment with HidAC chemotherapy, your consultant is the best person to discuss treatments with and to decide on the next step to take.

Glossary

Anthracycline

A chemotherapy drug that is also an antibiotic. It prevents cell division by disrupting the structure of DNA.

Chemotherapy

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

Complete remission

Means no evidence of leukaemia after treatment; where blast cells in the bone marrow are less than 5%, the blood cell counts are within normal limits and there are no symptoms of the disease.

Excipient

It is the inactive substance that serves as the vehicle or medium for a drug or other active substance.

Extravasation

It is when a chemotherapy medication or other drug leaks outside the vein onto or into the skin, causing a reaction.

Intravenous infusion

Liquid substances directly injected into a vein.

Myelosuppressive therapy

Like chemotherapy and radiation, it is a treatment that stops or slows the growth of blood-forming cells in the bone marrow. It kills normal cells and cancer cells in the bone marrow.

Necrosis

Cell necrosis is when cells die or cause to die because of a disease, injury, or failure of the blood supply.

Systemic infection

It is an infection that is in the bloodstream that affects the entire body.

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
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

Cancer Research UK

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

0808 800 4040
www.cancerresearchuk.org

Macmillan

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

0808 808 0000
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

Citizens Advice Bureau (CAB)

Offers advice on benefits and financial assistance.

08444 111 444
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

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Leukaemia Care
YOUR Blood Cancer Charity

