

Temozolomide

The possible benefits of this treatment vary; for some people chemotherapy may reduce the risk of the tumour coming back, for others it may control the tumour and its symptoms. Your doctor will explain to you whether you will receive chemotherapy or another type of treatment, or a combination of both. Your doctor or nurse will be happy to answer any questions you have about your treatment. You will find it useful to refer to the booklet 'SACT, a guide' which gives general information on systemic anti-cancer therapy and side effects.

Your treatment

Your doctor has prescribed a course of treatment with temozolomide.

Temozolomide is given by mouth as capsules once a day for 5 days.

The course is repeated every 28 days (4 weeks), usually for 6 or 12 cycles (months). If you have swallowing difficulties, please let your clinical team know, as they can advise on how best to manage taking oral chemotherapy.

You will have a routine blood test and be reviewed in clinic by a member of the medical team before the start of each cycle of treatment. Occasionally we may not be able to go ahead with your treatment until your blood counts are back to a safe level. If this happens, your chemotherapy may be delayed a week or until your counts have recovered.

If you forget to take the 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.

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.

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.



How to take temozolozide:

- Temozolomide capsules should be swallowed whole, with glass of water, on an empty stomach (2 hours since last meal and 1 hour before you next eat). Tablets can be taken at any time of day i.e. morning or evening.
- 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 a 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.
- 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 to 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 your 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.

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.

- **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 advised that you 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 capsules and contact your specialist nurse or The Christie Hotline. They will advise you whether it would be appropriate to manage this with the addition of over-the-counter anti-histamine.

- **Lethargy**

Temozolomide chemotherapy may make you feel tired and lacking in energy. If you do feel tired, take rest and get help with household chores. If necessary, take time off work. Gentle exercise such as walking can help.

- **Headache**

Let your clinical team know if you get headaches while you are on treatment.

- **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.

- **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.

- **Loss of appetite**

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

- **Hair thinning**

Hair loss is very unusual with this treatment. In rare cases some hair loss may occur during treatment. It is advisable to avoid perms, colours, use of hot brushes and vigorous, frequent washing that could increase hair loss. Please remember that this is a temporary side effect, and your hair will grow back when your treatment is completed. Very rarely, hair loss can be permanent.

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

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 every time you come to the clinic for your treatment. Occasionally, we may need to delay or suspend your chemotherapy until your liver blood tests have improved. If this happens, your clinical team will discuss it with you.

- **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)

- **Kidney problems**

Temozolomide rarely affects kidney function. Your kidney function will be monitored every time you come to the clinic for your treatment.

- **Severe chest infection**

Temozolomide chemotherapy can make you more prone to particular types of chest infection. If you develop a cough associated with shortness of breath, contact The Christie Hotline or your GP.

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.

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 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

Some side effects may become evident only after a number of years. In reaching any decision with you about treatment, the potential benefit you receive from treatment will be weighed against the risks of serious long term side effects to the heart, lungs, kidneys and bone marrow. With some drugs there is also a small but definite risk of developing another cancer. If any of these problems specifically applies to you, the doctor will discuss these with you and note this on your consent form.

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 two 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