

Radiotherapy with temozolomide for the treatment of high grade glioma

This factsheet provides information about treatment with radiotherapy combined with chemotherapy for high grade gliomas.

A high grade glioma is a malignant (cancer) primary brain tumour generally treated with surgery followed by radiotherapy. Temozolomide is a chemotherapy (anti-cancer) drug, which is given by mouth and has been shown to be beneficial in high grade gliomas. Adding temozolomide to radiotherapy has been shown to improve life expectancy with few additional side effects.

This factsheet provides information about temozolomide and what to expect during radiotherapy. Your doctor will have discussed alternative treatments with you.

Radical brain radiotherapy

Your doctors have recommended that you have a course of radiotherapy to the brain. This is to reduce the risk of damage to the brain from a tumour. They have weighed the expected benefits against possible side effects, and the risk of damage from an untreated tumour is far greater than the small possible risk of damage caused by radiation treatment.

On your first visit to see the doctor in the outpatients department, we will give you an appointment to attend the mould room and a date for a CT scan as part of the planning for the radiotherapy. The preparation for radiotherapy will take approximately two to three weeks.

We will give you the start date of your radiotherapy treatment as well as a list of telephone numbers outlining who to contact if you have any problems in the meantime. We will provide written information on CT planning, brain tumours, hair care and radiotherapy in general. This is also available online via [The Royal Marsden Patient Information library](#).

Why is there a gap before I start treatment?

After the CT scan is taken, the doctors looking after you will use the pictures to decide exactly where to give radiation through a process called computer planning. This process involves a team of doctors, physicists and radiation technologists (sometimes called planners) and takes about one week to complete.

At the end of the planning, the team looking after you will know how the treatment should be given (such as how many beams of radiation, from which direction and exactly how much radiation dose should be given in each daily treatment).



What happens before the first treatment with radiotherapy?

Mould room

The first appointment before you start treatment will be at the mould room. Here, we will make an impression of your head and face to make an accurately fitting face mask. This is not painful or uncomfortable and the whole process will take around 20 minutes. The mask is put on during treatment to make sure that you lie in the same position each time you have treatment.

Computerised tomography (CT) scan

You will have a CT scan in this mask so that we can plan your treatment. You may or may not have contrast (injection of dye) for this procedure - you will be asked not to eat or drink for one hour before the scan, **if** you need an injection. This is because of the possibility of being sick and vomiting. Please tell the radiographer before the investigation if you have any known allergies to contrast or to Iodine. You will need a blood test as preparation for this scan. Please note that this is not a diagnostic scan.

What happens during treatment?

Radiotherapy treatment is usually daily (excluding weekends and bank holidays) over a period of several weeks. The individual length of the treatment will be discussed with you in clinic but it is usually about six weeks. Each treatment is approximately 10 - 20 minutes long. Although you will be on your own during treatment, the radiographers are able to see you and hear you by means of a TV monitor and intercom system and they can talk to you.

While you are having treatment you should not feel anything - it is a painless procedure. During the treatment, the radiotherapy machine may move and make different noises - this is normal and nothing to worry about.

When do I have chemotherapy?

You will start temozolomide treatment on the first or second day you have radiotherapy. You will have a blood test taken some days before this appointment. This blood test will be repeated every week while you are taking temozolomide.

What side effects should I expect during and after treatment?

During radiotherapy treatment you are likely to notice skin changes, lose some of your hair and get tired. Further information is outlined below:

Nausea

Feeling sick (nausea) is not generally associated with radiotherapy to the brain. However chemotherapy may cause sickness. We will give you anti-sickness medication with your temozolomide prescription. If you continue to feel sick, please contact your specialist nurse, and we will give you another anti-sickness medication.

Skin changes to the scalp

Skin changes due to radiotherapy only happen in the area being treated. Your scalp may become red, as though you have been sitting out in the sun. It may feel hot and itchy. This is usually followed by dry and flaky skin. It may appear unsightly to you but this is part of normal skin



healing. During this stage it is best to apply an unperfumed moisturising cream, such as aqueous cream and E45. For a short time the skin on your head will be more sensitive to the sun after radiotherapy. You should protect your head from direct sunlight with a scarf or a hat and use sunscreen containing sun protection factor (SPF) indefinitely after radiotherapy.

Hair loss

It is usual to lose hair during radiotherapy. Hair loss may be permanent following the six week course of radiotherapy but this depends on the exact position of the tumour. We will discuss this with you in more detail during your first consultation.

