

Panobinostat (Farydak®)

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 panobinostat (Farydak®). This is to treat your relapsed and/or refractory multiple myeloma.

You will take panobinostat with two other medicines: bortezomib (Velcade®) and dexamethasone. Panobinostat works with these medicines to prevent the growth and survival of myeloma cells in your body.

Panobinostat and dexamethasone are pills that you will take at home. Your Velcade® injection will be administered by a doctor in a clinic.

You will be treated initially for 8 cycles. The total duration of treatment can be up to 16 cycles (48 weeks).

You will take panobinostat on days 1, 3, 5, 8, 10 and 12 of a 21-day cycle.

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 your temperature is 37.5°C or above, or below 36°C or you have symptoms of an infection, contact The Christie Hotline straight away.



Other medicines

- **Do not** eat star fruit, grapefruit, or pomegranate, or drink grapefruit or pomegranate juice, while taking panobinostat. These products may increase the amount of medicine in your blood.
- Vitamins or herbal supplements may also interact with panobinostat so be sure to tell your doctor if you are taking anything else.

Possible side effects

Chemotherapy can cause many different side effects. Some are more likely to occur than others. We are all different, so we may get different side effects with varying severity. 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.

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.

Stop taking panobinostat and seek medical help immediately if you experience any of the following:

- difficulty breathing or swallowing, swelling of the face, lips, tongue or throat
- severe headache, feeling weak or paralysis of limbs or face, loss of consciousness
- fast breathing or feeling dizzy
- sudden crushing chest pain, increased or irregular heartbeat
- coughing up blood, nose bleed
- vomiting blood, black or bloody stool
- fever
- stomach or abdominal pain
- nausea or diarrhoea
- low urine output or feeling thirsty
- yellowing of the skin and whites of the eyes.

Common side effects (more than 1 in 10)

• Anaemia

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.

You will have a routine blood test every day while you are in hospital to monitor the effects of the chemotherapy, but please tell your nurse if you experience any of the symptoms listed above.

• Nausea and vomiting (sickness)

The severity of this varies from person to person. Anti-sickness medication may 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 The Christie, because your anti-sickness medication may need to be changed or increased.

• Diarrhoea

If this becomes a problem during or after your treatment, anti-diarrhoea tablets can be prescribed by

your doctor. Ask the staff for a copy of 'Eating: help yourself' which has some useful ideas about diet when you are having treatment.

- **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.

Uncommon side effects (less than 1 in 10)

- **Changes to your heartbeat**

Panobinostat may cause changes to your heartbeat. Tell your doctor or nurse if you notice your heartbeat is irregular or you feel more breathless than normal. They will check your heartbeat regularly.

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, and for at least 3 months after the last dose of panobinostat. 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.

Contacts

If you have any general questions or concerns about your treatment, please contact the Haematology team.

Myeloma nurse specialist - **0161 446 8167**

Haematology and transplant day unit - **0161 446 3925**

General enquiries - **0161 446 3000**

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

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 **patient.information@christie.nhs.uk**

For information and advice visit the cancer information centres at Withington, Oldham or Salford. 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