



Pentostatin (Nipent[®])

This leaflet is offered as a guide to you and your family. Your treatment will be fully explained by your doctor or nurse, who will be happy to answer any questions.

This treatment can have serious or possibly life-threatening side effects. It is very important that you report side effects straight away.

Pentostatin is a type of therapy used to slow or stop the growth of certain cells in your body called lymphocytes. The length of treatment depends on how well your body responds to them but will initially be 12 treatments. These will be given at 2-weekly intervals in the haematology and transplant unit outpatients department.

Your treatment

How is it given

Pentostatin may be given by injection or via infusion through a fine tube (cannula) placed into the vein of your arm over 20-30 minutes. Before and after the Pentostatin you will also be given some fluids by infusion to help reduce potential side effects of treatment.

The treatment is usually given every 2 weeks. The length of your treatment will depend on your response and tolerance to the drug.

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. A normal temperature is between 36°C and 37°C.

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.

Possible side effects

Each person's reaction to Pentostatin is different. Some people have very few side effects, while others may experience more. The side effects described in this information will not affect everyone who is given Pentostatin.

We have outlined the most common side effects as well as rarer ones, so that you can be aware of them if they occur. However, we have not included those which are very rare and therefore extremely unlikely to affect you.

If you notice any effects that you think may be due to the drug, but that are not listed in this information, please discuss these with your doctor or nurse.

Common side effects

• Allergic reaction

An allergic reaction may occur while you are having the drip or shortly afterwards. Signs of an allergic reaction include skin rashes and itching, high temperature, shivering, reddening of the face, dizziness, headache, breathlessness, anxiety and a feeling that you want to pass urine. You will be monitored for any signs of an allergic reaction while your treatment is being given. Tell your doctor or nurse immediately if you experience any of these symptoms.

• Fever and chills at infusion

These may occur with Pentostatin but they do not usually last long. Your doctor may prescribe medicines to reduce these effects.

• Lowered resistance to infection

Pentostatin can reduce the production of white blood cells by the bone marrow, making you more prone to infection. This effect can begin seven days after treatment has been given.

You will have a blood test before having more Pentostatin to make sure that your cells have recovered. Occasionally it may be necessary to delay your treatment if the number of blood cells (the blood count) is still low.

• Bruising or bleeding

Pentostatin can reduce the production of platelets (which help the blood to clot).

• Anaemia (a low number of red blood cells)

While having treatment with Pentostatin you may become anaemic. This may make you feel tired and breathless. Let your doctor or nurse know if these symptoms are a problem.

• Feeling sick (nausea) and being sick (vomiting)

If you do feel sick this may begin a few hours after the treatment is given and last for up to a day. Your doctor can prescribe very effective anti-sickness (anti-emetic) drugs to prevent, or greatly reduce, nausea and vomiting. If the sickness is not controlled, or continues, tell your doctor or nurse; they can prescribe other anti-sickness drugs which may be more effective. Some anti-sickness drugs can cause constipation. Let your doctor or nurse know if this is a problem.

• Lethargy (feeling weak) and fatigue (extreme tiredness)

You may suffer from fatigue. It is important to allow yourself plenty of time to rest.

- **Loss of appetite**

If your appetite is affected please tell your doctor or nurse as they will be able to offer you support with advice on boosting your appetite, coping with eating difficulties and maintaining weight. We may refer you to the dietitian for extra help and advice.

Uncommon side effects

- **Skin changes**

Your skin may feel dry and may itch. Some people notice spots (like acne) on their face or upper body. This usually returns to normal a few months after the treatment has finished. If this occurs please tell your doctor or nurse as treatment with creams may help.

- **Dry and gritty eyes**

Dry and gritty eyes can occur due to inflammation of the lining (conjunctiva) of the eyelids. If this happens it is important to tell your doctor or nurse who can prescribe soothing eye drops.

- **Diarrhoea**

This can usually be controlled with anti-diarrhoea medicines but let your doctor or nurse know if it is severe or if it continues. It is important to drink plenty of fluids if you do have diarrhoea.

- **Mouth sores and ulcers**

Your mouth may become sore, or you may notice small ulcers during this treatment. Drinking plenty of fluids, and cleaning your teeth regularly and gently with a soft toothbrush, can help reduce the risk of this happening. Tell your nurse or doctor if you have any of these problems.

Rare side effects

- **Your liver may be temporarily affected**

Pentostatin may cause changes in the way that your liver works, though your liver will return to normal when the treatment is finished. This is very unlikely to cause you any harm, but your doctor will monitor this carefully. Samples of your blood will be taken from time to time to monitor your liver and check that it is working properly.

- **Your kidneys may be affected**

Usually this does not cause any symptoms and the effect is usually mild, but if the effect is severe the kidneys can be permanently damaged unless treatment is stopped. For this reason your kidneys will be checked by a blood test before each treatment. If necessary, we may give you medicine to help you to pass urine. If you are asked to drink extra fluid it is important to do this, or to let your nurse or doctor know if you find this difficult, perhaps because you are feeling sick.

- **Changes to the lungs**

Higher doses of Pentostatin may cause some changes to lung tissue. Tell your doctor if you notice any coughing or breathlessness.

- **Changes in the way your heart works**

Higher doses of Pentostatin may cause changes in the muscle of the heart. This can affect how the heart works. The effect on the heart depends on the dose given. It is very unusual for the heart to be affected if you receive standard doses. Tests to see how well your heart is working may sometimes be carried out before the drug is given.

- **Hair loss**

Hair loss is rare, but your hair may become thinner, or occasionally fall out completely. If this occurs it usually begins about 3 to 4 weeks after starting treatment, although it may occur earlier. It is temporary and your hair will grow back once the treatment is finished. Your nurse can give you advice about coping with hair loss.

- **Pentostatin leakage into the tissue (extravasation)**

If Pentostatin leaks into the tissue around the vein it can damage the tissue in that area. If you notice any stinging or burning around the vein while the drug is being given, or any leakage of fluid from the cannula site, it is very important that you tell the doctor or nurse immediately

If the area around the injection site becomes red or swollen at any time you should notify the doctor or nurse immediately.

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 use a condom during sexual intercourse. 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. If you have any concerns about your fertility, please discuss this with your doctor or chemotherapy nurse before you start treatment.

Before taking pentostatin

Tell your doctor or nurse of any prescription or non-prescription drugs (including vitamins and supplements) you are currently taking.

What should I avoid while on pentostatin?

Pentostatin can lower the activity of your immune system making you susceptible to infections. Avoid contact with people who have colds, the flu, or other contagious illnesses and do not have vaccines that contain live strains of a virus (e.g., live oral polio vaccine) during treatment with Pentostatin. In addition, avoid contact with individuals who have recently been vaccinated with a live vaccine. There is a chance that the virus can be passed on to you.

Late side effects

Some side effects may become evident only after a long time. 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 and Transplant Unit.

- Jo Tomlins, Leukaemia Nurse on 0161 446 8010
- Haematology and Transplant 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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Details of the sources used are available, please contact Patient.Information@christie.nhs.uk