

# Thiotepa: information for families

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

## What is thiotepa?

Thiotepa is a chemotherapy medicine used in combination with other drugs for the treatment of certain types of cancer in children. It is also used before bone marrow transplantation or high dose therapy with stem cell rescue to help treat certain types of cancer and metabolic conditions.

## How is thiotepa given?

It is given as an infusion into a vein (intravenously) through a central venous catheter, implantable port or a PICC line in hospital.

## What are the side effects of thiotepa?

### Nausea and vomiting

Anti-sickness drugs will be given to reduce or prevent these symptoms. Please tell your doctor or nurse if your child's sickness is not controlled or persists.

### Bone marrow suppression

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

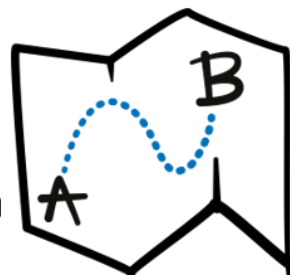
Your child's blood counts will be examined regularly to see how well the bone marrow is working. Please tell your doctor if your child seems unusually tired, has bruising or bleeding, or any signs of infection, especially a high temperature.

### 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 the mouth care 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 have a sore tummy too. This can cause pain and bloating as well as diarrhoea. Please tell the



doctor or nurse if your child has diarrhoea that is not controlled or persists. It is important that your child drinks lots of fluids.

### 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.

### Liver function

Thiotepa can sometimes cause some changes to your child's liver function. This should return to normal when the treatment is finished. Blood tests will be taken to monitor your child's liver function. If you notice that the whites of your child's eyes or their skin becomes yellow, please let your doctor or nurse know immediately.

### Allergic reaction

Some children receiving thiotepa may have an allergic reaction to the drug. This reaction may be mild to severe.

Signs of a **mild** allergic reaction include skin rashes and itching, high temperature, shivering, redness of the face, a feeling of dizziness or a headache. If you see any of these signs, please report them to a doctor or nurse.

Signs of a **severe** allergic reaction include any of the above, as well as shortness of breath or chest pain. If your child shows signs of a severe allergic reaction, call a doctor or nurse immediately.

### Loss of appetite

Your child may 'go off' food and their appetite may be reduced during treatment. The dietitian at the hospital will be able to suggest ways of making food more attractive to your child.

### Tiredness

Your child may feel a bit more tired than usual. If you are concerned please tell your doctor or nurse.

### Skin changes

Thiotepa may cause changes to your child's skin such as an itchy rash or erythema of the palms and soles. A week or two after the infusion, their skin may develop a darker colour than usual and start to flake. This is usually temporary and their skin should return to normal.

### Fertility

Depending on the combination of medicines and the dose that your child is given, their fertility may be affected. If you feel you would like more information, please discuss this with your doctor.

### Secondary cancers

There is a very small risk of your child developing a second cancer after many years. If you would like more information, please discuss this with your doctor.

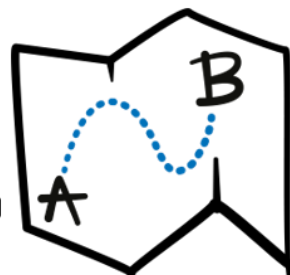
### Interactions with other medicines

Some medicines can interact with thiotepa, 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

Your child's body will get rid of the thiotepa medicine through their skin in sweat so you will need to look after their skin carefully until their blood counts return to normal levels. We advise the following steps to protect your child and yourself:

- Three to four hours after the first dose of thiotepa, your child should have a shower or bath and then twice a day after that. If their skin starts to flake, they should have up to four showers or baths a day. They should pay special attention to washing skin folds, such as the groin, armpits and



neck, as these areas can become sweaty and damp. If your child has a lot of night sweats, you may need to wake them during the night for a shower or wash.

- We suggest using water and a soap-free cleanser in the shower or bath, but make sure it is rinsed off thoroughly. Pat your child's skin dry rather than rubbing to avoid making it sore and make sure you dry skin folds (as above) thoroughly. You should then apply aqueous cream or olive oil over their entire body (especially skin folds) after each bath or shower to stop their skin becoming dry.
- After each shower or bath, your child should wear clean, loose fitting clothes. Bed sheets should also be changed after each shower or bath. Everyone looking

after your child should wear a barrier, either long clothing or a small blanket, to avoid contact with the skin. You should wear gloves before handling your child's clothing and bedlinen.

- Your child should not use any other moisturizer or barrier cream, antiperspirant or deodorant until their blood counts are back to normal levels. They should avoid tight clothing or dressings which could allow sweat to build up as this could increase the effects of the medicine.
- If your child is in nappies, you should change them every two hours at least. Wear gloves for nappy changes and use a warm flannel for cleaning rather than baby wipes.

## 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.

