

Temozolomide and capecitabine

For pancreatic neuroendocrine tumours

The possible benefits of treatment vary; for some people this chemotherapy may reduce the risk of the cancer coming back, for others it may control the cancer and its symptoms. Your doctor will explain 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 chemotherapy and side effects.

Your treatment

Your doctor has prescribed a course of treatment which includes 2 types of chemotherapy: temozolomide (capsules) and capecitabine (tablets). Both of these are taken by mouth. Please read the following important information.

Capecitabine

The tablets come in 2 strengths: 150mg and 500mg tablets. Your height and weight will help us to calculate how many tablets you need to take. Depending on the dose prescribed you may have 2 separate boxes - 1 box for each strength.

Take the capecitabine twice a day (morning and evening) 10 to 12 hours apart.

1. **Take the tablets every day for 14 days** (including Saturday and Sunday).
2. **This is followed by 14 days rest when you do not take any tablets.**
3. Take the tablets within 30 minutes after food, for example after breakfast and an evening meal. It doesn't have to be a large meal. It can be a snack such as a sandwich.
4. Take the tablets with water only. Some fruit juice such as fresh orange can interact with your medication.
5. **Store your tablets in a cool dry place out of reach of children.**
6. **If you miss a dose do not double up the next dose. Take your regular dose at the next scheduled time. Complete the course and do not extend beyond 14 days.**
Bring back any leftover tablets to clinic.

Temozolomide

Temozolomide should be taken on an **empty** stomach. We recommend that you do not eat for 1 to 2 hours before taking the temozolomide and for 1 to 2 hours afterwards. Temozolomide capsules come in a variety of strengths (5mg, 20mg, 100mg, 250mg) so you may need to take several capsules to make up a single dose. **Take your capsules once a day at bedtime. Take them for 5 days only, starting on the 10th day of your capecitabine tablets. You will stop taking both of the medications on the same day and then have 14 days without any medication.**

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.

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)

• 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.

• Bruising or bleeding

This treatment can reduce the production of platelets which help the blood clot. Let your doctor know if you have any unexplained bruising or bleeding, such as nosebleeds, bloodspots or rashes on the skin, and bleeding gums. You may need a platelet transfusion.

• Lethargy

Some chemotherapy may make you feel tired and lacking in energy. It can be frustrating when you feel unable to cope with routine tasks. If you do feel tired, take rest when necessary. Gentle exercise such as walking can be beneficial.

• Hand/foot skin reaction

Some people can experience reddening and peeling of the skin on the hands and feet and possibly some tingling and numbness. Simple moisturisers can help if this is mild, but if it interferes with walking or normal activities, please contact The Christie.

• 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 tablets. 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.

• Sore mouth

Your mouth may become sore or dry, or you may notice small mouth ulcers during this treatment. Drinking plenty of fluids and cleaning your teeth regularly and gently with a soft toothbrush can help to reduce the risk of this happening. To prevent infection you should use an antibacterial mouthwash (such as chlorhexidine - dilute this with water if your mouth is sore). Ask your doctor or nurse for advice. The SACT booklet also has general mouthcare advice. For a sore mouth your doctor/nurse can prescribe a Diffiam® mouthwash (this can also be diluted by half with water). If you continue to have a sore mouth, please ring The Christie Hotline for advice.

• Diarrhoea

Diarrhoea is a fairly common side effect of your treatment. If you have watery diarrhoea you should immediately take the anti-diarrhoea treatment that the doctor has prescribed for you. This is loperamide dispensed by The Christie pharmacy.

Follow the doctor's instructions EXACTLY: Take 2 loperamide capsules as soon as the first liquid stool occurs. Then take 1 capsule with each liquid loose stool. The maximum dose of loperamide in 24 hours is 8 capsules). If you continue to have more than 4 bowel movements a day (compared to pre-treatment) or bowel movements at night please ring The Christie Hotline on **0161 446 3658** for advice.

Uncommon side effects (less than 1 in 10)

• Rash

Temozolomide may cause an itchy rash. If this happens, stop taking your tablets and let your hospital doctor know.

• Skin changes

Sometimes as a result of the chemotherapy, your skin may appear darker in colour or lightly tanned, especially around the joints. This is known as hyper pigmentation. Depending on your skin tone, people may also develop noticeably lighter patches on their skin. The skin will return to normal when treatment is finished. Some chemotherapy can make your skin more sensitive to the sun than usual. Sit in the shade, avoid too much sun and use a high factor sun cream.

• Liver or kidney problems

Temozolomide can rarely affect liver and kidney function. Your kidney and liver function will be monitored every time you come to the clinic for your treatment.

• Hair thinning

Hair loss is very unusual with this treatment, though in rare cases some hair loss may occur. 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 and advice will be given. Drop in, contact **0161 446 8439** or email the-christie.informationcentre@nhs.net. Information about the wig service can 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

Rare side effects (less than 1 in 100)

• Severe skin reaction (Warning!)

Very rarely you may develop a severe skin reaction. If you experience tender red skin patches which subsequently blister please seek urgent medical advice. The skin changes may be preceded by fever, chest symptoms and photophobia (a need to squint or close your eyes, which is worse in bright light). These symptoms may be caused by conditions called toxic epidermal necrolysis (TEN) and Stevens Johnson syndrome (SJS).

Herbal medicine

Some herbal medicine including St John's Wort can affect the chemotherapy. You should tell your doctor or nurse if you are taking any herbal medication.

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.

• Chest pain or stroke (Warning!)

A small number of patients receiving capecitabine can experience chest pain (angina) or rarely have a heart attack. Extremely rarely this may lead to death. Other complications such as a stroke or a mini-stroke can happen but are exceptionally rare. If you develop any of these symptoms you should either contact The Christie Hotline for advice or in an emergency you should go immediately to your nearest Accident & Emergency department. You may have an electrocardiograph (ECG) to check your heart before you start your chemotherapy.

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.

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.

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:

Administration enquiries - **0161 918 7606/7610**

Chemotherapy nurse - **0161 918 7171**

Clinical trials unit - **0161 918 7663**

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

Your consultant is:

Your hospital number is:

Your key worker is:

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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