

# Nivolumab

This leaflet is offered as a guide to you and your family. The possible benefits of treatment vary: for some people immunotherapy may reduce the risk of the cancer coming back, for others immunotherapy may control the cancer and its symptoms. Nivolumab is a treatment which helps to reactivate the immune system so that you are able to fight the cancer. Your treatment will be fully explained by your doctor or nurse, who will be happy to answer any questions.

## Your treatment

Your doctor or nurse clinician has prescribed a course of treatment with Nivolumab. Nivolumab is given by an intravenous infusion **once every 2 weeks or every 4 weeks** and takes approximately one hour to give.

You will have a routine blood test before the start of each cycle of treatment. You will also be seen in clinic prior to each cycle initially, and then every few cycles. Your clinic appointment may not be on the same day as you are scheduled to have your treatment.

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

Tell your medical team if you are taking or are prescribed steroids (prednisolone/dexamethasone) as these interfere with the effect of nivolumab.

## Possible side effects

Nivolumab can cause many different side effects in different people. 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. If side effects are severe you may need to take a break from treatment, or have a dose reduction. A small number of people do not tolerate this treatment.

## **Very common side effects**

- **Diarrhoea**

Mild diarrhoea is common (less than 3 episodes a day). Anti-diarrhoea tablets can be prescribed by your GP to help control this. Severe diarrhoea is less common (4 episodes or more a day but if this occurs it can stop you from eating and drinking - which will cause you to become dehydrated. If this occurs you can feel weak and dizzy. You should contact The Christie Hotline on **0161 446 3658** for advice if this occurs. Colitis (severe diarrhoea) can occur - this may lead to tears or holes in the bowel which may be life threatening. Contact The Hotline immediately if you have bloody stools, dark/tarry or sticky stools, severe diarrhoea or very bad stomach ache.

- **Skin rash/Itching**

If you develop a skin rash and/or itching please contact The Christie. When going out in the sun you should wear high protection sun factor cream to protect your skin. You may be prescribed anti-histamines to help control any itching. Using a non-perfumed moisturiser may help to soothe the skin.

- **Fatigue (feeling tired/weak)**

Nivolumab may make you feel tired and lacking in energy, but it is not expected that you would feel tired enough to go to bed during the day time. Try to take rest and get help with household chores. If necessary take time off work. Gentle exercise such as walking can help.

- **Decreased appetite**

Nivolumab may cause you to lose your appetite. You should be weighed at every clinic appointment, if you continue to lose weight you may be prescribed dietary supplements to help with this. If required you can be referred to a community dietitian for dietary advice.

## **Common side effects (more than 1 in 10)**

- **Underactive thyroid gland (hypothyroidism)**

We screen for this using a simple blood test. It is quite common for patients being treated with nivolumab to have abnormal thyroid function test results. If your test results are abnormal you will be prescribed thyroid hormone replacement tablet (levothyroxine) to correct this. Physical symptoms of this include dry skin, shortness of breath, changes in your skin and hair, weight loss/gain and decreased appetite, increased sensitivity to the cold and tiredness.

- **Pneumonitis (inflammation of the lungs)**

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

- **Mucositis (sore mouth and ulcers)**

Nivolumab 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 Hotline.

- **Muscle, bone and joint ache**

Aches and pains can be experienced in the joints (arthralgia) and muscles (myalgia) can occur whilst having treatment with nivolumab. The severity of this varies from person to person. It is important to inform the hospital and then appropriate painkillers can be prescribed.

- **Inflammation**

Nivolumab can cause numbness, weakness, tingling and/or burning pain of the arms and legs. Nivolumab acts on your immune system and may cause inflammation of parts of your body. Inflammation may cause serious damage to your body and some inflammatory conditions can be life-threatening and need treatment or withdrawal of nivolumab.

- Inflammation of the eye (which causes pain, redness, visual problems)
- Inflammation of the pancreas (symptoms include severe pain in the upper abdomen, decreased appetite, nausea and vomiting)
- Loss of protective sheath around the nerves (symptoms may include numbness, loss of reflexes, uncoordinated movements, poorly controlled blood pressure, blurred vision and dizziness).
- Temporary inflammation of the nerves causing pain, weakness, and paralysis in the extremities.
- Inflammation of the stomach/intestines causing abdominal pain, abdominal bloating, indigestion, nausea/vomiting and loss of appetite

- **Allergic reaction**

This can occur whilst you are having the infusion of nivolumab. If you develop a rash, hives, itching, red/swollen/blistered or peeling skin with or without fever, wheezing, tightness in the chest or throat, trouble breathing or talking, unusual hoarseness or swelling of the mouth, face, lips, tongue or throat - tell a member of the medical team immediately, or if at home contact The Christie Hotline on **0161 446 3658**.

- **Skin and hair changes**

This may result in dry skin or redness of the skin. You may also develop vitiligo. This is a long term skin condition characterised by patches of the skin losing their pigment. The patches of skin affected becoming white. Unusual hair loss and hair thinning can also occur.

- **Diabetes**

Signs that you may have developed diabetes are insatiable thirst, passing increased amounts of urine, and an increased appetite with a loss of weight. If these occur you need to tell your medical team and this will be investigated further and treatment initiated if required.

- **Liver problems**

Signs and symptoms of this include yellow appearance of the skin and/or the eye (jaundice), pain on the right side of your stomach area or tiredness.

- **Problems with your hormone producing glands**

Fatigue, weight change or headache and visual disturbance can be signs and symptoms of hormone imbalance. If these occur you need to tell your medical team.

- **Altered kidney function**

Treatment with nivolumab can alter your kidney function, which will be monitored regularly throughout your time on this treatment. Any alterations in your kidney function shown by blood tests will be discussed with you and treated accordingly.

### **Serious and potentially life-threatening side effects**

In a small proportion of patients this treatment 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 while you are having the course of treatment, you or your partner use a condom during sexual intercourse. Chemotherapy can be 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 nurse clinician before you start treatment.

### **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

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

If you have any general questions or concerns about your treatment, please ring:

- The nurse specialist or nurse clinician for your clinical team

Your consultant is: .....

Your hospital number is: .....

Your key worker is: .....

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.

We try to ensure that all our information given to patients is accurate, balanced and based on the most up-to-date scientific evidence. If you would like to have details about the sources used please contact **patient.information@christie.nhs.uk**

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For more information about The Christie and our services, please visit **www.christie.nhs.uk** or visit the cancer information centre at Withington, Oldham or Salford.

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