



Oral temozolomide for children and young people

An information guide for patients, parents and carers

The purpose of this guide is to give information on the use of temozolomide in children and young people with cancer.

Please read this guide carefully alongside any patient information provided by the manufacturer. We have written this guide to give you more information about the use of this medicine in children and young people. Keep it somewhere safe so you can read it again.

What is temozolomide?

Temozolomide is a chemotherapy medicine commonly used in the treatment of certain types of cancer.

What preparations of temozolomide are available?

Temozolomide is available as 5mg, 20mg, 100mg, 140mg, 180mg and 250mg capsules. A liquid preparation may be available at some hospitals.

Where can I get temozolomide from?

You must only get temozolomide from your treating hospital. Please remember to bring all medication with you to each hospital visit.

How is temozolomide given?

Temozolomide is given by mouth once a day. It must not be given with food. Give at least one hour before food or two 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 or crush or chew the capsules. If nasogastric (NG) feeds are being given, then the administration of temozolomide can be timed around the feeds. Your hospital or shared care centre will be able to advise you on this. A dose of anti-sickness medicine should be given 30 minutes before each temozolomide dose.

How to give oral temozolomide if you/your child is unable to swallow whole capsules

For each dose you will need:

- anti-sickness medicine
- a pair of non-sterile disposable gloves
- apron and mask
- kitchen towel
- medicine cup and spoon
- oral syringe
- correct dose of temozolomide
- apple juice or apple sauce
- sealable plastic bag
- cytotoxic sharps bin (available from your hospital or shared care centre)

Follow the instructions below:

1. Put on the gloves, apron and mask.
2. Place some kitchen towel on the work surface.
3. Place a medicine cup containing 3ml to 5ml of apple juice or apple sauce, a medicine spoon and an oral syringe on to the towel.
4. Check all the information on the medicine is correct and that you understand the dose that is to be given, for example, a 160mg dose of temozolomide would be ONE 100mg capsule plus THREE 20mg capsules.
5. Open the packaging and place all of the capsules needed on the kitchen towel.
6. Working over the medicine cup, hold a capsule by each end and gently twist and pull the capsule open, emptying the contents into the medicine cup. Take care not to inhale any powder.
7. Repeat this for each capsule.

If using apple juice:

1. Carefully mix the powder into the apple juice with the medicine spoon.
2. Draw up all the liquid into the oral syringe.
3. Place the tip of the oral syringe into the mouth near to the inside surface of the cheek.
4. Gently push the plunger to give small amounts of the liquid into the side of the mouth.
5. If preferred, the liquid can be drunk directly from the medicine cup.
6. Add some more apple juice to the medicine cup and mix with the spoon.
7. Repeat if necessary to ensure the full dose has been given and no liquid containing temozolomide is left in the cup.

If using apple sauce:

1. Carefully mix the powder into the apple sauce with the medicine spoon.
2. Use the spoon to give the full dose.
3. Add some more apple sauce to the medicine cup and mix with the spoon.
4. Repeat if necessary to ensure the full dose has been given and no apple sauce containing temozolomide is left in the 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 one 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 bin is two thirds full, the sharps bin should be sealed. At the next visit, please RETURN the sharps bin to your hospital or shared care centre.

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 increase your/your child's risk of infection. A low haemoglobin count indicates anaemia which may cause unusual tiredness and a low platelet count may cause bruising or bleeding.

Please contact your hospital team if there are any signs of infection, especially a high temperature or unusual tiredness, bruising or bleeding.

Diarrhoea

If diarrhoea is severe or continuous, contact your hospital team for advice.

Headaches

If headaches develop, contact your hospital team.

Nausea (feeling sick) and vomiting (being sick)

If this occurs it is usually mild. Anti-sickness medicines can be given to reduce or prevent these symptoms. Anti-sickness medicine should be taken 30 minutes before each dose of temozolomide. Please contact your team if sickness is not controlled.

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.