During radiotherapy, you can continue to wash your hair as frequently as you normally would with some minor precautions:

- Use tepid water and a mild shampoo
- Do not use colourants or perm your hair
- Do not rub but pat your hair and scalp dry with a soft towel afterwards
- Do not use a hair dryer as even on a low setting it can cause irritation to the scalp
- If you are used to having a facial wet shave, you may continue to do this
- If you would like a wig, please discuss this when you are seen in clinic.

Tiredness

Radiotherapy may make you feel exhausted and you may find that your energy levels are lower than before. The tiredness can last for six to eight weeks after finishing radiotherapy. We tend to call this feeling 'somnolence'. During this period, have frequent rests, drink plenty of fluids and try not to overexert yourself. The addition of the temozolomide to the radiotherapy may make the tiredness worse.

Effects of radiation on the brain

The reason for giving radiation is to reduce the risk of damage to the brain from a tumour. While you may be concerned about the potential damage from radiation, however small, the risk of damage from the untreated tumour is far greater than the risk of damage caused by treatment. Radiotherapy is given so that the tumour and a margin (an area around the tumour) is treated over a period of six weeks.

The chances of radiotherapy damaging the brain are small - between 2% to 4%. This type of damage from radiation is called 'radiation necrosis' and would cause similar problems to the tumour itself. Treating the brain may have an effect similar to speeding up the ageing process. This may result in reduced short-term memory and concentration which may become noticeable many years after treatment. In very rare cases the treatment can affect the eyesight causing varying degrees of visual loss, and hearing may also become impaired.

We will discuss the risks and benefits of radiotherapy with you before you give consent to treatment. If you are unsure or do not understand what is being said, please tell the doctor or the specialist nurse working with your consultant.



Other things to be aware of

Support

At times, it may be necessary to involve other members of the hospital or community such as the physiotherapist, district nurse, occupational therapist or hospice nurse in your care. This is to ensure that all necessary support is there for you during and after treatment.

We will always discuss changes in your care with you and any change to the services provided will not be introduced unless you agree.

Steroids

If you are taking dexamethasone tablets (a steroid), please take them with food or with a milky drink. It helps not to take them late in the day (no later than mid-afternoon) as they may keep you awake at night. Do not stop taking steroids without medical advice. Always bring a list of your medications when attending clinic.

Driving

If you have had a brain operation and have a brain tumour, you must not drive until the DVLA allows to you. Please contact the DVLA to let them know about your condition and ask the clinic staff to discuss this with you in more detail, if needed.

Finance

If you are taking anti-epileptic medication (anticonvulsants), chemotherapy or have a continuing physical disability which means that you cannot go out without the help of another person, you are entitled to free NHS prescriptions. Ask at the chemist or pharmacy for an exemption certificate form FP92 and ask your doctor to sign this. You may be entitled to other benefits. Please discuss this with the nurse specialist who can refer you to the welfare benefits advisor. It may also help to keep a list of questions that you may wish to ask when attending treatment or clinic.

Follow up

Please make sure that you have a follow up appointment for medical review on completion of your radiotherapy. If you do not have one, please ask. If you need to change any of your appointments for any reason, please telephone the radiotherapy reception on 020 8915 6020.

Some of the terminology used in this leaflet may be unfamiliar; please do not hesitate to ask one of the team for further explanation if there is anything you do not understand.

Neuro-oncology team contact details

Please see separate sheet.



Taking temozolomide

Morning regime

1. On waking take anti-sickness tablet(s) - wait 30 minutes
2. Take temozolomide and do not eat or drink for one hour
3. Eat breakfast
4. Take other medication as per medication chart.

Evening regime

1. Do not eat or drink one hour before bedtime
 2. Take anti-sickness tablet(s) 30 minutes before bedtime
 3. At bedtime, take temozolomide and go to sleep.
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Temozolomide = chemotherapy (daily as instructed on bottle)

Co-Trimoxazole = antibiotic (Monday, Wednesday, Friday as instructed on bottle)

Ondansetron 8mg = anti-sickness tablet. Take one tablet 30 minutes before your chemotherapy and as instructed on the bottle (maximum twice a day). **This medication may cause constipation. If this occurs, please discuss this with your specialist nurse or GP immediately.**

Take the Ondansetron for the first 7 days of chemotherapy, then change to:

Cyclizine 50mg = anti-sickness tablet. Take one tablet 30 minutes before chemotherapy and as instructed on bottle (maximum of three times a day)

Ondansetron and Cyclizine can be taken together in cases of uncontrolled nausea.

