

# Temozolomide: information for families

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**This information sheet explains what temozolomide 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.**

This information sheet should be read in conjunction with any information provided by the manufacturer. However, please note that this information sheet explains about the use of temozolomide in children and young people so may differ from the manufacturer's information.

## What is temozolomide?

Temozolomide is a chemotherapy drug used to treat certain types of cancer.

## How is it given?

Temozolomide is given by mouth in the form of capsules, which are available in different strengths. You may be given a combination of different strengths of capsule in order to get the correct dose for your child.

Temozolomide should be taken once a day one hour before breakfast on an empty stomach with plenty of water.

Temozolomide is usually given for five days followed by a break of 23 days. This 28-day course is usually repeated, however if your child is having treatment such as radiotherapy they may be on a different treatment schedule.

## What are the side effects?

### Nausea and vomiting

Anti-sickness medicines can be given to reduce or prevent these symptoms. Please tell your doctor

or nurse if your child's sickness is very bad or lasts for more than a few days.

If your child has been prescribed anti-sickness medicine, they should have a dose 30 minutes before each dose of temozolomide.

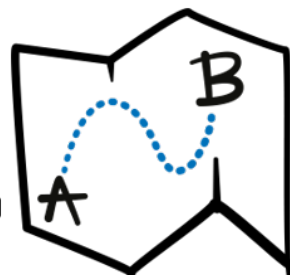
### Hair loss

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

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



## Loss of appetite

Your child may 'go off' food and their appetite may reduce 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.

## Constipation or diarrhoea

Please tell your doctor or nurse if your child has constipation or diarrhoea that is very bad or lasts for more than a few days.

## Pneumocystis pneumonia

Your child may be at risk of developing a particular chest infection if he or she is on a long course of temozolomide with radiotherapy or is having steroid and temozolomide treatment. This infection is called Pneumocystis Jiroveci pneumonia. You may hear the doctors and nurses referring to this as PCP as the infection 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 medicines that interfere with the body's ability to cope with infections may be at risk from this type of pneumonia. The symptoms of this infection are a raised temperature, rapid breathing and a dry cough. Your child may be given a medicine called co-trimoxazole (Septrin®) to help prevent PCP.

## Allergic reaction

Some children receiving temozolomide 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 you are in hospital and your child shows signs of a severe allergic reaction, call a doctor or nurse immediately. If you are at home and your child shows signs of a severe allergic reaction, call an ambulance immediately.

## Changes in liver function

Temozolomide may change how well your child's liver works. Blood tests (LFTs) will be taken to monitor your child's liver function during treatment. Please contact your doctor immediately if your child complains of pain in their right side or the whites of their eyes or their skin develops a yellow tinge.

## Interactions with other medicines

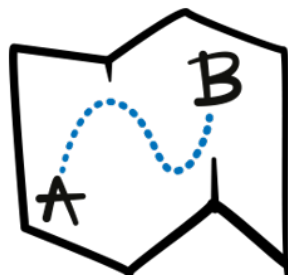
Some medicines can react with temozolomide, altering how well it works. Always check with your doctor or pharmacist before giving your child any other medicine, including medicines on prescription from your family doctor (GP), medicines bought from a pharmacy (chemist) or any herbal or complementary medicines.

## Making temozolomide into a mixture to give at home

You should prepare the mixture on a clean, clear working surface in a quiet room with the door closed.

You will need:

- Antisickness medicine (if prescribed)
- Temozolomide capsules
- Gloves, apron, mask
- Kitchen paper
- Medicine cup, medicine spoon, oral syringe
- Apple juice or apple sauce



- Plastic bags
  - Sharps bin
1. If prescribed, give a dose of anti-sickness medicine 30 minutes before each dose of temozolomide.
  2. Put on the gloves, apron and mask provided.
  3. Place some kitchen paper on the work surface; place a medicine cup containing 3 to 5ml of apple juice or apple sauce, a medicine spoon and an oral syringe on the kitchen towel.
  4. Check all the information on the medicine is correct for your child and that you understand the dose and the number of capsules to be given.
    - For example, a dose of 160mg is made up of 1 x 100mg capsule and 3 x 20mg capsules.
  5. Open the medicine bottle and place the capsules for the required dose on the kitchen towel. If the temozolomide looks different to usual – DO NOT USE – contact the ward or medicines information.
  6. Working over the medicine cup, hold the capsule by each end gently twisting and pulling the capsule open before emptying the contents into the medicine cup. Take care not to inhale any powder.
  7. Repeat step 6 for each capsule.
  8. Carefully mix the powder into the juice using the oral syringe and then draw up all the liquid into the oral syringe.
  9. Place the syringe into the side of your child's mouth and slowly push the plunger. If preferred your child can drink the liquid directly from the medicine cup.
  10. If you are using apple sauce, mix the powder with the sauce thoroughly and feed it to your child using the medicine spoon.
  11. Add some more apple juice or apple sauce to the medicine cup and mix. Give to your

child. Repeat if necessary to ensure the entire dose has been given.

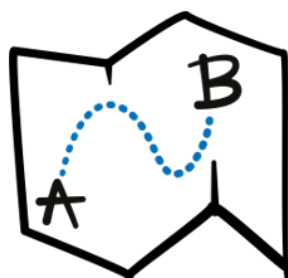
12. Wrap the empty capsules, all the utensils, gloves, mask and apron in the kitchen paper, seal in a plastic bag and put in the sharps bin.
13. Return to hospital for disposal as cytotoxic waste after completion of each course.
14. Wash hands thoroughly with soap and water
15. Food should not be eaten until at least one hour after the temozolomide dose.

## Accidental spillages

- If contact occurs with your skin, you must wash the area immediately, using plenty of water. If the skin is sore you should contact your GP (family doctor) for advice.
- If contact occurs with your eyes, wash immediately with plenty of water for at least ten minutes. If after this your eyes are sore you should go to your nearest Accident and Emergency (A+E) department.
- If you spill these medicines on the work surface or floor, wearing gloves, cover the spillage with kitchen paper. Wipe the area with water then clean with household cleaner and water. Used kitchen paper and other items used to clean up the spillage should be double bagged and disposed of with the household waste.
- If any of the medicine is spilt on clothing, the spill should be blotted dry with kitchen paper. Clothing should be removed immediately and washed separately from other items. Used kitchen paper should be disposed of as above.

## Important

- Keep all medicines and tablets in a safe place where children cannot reach them.



- Temozolomide should be kept in their original container in a cool, dry place away from direct sunlight or heat.
- You should handle these medicines with care, avoiding touching them where possible. If you are pregnant or think you could be pregnant, please discuss handling instructions with your doctor, nurse or pharmacist.
- If your child vomits after taking the dose, inform the doctor or nurse. Do not give them another dose.
- If you forget to give your child their dose, do not give them a double dose. Inform your doctor or nurse and keep to your child's regular schedule.
- Vomit and dirty disposable nappies should be placed inside two rubbish bags and disposed of along with your normal rubbish.
- If the doctor decides to stop treatment, return any remaining capsules to the pharmacist. Do not flush or throw them away.

## 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.

