



# Cytarabine: information for families

This information sheet explains what cytarabine is, how it is given and some of the possible side effects. Each person reacts differently to medicines, so your child will not necessarily suffer from every side effect mentioned. If you have any questions or concerns, please speak to your doctor, nurse or pharmacist.

Please read this in conjunction with any patient information leaflet provided by the manufacturer. However, please note that this information sheet explains about the use of cytarabine in children and young people so may differ from the manufacturer's information.

## What is cytarabine?

Cytarabine is a chemotherapy medicine used to treat certain types of cancer and leukaemia.

## How is it given?

Cytarabine is usually given in one of three ways:

- By a slow injection or infusion into a vein (intravenously or IV) through a cannula, central venous catheter, implantable port or PICC line.
- By injection under the skin (subcutaneously or 'SC').
- By injection through a needle which is inserted into one of the spaces between the bones in the lower back. This is known as a lumbar puncture or intrathecal administration of medicine.

Children may be able receive some of their cytarabine injections at home, given by the community nursing team

## What are the side effects?

The side effects listed below are more common when higher doses of cytarabine are given to your child as an inpatient. If your child is receiving

lower doses of cytarabine as an outpatient, the side effects are likely to be less frequent and less severe.

### Nausea and vomiting

Anti-sickness drugs can be given to reduce or prevent these symptoms. Please tell your doctor or nurse if your child's sickness is very bad or continues for more than a few days.

### Flu-like symptoms

These tend to occur six to twelve hours after the medicine is given. Your child may have headaches and tiredness, aching joints and muscles, a high temperature and chills.

Paracetamol may be given to relieve these symptoms **only** if your child is not neutropenic. However, if your child is having cytarabine at home and has a raised temperature of 38.0°C or above, you should contact your shared care hospital. They should **not** be given paracetamol. If your child complains of hot or cold flushes during the administration of cytarabine they will need a medical review at your shared care hospital.

### **Bone marrow suppression**

There will be a temporary reduction in how well your child's bone marrow works. This means they may become anaemic (reduced red blood cells), bruise or bleed more easily than usual, and have a higher risk of infection.

Your child's blood counts will be checked regularly to see how the bone marrow is working. Please tell your doctor if your child seems unusually tired, has bruising or bleeding, or any signs of infection, especially a high temperature.

### **Conjunctivitis**

Eye inflammation, infection or red eye can occur when high doses of the medicine are given. Eye drops will be given to prevent this.

### **Mouth sores and ulcers**

Your child may get painful or bleeding gums, ulcers or a sore mouth. You will be given advice about appropriate mouth care including a copy of our leaflet. If your child complains of having a sore mouth, please tell your doctor or nurse.

### **Diarrhoea**

If your child has a sore mouth, they will often also have a sore tummy too. This can cause pain and bloating as well as diarrhoea. Please tell your doctor or nurse if your child has diarrhoea which is very bad or continues for more than a few days. It is important that your child drinks lots of fluids.

### **Skin rash**

Cytarabine can cause an itchy rash. Please tell your doctor or nurse if your child develops a rash. They will advise you on the appropriate treatment to use.

### **Lethargy, sleepiness, dizziness and loss of balance**

This is very rare and only occurs when high doses are given. If you notice these effects it is important to report them to your doctor immediately.

### **Hair loss**

Your child may lose some or all of their hair or it may become thinner. This is temporary and the hair will grow back once the treatment is finished.

### **Interactions with other medicines**

Some medicines can react with cytarabine, altering how well it works. Always check with your doctor or pharmacist before giving your child any other medicine, including medicines on prescription from your family doctor (GP), medicines bought from a pharmacy (chemist) or any herbal or complementary medicines.

### **Taking cytarabine syringes home**

Cytarabine is a relatively stable product and short term changes in temperature up to 40°C should not affect the given expiry date. When taking cytarabine syringes home, reduce temperature changes by keeping the syringes out of direct sunlight and keep them in an insulated container if you are travelling a long way. Please discuss this further with nursing staff.

### **Storage of cytarabine at home**

Store the cytarabine inside a plastic container in the bag supplied by the Pharmacy Cytotoxic Unit at GOSH in a normal domestic fridge as soon as you return home.

Keep the box out of the reach of children and away from any food. It must not be frozen. Please remove from the fridge 30 minutes before use to let it reach room temperature.

If the cytarabine syringes are out of the fridge for more than six hours, contact GOSH for advice.

## Accidental spillages

Spillage is unlikely as each cytarabine dose is packaged in a sealed bag. However, if a spillage does occur follow the advice below:

- If contact occurs with your skin, you must wash the area immediately, using plenty of water. If the skin is sore you should contact your GP (family doctor) for advice.
- If contact occurs with your eyes, wash immediately with plenty of water for at least 10 minutes. If your eyes are sore after this, you should go to your nearest Accident and Emergency (A&E) department.
- If you spill any cytotoxic medicines on the work surface or floor, wearing gloves, cover the spillage with kitchen paper. Wipe the area with water then clean with household cleaner and water. Used kitchen paper and other items used to clean up the spillage should be double bagged and disposed of with the household waste.
- If any cytotoxic medicine is spilt on clothing, the spill should be blotted dry with kitchen paper. Clothing should be removed

immediately and washed separately from other items. Used kitchen paper should be disposed of as above.

If any type of spillage occurs you should contact GOSH for advice immediately.

## Important

- Keep all medicines in a safe place where children cannot reach them.
- You should handle this medicine with care, avoiding touching it where possible. If you are pregnant or think you could be pregnant, please discuss handling instructions with your doctor, nurse or pharmacist. Please see our *Special handling requirements* information sheet for further details.
- If you forget to give your child a dose, do not give a double dose. Inform your doctor or nurse and keep to your child's regular schedule.
- If your doctor decides to stop treatment with cytarabine or the medicine passes its expiry date, return any remaining syringes to the pharmacist. Do not flush them down the toilet or throw them away.

## Useful numbers

- GOSH switchboard 020 7405 9200
- Pharmacy medicines information 020 7829 8608 (Monday to Friday from 9am to 5pm)

## Disclaimer

Please read this information sheet from GOSH alongside the patient information leaflet (PIL) provided by the manufacturer. If you do not have a copy of the manufacturer's patient information leaflet please talk to your pharmacist. A few products do not have a marketing authorisation (licence) as a medicine and therefore there is no PIL.

For children in particular, there may be conflicts of information between the manufacturer's patient information leaflet (PIL) and guidance provided by GOSH and other healthcare providers. For example, some manufacturers may recommend, in the patient information leaflet, that a medicine is not given to children aged under 12 years. In most cases, this is because the manufacturer will recruit adults to clinical trials in the first instance and therefore the initial marketing authorisation (licence) only covers adults and older children.

For new medicines, the manufacturer then has to recruit children and newborns into trials (unless the medicine is not going to be used in children and newborns) and subsequently amend the PIL with the approved information. Older medicines may have been used effectively for many years in children without problems but the manufacturer has not been required to collect data and amend the licence. This does not mean that it is unsafe for children and young people to be prescribed such a medicine 'off-licence/off-label'. However, if you are concerned about any conflicts of information, please discuss with your doctor, nurse or pharmacist.