



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

# Temozolomide

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.

**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.**

### What is temozolomide?

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

### How is it given?

Temozolomide (brand name Temodal®) 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 21 days at a time followed by a seven day break. It can also be 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 he or she may be on a different treatment schedule.



### 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 not controlled or persists. If your child has been prescribed anti-sickness medicine, he or she should have a dose 30 minutes before each dose of temozolomide.
- **Hair loss:** Your child may lose some or all of his or her 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 he or she may become anaemic, 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 his or her 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 not controlled or persists.
- **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.

- **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.

## 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.





## Important information you should know about temozolamide

- Keep all medicines and tablets in a safe place where children cannot reach them.
- Temozolamide 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.
- If your child cannot swallow the temozolamide capsules, you can make them into a mixture as follows
- You will need:
  - Antisickness medicine (if prescribed)
  - Temozolamide capsules
  - Gloves, apron, mask
  - Kitchen towel
  - Medicine cup, medicine spoon, oral syringe
  - Fruit juice (not grapefruit) or apple sauce
  - Plastic bags
  - Sharps bin



- This procedure should be carried out on a clean, clear working surface in a quiet room with the door closed.
  1. If prescribed, give a dose of anti-sickness medicine 30 minutes before each dose of temozolamide.
  2. Put on the gloves, apron and mask provided.
  3. Place some kitchen towel on the work surface; place a medicine cup containing 3 to 5ml of fruit 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 Temozolamide 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 back 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 fruit 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 towel, 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.
- If you accidentally spill the mixture, wash the area thoroughly with plenty of water.
  - If the mixture accidentally gets into your eyes, wash with plenty of running water for 10 minutes.
  - 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.

#### Notes

#### Useful telephone numbers

GOS switchboard:	020 7405 9200
Pharmacy Department:	020 7829 8680
Pharmacy Medicines Information:	020 7829 8608

Compiled by the Pharmacy department in collaboration with the Child and Family Information Group

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[www.goshfamilies.nhs.uk](http://www.goshfamilies.nhs.uk)

[www.childrenfirst.nhs.uk](http://www.childrenfirst.nhs.uk)

