This factsheet provides information on the use of temozolomide in children and young people with cancer. Please read this factsheet carefully alongside any patient information provided by the manufacturer. Keep it somewhere safe so you can read it again.

For most medicines, information is provided by the manufacturer in the medicine package. However, this does not always tell you everything you need to know about the use of this medicine in children and young people. We have written this factsheet to give you some extra information.

What is temozolomide?
Temozolomide is a chemotherapy medicine used to treat certain types of cancers.

What preparations of temozolomide are available?
Temozolomide is available as 5mg, 20mg, 100mg, 140mg, 180mg and 250mg capsules. A liquid preparation may be available in some hospitals.

Where can I get temozolomide from?
Temozolomide must only be obtained from the hospital at which you/your child is being treated. Please remember to bring all medication with you at each hospital visit.

How is temozolomide given?
Temozolomide is given by mouth once a day. Temozolomide must not be given with food, give at least 1 hour before food or 2 hours after food. Instructions will be on the label or on the patient dosing information chart. The capsules should be swallowed whole with plenty of water or apple juice. Do not break, crush or chew the capsules. If your child is having nasogastric feeds (NG feeds), then the administration of temozolomide can be timed around their feeds. The nursing team or pharmacist at your hospital will be able to advise you on this. A dose of anti-sickness medicine should be given 30 minutes before each temozolomide dose.

The information below on how to give oral temozolomide is for patients that are unable to swallow the temozolomide capsules.

How to give oral temozolomide:
For each dose you will need
- Anti-sickness medicine
- A pair of non-sterile, disposable gloves
- Apron and mask
- Kitchen towel
- Medicine cup/medicine spoon, oral syringe
• Correct dose of temozolomide
• Apple juice or apple sauce
• Sealable plastic bag
• A cytotoxic sharps bin available from the hospital or shared care centre at which your child is being treated

Please follow the instructions below:

• Put on the gloves, apron and mask
• Place some kitchen towel on the work surface, then place a medicine cup containing 3 to 5mls of apple juice or apple sauce, a medicine spoon and an oral syringe on the kitchen towel
• Check all the information on the medicine is correct for your child and that you understand the dose that is to be given, for example, temozolomide 160mg = (1x100mg) + (3x20mg) capsules
• Open the medicine bottle(s) and place the capsules for the required dose on the kitchen towel
• Working over the medicine cup hold the capsule by each end and gently twist and pull the capsule open emptying the contents into the medicine cup. Do this for each capsule.
• Take care not to inhale any powder

If using apple juice:
• Carefully mix the powder into the apple juice with the medicine spoon, then draw up all the liquid into the oral syringe
• Place the syringe into the back of the mouth and slowly push the plunger. If preferred your child can drink the liquid directly from the medicine cup.
• Add some more apple juice to the medicine cup and mix with the spoon. Repeat if necessary to ensure the full dose has been given.
• Please ensure all the apple juice containing the temozolomide is given and no liquid is left in the medicine cup

If using apple sauce:
• Carefully mix the powder into the apple sauce with the medicine spoon, then use the medicine spoon to give your child the full dose
• Add some more apple sauce to the medicine cup and mix with the spoon. Repeat if necessary to ensure the full dose has been given.
• Please ensure all of the apple sauce containing the temozolomide is given and that no apple sauce is left in the medicine cup

Wrap all the utensils and gloves in the kitchen towel, seal in a plastic bag and place in the cytotoxic sharps bin. Wash hands thoroughly with soap and water.

Food should not be eaten until at least 1 hour after the temozolomide dose has been given.

When not in use, the cytotoxic sharps bin must be closed, (but not sealed) and stored out of reach of children.

When each course is finished, or the cytotoxic sharps bin is two thirds full, the sharps bin should be sealed.

At the next hospital visit please RETURN the sharps bin to the hospital or shared care at which you/your child is being treated.

Are there any possible side effects?

It is important to remember that everyone reacts differently to chemotherapy. Some will have very few side effects whilst others will have more. The side effects listed below will not affect everyone who is given temozolomide and may be different if more than one chemotherapy drug is given.

