

High dose cytarabine

The possible benefits of treatment vary; for some people this chemotherapy may reduce the risk of the cancer coming back, for others it may control the cancer and its symptoms. Your doctor will explain to you whether you will receive chemotherapy or another type of treatment, or a combination of both. Your doctor or nurse will be happy to answer any questions you have about your treatment. You will find it useful to refer to the booklet 'Chemotherapy, a guide' which gives general information on chemotherapy and side effects.

Your treatment

Your doctor or nurse clinician has prescribed for you a treatment called high dose cytarabine. This treatment is usually part of the consolidation treatment for acute myeloid leukaemia. 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.

Your treatment includes:

Cytarabine via an infusion (drip) over 4 hours.

You will receive a total of 6 doses which takes 5 or 6 days to administer.

This treatment can have serious or possibly life-threatening side effects. It is very important that you report side effects straight away. Don't delay, if you feel unwell, please ring The Christie Hotline on **0161 446 3658**. The lines are open 24 hours a day.

Increased risk of serious infection

You are vulnerable to infection while you are having chemotherapy. Minor infections can become life-threatening in a matter of hours if left untreated. Symptoms of infection include fever, shivering, sweats, sore throat, diarrhoea, discomfort when you pass urine, cough or breathlessness. We recommend that you use a digital thermometer so you can check your temperature. You can buy one from your local chemist.

If you feel unwell, you have symptoms of an infection or your temperature is 37.5°C or above, or below 36°C contact The Christie Hotline straight away.



Possible side effects

Chemotherapy can cause many different side effects. Some are more likely to occur than others. Everyone is different and not everyone gets all the side effects. Most side effects are usually temporary, but in some rare cases they can be life-threatening. It is important to tell your hospital doctor or nurse about any side effects so they can be monitored and, where possible, treated.

Common side effects (more than 1 in 10)

• 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, and 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 or nurse know if these symptoms are a problem. You may need a blood transfusion.

You will have a routine blood test every day while you are in hospital to monitor the effects of the chemotherapy, but please tell your nurse if you experience any of the symptoms listed above.

• Nausea and vomiting (sickness)

The severity of this varies from person to person. Anti-sickness medication will be given along with your chemotherapy to prevent this. If you continue to feel or be sick, tell your nurse because your anti-sickness medication may need to be changed or increased.

• Hair loss

Hair loss is usually total. The hair falls out gradually 10 to 14 days following your first course of treatment. The time scale varies from person to person. Please remember that this is a temporary side effect and your hair will grow back when your treatment is completed. Very rarely, hair loss can be permanent.

The cancer information centre offers a coping with hair loss service to all patients where support, information and advice will be given. Drop in, phone **0161 446 8100** or email the-christie.informationcentre@nhs.net. Information about the wig service can also be found here and vouchers for wigs can also be obtained for eligible patients. The wig room provides a drop in service please see The Christie leaflet 'The wig fitting service' for further information.

The Maggie's Centre can support you with hair loss by helping you consider the practicalities as well as the emotional impact. Maggie's provides expert care and support to everyone with cancer and those who love them. You can call into Maggie's Monday to Friday, 9am-5pm to speak with their professional team, their address is Maggie's Manchester at The Robert Parfett Building, 15 Kinnaird Road, Manchester, M20 4QL or you can call them on **0161 641 4848** or email manchester@maggies.org.

• Eye irritation

This is a known side effect of the cytarabine at the dose given in this treatment. We will give you eye drops to try to prevent this, but please let your nurse or doctor know if your eyes feel uncomfortable.

• Lethargy/flu-like symptoms

Some chemotherapy may make you feel tired and lacking in energy. It can also cause aching muscles and bones and occasionally high temperatures. It can be frustrating when you feel unable to cope with routine tasks. If you do feel tired, take rest when necessary. Gentle exercise such as walking can be beneficial.

Uncommon side effects (less than 1 in 10)

- **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** is when chemotherapy leaks outside the vein. If you develop redness, soreness or pain at the injection site **at any time** please let us know straightaway.

- **Diarrhoea**

If this becomes a problem during or after your treatment, anti-diarrhoea tablets can be prescribed by your doctor. Ask the staff for a copy of 'Eating: help yourself' which has some useful ideas about diet when you are having treatment.

- **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. We can prescribe a mouthwash for you to use during treatment. You can dilute this with water if your mouth is sore. Ask your doctor or nurse for further advice. There is also general mouth care information in the chemotherapy booklet. If you continue to have a sore mouth, please contact The Christie Hotline.

Occasionally during treatment you may experience a **strange taste**, sometimes described as metallic or bitter. A strongly flavoured sweet or mint will help to disguise this.

- **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, we may need to alter the dose of chemotherapy.

- **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.

Rare side effects (less than 1 in 100)

- **Skin changes**

Sometimes as a result of the chemotherapy, your skin may appear darker in colour or lightly tanned, especially around the joints. This is known as hyperpigmentation. The skin will return to normal when treatment is finished. Some chemotherapy can make your skin more sensitive to the sun than usual. Sit in the shade, avoid too much sun and use a sunblock cream. Dark skinned people may develop noticeable light patches on their skin.

Serious and potentially life threatening side effects

In a small proportion of patients chemotherapy can result in very severe side effects which may rarely result in death. The team caring for you will discuss the risk of these side effects with you.

Sex, contraception and fertility

Protecting your partner and contraception: We recommend that you or your partner use a barrier form of contraception 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 in the vagina. If you suspect that you may be pregnant please tell your doctor immediately.

Fertility: This chemotherapy may affect your ability to have children. Your doctor or nurse should have discussed this with you. If not, please ask them before you start treatment.

Late side effects

Some side effects may become evident only after a number of years. In reaching any decision with you about treatment, the potential benefit you receive from treatment will be weighed against the risks of serious long term side effects to the heart, lungs, kidneys and bone marrow. With some drugs there is also a small but definite risk of developing another cancer. If any of these problems specifically applies to you, the doctor will discuss these with you and note this on your consent form.

Contacts

If you have any general questions or concerns about your treatment, please contact the haematology team.

Haematology nurse specialists	0161 918 7962
Haematology and transplant day unit	0161 446 3924
General enquiries	0161 446 3000
For urgent advice ring The Christie Hotline	0161 446 3658 (24 hours a day, 7 days a week).

Your consultant is:

Your hospital number is:

Your key worker is:

Flu vaccinations

Is it alright for me to have a flu jab during the time I'm having chemotherapy?

It's safe to have a flu jab, but depending on the sort of chemotherapy you have had, it may not give quite as much protection against infection as usual. Some patients may need 2 vaccinations. However, if you're thinking of having any other vaccinations, do check with your Christie doctor first, because some vaccines should be avoided.

COVID-19 vaccinations

We advise that all patients receive a COVID-19 vaccination when this is offered. Your doctor will discuss with you the best time to have this.

Notes:

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If you need information in a different format, such as easy read, large print, BSL, braille, email, SMS text or other communication support, please tell your ward or clinic nurse.

The Christie is committed to producing high quality, evidence based information for patients. Our patient information adheres to the principles and quality statements of the Information Standard. If you would like to have details about the sources used please contact **the-christie.patient.information@nhs.net**

For information and advice visit the cancer information centres at Withington, Oldham, Salford or Macclesfield. Opening times can vary, please check before making a special journey.



Contact The Christie Hotline for
urgent support and specialist advice
The Christie Hotline: 0161 446 3658
Open 24 hours a day, 7 days a week