

Irinotecan, fluorouracil, folinic acid

Includes IrMdG (Irinotecan and Modified deGramont)

The possible benefits of this 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, Fluorouracil (5FU) and Folinic Acid.

Day 1 Irinotecan is given via a drip over 90 minutes with Folinic Acid by drip over 60 minutes followed by 5FU short infusion over 5 minutes, and then 5FU as a slow infusion over 46 hours (at home) via a pump through a central venous catheter.

Day 3 District nurse home visit to take pump off and flush line.

Day 15 Repeat of day 1 and start of next cycle of treatment

The treatment is repeated every 2 weeks for a total of 6 to 12 cycles.

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.

You will also have a one-off blood test to check for DPD deficiency and that it is safe for you to have this treatment. See page 2.

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.



After Cycle 2 of treatment, if clinically possible you will have your treatment at a location closer to home. The Christie is committed to providing treatment closer to home as part of the Outreach and Christie at Home service.

Testing for DPD deficiency

The body makes enzymes which break down chemotherapy drugs so that chemotherapy doesn't build up in the body and cause severe side effects. A very small percentage of the population (approximately 1 in 20), either do not produce or produce less of an enzyme called DPD which would normally break down the chemotherapy drugs 5-FU and capecitabine. This is called DPD deficiency. Reduced production of DPD is not an issue in day-to-day life, but it might mean that some patients experience severe and sometimes life-threatening side effects after 5-FU or capecitabine chemotherapy is given. Patients with DPD deficiency are more likely to develop severe mouth ulcers and diarrhoea, and very low blood counts increasing vulnerability to life-threatening infections.

In order to check that it is safe for you to have this treatment, your team will be arranging a one off blood test. This test checks for some of the commonest abnormalities which can cause DPD deficiency. Your medical team will discuss the test results with you and can confirm whether you will be able to go ahead with your planned chemotherapy, or whether any changes need to be discussed.

Although DPD testing identifies many patients who are at risk of severe side effects from 5-FU and capecitabine, it does not identify all at risk patients. Severe and sometimes life-threatening side effects can occur in patients who have had a normal test result. Therefore it is important that patients receiving chemotherapy monitor their symptoms carefully and contact The Christie Hotline on **0161 446 3658** if they become unwell.

Herbal medicines:

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.

Other medicines:

Some medicines can be harmful to take when you are having chemotherapy. Let your doctor know about any medications you are taking including non-prescribed medicines such as complementary therapies and herbal remedies.

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 this with you the best time to have this.

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. Anti-sickness medication will be given along with your chemotherapy to prevent this. You may also be given anti-sickness tablets to take at home. If you continue to feel or be sick, contact your GP or this hospital, because your anti-sickness medication may need to be changed or increased.

• Delayed or persistent diarrhoea (Warning!)

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 these instructions **EXACTLY**:

Take 2 loperamide capsules/tablets as soon as the first liquid stool occurs. If you continue to have episodes of liquid stools, then take 1 capsule/tablet with each episode (allow at least 2 hours between doses). The maximum number of capsules/tablets you can take is 8 in a 24 hour period.

If the diarrhoea persists for more than 24 hours despite the loperamide contact The Christie Hotline on **0161 446 3658**.

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.

• 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 sore mouth, please contact The Christie Hotline.

• Skin and nail changes

PPE (palmar-plantar erythema): The skin on your hands and feet may become very dry, red and sore with some cracking. Tell your doctor. Cream and tablets can be prescribed to help. Your chemotherapy dose may need to change. Try to keep your hands and feet cool and if possible, uncovered.

Hyperpigmentation: Less commonly, your skin may appear darker in colour or lightly tanned, especially around the joints. This is known as hyper pigmentation. Asian and African-Caribbean people may develop noticeable light patches on their skin. The skin will return to normal when treatment is finished.

Increased sensitivity to the sun: Your skin will tan or burn in the sun more easily. Sit in the shade, avoid too much sun and use a high factor sunblock cream and wear a hat.

Nail changes: You may have a blue tinge or darkening of the nails, flaking of the nails and thickening of the area where the nail starts growing.

- **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 and get help with household chores. If necessary, take time off work. Gentle exercise such as walking can be beneficial.

- **Cholinergic 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.

- **Hair thinning**

It is uncommon to lose hair with this treatment although it may thin a little. 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 service 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 **8107** 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 runs a Talking Heads hair loss support workshop for anyone who is anticipating or experiencing hair loss (both men and women). These sessions cover the practicalities of hair loss as well as offering support with its emotional impact. Contact Maggie's on **0161 641 4848** or email manchester@maggies.org.

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.

- **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.

- **Sore eyes**

You may get a dry, gritty feeling in your eyes following treatment. If this happens, using Hypromellose eyedrops will help to ease the discomfort. If the problem persists, contact your doctor at The Christie. Your eyes may also water. Often this will improve in time and needs no specific treatment.

Serious and potentially life-threatening side effects

- **Chest pain or stroke (Warning!)**

A small number of patients receiving 5-Fluorouracil (5FU) or 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 mini-stroke can happen but are exceptionally rare. If you develop any of these symptoms you should contact your hospital doctor for advice. In an emergency you should go immediately to your nearest accident and emergency department.

- **Blood clot (Warning!)**

During chemotherapy you are more at risk of blood clots in the legs (DVT) or lungs (PE). Occasionally these clots can be life-threatening. To help prevent clots, keep mobile and drink plenty of non-alcoholic fluids (around 2 to 3 litres per day). Symptoms of a blood clot include breathlessness; chest pain; fainting; coughing up blood or pain; redness; swelling or warmth in an arm or leg. If you develop any of these symptoms, you should ring **999** or go immediately to your nearest accident or emergency department.

- **Increased risk of serious infection**

As discussed earlier chemotherapy results in an increased risk of severe infections which can be life threatening.

Sex, contraception and fertility

Protecting your partner and contraception

We recommend that you or your partner use a condom 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.

- **For female patients only**

Menopausal symptoms

When the ovaries stop working due to chemotherapy or during a natural menopause most women experience symptoms such as hot flushes, sweats (night and day) and vaginal dryness. These hormonal changes can make the vagina feel as though it has shrunk and become less easy to stretch. This is called vaginal atrophy and can result in discomfort, pain on sexual intercourse, itching and recurrent urine infections. If your ovaries don't start to work again the vaginal symptoms can be permanent, although the flushes and sweats tend to reduce and stop over a small number of years. Some women who have already gone through menopause may notice their symptoms worsening for a time after chemotherapy.

The vaginal symptoms can start early and the longer they are left the harder they can be to treat. Please contact your specialist nurse either in clinic or by phone when the symptoms first develop if you would like help. Symptoms can be managed in several ways including gels, essential oil pessaries and sometimes local oestrogen replacement. You may also find it helpful to request the booklet 'Menopausal symptoms and breast cancer' by Breast Cancer Now (either from your breast care nurse, the cancer information centre at The Christie or online).

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.

Contacts

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**

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