What are the common side effects?

Reduced bone marrow function
Blood counts will be checked regularly to see how the bone marrow is working. A low neutrophil count can make you/your child more at risk of infection. A low haemoglobin count indicates anaemia which may make you/your child unusually tired and a low platelet count may cause bruising or bleeding.

Please contact the hospital at which you/your child is being treated if there are signs of any infection, especially a high temperature or if they show signs of unusual tiredness, bruising or bleeding.

Diarrhoea
If diarrhoea is severe or continuous, contact the hospital at which you/your child is being treated.

Nausea (feeling sick) and vomiting (being sick)
Anti-sickness drugs can be given to prevent or reduce these symptoms. Anti-sickness medicine should be taken 30 minute before each dose of temozolomide. Please contact the hospital at which you/your child is being treated, if sickness is not controlled.

Headaches
Contact the hospital at which you/your child is being treated if headaches develop.
Constipation
This can usually be relieved by drinking plenty of fluids, and eating a high fibre diet. Sometimes medicines (laxatives) may be needed to stimulate the bowel.

Taste changes
Food may taste different. Normal taste will usually come back after the treatment finishes.

Rashes
Temozolomide can cause a rash which may be itchy. If this happens contact the hospital or shared care centre at which you/your child is being treated.

What are the less common side effects?

Hair loss
Some or all hair may be lost, including eyebrows and eyelashes. This is temporary and the hair will grow back once the treatment is finished. Hair loss could be permanent if taking temozolomide alongside a course of radiotherapy.

Dizziness
If this happens contact the hospital at which you/your child is being treated for advice.

Shortness of breath
Contact the hospital at which you/your child is being treated immediately if breathlessness develops when on temozolomide.

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

Which tests/investigations may take place before, during or after treatment with temozolomide?

Full blood count
A full blood count will be done regularly at your hospital or by your community team. The dose of temozolomide may need to be adjusted according to the result. The new dose will be recorded on the label or on the patient dosing information chart.

How should the medicine be handled and stored?

- Keep out of reach and sight of children
- Store capsules at room temperature
- Keep out of direct sunlight
- Always handle these medicines with care. Handle as little as possible and always wear gloves.
- If you are pregnant or think you could be pregnant, please discuss handling instructions with your doctor, nurse or pharmacist

Is there anything else I should know about or do?

Contact the hospital at which you/your child is being treated if:

- A dose of temozolomide is forgotten
- Vomiting occurs after taking the dose
- Too much temozolomide is given

Does temozolomide interact with any other medicines?

Some medicines can affect how well temozolomide works. Always tell the prescriber about any other medication that is being taken. Make sure and check with the doctor or pharmacist before taking any other medicines. This includes supplements, herbal and complementary medicines.

Any temozolomide that has not been given, or is out of date, must be returned to the hospital at which you/your child is being treated.

Do not throw away at home.
If you have any questions about temozolomide please contact the hospital at which you/your child is being treated. This factsheet only gives general information.

You must always discuss individual treatment with the appropriate member of staff. Do not rely on this factsheet alone for information about treatment. Further information is available on the following websites. This information may not include advice on use in children or young people.

- xpil.medicines.org.uk
- www.macmillan.org.uk

Important contact numbers:

- [Insert contact numbers here]

This factsheet was written by Judith Delaney (formerly Lead Pharmacist at Great Ormond Street Hospital in London and past Chair of the CCLG Pharmacy Group) and Anna Kinsella (Advanced Clinical Pharmacist in Paediatrics at Leeds General Infirmary) in conjunction with the CCLG Publications Committee, comprising multiprofessional experts in the field of children’s cancer.

CCLG makes every effort to ensure that information provided is accurate and up-to-date at the time of printing. We do not accept responsibility for information provided by third parties, including those referred to or signposted to in this publication. Information in the publication should be used to supplement appropriate professional or other advice specific to your circumstances.

Publication of this factsheet was funded by CCLG.

© CCLG 2016

Published by CCLG December 2016
Next review date: December 2019