



Temozolomide (oral) with concurrent radiotherapy to the brain

This leaflet is offered as a guide to you and your family. You will find it useful to refer to the following booklets:

Chemotherapy: a guide which gives general information on chemotherapy and side effects.

Radiotherapy for brain tumours – a guide for patients and their carers which gives general information on radiotherapy to the brain and side effects.

The possible benefits of treatment vary: for some people chemotherapy and radiotherapy may reduce the risk of the cancer coming back, for others the treatment may control the cancer and its symptoms. Your treatment will be fully explained by your doctor, nurse or specialist radiographer, who will be happy to answer any questions.

Your treatment

Your doctor has prescribed a course of treatment with Temozolomide and radiotherapy.

There may be two parts to your treatment. Temozolomide is initially taken for six weeks alongside radiotherapy. This will be followed by a four-week break after which you will attend a follow-up appointment where your doctor will discuss with you whether to treat you with further Temozolomide.

Part 1: A six week course of Temozolomide and radiotherapy

- Radiotherapy is given daily Monday to Friday but not at weekends.
- You should take the Temozolomide once daily before radiotherapy for 42 continuous days (six weeks) **including weekends** when you do not have radiotherapy. Your total daily Temozolomide dose may be made up of several Temozolomide tablets of different strengths. If you are unsure about how to take your tablets, please ask your pharmacist or specialist radiographer.

You will be prescribed anti-sickness medication. This should be taken about 30 minutes before taking the Temozolomide. You will also have been prescribed preventative antibiotics (co-trimoxazole) to reduce the risk of chest infections to be taken on Mondays, Wednesdays and Fridays.

Your doctor may have prescribed other medications such as steroids (dexamethasone), anti-epileptics, stomach-protecting drugs or painkillers – these should be taken as prescribed in the usual way. It is usually fine to continue to take any other medications you have been prescribed that are not related to your brain tumour, such as blood pressure tablets. Please check these with your doctor.

If you are ever unsure about when you should take your Temozolomide, please check with your doctor, nurse or specialist radiographer.

Part 2: Temozolomide taken for 5 days out of each 28 day cycle

This usually starts about 4 weeks after completion of Part 1.

- You should take your Temozolomide once daily for 5 days at the dose prescribed by your doctor.
- Take the Temozolomide on an empty stomach before a meal or at bedtime. This may help reduce the nausea associated with taking the medication.
- Take your anti-sickness medication about 30 minutes before taking the Temozolomide.
- You will then have a break for 23 days before starting the next cycle.
- Follow-up scans will be carried out at least once during this time and again after 6 cycles.
- Continue taking any other medications you have been prescribed.

The dose of Temozolomide is based on your height and weight. The number of treatment cycles will depend on how you respond to the treatment. Always follow the specific instructions given to you by your doctor.

Possible side effects

Chemotherapy can cause many different side effects. Some are more likely to occur than others. Everyone is different and not everyone gets all the side effects. Most side effects are usually temporary, but in some rare cases they can be life-threatening. It is important to tell your hospital doctor or nurse about any side effects so they can be monitored and, where possible, treated.

Common side effects (more than 1 in 10)

• Nausea and vomiting

Nausea and vomiting are a common side effect of Temozolomide. Your doctor will prescribe medications to help control these.

• Drop in blood levels

Temozolomide can reduce certain types of blood cells which can have serious effects. You will have weekly blood tests throughout your treatment to monitor your blood levels.

Platelets are the part of the blood that helps the blood to clot. A drop in your platelets can cause bruising, nose bleeds or bleeding gums. If you experience any of these please tell the radiographers as you might need to have an extra blood test.

A drop in your red cells may make you feel tired and look pale or be short of breath. Please tell the radiographers if you develop a shortness of breath as you might need to have extra tests.

A drop in your white cells can lead to an increased risk of infection. If this occurs you might experience high temperature, aching muscles, cough, shortness of breath, sore throat, pain on passing urine or you may feel cold and shivery. **You MUST phone The Christie Hotline on 0161 446 3658 if you think you are developing an infection – do not wait until the next day.**

We recommend that you use a digital thermometer so you can check your temperature. You can buy one from your local pharmacy or supermarket.

If your blood counts are low, it may be necessary to interrupt your Temozolomide and/or give you transfusions of platelets or red blood cells. It might even be necessary to give you injections to boost the white cell count. If any of these become necessary, the doctor will explain this in detail to you.

Blood counts usually recover after treatment finishes, but very occasionally low blood counts may persist and you may be admitted to hospital. In very rare situations this can be life-threatening. If this becomes necessary, your doctor will discuss this more fully with you.

- **Other side effects**

Other common side effects include headache, feeling tired, rash, loss of appetite and constipation or diarrhoea. Some of these will be similar to side effects from the radiotherapy. Please discuss any concerns with your doctor or specialist radiographer.

Uncommon side effects (less than 1 in 10)

- **Hair loss**

Hair loss with Temozolomide is uncommon but hair loss will occur as a result of radiotherapy to the brain. (See page 4)

- **Liver problems**

This treatment can occasionally cause abnormal liver blood tests and jaundice. This is rarely very severe, but your liver function will be monitored every time you come to the clinic for your treatment.

- **Severe and ongoing bone marrow suppression**

While some reduction in the numbers of white blood cells (infection fighting cells), red blood cells and platelets occurs in almost everyone receiving this treatment, this can occasionally be more severe and long-lasting, and could prevent the continuation of chemotherapy. Your doctor can discuss this with you.

