

## Ipilimumab and nivolumab

Ipilimumab and nivolumab are types of anti-cancer treatment called immunotherapy. The possible benefits of this 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.

### Your treatment

Your oncology team has prescribed a course of treatment with ipilimumab and nivolumab.

This treatment is given by intravenous infusion **once every 3 weeks for a total of 4 cycles.**

**Ipilimumab is given over 90 minutes and nivolumab is given over 60 minutes.**

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.

### If you are taking any other medications

Please inform your oncology team if you are taking any medications. Most importantly, tell your medical team if you are prescribed steroids (prednisolone/dexamethasone) or any other medications that suppress the immune system as these can interfere with the effect of nivolumab.

### Infusion related reactions

Occasionally side effects can occur while you are having the infusion. These may include chills, fever and shivering. If you have any of these side effects please tell your nurse straight away, even though your progress will be monitored regularly.

Rarely, you may also develop a skin rash, headache, sore throat or sickness. If this happens or you notice any swelling around the eyes and face, feel dizzy or faint, or have any shortness of breath during the treatment, please tell the nurse or doctor immediately. This may be an allergic reaction and the drip may need to be slowed down or stopped. You may feel tired or have a headache. These symptoms are related to your treatment and usually resolve when the infusion has finished. If you do have any reactions to your treatment, we may be able to give you medication to prevent this on your next infusion.



## Possible side effects

Nivolumab can cause many different side effects. Some are more likely to occur than others and some people may not get any side effects at all. The side effects may be of varying severity. Most side effects are usually temporary, but in some rare cases they can be life-threatening. It is important to tell your oncology team 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 and possibly have a different treatment to control the side effects. A small number of people do not tolerate this treatment and have to discontinue it permanently.

## Very common side effects (more than 1 in 10)

### • General fatigue

This treatment 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 daytime. Try to take rest and get help with household chores. If necessary, take time off work. Gentle exercise such as walking can help. You may be experiencing an imbalance in certain hormones (see below for other signs of this condition).

### • Diarrhoea

Mild diarrhoea is common (less than 3 episodes a day). Anti-diarrhoea tablets can be prescribed by your GP or bought from the pharmacy to help control this.

Severe diarrhoea is less common (4 episodes or more a day). If this occurs, you may become dehydrated especially if you stop eating and drinking. Dehydration can make you feel weak and dizzy.

### • Colitis (very severe diarrhoea)

You should contact The Christie Hotline for advice if you are passing stools more than 4 times a day with any of the associated symptoms:

- waking in the night to pass stools
- pain in your abdomen
- blood or mucus in the stool
- vomiting

If colitis occurs, you will have to be admitted to hospital for treatment. We may have to interrupt treatment with nivolumab and treat with steroids or other immune suppressing medications.

### • Joint and muscle pain

This treatment can cause pains in your joints or muscles. For mild to moderate pain you should contact your GP for pain relief. If you experience severe joint or muscular pain during treatment that is limiting your movement, please contact The Christie Hotline for advice. Please inform us at the start of treatment if you have any existing joint or muscle problems.

### • Skin rash/itching

If you develop a skin rash and/or itching, please let your oncology team know. You may be prescribed antihistamines and topical creams to help control any itching and relieve a rash. Using a non-perfumed moisturiser may help to soothe the skin. When going out in the sun you should wear high sun protection factor cream to protect your skin (SPF 50). In very rare instances the rash can be quite bad and would require steroid tablets. During this time treatment would have to be interrupted and we may have to refer you to a dermatologist for further management.

## Common side effects (up to 1 in 10)

### • Penumonitis (inflammation of the lungs)

Some patients may experience feelings of breathlessness or develop a persistent cough which is new.

This could be a sign of pneumonitis. If this happens contact The Christie Hotline for advice. You may need to have a chest X-ray and a course of steroids if you are diagnosed with pneumonitis. Treatment may be interrupted at this time to allow the pneumonitis to resolve.

- **Liver problems**

The treatment can affect how the liver works. We monitor your liver function with blood tests before each cycle of treatment. Signs and symptoms of an abnormal liver function include yellow appearance of the skin and/or the eye (jaundice), pain on the right side of your stomach area, easy bruising or bleeding or tiredness. If you notice any of these symptoms call the Christie Hotline.

