

Temozolomide Chemotherapy - instructions for taking during your radiotherapy for a primary brain tumour

Information for patients



This information is for patients who are going to have radiotherapy and chemotherapy for a primary brain tumour.

Your consultant or nurse specialist should be your first contact for information. If you are not sure about any information given about your treatment, please contact your consultant or nurse specialist. Please see contact details on page 10.

This leaflet will explain:

- What Temozolomide is and what it does.
- What the treatment involves.
- How to take the capsules.
- The most common side-effects you may have.
- Other medicines.
- Frequently asked questions.
- Who to contact when you need advice.

What is Temozolomide?

Temozolomide is a chemotherapy drug. Chemotherapy affects cell growth, especially in cells that are growing rapidly such as cancer cells. Temozolomide works with your radiotherapy treatment and is taken by mouth as a capsule (or capsules). You will take the capsule(s) yourself at home for the six weeks of your radiotherapy. You will need a blood test every week and will see your consultant or nurse specialist.

Your treatment is given in two stages:

Stage one

You will take Temozolomide once every day, seven days a week, even though radiotherapy is only given five days a week. This will last for six weeks. Following this you will have a four week rest period.

Stage two

Your chemotherapy will now be given to you in a 28 day cycle. This means you will take the capsules as prescribed by your consultant for five days, followed by a break for 23 days, before starting your next cycle. You may have up to six cycles in total. This will be explained to you by your consultant in clinic and will depend on your progress and how well you cope with the treatment.

What medicine will I be given?

Temozolomide - Chemotherapy, enough to last you until your next review appointment.

Co-Trimoxazole - Antibiotic, medicine to fight infections.

Ondansetron - Anti-sickness (a strong anti-sickness medicine for the first few days of chemotherapy).

Metoclopramide - Anti-sickness (to be taken if needed after the first few days of Ondansetron).

You may also be taking Dexamethasone (steroid). You will be advised on the dose of Dexamethasone you need. Please note this dose may change during your treatment.

You may already be taking other medications before your diagnosis. These may have been prescribed by your GP.

It is important that you inform your consultant of any medications that you are taking. Do not stop any medications without medical advice.

Stage one

Temozolomide and radiotherapy

You will start taking your Temozolomide on the first day of your radiotherapy. You will take Temozolomide once every day, seven days a week, even though radiotherapy is only given five days a week. This will last for six weeks and includes weekends and bank holidays.

During your radiotherapy Temozolomide should be taken:

- About one hour before your radiotherapy treatment time. This is to allow time for the drug to be absorbed. Please do not worry if your radiotherapy has been delayed for over one hour. As long as the drugs are taken 1-3 hours before your radiotherapy it will be all right.
- Please take your capsule(s) on an empty stomach. This may help to reduce any feelings of sickness and helps to make sure it is absorbed quickly. To make sure your stomach is empty do not eat anything for 3-4 hours before taking your capsules. Try to only have a light meal before this time. If you are worried about how you are going to plan this, especially if you are diabetic, then please speak to your consultant, nurse specialist or radiographer for advice.

- We will work out how many capsules you will need each day by using your height and weight. If your dose is not available as one capsule you may need to take more than one capsule from different bottles . Please check before taking your capsules to make sure the correct dose is taken. The capsules should be taken with a full glass of water.

- **Never chew the capsule(s).**
- **Always swallow it whole.**
- **Do not open or split the capsule(s).**



Every Wednesday you will have a blood test. You do not have to wait for the results. You will see your consultant or nurse specialist the following day in clinic. They will check your blood results and see how you are feeling before prescribing your chemotherapy for the following week.

Your chemotherapy will be given to you each week from the hospital pharmacy.

Following your six weeks of radiotherapy and chemotherapy you will have a four week rest period. After your four week rest you will be seen at a chemotherapy outpatient clinic. Before seeing your doctor you will have a blood test. You will be seen by your doctor, who will check to see how you are feeling and discuss any side-effects from the radiotherapy and chemotherapy. Your doctor will discuss with you any further treatment.

Stage two

For stage two you will take the Temozolomide capsules for five days followed by a break for 23 days, in total a 28 day cycle.

Stage two of your treatment is chemotherapy only

Day 1-5 take
Temozolomide

Day 6 - 28 break from chemotherapy
(Do not take Temozolomide)

At the end of this cycle you will be seen again in an outpatient clinic. You will again have a blood test and see your doctor, who will prescribe your next cycle of chemotherapy if you are well enough.

Stage two can be repeated once every four weeks for six months. This will depend on your blood results, how well you cope with any side-effects you may have and your general health. Please refer to the previous information in this leaflet on how to take your capsule, as this advice still applies.

Remember

- **Never chew the capsule(s).**
- **Always swallow it whole.**
- **Do not open or split the capsule(s).**



The most common side-effects

Nausea and vomiting

You may feel sick (nausea) or vomit while you are on your treatment. For most patients, this can be eased with medication. You will be given anti-sickness medicine when you start your treatment for both stage one and stage two. We advise you take these as prescribed to try to control any nausea and vomiting. If you need more advice please speak to your consultant, nurse specialist or radiographer.

