

Irinotecan and temozolomide

The possible benefits of treatment vary; for some people chemotherapy may reduce the risk of the cancer coming back, for others it may control the cancer 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 'Chemotherapy, a guide' which gives general information on chemotherapy and side effects.

Your treatment

Your doctor or nurse clinician has prescribed for you a treatment which includes the chemotherapy irinotecan and temozolomide.

Day 1 to 5 Temozolomide capsules taken by mouth

Irinotecan intravenous (IV) infusion over 1 hour

Day 6 and 7 No treatment

Day 8 to 12 Irinotecan IV infusion over 1 hour

The treatment is repeated every 3 weeks.

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 your daily dose.

You will have a routine blood test 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.

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)

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.

Hair thinning

Most people will lose all of their hair following this type chemotherapy. The hair falls out gradually 10 to 14 days following your first course of treatment. The time scale varies from person to person. 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. Maggie's provides expert care and support to everyone with cancer and those who love them. You can call into Maggie's Monday to Friday, 9:00am-5:00pm to speak with their professional team, their address is Maggie's Manchester at The Robert Parfett Building, 15 Kinnaird Road, Manchester, M20 4QL or you can call them on **0161 641 4848** or email **manchester@maggies.org**

Uncommon side effects (less than 1 in 10)

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.

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.

• Chemotherapy reaction

Sometimes during the infusion or within 24 hours of the infusion of irinotecan you may get some of these symptoms: abdominal cramps, diarrhoea, sweats, dizziness, excess saliva, watery eyes, tiredness and occasionally problems with vision. These side effects can easily be managed with an injection underneath the skin. Tell your chemotherapy nurse or doctor if you have any of these symptoms. If you have this reaction, you will normally need an injection before each treatment.

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• Delayed or persistent diarrhoea

If the diarrhoea starts more than 24 hours after your chemotherapy, you should immediately take the anti-diarrhoea treatment that the doctor prescribed for you. This is the loperamide dispensed by The Christie pharmacy.

Follow your doctor's instructions exactly:

Take 2 loperamide capsules as soon as the first liquid stool occurs. Then take one capsule with each liquid loose stool. (The maximum dose of loperamide in a day is 8 capsules).

If the diarrhoea persists for more than 24 hours despite the loperamide you should start taking the ciprofloxacin antibiotic given to you on your first visit. Make sure you complete the 5-day course of the antibiotic. Contact The Christie if the diarrhoea persists. You can continue to take the loperamide. You must tell your doctor if:

- you have a temperature/fever as well as diarrhoea
- you have nausea/vomiting as well as diarrhoea
- you still have diarrhoea 48 hours after starting the diarrhoea treatment

Rash

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

• 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. We can prescribe a mouthwash for you to use during treatment. You can dilute this with water if your mouth is sore. Ask your doctor or nurse for further advice. There is also general mouth care information in the chemotherapy booklet. If you continue to have a sore mouth, please contact The Christie Hotline. Occasionally during treatment you may experience a strange taste sometimes described as metallic or bitter. A strongly flavoured sweet or mint will help to disguise this.

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 hyperpigmentation. 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 sunblock cream. Asian and African-Caribbean people may develop noticeable light patches on their skin.

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.

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.

Herbal medicine

Some herbal medicine including St John's Wort can affect the chemotherapy. You should let your doctor or nurse know if you are taking any herbal medication, complementary or alternative medicines, including vitamins, minerals and medicines purchased over-the-counter.

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 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 the area where you are having treatment:

Administrative enquiries - 0161 918 7606/7610 Chemotherapy nurse - 0161 918 7171 Clinical trials unit - 0161 918 7663 Sarcoma clinical nurse specialist - 0161 446 3094 Palatine treatment ward - 0161 446 7233/7234

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

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