

E.O.X.

This leaflet is offered as a guide to you and your family. 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 epirubicin, oxaliplatin and capecitabine. The treatment is given every 3 weeks for 6 to 8 cycles.

Day 1 Epirubicin is given as a bolus (or injection) directly into a vein, usually with a drip running in at the same time. This is repeated every 3 weeks

Oxaliplatin is given via a drip over 2 hours. This is repeated every 3 weeks

Capecitabine tablets taken twice daily - starting on Day 1 for 21 days

Capecitabine tablets come in two strengths (150mg and 500mg). We will calculate your dose according to your height and weight. You may need to take multiple tablets to achieve the correct dose. You should take the capecitabine tablets with a glass of water twice daily, about 12 hours apart and within 30 minutes of a meal.

Day 15 Visit to clinic. Blood tests.

Day 21 Start at Day 1 again.

You will have a routine blood test before the start of each cycle of treatment.

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.

Capecitabine will interact with warfarin (a blood thinning tablet). You should tell your doctor if you are taking warfarin and a different blood thinning tablet can be prescribed. Capecitabine also interacts with phenytoin and allopurinol. Tell your doctor if you are taking these drugs.

Blood sugar

You will receive a dose of intravenous steroids before each treatment. If you are diabetic, you should monitor your blood sugar levels during your treatment. If your blood sugar levels are affected, you should speak to your doctor about your diabetic medications.

- **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.

Other 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)



- **Blood clots**

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.

- **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. Tell your doctor 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.

- **Epirubicin**

Because of its red colour, Epirubicin may discolour your urine red or pink for up to 24 hours following treatment. This is perfectly normal and nothing to worry about.



- **Sensitive reactions**

Difficulty in swallowing. Sometimes you may experience unpleasant feelings in the throat, particularly when swallowing which can give the sensation of shortness of breath. However, you will still be able to breathe normally. These sensations usually occur while you are receiving oxaliplatin and may be dealt with by slowing down the infusion of oxaliplatin from 2 to 6 hours. Also, taking a warm (not hot) drink can help if cold air is causing you swallowing difficulties.



- **Numbness in fingers and toes**

Oxaliplatin can increase the sensitivity of the nerve endings. You may develop pins and needles, tingling or numbness, or pains like small 'electric shocks' and may have difficulty in carrying out delicate tasks such as buttoning clothes (this may sometimes occur in association with cramps). These symptoms are often triggered by exposure to cold. Take care with extreme drops of temperature, for example, opening fridges or freezers. Avoid drinking iced drinks and eating very cold food for 24 hours before the treatment and for 24 hours afterwards. The chance of these symptoms occurring increases as you receive more oxaliplatin and will improve over time once you stop treatment. Rarely, the numbness can be permanent. **Please see the Appendix at the back of this leaflet for further information.**



- **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.

- **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 will 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. **If you are taking capecitabine and you feel sick or are sick, please contact The Christie Hotline on 0161 446 3658 for advice.**

- **Hair loss**

Hair loss is usually total. 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. If you would like an appointment with the wig service, this can be arranged for you. Ask the staff for a copy of the 'wig fitting service at The Christie'.

- **Watery eyes**

Your eyes may also water. Often, this will improve in time and needs no specific treatment but if you have ongoing symptoms please discuss this with your doctor or nurse.

- **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 given which can help. Your chemotherapy dose may need to change. Try to keep your hands and feet cool and if possible, uncovered.

If you are taking capecitabine tablets and your hands and/or feet become sore, please contact The Christie Hotline on 0161 446 3658 for advice.

- **Increased sensitivity to the sun**

Your skin will tan/burn in the sun more easily. Sit in the shade, avoid too much sun and use a sunblock and wear a hat.

- **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.

- **Vein pain**

This chemotherapy can cause pain along the vein during and after treatment. This should only be temporary but contact your hospital doctor or nurse if this becomes severe.

Uncommon side effects (less than 1 in 10)



- **Chest pain or stroke**

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 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.

- **Extravasation** is when chemotherapy leaks outside the vein. If you develop redness, soreness or pain at the injection site **at any time** please let us know straightaway.

- **Tinnitus & high frequency hearing loss**

You may develop tinnitus (ringing in the ears), this sensation should subside when your treatment finishes. High frequency hearing loss can also occur with this chemotherapy, this may be permanent.



- **Diarrhoea**

If you are taking capecitabine tablets and you have diarrhoea (more than 4 times in a day or once during the night) stop taking the tablets and contact **The Christie Hotline immediately on 0161 446 3658.**

If you are having fluorouracil via a pump and diarrhoea becomes a problem, anti-diarrhoea tablets can be bought from a pharmacy or prescribed by your GP for a temporary period until this is resolved. If this problem persists contact The Christie. Ask the staff for a copy of 'Eating: help yourself' which contains some useful ideas about diet when you are having treatment.

- **Hyperpigmentation**

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

Rare side effects (less than 1 in 100)



- **Weakness of the heart**

Epirubicin can affect the heart and weaken the heart muscle. This is uncommon and is associated with increasing the dose of the treatment. Your treatment will not exceed the maximum dose. If there is any concern about your heart, a scan of the heart will be done before the start of your treatment.

