The Christie
NHS Foundation Trust

Temozolomide with concurrent radiotherapy to the brain followed by temozolomide monotherapy

The possible benefits of this treatment vary; for some people chemotherapy and radiotherapy may reduce the risk of the cancer coming back, for others it may control the cancer and its symptoms. Your doctor, nurse or specialist radiographer will be happy to answer any questions you have about your treatment. You will find it useful to refer to the booklets 'SACT, a guide' which gives general information on systemic anti-cancer therapy and side effects, and 'Radiotherapy for brain tumours, a guide for patients and their carers,' which gives general information on radiotherapy to the brain and side effects.

Your treatment

There may be 2 parts to your treatment.

Temozolomide is initially taken for 3 to 6 weeks alongside radiotherapy (concurrent phase).

This will be followed by a 4 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 (monotherapy phase, also referred to as adjuvant temozolomide).

This treatment can have serious or possibly life-threatening side effects. It is very important that you report side effects straight away. Don’t delay, if you feel unwell, please ring The Christie Hotline on **0161 446 3658**. The lines are open 24 hours a day.

Part 1: temozolomide with radiotherapy (concurrent phase)

- Radiotherapy is given daily Monday to Friday, but not at weekends.
- You should take the temozolomide once daily during your course of radiotherapy including **at weekends**, when you do not have radiotherapy.
- If you forget to take the temozolomide capsules, take the missed dose as soon as possible the same day. If a full day has gone by, let your clinical team know. **Do not take a double dose.**
- You will have a routine blood test and be reviewed by a member of the clinical team once every week during radiotherapy, or more often if necessary. If your blood tests show abnormalities, we may ask you to stop or pause your temozolomide until your blood tests have returned to a safe level. Your clinical team will explain this to you.

- You will also be prescribed antibiotics (co-trimoxazole, also called septrin) to reduce the chance of you developing certain types of chest infections while you are taking chemotherapy. It is important to take these on Mondays, Wednesdays and Fridays throughout your course of treatment, even if you are feeling well. You can take these tablets at any time of the day.

Part 2: temozolomide (monotherapy phase)

This usually starts 4 weeks after completion of Part 1.

- You should take your temozolomide once daily for 5 days, at the dose prescribed by your doctor, followed by 23 days without treatment before starting the next cycle.
- If you forget to take the temozolomide capsules, take the missed dose as soon as possible within the same day. If a full day has gone by, let your clinical team know. **Do not take a double dose.**
- Follow-up scans will usually be carried out after your second cycle of treatment and again after 6 cycles.
- You will have a routine blood test and be reviewed in clinic by a member of the clinical team before the start of each cycle of treatment. Occasionally we may not be able to go ahead with treatment until your blood counts are back to a safe level. If this happens your chemotherapy may be delayed a week or until your blood counts have recovered.
- The number of treatment cycles will depend on how you respond to the treatment but will usually last a total of 6 to 12 months.
- Always follow the specific instructions given to you by your clinical team.

How to take temozolomide

- Take the temozolomide on an empty stomach (2 hours after food and 1 hour before food).
- During radiotherapy, you should take your temozolomide in the mornings.
- During the monotherapy phase, it can be taken either in the morning or at bedtime, but try to take it at approximately the same time on each day of the 5 day course.
- Your total daily temozolomide dose may be made up of several temozolomide capsules of different strengths. If you are unsure about how to take your capsules, please ask your specialist radiographer or another member of your clinical team.
- The capsules should never be opened or crushed. If they become damaged, avoid getting the powder on your skin or in your eyes. If you accidentally get some on your skin or in your eyes you should wash immediately.
- Take your anti-sickness medication (ondansetron) 30 minutes to 1 hour before taking the temozolomide capsules for the first 5 days.
- If you vomit after you take the temozolomide capsules, do not take a second dose that day.
- If required, you can repeat a dose of ondansetron 8 - 12 hours after the first dose.
- You will also be provided with an alternate anti-sickness medicine (metoclopramide), which may be used after your ondansetron is finished or used in combination with ondansetron if required.
- If you continue to feel sick or vomit, please contact The Christie Hotline or your GP as you may need a review of you anti-sickness tablets.
- 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 clinical team or The Christie Hotline.

Increased risk of serious infection

You are vulnerable to infection while you are having chemotherapy. Minor infections can become life threatening in a matter of hours if left untreated. Symptoms of infection include fever, shivering, sweats, sore throat, diarrhoea, discomfort when you pass urine, cough or breathlessness. We recommend that you use a digital thermometer so you can check your temperature. You can buy one from your local chemist.

If you feel unwell, you have symptoms of an infection or your temperature is 37.5°C or above, or below 36°C contact The Christie Hotline straight away.

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)

• Prone to bleeding (Warning!)

Temozolomide can often affect your platelet count. Platelets are the part of the blood which helps blood to clot, so you may have nose bleeds, bruising or bleeding, (for example from the gums). Sometimes you may need platelet transfusions. If significant bleeding occurs, please ring The Christie Hotline on **0161 446 3658**.

