Great Ormond Street Hospital for Children NHS Foundation Trust: Information for Families

Nebulised pentamidine

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 pentamidine in children and young people so may differ from the manufacturer's information.

This information sheet explains what pentamidine 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.

What is pentamidine?

Nebulised pentamidine is a medicine given to children to prevent 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 treatment with medicines that 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.

How is it given?

Pentamidine is inhaled via a special nebuliser once a month. Air is blown through the nebuliser via a mouthpiece. If your child is unable to hold a mouthpiece, then a face mask can be used. The process will take about 20 minutes.

What are the side effects?

Strange taste

It is possible that your child may experience a strange taste while using the nebuliser. If this occurs, the nebuliser can be stopped temporarily so that your child can have a drink.

Cough, shortness of breath and wheezing

Please inform your doctor or nurse if your child has a history of wheeziness, asthma or has recently had a cough, cold or high temperature. The doctor will assess your child and may prescribe a different inhaler or nebuliser to open your child's breathing passages before the pentamidine is given, if it is felt necessary.

Nausea and vomiting

Please tell your doctor if your child's sickness is not controlled or persists.

Light-headedness

If this occurs while your child is receiving pentamidine, the nebuliser should be stopped and the doctor informed.

Skin rash

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

Interactions with other medicines

Some medicines can react with pentamidine, 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 information you should know

Pentamidine is possibly harmful to the unborn child, although this has not been proved. The following guidelines for safety are advised:

- Your child will be given nebulised pentamidine in a separate room, away from other children and parents. If given at home, it should be carried out in a well ventilated room with windows open to outside air. It is not advisable for other people to remain in the room during nebulisation, especially if they are pregnant, breastfeeding or planning to become pregnant. You should discuss this with your doctor or nurse.
- If you choose to sit in the room with your child, then you must wear a face mask. Where possible, do not sit your child on your lap because you will breathe the pentamidine in from behind.

If at any point your child needs a rest, the air cylinder should be turned off so pentamidine is not blown into the room. Your doctor or nurse will show you how to do this before your child has the pentamidine.

Useful numbers

GOSH switchboard

020 7405 9200

Pharmacy medicines information 020 7829 8608 (Monday to Friday from 9am to 5pm)

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