- **Skin and hair changes**

Vitiligo is a long-term skin condition characterised by patches of the skin losing their pigment. The patches of skin affected become white. Unusual hair loss and hair thinning can also occur.

- **Peripheral neuropathy**

You may experience symptoms such as pins and needles, numbness and tingling or a burning sensation that usually occurs in the hand and feet and can also occur in the face. Some people may feel this can affect walking and using hands for daily activities. If you are troubled by these symptoms contact your oncology team for further advice and symptom management.

- **Problems with your hormone producing glands**

The main glands that can become affected are the thyroid gland, the pituitary gland and the adrenal glands. These glands produce certain hormones. Any changes in hormone levels will be corrected by means of tablets which will most likely have to be taken for the rest of your life.

#### **Inflammation of the thyroid gland (thyroiditis)**

We screen for this using a simple blood test. It is quite common for patients being treated with nivolumab and ipilimumab to have abnormal thyroid function test results. If your test results are abnormal you will be prescribed tablets to correct this. Thyroid levels can become too low which may give symptoms such as tiredness, dry skin, brittle hair and nails, weight gain and increased sensitivity to the cold. If thyroid levels are high you may experience palpitations, feeling hot and sweaty, weight loss, palpitations and anxiety. If you experience any of these symptoms contact your oncology team for further advice.

#### **Inflammation of the pituitary (hypophysitis)**

Most common symptoms are headache that isn't relieved by painkillers, nausea and vomiting, changes in your vision, and tiredness. If you experience any of these please inform your oncology team. Diagnosis of this condition is usually by means of a scan and blood tests.

#### **Problems with the adrenal glands**

The adrenal glands produce cortisol which is a steroid hormone. A problem with the adrenal glands or the pituitary may cause changes in the cortisol levels in the body. Any changes in cortisol levels will be seen in routine blood tests. However, you may feel faint, dizzy, experience weakness, fatigue or feel nauseous. You must report this to your oncology team.

- **Eye problems**

This treatment can cause problems with your eyes. You may experience dry eyes, blurred vision or very rarely inflammation in the middle layer of the eye (uveitis). If you experience any eye symptoms such as swollen or red eyes, any changes to your vision or sensitivity to light report these to your oncology team. You may need to visit an optician or ophthalmologist for further investigation.

## Uncommon side effects (up to 1 in 100)

### • Altered kidney function

Treatment with nivolumab can alter your kidney function. If you have pre-existing kidney disease this should be discussed with your oncology team. Before each cycle of treatment, we will do a blood test to check your kidney function. Any changes in your kidney function will be discussed with you and treated accordingly. Treatment may be interrupted to allow your kidney function to normalise

### • Altered blood sugar levels (Diabetes)

Treatment can cause an alteration in blood sugar levels as it can affect your pancreas. You will have regular blood tests to check your blood sugars. 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 oncology team, and this will be investigated further. If you are found to be diabetic, we will start appropriate treatment. Treatment with nivolumab will continue without interruption.

## Rare side effects (less than 1 in 100)

### • Effects on the heart

This treatment can affect the way the heart works. This is a very rare side effect but can become very serious. **If you have chest pain dial 999 immediately for emergency services.**

Otherwise contact The Christie Hotline straight away if you

- feel like your heart is beating too fast or too slow
- are breathless, dizzy or faint

### • Problems with the nervous system

Treatment can cause problems with the nervous system which then can affect muscular function. Myasthenia is a condition in which muscles may feel weak. You may experience droopy eyelids, difficulty in speaking or making facial expressions, chewing and swallowing, weak arms, legs or neck. This is a very rare side effect of treatment but is potentially life threatening. These side effects are also similar to symptoms of a stroke. **It is advisable to call the emergency services on 999 to rule out a stroke first.**

## Serious and potentially life threatening side effects

In a very small number 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.

Not all side effects are listed above and there may be some rare and unusual side effects that we are unaware of. Please contact your medical team if you experience any unusual symptoms.

## Sex, contraception and fertility

### Protecting your partner and contraception

It is important that you do not get pregnant or father a child whilst on immunotherapy. There is evidence that these drugs can affect the unborn child. It is important that you use effective birth control for as long as you are on the treatment and for at least 4 months after. If you suspect that you may be pregnant, please tell your doctor immediately.

### Fertility

This immunotherapy 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: .....

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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 **the-christie.patient.information@nhs.net**

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