• Nausea and vomiting (sickness)

The severity of this varies from person to person. You will be given anti-sickness tablets to take home and it is helpful to take an anti-sickness tablet around 30 minutes before your temozolomide capsules each day. If you continue to feel or be sick, contact your GP or The Christie, because your anti-sickness medication may need to be changed or increased.

• Rash

Temozolomide may cause an itchy rash. If this happens, stop taking your temozolomide capsules and contact The Christie Hotline or your specialist nurse. They will advise whether it would be appropriate to manage this with the addition of over-the-counter antihistamine.

• Constipation

You may become constipated during this treatment. Try to drink plenty of fluids and eat foods high in fibre. You can also try simple laxatives which you can buy from a pharmacy, but make sure you tell your Christie clinical team about this. They can prescribe stronger laxatives if necessary.

• Loss of appetite

If this becomes a problem while you are having treatment, ask staff for a copy of the booklet 'Eating - help yourself'.

• Other side effects

Other common side effects include headache, feeling tired, and hair loss. Some of these will be similar to side effects from the radiotherapy (see page 5). Please discuss any concerns with your doctor or specialist radiographer.

Uncommon side effects (less than 1 in 10)

• Anaemia (low number of red blood cells)

While having this treatment, you may become anaemic. This may make you feel tired and breathless. Let your doctor or nurse know if these symptoms are a problem. You may need a blood transfusion.

• 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 during treatment. If liver blood tests are abnormal, it is sometimes necessary to stop or interrupt chemotherapy until they recover.

• 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. It may require you to return to the hospital for blood tests or blood or platelet transfusions even after your temozolomide has stopped. Your doctor can discuss this with you.

• Diarrhoea

If this becomes a problem while you are having treatment, anti-diarrhoea medication can be prescribed by your GP until this is resolved. If this problem persists, contact The Christie. If you have mild diarrhoea anti-diarrhoea tablets from the pharmacy may help.

Rare side effects (less than 1 in 100)

• Severe chest infection

Temozolomide chemotherapy can make you more prone to a particular type of chest infection (pneumocystis pneumonia). You will be prescribed preventative antibiotics (co-trimoxazole) 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 pharmacies or 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 with radiotherapy. Most hair loss is temporary, although unfortunately for some people it may be permanent. This will depend on the dose and length of radiotherapy you have had. Hair loss usually begins 3 to 4 weeks after starting treatment. Sometimes hair may grow back a different colour, texture and possibly thinner than before. It usually starts to grow back around 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.

The cancer information centre offers a coping with hair loss service to all patients where support, information and advice will be given. Drop in, contact **0161 446 8100** or email **the-christie.informationcentre@nhs.net**. Information about the wig service can also be found here and vouchers for wigs can also be obtained for eligible patients. The wig room provides a drop in service, please see The Christie leaflet ‘The wig fitting service’ for further information.

The Maggie's Centre can support you with hair loss by helping you consider the practicalities as well as the emotional impact. You can call into Maggie's Monday to Friday, 9am to 5pm to speak with their professional team. Maggie’s provide expert care and support to everyone with cancer and those who love them. Contact Maggie’s on **0161 641 4848**, email: **manchester@maggies.org** or drop in, their address is The Robert Parfett Building, 15 Kinnaird Road, Manchester, M20 4QL

• Skin changes

Some people develop a skin reaction, similar to sunburn, while 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 and fertility

Protecting your partner and contraception: We recommend that you or your partner use a barrier form of contraception during sexual intercourse, whilst having 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.

You should not get pregnant or attempt to get somebody pregnant while being treated with temozolomide and up to 6 months after receiving the last dose. If you suspect 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.

Flu vaccinations

Is it alright for me to have a flu jab during the time I'm having chemotherapy?
It's safe to have a flu jab, but depending on the sort of chemotherapy you have had, it may not give quite as much protection against infection as usual. Some patients may need 2 vaccinations. However, if you're thinking of having any other vaccinations, do check with your Christie doctor first, because some vaccines should be avoided.

COVID-19 vaccinations

We advise that all patients receive a COVID-19 vaccination when this is offered. Your doctor will discuss with you the best time to have this.

Contacts

If you have any general questions or concerns about your treatment, please ring:

Your consultant's secretary:	Professor McBain	**0161 918 7008**
	Dr Patel/Dr Borst	**0161 446 3362**
	Dr Colaco/Dr Whitfield	**0161 918 7197**

For urgent advice ring The Christie Hotline on **0161 446 3658** (24 hours a day, 7 days a week).

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If you need information in a different format, such as easy read, large print, BSL, braille, email, SMS text or other communication support, please tell your ward or clinic nurse.

The Christie is committed to producing high quality, evidence based information for patients. Our patient information adheres to the principles and quality statements of the Information Standard. If you would like to have details about the sources used please contact **the-christie.patient.information@nhs.net**

For information and advice visit the cancer information centres at Withington, Oldham, Salford or Macclesfield. Opening times can vary, please check before making a special journey.

Contact The Christie Hotline for urgent support and specialist advice

The Christie Hotline: 0161 446 3658

Open 24 hours a day, 7 days a week

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The Christie Patient Information Service
Tel: 0161 446 3000 www.christie.nhs.uk