Hair loss

Temozolomide may cause some or all hair to fall out, including eyebrows and eyelashes. This is temporary and hair will grow back when treatment has finished. Hair loss could be permanent if taking temozolomide alongside a course of radiotherapy.

Taste changes

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

Rashes

Temozolomide can cause a rash which may be itchy. If this happens, contact your hospital team for advice.

What are the less common side effects?**Dizziness**

If feelings of dizziness happen, contact your hospital team for advice.

Shortness of breath

Contact your hospital team immediately if breathlessness develops whilst taking temozolomide.

Is there anything else I should know about or do?

Contact your treating hospital if:

- a dose of temozolomide is forgotten
- vomiting occurs after taking the dose
- too much temozolomide is given

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.

Does temozolomide interact with any other medicines?

Some medicines can affect how well temozolomide works. Always tell the doctor about any other medication being taken. Check with your doctor or pharmacist

before taking any other medicines. This includes supplements and herbal or complementary medicines.

How should the medicine be handled and stored?

- always handle medicines with care
- keep in a safe place, out of reach and sight of children
- store the capsules at room temperature
- keep out of direct sunlight
- handle as little as possible and always wear gloves
- if you are pregnant or think you could be pregnant, discuss handling instructions with your doctor, nurse or pharmacist

Any temozolomide that has not been given, or is out of date, must be returned to your treating hospital. **Do not throw away at home.**

Please read the CCLG factsheet – ‘Safe handling of chemotherapy medicines’

Pregnancy

If you are sexually active while taking anti-cancer drugs or medicines, it is important to use contraception such as condoms, the pill or coil to avoid pregnancy. You may need to take a pregnancy test to confirm you are not pregnant before taking this medicine. Contraception should continue for a while after treatment finishes. Your team will advise how long you should continue using contraception.

Fertility

Depending on the type, dose and combination of medicines given during your treatment, it is possible that fertility may be affected. For girls, this means that it may be harder for them to become pregnant in the future. For boys, this may mean that their sperm is less fertile which can affect their chance of having children in the future. If you would like more information about this, please discuss with your medical team.

If you have any questions about temozolomide, please contact your treating hospital. This guide only gives general information.

Always discuss individual treatment with your medical team. Do not rely on this guide alone for information about treatment.

i USEFUL ORGANISATIONS

Children's Cancer and Leukaemia Group (CCLG) publishes a variety of free resources to order or download. www.cclg.org.uk

Young Lives vs Cancer offers practical support to children and young people with cancer and to their families. www.younglivesvscancer.org.uk

Macmillan Cancer Support offers support and advice to those affected by cancer. www.macmillan.org.uk

EMC (Electronic Medicines Compendium) offers up-to-date, approved and regulated information for licensed medicines. www.medicines.org.uk



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With thanks to Tasneem Khalid, Senior Oncology Pharmacist, The Christie, Manchester, and the Neonatal and Paediatric Pharmacists Group (NPPG) Paediatric Oncology Pharmacists Steering Committee who reviewed this factsheet on behalf of the CCLG Information Advisory Group, comprising parents, survivors and multi-professional experts in the field of children's cancer.

Children's Cancer and Leukaemia Group (CCLG) is a leading national charity and expert voice for all childhood cancers.

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Registered charity in England and Wales (1182637) and Scotland (SC049948).

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This edition: July 2024
Next review date: July 2027



Each week in the UK and Ireland, more than 30 children are diagnosed with cancer. Our network of dedicated professional members work together in treatment, care and research to help shape a future where all children with cancer survive and live happy, healthy and independent lives.

We fund and support innovative world-class research and collaborate, both nationally and internationally, to drive forward improvements in childhood cancer. Our award-winning information resources help lessen the anxiety, stress and loneliness commonly felt by families, giving support throughout the cancer journey.

Publication of this factsheet was funded by CCLG. If you would like to help, text 'CCLG' to 70085 to donate £3. You may be charged for one text message at your network's standard or charity rate. CCLG (registered charity numbers 1182637 and SC049948) will receive 100% of your donation.

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