

*The* ROYAL MARSDEN

NHS Foundation Trust

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# Everolimus (Affinitor®) for pancreatic neuroendocrine tumours

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**GI Unit**

**Patient Information**



**NHS**



## Introduction

Your doctor has recommended treatment with a medicine called everolimus. They have weighed the expected benefits in terms of controlling your cancer against the possibility of side effects. Your doctor will have discussed these with you. If you are still unsure about the benefits of treatment with everolimus, then please ask.

Everolimus is a man-made medicine known as a kinase inhibitor. It 'switches off' a cell's ability to produce proteins which are responsible for creating new cells and blood vessels.

The aim of this treatment is to stabilise or possibly to shrink your cancer. It is not possible to predict, before you start treatment, how your cancer will respond. This leaflet explains what you can expect from the treatment you will receive and ways of managing some of the side effects you may experience.

## Treatment plan

- Everolimus is a white to yellow coloured tablet and the strengths available are 5mg and 10mg.
- Your doctor will tell you what dose of everolimus you need to take. The usual dose is 10mg once a day to be taken continuously. Your doctor may adjust the dose. Sometimes everolimus is given at a dose of 5mg daily or on alternate days.
- Everolimus is taken with a glass of water, with or without food at the same time each day.

Treatment is usually given for 12 weeks and then your response is assessed by CT scan. If your cancer has shrunk or has not grown, then you may continue with further treatment, following discussion with your doctor. The doctors will review you in clinic monthly.

## Side effects

All medicines can have some side effects and this includes everolimus. These vary and for some people they may not occur.

### **The more common side effects are:**

- Sore or sensitive tongue or mouth
- Skin rash (including acne)
- Diarrhoea, abdominal pain
- Tiredness (fatigue)
- Infections
- Nausea (feeling sick).

### **The less common side effects are:**

- Swelling of arms and legs – usually this is mild and goes away when treatment ends
- Loss of appetite – this may lead to weight loss
- Changes in blood test results – we will monitor your liver and kidney function, cholesterol, triglyceride and glucose levels during your treatment
- Lung problems, which in rare cases can be serious. If you have an irritating cough or are regularly short of breath, you should contact your doctor
- Vomiting
- Headache
- Fever
- Anaemia.

We have listed the most common side effects of this chemotherapy. You may experience some or several of these side effects listed above and they may be mild, moderate or severe. Some can occasionally be life-threatening or lead to death and occur in 0.5-5% of cases (less than one in 100 people). All side effects will be discussed with you, however please raise any questions that you may have with your medical team or Clinical Nurse Specialist (CNS).

As with all drugs, there may be other side effects not mentioned here that you may experience. Because of the risk of side effects, it is important that you:

- **Always** tell your doctor if you suffer from any of these side effects, or if you have experienced any new symptoms since your last visit. Your doctor can help you by giving you medication or advice, to reduce or stop these side effects from occurring in the future.
- **Always** tell your doctor about any other medicine you are taking or planning to take, including herbal and complementary therapies.
- **Always** consult your doctor before having any other procedure, for example, dental work or vaccinations.

## Interactions with other medicines

Everolimus can interact with some other medicines. This can result in the drugs not working as well or cause severe side effects. Medicines to avoid if possible include:

- Ciclosporin, clarithromycin, erythromycin, ketaconazole, ritonavir
- Carbamazepine, phenytoin, rifampicin, dexamethasone, prednisolone
- St John's Wort, grapefruit or grapefruit juice.

Below are some suggestions for managing some of the more common side effects.

### **Sore mouth**

- It is important that you keep your mouth clean
- Drink plenty of fluids
- Use a mouthwash or rinse your mouth with salty water regularly
- Avoid hot drinks
- Avoid rough, coarse foods
- Avoid hot, spicy foods
- Changing to an infant toothpaste can reduce stinging when brushing your teeth, and using a toothbrush with softer bristles may help
- Contact your hospital nurse or doctor if you are unable to eat or drink because your mouth is sore.

### **Rash**

- Use moisturising creams on your skin immediately after a shower and before going to bed from the start of your therapy, if possible
- Your doctor will be able to prescribe anti-histamines to relieve itching
- Use coal tar shampoo to help relieve scalp discomfort
- Wear loose clothing
- Avoid hot showers
- Avoid direct sunlight
- Use a sun cream with sun protection factor (SPF) of at least 15.



### **Diarrhoea or abdominal cramping or bloating**

- Your doctor can prescribe anti-diarrhoeal and antispasmodic medications for you
- Peppermint water/capsules may be useful for controlling abdominal pain
- Drink plenty of fluids
- Increase dietary fibre and bulking foods such as bananas, rice, apples and toast
- Keep a food diary - this will help you find out if certain foods trigger diarrhoea
- Avoid spicy food, dairy food, high fat or high sugary foods.

### **Fatigue**

- Rest as you need to
- Eat a balanced nutritious diet and drink plenty of fluids
- Light exercise can be useful to increase your energy levels
- Time activities for when you feel you have the most energy
- Accept help if family or friends offer it - it helps you and makes them feel useful.

## Infections

Everolimus may reduce the rate at which white blood cells are produced in your bone marrow. This may put you at increased risk of bacterial or viral infection. If your temperature goes above 37.5°C or you develop any unexplained bruising or bleeding, then contact your hospital doctor.

## Nausea

Your doctor can prescribe anti-sickness medicine to help with this.

## Fertility, pregnancy and breastfeeding

- **Fertility** – Male and female fertility may be affected by everolimus. If it is relevant to you, you may wish to discuss the issue of fertility with your doctor before treatment is started.
- **Pregnancy** – Everolimus may cause harm to an unborn child. We recommend that you or your partner use a barrier method of contraception (such as condoms) during treatment and for two weeks after stopping everolimus treatment. If you know you are pregnant before starting treatment or you or your partner become pregnant during treatment, you must tell your doctor immediately.
- **Breastfeeding** – It is not known if everolimus is secreted in breast milk. However, as many drugs are excreted in human breast milk, and the effects of everolimus on infants have not been studied, breastfeeding is not recommended while receiving everolimus.



## Contact details

Please contact your CNS or The Royal Marsden Macmillan Hotline if you have any concerns or questions:

Clinical Nurse Specialist (Chelsea and Sutton) via switchboard on 0208 642 6011

Name:.....

Telephone:.....

**Pharmacy Medicines Helpline:** via the Hotline below  
(Monday to Friday, 9am – 5pm)

**or**

Email: *medicines.information@rmh.nhs.uk* giving full details of your enquiry and a contact telephone number.

Alternatively, please call:

**The Royal Marsden Macmillan Hotline:** 020 8915 6899  
(available 24 hours a day, 7 days a week)

## Notes and questions

## References

This booklet is evidence based wherever the appropriate evidence is available, and represents an accumulation of expert opinion and professional interpretation.

Details of the references used in writing this booklet are available on request from:

The Royal Marsden Help Centre  
Freephone: 0800 783 7176  
Email: [patientcentre@rmh.nhs.uk](mailto:patientcentre@rmh.nhs.uk)

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Should you require information in an alternative format, please contact The Royal Marsden Help Centre.

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[royalmarsden.org](http://royalmarsden.org)

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