



# Busulfan: information for families

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

## What is busulfan?

Busulfan is a chemotherapy medicine used before bone marrow transplant or high dose therapy with stem cell rescue to help treat certain types of cancer and metabolic conditions.

## How is it given?

It is given as an infusion into a vein (intravenously or IV) through a central venous catheter, implantable port or PICC. It is usually given either twice a day or four times a day for four days.

## What are the side effects?

### Nausea and vomiting

Anti-sickness drugs can be given to reduce or prevent these symptoms, although this may not be allowed in some treatment protocols. 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.

### Diarrhoea or stomach pain

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 very bad or continues for more than a few days. 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.

### **Skin discolouration**

Busulfan may cause your child's skin to develop a darker colour. This is usually temporary and should disappear once treatment has finished.

### **Changes in liver function**

Busulfan can sometimes cause significant changes to how well your child's liver works. This should return to normal when the treatment is finished.

Blood tests (LFTs) will be taken to monitor your child's liver function and their weight and tummy measurement will be recorded.

If you notice the whites of your child's eyes or their skin becoming yellow, please let your doctor or nurse know immediately.

### **Lung problems**

Busulfan may cause changes to the lung function. If your child develops a cough, has difficulty breathing or chest pain, please tell your doctor or nurse immediately

### **Fits or seizures**

There is a small risk that your child may have a fit or seizure during busulfan treatment. If your child is thought to be at risk, medicine will be given to help stop this from happening.

## **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

## **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 busulfan, 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 these medicines leak 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.

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.