

## **General Immunotherapy.**

**This leaflet is to be given in conjunction with Nivolumab, Ipilimumab, Pembrolizumab, Durvalumab, Atezolizumab leaflets.**

This leaflet provides general information for patients who are receiving any of the above Checkpoint Inhibitor Immunotherapy treatment. This leaflet will explain what immunotherapy is and when and how it is given. It will also tell you about the common side effects that you may experience. The importance of reporting these side effects and how to report them. It will also provide you with information about the acute oncology service and as to what may happen if you were admitted to another hospital and why we would need to do this.

Contact details and useful links are given at the end of the leaflet.

## **What is Immunotherapy and why am I having it?**

Immunotherapy is NOT chemotherapy. Immunotherapy is the name given to a group of drugs which help to boost our immune system to recognise, identify and destroy cancer cells. Your oncologist has prescribed immunotherapy because it has been found to be effective in treating your type of cancer.

## **How does immunotherapy work?**

One reason that cancer cells thrive is because they are able to hide from your immune system. Certain immunotherapies can mark cancer cells so it is easier for the immune system to find and destroy them, other immunotherapies boost your immune system to work better against cancer. The immune system defends and protects our bodies from infection and disease. It is made up of organs and special cells that work

together to find and fight germs such as viruses, bacteria, or abnormal or unhealthy cells that cause disease such as cancer. But some cancer cells can hide from the immune system because they look a lot like the normal cells. In some cases the immune system may find cancer cells, but it isn't strong enough to destroy all of them. Immunotherapy helps the immune system to recognise and destroy cancer cells.

## **How often will I receive this treatment?**

Depending on the type of immunotherapy you are given, it will be given once every two or four weeks, and the duration of treatment will also depend upon the response of the drug, and this is something that your Oncologist and Nurse Specialists will discuss with you.

## **How often will I see my Oncology Team?**

You will need to be seen in the outpatient clinic regularly. This will be a few days before each treatment. At each outpatient clinic your team will check how you are feeling and discuss any problems you may have. This is so we can check how the treatment is affecting you. You may be contacted at other intervals to check your blood. Your team will give you a plan.

## **Before you start immunotherapy**

Tell your doctor about any medicines you are taking, have recently taken, or might take.

Make sure your Oncologist knows if you:

- Have an autoimmune disease( a condition where the body attacks its own cells)
- Have pneumonia or inflammation of the lungs (called pneumonitis)
- Have had previous allergic reactions to monoclonal antibody therapies
- Have had a chronic viral infection of the liver, including hepatitis B (HBV) or hepatitis C (HCV)
- Have human immunodeficiency virus (HIV) infection or acquired immune deficiency syndrome (AIDS)
- Have had any problems with your heart

### **How is Immunotherapy given?**

Your treatment is given through a drip into a vein in the back of your hand or arm.

### **Where will my treatment be given?**

The immunotherapy is given in the day case treatment areas at Velindre. Our day cases are called 'Chemotherapy day Unit' and 'Rhosyn Unit'. You may also be asked to attend one of our outreach treatment units that are closer to your home. You may not have your treatment in the same unit for each infusion. The reason why this happens is to ensure that you have your treatment at the right time interval and due to the capacity of spaces available on the units you may move around. Please be assured that wherever you have your immunotherapy, the staff looking after you are all experts in administering these treatments. The treatment areas are often limited for space, so we politely ask that you limit the person

sat with you to just one. We would advise you to bring in some snacks or drinks, reading matter and or electronic devices (with headsets) to keep you occupied whilst you are having your treatment. Please note that Velindre NHS Trust accepts no liability to loss or damage of personal property during your visit.

### **How long will the treatment take?**

The Infusion takes between 30 minutes to 90 minutes for each infusion, depending on the type of immunotherapy you are prescribed.

### **Giving your consent to treatment**

Your Oncologist and Clinical Nurse Specialist will discuss with you the risks and intended benefits of the immunotherapy treatment. Immunotherapy can only be given with your agreement. Once you feel that you have been provided with information, and had the opportunity to have any questions answered your consent will be obtained by signing a consent form.

By giving your consent to treatment, it is advisable to think of it as a contract between your oncology team, who have a duty of care for your wellbeing, and a contract by you, to report promptly to your oncology team any side effects that you may experience so that we can manage them appropriately.

