Actinomycin D: information for families

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

What is actinomycin D?

Actinomycin D (also known as dactinomycin) is a chemotherapy medicine which is used to treat certain types of cancer.

How is it given?

It is given as an injection 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.

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.

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.

Hair loss

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

Diarrhoea or stomach pain

Please tell your doctor or nurse if your child has diarrhoea or stomach pain which is very bad or continues for more than a few days. It is important that your child drinks lots of fluids.

Inflammatory skin reaction

Sometimes actinomycin D may cause your child's skin to become red and sore in the areas which have recently been treated with radiotherapy.

Changes in liver function

Actinomycin D may change how well your child's liver works. These changes may happen rapidly. Blood tests (LFTs) will be taken to monitor your child's liver function during treatment. Please discuss this with your doctor.

Interactions with other medicines

Some medicines can react with actinomycin D, 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 actinomycin D 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.

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.