Rare side effects (less than 1 in 100)

- **Severe chest infection**

Temozolomide chemotherapy can make you more prone to particular types of chest infection (pneumocystis pneumonia). You will be prescribed preventative antibiotics to take during the first part of your treatment which will be continued if your blood counts are low, but if you develop a cough associated with shortness of breath, contact The Christie Hotline or your GP.

- **Kidney problems**

Temozolomide rarely affects kidney function. Your kidney function will be monitored regularly.

- **Serious and potentially life threatening side effects**

In a small proportion of patients chemotherapy can result in very severe side effects which may rarely result in death. The team caring for you will discuss the risk of these side effects with you.

Side effects of radiotherapy treatment

- **Headaches**

Headaches are a very common side effect of radiotherapy to the brain. These may be due to increased swelling as a result of the treatment. You may be prescribed a drug called dexamethasone for this. Always remember to carry your steroid card which has instructions about taking dexamethasone. You can also take painkillers to help you such as paracetamol. It is important to tell the radiographers who are treating you if you are having headaches.

- **Feeling sick and altered taste**

Occasionally some people may have feelings of sickness. This can usually be effectively treated by anti-sickness drugs which your doctor can prescribe. You may also find that food tastes different. If your appetite is affected, try to eat little and often. If you don't feel like eating, you can replace meals with nutritious, high calorie drinks. These are available from most chemists and can be prescribed by your GP. The 'Eating - Help yourself' booklet provides further information. Advice is also available from your specialist radiographer and the cancer information centre.

- **Tiredness**

Radiotherapy often makes you feel tired. It builds up towards the end of treatment and can last for several weeks after treatment has finished. Rest when you need to but try to maintain your daily activities as much as you can because we know that this can be beneficial. The Macmillan leaflet 'Coping with fatigue' provides further advice on this and is available from the cancer information centre.

- **Somnolence (sleepiness)**

This side effect occurs during the treatment, but can increase for a time after the radiotherapy has finished. You may find that you slow down, have little energy and feel that you cannot be bothered to do much. This period is generally worse about 2 weeks after treatment has finished and usually starts to go away within another week. It can sometimes get worse again 4 to 6 weeks after treatment has finished. If you are concerned, contact the team treating you or your GP.

- **Hair loss**

You will lose any hair within the areas that are being treated. Most hair loss is temporary although unfortunately for some people it may be permanent. This will depend on the dose and different length of treatment you have had. Hair loss usually begins 3 to 4 weeks after starting the treatment. Sometimes the hair may grow back a different colour, texture and possibly thinner than before. It usually starts to grow back 2 to 4 months after finishing radiotherapy.

Please do not shave your head or cut your hair very short without discussing this with the radiographers. This is because it can affect the fitting of the mask which is important to ensure that your radiotherapy is given accurately.

If you would like an appointment with the wig service, this can be arranged for you by visiting the Cancer Information Centre (department 7). It is a good idea to get your wig before you lose a lot of hair which you can then match to your natural colour. Ask the staff for a copy of the leaflet 'The Wig Fitting Service'. A selection of headscarves and turbans is available from 'Headstart' which is a free service run by experienced volunteers. For appointments please ring 0161 918 7138.

- **Skin changes**

Some people develop a skin reaction, similar to sunburn, whilst having radiotherapy. This normally happens after 3 to 4 weeks. People with pale skin may find the skin in the treatment area becomes red and itchy. People with darker skin may find that their skin becomes darker and can have a blue or black tinge. The amount of reaction depends on the area being treated and the individual's skin. Some people may experience no skin changes at all.

Your treatment radiographers will be looking for these reactions and can advise you about the best way to take care of your skin during radiotherapy.

- **Other changes such as worsening of tumour-related symptoms**

Some people find that the symptoms of the brain tumour temporarily get worse either during or just after the radiotherapy has finished. This can make them think that their tumour is getting worse but, in fact, may be a reaction to the radiotherapy treatment. If you find this is happening to you, it is important to discuss it with your doctor, nurse or specialist radiographer, who will be able to give you the right advice, treatment and support.

Sex, contraception & fertility

Protecting your partner and contraception: We recommend that you or your partner use a condom during sexual intercourse while you are having the course of chemotherapy. Chemotherapy is dangerous to unborn babies and this will also protect you and your partner from any chemotherapy drugs that may be present in semen and in the vagina. If you suspect that you may be pregnant please tell your doctor immediately.

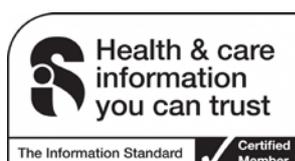
Fertility: This chemotherapy may affect your ability to have children. Your doctor or nurse should have discussed this with you. If not, please ask them before you start treatment.

Late side effects

There is a risk of developing side effects many months or years after your radiotherapy treatment has finished. Depending upon the area of the brain being treated, you may experience a cataract, dry eye, effects on your memory or thinking, an underactive pituitary gland (needing hormone replacement), some permanent hair loss where the tumour is close to the skull, or rarely, a tumour cause by the radiation. Your doctor will discuss and explain these further to you.

Contacts

Consultant	Secretary number
Dr Gattamaneni	0161 446 3362
Dr McBain	0161 918 7008
Dr Tran	0161 918 7197
Dr Whitfield	0161 918 7197
Neuro oncology nurse specialist	0161 446 8441
Neuro oncology specialist radiographer	0161 446 8395
Mould room (mask making)	0161 446 3525
Pat Seed department (MRI scanning)	0161 446 3884
Radiotherapy appointments	0161 446 3648
Christie Hotline	0161 446 3658



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Details of the sources used are available, please contact Patient.Information@christie.nhs.uk