### **Immunotherapy Education sessions for patients and families.**

Here at Velindre Cancer centre the patient is placed at the centre of our care. We believe that it is important to provide patients and families with the correct information, and have the opportunity to attend our education session, which is specifically tailored for patients about to receive or receiving 'checkpoint inhibitor' immunotherapy treatments. It is not compulsory to attend, but we would strongly advise your

attendance so that you have the opportunity to learn about the treatments, learn how to recognise the potential side effects, and know when and how to report those side effects.

### **The QR Code**

For some smartphones you can scan a reader through your camera, for other phones you may need to download a free QR reader app. Once you scanned the QR code it will take you directly to the Velindre Immunotherapy Guidelines. The guidelines are written with healthcare professionals in mind, and useful if you away on holiday or need admission to another hospital, or just for your interest.



### **The Treatment helpline & Immunotherapy Alert Card**

Here at Velindre Cancer Centre we have a 24 hour, 7 days a week service. This service is your first point of contact if you suspect that you are having a side effect from your 'checkpoint inhibitor' immunotherapy.

### **Vaccinations and 'Checkpoint Inhibitor' Immunotherapy**

Please check with your Velindre team before you have a vaccination. There is no known contraindication in having the flu vaccine with immunotherapy.

**Immunotherapy can cause serious side effects which need to be treated straight away**

### **Potential Side effects**

Like all medicines, 'checkpoint inhibitor' immunotherapies can have side effects, although not everyone gets them. When you have immunotherapy you can have some serious side effects. You may experience more than one side effect at the same time. It is very important to report the side effects straight away to the treatment line and or your Oncology team. Your doctor will recommend other medications, usually steroids in order to prevent more severe complications, and reduce your symptoms. Your doctor may decide to withhold the next dose of immunotherapy, or stop your treatment if the symptoms become severe. Therefore prompt reporting is essential.

If you develop any side effects with your treatment or your symptoms worsen, tell us immediately. It is also important that you do not try to treat your symptoms on your own.

Please note that these signs and symptoms are sometimes delayed and may develop weeks or months after your last dose.

## The potential side effects of your treatment

**Please see your individual immunotherapy leaflet for advice on managing side effects.**

The side effects are related to the way in which the medicine fights the cancer by boosting the immune system. These side effects are different from the side effects experienced with other types of cancer treatment, for example, chemotherapy. The side effects listed are representative of what *can* occur, and are not meant to frighten you, but to inform you.

The important thing to remember is that side effects which are reported early are much easier to treat. Most can be managed easily with expert advice. Please follow the information we give you about when to contact us for advice (see back page) as some side effects if not treated can become life threatening.

### Possible Side effects.

Lung problems (inflammation of the lungs)

- Shortness of breath
- Chest pain
- Coughing

Intestinal problems (inflammation of the intestines/colitis)

- Diarrhoea or more bowel movements than usual
- Stools that are black, tarry, sticky or contain blood or mucous
- Pain or tenderness in your stomach area
- Nausea or vomiting

Liver problems (inflammation of the liver)

- Nausea or vomiting
- Feeling less hungry
- Pain on the right side of the stomach

- Yellowing of your skin or whites of your eyes
- Dark urine
- Bleeding or bruising more easily than normal

Kidney problems (inflammation of the kidney)

- Changes in the amount or colour of your urine

Hormone gland problems (especially thyroid, pituitary, adrenal)

- Rapid heart beat
- Weight loss or weight gain
- Increased sweating
- Hair loss
- Feeling cold
- Constipation
- Deeper voice
- Muscle aches
- Dizziness or fainting
- Headaches that will not go away, or unusual headache

Type 1 diabetes

- Feeling more thirsty or hungry
- Needing to urinate more often
- Weight loss

Skin problems (inflammation of the skin)

- Rash
- Itching
- Skin blistering
- Peeling or sores
- Ulcers in the mouth, lining of the nose, throat or genital areas

Problems with other organs

- Eyes: changes in eyesight
- Muscles: pain or weakness
- Heart: shortness of breath, irregular heartbeat, feeling tired, or chest pain
- Pancreas: abdominal pain, nausea, and vomiting

- Nerves: temporary inflammation that causes pain, weakness and paralysis in the arms and legs
- Rejection of a solid organ transplant after receiving immunotherapy (tell your doctor if you have had a solid organ transplant).
- Immune disorder that can affect lungs, skin, eyes and/or lymph nodes
- Brain: inflammation that may cause confusion, fever, memory problems or seizures

#### Infusion reactions

- Shortness of breath
- Itching or rash
- Dizziness
- Fever

If you have any side effects, including any possible side effects not listed here, contact your oncologist or treatment helpline.