- **Kidney function**

Some chemotherapy can affect your kidneys. It is important to monitor how your kidneys are working while you are having treatment. We do this by a blood test, but a more accurate assessment with a GFR can be arranged if there are concerns about your kidney function. It is important to drink plenty of fluids (at least 8 cups) the day before and for a few days after chemotherapy.

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 & 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.

Loss of periods

Due to the effect of chemotherapy on the ovaries, you may find that your periods become irregular or stop. This is more likely in women over the age of 40 when most women will notice some change in their periods. It is less common in women under the age of 40 but does still happen and can result in significant menopausal symptoms (see section below). Even if your periods stop completely during chemotherapy your periods may come back several years later. This means that you may be able to become pregnant even many years after chemotherapy. It is very important to use contraception if you don't want to get pregnant.

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 Care (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.

- **Tinnitus & high frequency hearing loss** – this may be permanent
- **Tingling & numbness in the fingers or toes** – this may be permanent.

Contacts

If you have any general questions or concerns about your treatment, please ring the area where you are having treatment:

- Administration enquiries **0161 918 7606/7610**
- Chemotherapy nurse: **0161 918 7171**
- Clinical trials unit **0161 918 7663**

For urgent advice ring The Christie Hotline on **0161 446 3658** (24 hours)

Your consultant is:

Your hospital number is:

Your key worker is:

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.

We try to ensure that all our information given to patients is accurate, balanced and based on the most up-to-date scientific evidence. If you would like to have details about the sources used please contact **patient.information@christie.nhs.uk**

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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
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Appendix

Oxaliplatin-induced peripheral neuropathy

Oxaliplatin is a commonly prescribed drug used in the treatment of gastrointestinal cancers. It has been used for many years, and the safety profile and side-effects are well known. **Peripheral neuropathy** (nerve damage) is a common side effect due to the effects of oxaliplatin on the nerves. Almost all patients experience temporary symptoms of pins and needles exacerbated by exposure to the cold. However, repeated treatment can cause persistent numbness to develop in more than 30% of patients treated with oxaliplatin, which can be long lasting, troublesome and permanent in up to 10% of patients.

It is important that patients and their carers are alert to the signs and symptoms of peripheral neuropathy. The symptoms should improve slowly after the treatment has finished, but in some people they may never go away and have potential to affect their quality of life forever. Sometimes the effects of the nerve damage become apparent, or even worsen **after** the discontinuation of the chemotherapy.

Oxaliplatin, in combination with fluorouracil or capecitabine-based chemotherapy, is used to treat patients with cancers such as stomach, oesophagus, pancreas or biliary tract in a number of different situations. Please do not worry if you are advised to stop oxaliplatin if you develop signs and symptoms of peripheral neuropathy. It is much safer to stop sooner rather than later, and you can still continue to receive and benefit from your fluorouracil or capecitabine-based chemotherapy.

Signs and symptoms of peripheral neuropathy:

For most individuals, tingling in hands will be triggered by anything **cold**, such as iced drinks and cold air. If you notice that your symptoms are related to the cold, you should avoid cold food and drinks and wrap up warmly (wear gloves, socks and a scarf to cover your nose and mouth) in the cold weather. Use gloves when taking things out of the freezer or fridge. These symptoms are generally short lived and expected with the use of oxaliplatin. If however you have these symptoms all the time, you do need to inform the cancer specialist and the nurse treating you.

The symptoms of peripheral neuropathy are known to worsen in terms of severity and duration with successive treatments. This is known as a *cumulative* effect. These symptoms can include numbness, tingling and cramping of the hands and feet. You may also find it hard to fasten buttons or to do other fiddly tasks such as tying shoelaces. In more severe or established cases one can experience difficulties writing, using a computer keyboard or difficulties in day to day walking (unable to feel the ground). In severe cases, these symptoms can mean that it is no longer safe for a patient to drive. This is why we want to emphasise the need to stop the drug in a timely manner, rather than carry on too long, causing more difficulties.

The medical team would want to review and adjust the dose of the oxaliplatin drug to account for this and reduce the risk of more severe permanent nerve damage. Therefore every time you attend for a chemotherapy review you should be asked

whether you have had any numbness, cramping or tingling of the hands or feet and whether they are worsening.

If persistent symptoms are present, the oxaliplatin drug will be stopped. There is no proven treatment to help reverse existing nerve damage, although symptoms often improve slowly over time. If you have pain associated with the numbness additional medications may be suggested to try to help reduce the pain. If a clinical trial is available your medical team will discuss this with you.

Self-care advice:

- Whilst receiving and after treatment with oxaliplatin, avoid cold temperatures and objects. For example, cold drinks, ice cream, washing in cold water. Many patients wear gloves when using the fridge or freezer.
- Cover yourself with a blanket while you are receiving your oxaliplatin infusion
- In winter, after receiving your treatment, take care when leaving the chemotherapy unit as the cold air outdoors can cause you to feel like you can't get your breath. Put on a scarf, gloves and warm coat before going outdoors.
- During the summer, avoid direct contact with air conditioning.
- If persistent symptoms occur mention this at your next hospital visit to the medical or nursing teams so that we can discuss what to do next.

If your tingling or numbness symptoms are persisting or worsening all the time (i.e. no full recovery before next dose), you should certainly inform your cancer specialist and chemotherapy nurse when you attend for a review.

The earlier the medical and nursing team are made aware of any signs of nerve damage, the sooner your treatment plan can be adjusted to reduce the risk of you developing any long-term nerve damage.