

Panobinostat (Farydak[®])

Treatment Guide

What is panobinostat?

Panobinostat, also known as Farydak®, is a histone deacetylase (HDAC) inhibitor drug used in the treatment of myeloma.

How does it work?

Panobinostat works by blocking the action of a protein called histone deacetylase (HDAC) in myeloma cells. This changes the way the myeloma cells are controlled.

In normal cells, there are genes that control cell survival and prevent cells from multiplying out of control.

When normal cells turn into myeloma cells, one of the changes that happens is that the genes

controlling cell survival are switched off by a protein called histone deacetylase (HDAC).

When this happens, the myeloma cells can multiply out of control.

Panobinostat blocks this process in myeloma cells, so that the 'control' genes are switched back on, and the myeloma cells are stopped from growing and multiplying.

How is panobinostat given?



Panobinostat is a capsule which is taken by mouth (orally). The capsule should be swallowed whole, with water.



Panobinostat is normally given in combination with 2 other myeloma treatments, bortezomib and dexamethasone.



Panobinostat is usually given for 2 weeks, followed by 1 week off. Together, this makes a 3-week treatment cycle, which is repeated for a number of cycles. Panobinostat is not given every day.

Possible side effects

Panobinostat has a number of possible side effects which can vary from patient to patient. You will experience some side effects, but it is unlikely you will experience them all and most side effects will ease once treatment has finished. Always report any side effects to your healthcare team as soon as possible so they can be treated quickly.

The side effects listed here are those experienced most often. For a complete list of side effects please refer to the patient information leaflet which is included in the pack with the treatment. If you do not have this, ask your healthcare team for it.



Myeloma UK provides a wide range of information booklets about side effects and their management. Relevant booklets are signposted beneath each side effect on the following pages.

You can find these along with all of our information booklets online at myeloma.org.uk/library.

You can also find out more about the management of these side effects by asking your healthcare team or by contacting Myeloma UK.



0800 980 3332



AskTheNurse@myeloma.org.uk



myeloma.org.uk



Heart problems

Panobinostat can cause heart problems or worsen pre-existing heart conditions. You should report any chest pain or changes in your heartbeat to your healthcare team immediately.



Call 999 if you experience any severe chest pain or tightness.



Risk of infection

Panobinostat may affect your immune system, increasing your risk of infection. Common signs include: high or low temperature (37.5°C or above, or below 36°C), feeling shivery or cold, peeing (passing urine) more often or pain when peeing, and cough or cold symptoms.



Contact your healthcare team or out of hours service immediately if you think you have an infection. Infections can become serious if not treated quickly.



For more information see the **Infection and myeloma Infosheet** from Myeloma UK



Gut problems

Panobinostat can cause nausea and vomiting. You may be given anti-sickness (anti-emetic) medicines to prevent or reduce nausea and vomiting. You must take them as prescribed rather than waiting until you feel sick. There are several types of anti-sickness medicine and if the one you have is not effective, ask to try another.

Panobinostat can also cause diarrhoea, indigestion, or abdominal pain. You may be given medicines to help with these side effects.

Drink plenty of fluids to avoid dehydration, especially if you have been vomiting or have diarrhoea. If vomiting is prolonged and you cannot keep food down, contact your healthcare team for advice.



For more information see the **Nausea and vomiting Infosheet** and the **Diarrhoea and constipation Infosheet** from Myeloma UK



Appetite loss

Panobinostat can cause appetite loss. If you start losing weight, or are concerned about your appetite, ask to be referred to a dietitian. They may be able to offer high-calorie food and drink supplements.



For more information see chapter 6 (Diet) in the **Living well with myeloma Infopack** from Myeloma UK



Too much fluid in the body

Panobinostat can cause swelling of the legs or feet, caused by too much fluid in the body. This is called peripheral oedema. If you are struggling with swollen legs or feet, your healthcare team may prescribe some water tablets (diuretics) to help your body remove the excess fluid.



Insomnia

Panobinostat can cause problems with sleeping at night (insomnia). This may be minimised by taking panobinostat in the morning. Speak to your healthcare team if insomnia is affecting you.



Low blood pressure

Panobinostat can cause low blood pressure. This may cause you to feel faint or dizzy when you stand. Speak to your healthcare team if you experience these symptoms.

If you feel dizzy or lightheaded when taking panobinostat, you should not operate machinery or drive a car.



Fatigue

Fatigue is a feeling of extreme tiredness that is not relieved by sleep. It usually resolves after treatment has finished. Your treatment, any side effects, and your mental health can all impact fatigue. Treating any medical causes such as anaemia, can help to manage fatigue. Allowing time for rest, gentle exercise, and complementary therapies such as massage may also help.



For more information see the **Fatigue and myeloma Infoguide** from Myeloma UK.



Anaemia and bleeding

Panobinostat can decrease the number of red blood cells, causing anaemia. Symptoms include: looking pale, shortness of breath, and fatigue. Panobinostat can also decrease the number of platelets, increasing your risk of bleeding or bruising. Treatment for these side effects can ease symptoms and boost your blood cell counts.



For more information see the **Fatigue and myeloma Infoguide** and the **Bleeding and bruising Infosheet** from Myeloma UK.

Important information about panobinostat



You must not take panobinostat during pregnancy, as it is expected to be harmful to the baby. You must use effective contraception while on this treatment, and for 6 months after treatment has finished, if you or your partner could become pregnant.



You should not breastfeed when taking panobinostat as it is not known if it can pass to the milk.



You should not have pomegranate, grapefruit, or starfruit (including juices) when taking panobinostat, as they can increase the amount of panobinostat in your blood.



Supplements or herbal medicines that have not been prescribed by your haematologist may cause harm when taken alongside your prescribed treatment.

You must speak to your healthcare team before taking any kind of supplement or alternative treatment, including herbal, traditional or natural medicines and remedies, and vitamins or wellbeing supplements, to ensure it is safe to do so.



If you have any questions about your treatment, speak to your healthcare team. They are the best people to ask if you have questions about your individual situation. The information in this publication is not meant to replace their advice.



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We're here for everything a diagnosis of myeloma brings

Get in touch to find out more about how we can support you

Call the Myeloma Infoline on



0800 980 3332

Email Ask the Nurse at

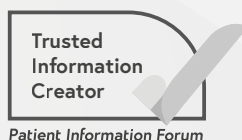


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Visit our website at



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We appreciate your feedback

Please fill in a short online survey about our patient information
at **myeloma.org.uk/pifedback** or email any comments to
patientinfo@myeloma.org.uk



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myeloma.org.uk/about-our-information