

Everolimus (Afinitor®) for pancreatic neuroendocrine tumours

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 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 everolimus. This is taken by mouth once a day without a break. This treatment can be repeated for as long as you are benefitting from it, and the side effects are tolerated.

Method of administration:

- everolimus tablets should be taken orally once daily at the same time every day consistently, either with or without food. Everolimus tablets should be swallowed whole with a glass of water. The tablets should not be chewed or crushed.
- if you miss a dose: and it is less than 12 hours until your next dose, skip the missed dose and continue with your normal schedule.
- the blister pack containing the everolimus tablets should be opened only when you are about to take them as they sensitive to light and air.

Store your medicine in a cool, dry place, out of reach of children.

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.

Drug interactions

Some medicines interact with everolimus, either making it less effective or more likely to cause side effects. Please check with your GP and pharmacist that any new medicines are safe. Drugs which should be avoided include itraconazole, fluconazole, clarithromycin, erythromycin, high dose steroids, diltiazem, verapamil, rifampicin, rifabutin, carbamazepine, warfarin and phenytoin. Live vaccines should also be avoided. If you are in any doubt you should contact The Christie Hotline on the number above.

Please do not eat grapefruit, Seville oranges or star fruit, or drink their juices while you are taking everolimus. St John's Wort should also be avoided.



Risk of infection

You are vulnerable to infection while you are having everolimus. 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.

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 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.

Possible side effects

Everolimus 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)

• **Stomatitis (sore mouth and mouth ulcers)**

Everolimus can cause a sore mouth and ulcers. Usually this is mild and responds to mouth washes. If it is severe enough to stop you eating and drinking normally, please contact The Christie.

• **Rash**

Everolimus may make you more sensitive to the sun and can cause a rash. If this is widespread, please contact The Christie. Sit in the shade, avoid too much sun and use a high factor sunblock cream. You may take anti-histamines if the rash is itchy, and you may use non-perfumed moisturising cream to soothe the skin.

• **Diarrhoea**

Diarrhoea is a 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 these instructions EXACTLY: Take 2 loperamide capsules 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 dose of loperamide is 8 capsules/tablets per day, however some patients with a stoma may require more than this to control output.

If you have a stoma or notice capsules in stoma output, you should ask for tablets rather than capsules.

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.

- **Tiredness or fatigue**

Everolimus may make you feel tired and lacking in energy, but we would not expect you to be in bed during the daytime. Try to take rest and get help with household chores. If necessary take time off work. Gentle exercise such as walking can be beneficial. Taking your tablets at bedtime instead of after breakfast can help.

- **Delayed wound healing**

Everolimus also delays wound healing. **The tablets will usually have to be stopped before and after surgery or dental extraction, and should not usually be taken if you have an open wound, leg ulcer or pressure sore.** Let your nurse or doctor know if any of these issues occur.

- **Anaemia**

While having this treatment you may become anaemic. This may make you feel tired and breathless. Let your nurse or doctor know if these symptoms are a problem. You may need a blood transfusion.

- **Raised blood sugar**

If you are a diabetic, you may notice that your blood sugar readings are higher than usual. Please discuss this with your doctor if it occurs. Your diabetes medication may need to be reviewed.

Uncommon side effects (less than 1 in 10)

- **Prone to bleeding**

Everolimus can make you prone to bleeding. You may have bruising or bleeding, for example, from the nose, gums or in the urine. Contact The Christie Hotline if this occurs. A small number of patients have experienced serious bleeding complications.

- **Nausea and vomiting**

This is not a common problem but, if this does occur, you can be prescribed some anti-sickness tablets by your doctor.

- **Pneumonitis (breathlessness)**

Some patients may experience a feeling of breathlessness, or develop a cough. If this happens please tell your doctor, or contact The Christie so that investigations and treatment can be undertaken.

- **Fluid retention (swelling of the ankles)**

Sometimes everolimus may cause your feet/legs to become swollen. If this is mild, no specific treatment is needed. Keeping your feet and legs raised may help. Tell your doctor if the swelling is severe.

Rare side effects (less than 1 in 100)

- **Raised cholesterol**

Your cholesterol level may become raised while you are taking everolimus. This is checked on regular occasions when you visit The Christie. Your doctor will advise if any treatment is necessary.

- **Reactivation of hepatitis**

There have been rare reports of reactivation of viral hepatitis (for example, hepatitis B or C). Please tell your doctor if you have ever been diagnosed with hepatitis.

Serious and potentially life threatening side effects

In a small proportion of patients anti-cancer therapy 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.

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 everolimus, and for 8 weeks following treatment. Anti-cancer drugs may be dangerous to unborn babies and this will also protect you and your partner from any 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: Everolimus 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.

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