



Fludarabine: information for families

This information sheet explains what fludarabine 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 fludarabine in children and young people so may differ from the manufacturer's information.

What is fludarabine?

Fludarabine is a chemotherapy medicine used to treat certain types of leukaemia such as acute myeloid leukaemia (AML) and bone marrow transplants.

How is it given?

It is given as an infusion into a vein (intravenously or IV) through a cannula, central venous catheter or implantable port.

What are the side effects?

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.

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, bleeding, or any signs of infection, especially a high temperature.

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.

Skin reactions

Your child may have skin rash, redness, inflammation or blistering of skin. These symptoms will disappear once the treatment is finished.

Hair loss

Your child may lose some or all of their hair, including eyebrows and eyelashes. This is temporary and the hair will grow back once the treatment has finished.

Fever and chills

Your child may develop a fever and chills shortly after fludarabine is given. This effect is temporary and paracetamol may be given to relieve these symptoms.

Blurred vision

If your child complains of blurred vision or painful eyes, please inform your doctor or nurse.

Pneumocystis pneumonia

Your child is at risk of developing a type of chest infection called Pneumocystis Jiroveci pneumonia. You may hear the doctors and nurses referring to this as 'PCP' as it was previously called Pneumocystis Carinii pneumonia.

This infection is due to an organism (bug) that is probably present in most people's lungs. Children who are receiving long term drugs which interfere with the body's ability to cope with infections may be more at risk from this type of pneumonia. The symptoms of this infection are a raised temperature, rapid breathing and a dry cough.

Your child should take co-trimoxazole (Septrin®) for the duration of fludarabine treatment and for three months after treatment has finished. If your child has had a bone marrow transplant, treatment with co-trimoxazole will be stopped for the duration of the transplant and re-started as your child's blood counts improve.

Numbness, tingling, aches and pains

This can happen because of the effect of fludarabine on your child's nervous system. Your child may complain of aches and pains in their legs.

Useful numbers

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

If you notice your child has difficulty walking, please tell the doctor. These side effects are temporary and usually wear off a few months after treatment has finished.

In some younger children, their eyelids may droop a little while taking fludarabine. This again is due to the effect on the nervous system.

Swelling

This can be caused by an increase in fluid in the body. If you notice any swelling or puffiness around your child's limbs, especially the ankles, please tell your doctor or nurse.

Interactions with other medicines

Some medicines can interact with fludarabine, 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.

Important

If fludarabine leaks into the tissues underneath your child's skin, they can damage the tissue in this area. This is called extravasation.

- If given through a cannula and your child complains of stinging and burning around the cannula, please tell your doctor or nurse immediately.
- If given through a central venous catheter or implantable port and your child complains of pain around their chest or neck, please tell your doctor or nurse immediately.

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.