#### **It is important to be aware of symptoms**

If you notice any symptoms while receiving immunotherapy, you should talk to your oncologist/Clinical Nurse Specialist or treatment helpline straight away. Be aware that these side effects may still occur after the final dose of immunotherapy, and for some time, up to two years after completing treatment.

Certain medications, such as steroids, may be used to reduce your symptoms. Your oncologist may delay or completely stop your treatment if side effects are too severe.

**Do not attempt to diagnose or treat side effects yourself**

#### **What to do if your symptoms occur when you are away from home**

It is important that you contact your oncologist whenever symptoms occur. Here at Velindre Cancer Centre we have a **24/7 Treatment Helpline 029 20615888** and ask for the treatment helpline. **Always carry your Immunotherapy Alert Card.**

The alert card contains important information about the symptoms that need to be reported immediately, and it alerts other doctors that you are being treated with immunotherapy. The alert card also has **the QR Code** which can be scanned to a smart phone device and directly download Velindre Cancer Centres Immunotherapy toxicity guidelines. This can guide the doctors or nurses looking after you, either at another hospital or abroad.



#### **Why might I be admitted to another hospital?**

At Velindre we specialise in cancer care, therefore, from time to time, we need to refer to our colleagues at other larger hospitals to access a speciality. For example, gastroenterologists, lung specialists, hormone specialist, skin or heart specialist. This is to ensure that you receive the most appropriate care in the most appropriate setting.

Due to the varied nature of side effects that can occur. It is important that you are under the care of a consultant who is a specialist. This means you will be admitted to your local hospital for management of this side effect.

If you are admitted to hospital it is important that you tell them you are having immunotherapy treatment. You should show the nurse or doctor your immunotherapy alert card. They are also able to download the management & guidelines for toxicity management from the QR code.

Please ask them to let us know that you have been admitted. Our telephone number is on the back page.

### Acute Oncology Service

Within key health board hospitals there is an Acute Oncology Nurse. This nurse provides information regarding your care and treatment to your oncology team through email and telephone. You will rarely see your oncologist who is based in VCC during this time, but please be reassured that they are aware of your admission and are receiving information regarding your care through the acute oncology service. Please feel free to contact your Specialist Nurse at VCC at this time.

### References

YERVOY (ipilimumab) Package Leaflet. Available at [www.medicines.org.uk](http://www.medicines.org.uk)

Ledezema B, Heng A. Real- world impact of education: treating patients with ipilimumab in a community practice setting. Cancer Manag Res 2014;6:5-14.

YERVOY (ipilimumab) Summary of Product Characteristics. Available at [www.medicines.org.uk](http://www.medicines.org.uk)

### Useful Websites

Cancer Research UK [www.cancerresearch.org.uk](http://www.cancerresearch.org.uk)

Healthtalkonline [www.healthtalkonline.org](http://www.healthtalkonline.org)

(Personal experiences of health and illness)

Macmillian Cancer Support [www.macmillan.org.uk](http://www.macmillan.org.uk)

Tenovus [www.tenovus.com](http://www.tenovus.com)

### Contact telephone numbers

**Velindre Cancer Centre: 029 2061 5888**

If you are unwell at home and need immediate attention at any time of day or night ask for the treatment helpline.

**Appointments Booking Team: 029 2061 5888**

**Ext: 6248 or 5803**

Monday- Friday 9am-5pm for queries about your immunotherapy appointments.

Or email: [chemobookingcentre@wales.nhs.uk](mailto:chemobookingcentre@wales.nhs.uk)

**Pharmacy Department: 029 2061 5888**

**Ext: 6223**

Monday- Friday 9am-5pm for queries about your medicines.

**Tenovus Freephone Cancer Support 0808 808 1010**

7 days a week 8am-8pm for general queries on cancer.

**Velindre Supportive Care Team 029 2061 5888**

The supportive care team here at Velindre provides a range of services from welfare rights advice, to spiritual support. They also have access to information leaflets and support groups in your local area. You can contact them via the hospital switchboard, just ask for the supportive care team.