If you are still feeling sick, even when you take the anti-sickness capsules please talk to a member of staff. This can be at your next appointment if you are coming every day or you can call the 24 hour contact numbers in your chemotherapy booklet.

Low blood counts

Chemotherapy may slow down the production of your blood cells, but this is temporary. You will have a regular blood test, called a Full Blood Count (FBC), to make sure that you have enough healthy blood cells.

The bone marrow is the part of the body where blood cells are made. Red blood cells give you energy, white blood cells fight infections and platelets help the blood clot, to prevent bleeding. If your blood count is too low you may experience some of the problems below:

- **Low red cells (anaemia)** – cause you to become tired and short of breath.
- **Low white cells** – increase your risk of infection.
- **Low platelets** – can cause unusual bruising or bleeding.

To try and reduce the risk of infection we will prescribe a daily antibiotic medicine (Co-Trimoxazole). You will need to take this every day during your radiotherapy and chemotherapy (stage one). *You do not take the antibiotic during stage two (chemotherapy alone).*

Antibiotics can reduce the risk of infections but you should still be aware of the following:

- High temperature or fever, feeling hot or cold, shivery or feel unwell. Please check your temperature with a thermometer (a normal temperature is 37°C or 98.4°F). If your temperature is 38°C (100°F) or higher, please ring the hospital team immediately.
- Feeling very unwell or having symptoms of infection, even if you don't have a temperature, please ring the hospital team immediately.

If you have any of the above symptoms or are feeling seriously unwell please contact:

St James's University Hospital (0113) 243 3144 and ask for the Oncology Patient Enquiries Bleepholder.

- Sometimes this antibiotic can cause a rash.

Tiredness (fatigue)

It is common to feel tired during radiotherapy and chemotherapy and for several months after treatment is finished. There is an information leaflet available about *'Coping with Fatigue'*. Please ask your nurse or doctor for further information.

Less common side-effects

- Taste changes
- Constipation
- Rash

Please see your radiotherapy booklet for further side-effects caused by radiotherapy.

Frequently asked questions

What should I do if I miss a dose of chemotherapy?

Take the missed dose as soon as possible during the same day. If this is during your radiotherapy treatment please tell the radiographer as soon as you arrive. If a full day has passed check with your doctor or specialist nurse on the telephone number provided. Do not double the dose unless you are advised to do so by your hospital medical team.

What should I do if I am sick after a dose?

Contact Bexley Wing (using the 24 hour number in your chemotherapy booklet) for advice. Do not take any more capsules without advice from your medical team .

If I am diabetic when should I take my medication?

Please discuss this with your consultant or nurse specialist.

How should I store my Temozolomide?

Store it in a cool dry place out of reach of children and pets. Do not store above 25°C (77°F).

Telephone for advice if:

- Your temperature rises above 38°C (100.4°F) as this could mean you have an infection.
- You have any bruising or bleeding that you cannot explain.
- You feel tired or short of breath, as this may mean that you are anaemic.
- You feel unwell generally and require advice.

If you have any of the above symptoms or are feeling seriously unwell please contact:

St James's University Hospital (0113) 243 3144 and ask for the Oncology Patient Enquiries Bleepholder.

Please look in your information folder for any further advice about your chemotherapy or radiotherapy.

Who to contact

For any non-urgent advice or concerns during your treatment, please contact your nurse specialist who is also your keyworker.

Your keyworkers are available Monday-Friday:

Gill Boyer (0113) 206 7772

Sarah Peace (0113) 206 8568

Lianne O'Malley (0113) 206 8830

This may be an answer machine. If it is, we will return your call but this may not be the same day. If the problem is more urgent then use the 24 hour number above.

Leeds Cancer Support

Leeds Cancer Support complements care provided by your clinical team. We offer access to information and a wide range of support, in a welcoming environment for you, your family and friends.

We can be found in the information lounges in Bexley Wing and also in the purpose built Sir Robert Ogden Macmillan Centre.

The Sir Robert Ogden Macmillan Centre

The centre is on the St James's Hospital site and offers a variety of support services including counselling, support groups and complementary therapies. These therapies include Reiki, relaxation and visualisation, hand and foot massage and many others. You can just drop in for a coffee and a chat anytime. Open from 10am - 4pm Monday to Friday.

Information Centre Level 1 Outpatients Department

Open from 10am - 4pm. Tel: (0113) 206 8816

Information Lounge Level -2 Radiotherapy Department

Open from 8.30am - 6.00pm. Tel: (0113) 206 7603

Sir Robert Ogden Macmillan Centre

Open from 10am - 4pm. Tel: (0113) 206 6498

All the above services can be emailed on:

[*leedsth-tr.Cancersupport@nhs.net*](mailto:leedsth-tr.Cancersupport@nhs.net)



What did you think of your care?

Scan the QR code or visit bit.ly/nhsleedsfft

Your views matter



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