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# Immunotherapy

Chemotherapy, Immunotherapy,  
and Supportive Medicines

**A guide for patients and carers**

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## What is Immunotherapy?

The immune system is the body's natural defence system and helps to protect you from infections and other diseases.

Immunotherapy is a type of cancer treatment that helps your immune system to fight cancer, by improving the immune cells natural ability to target the cancer cells. Immunotherapy is a drug that reactivates a person's immune system so it can track down and kill their own cancer cells.

## How does Immunotherapy Work?

The immune system recognises when a foreign organism enters into the body, for example a bacteria, and then attacks it, preventing it from causing harm. This process is called an immune response.

The immune system will attack cancer cells in the body when it is able to recognise them. However, cancer cells often find ways to disguise themselves or mutate, and because of this, the immune system does not always recognise them as dangerous. In addition, the natural immune response to cancer cells is often not strong enough to fight off cancer cells.

Immunotherapy works by activating our immune system and making it able to recognise cancer cells and destroy them.



## Which drugs are immunotherapies?

There is an ever growing number of agents but the ones that are used for treatment in the UK\* are:

### Pembrolizumab

For further information regarding this drug – visit:

**[www.macmillan.org.uk/cancer-information-and-support/treatments-and-drugs/pembrolizumab](http://www.macmillan.org.uk/cancer-information-and-support/treatments-and-drugs/pembrolizumab)**

### Nivolumab

For further information regarding this drug – visit:

**[www.macmillan.org.uk/cancer-information-and-support/treatments-and-drugs/nivolumab](http://www.macmillan.org.uk/cancer-information-and-support/treatments-and-drugs/nivolumab)**

### Ipilimumab

For further information regarding this drug – visit:

**[www.macmillan.org.uk/cancer-information-and-support/treatments-and-drugs/ipilimumab](http://www.macmillan.org.uk/cancer-information-and-support/treatments-and-drugs/ipilimumab)**

### Atezolizumab

For further information regarding this drug – visit:

**[www.macmillan.org.uk/cancer-information-and-support/treatments-and-drugs/atezolizumab](http://www.macmillan.org.uk/cancer-information-and-support/treatments-and-drugs/atezolizumab)**

### Avelumab

For further information regarding this drug – visit:

**[www.chemocare.com/chemotherapy/drug-info/avelumab.aspx](http://www.chemocare.com/chemotherapy/drug-info/avelumab.aspx)**

## Cemiplimab

For further information regarding this drug – visit:

**[www.chemocare.com/chemotherapy/drug-info/cemiplimab-rwlc.aspx](http://www.chemocare.com/chemotherapy/drug-info/cemiplimab-rwlc.aspx)**

## Durvalumab

For further information regarding this drug – visit:

**[www.macmillan.org.uk/cancer-information-and-support/treatments-and-drugs/durvalumab](http://www.macmillan.org.uk/cancer-information-and-support/treatments-and-drugs/durvalumab)**

*\*Correct as of July 2022*

## Are Immunotherapy drugs given in combination?

Immunotherapy treatments can either be given on their own or, increasingly, in combination. They can be given in combination with chemotherapy drugs, targeted drugs or in some cases both. Immunotherapies can also be given in combination with each other with the combination of ipilimumab and nivolumab being the most common.

If you are receiving the Ipilimumab and Nivolumab combination then you will receive four combined treatments (one given every 3 weeks) before going on to receive only nivolumab every 4 weeks for up to 2 years.

If you are receiving immunotherapy with chemotherapy then sometimes the chemotherapy will be given at the beginning



and then the immunotherapy alone is continued. In some chemotherapy and targeted therapy combinations all drugs are carried on together.

If you get side effects from your treatment sometimes one (or more) of the drugs are stopped and others are continued.

Radiotherapy may also be given whilst on immunotherapy.

## How is Immunotherapy treatment given?

Immunotherapy is given intravenously (through a vein). How often will depend on the drug you are prescribed. Treatment can take between 1 to 3 hours to give.

You will receive your treatment at one of our hubs throughout the region:

- Clatterbridge Cancer Centre Liverpool – Floor 6
- Clatterbridge Cancer Centre Wirral – Delamere Ward
- Clatterbridge Cancer Centre Aintree – Marina Dalglish Centre
- Halton General Hospital
- St Helens and Knowsley Teaching Hospitals NHS Trust
- Clatterbridge in the Community – Home Treats

After you have received your first treatment you will be given appointments for your next treatment.

## Immunotherapy Alert Card

You will be given one of these at your pre-assessment appointment. Put it in your wallet/purse and keep it with you at all times.

If you are advised to attend your local Accident and Emergency department/local health care provider, it is important that you inform them that you are currently on or have been on immunotherapy treatment by presenting your immunotherapy alert card. This will provide a lot of information to your A&E department or relevant healthcare provider as the symptom management may be different.

When you have completed your immunotherapy treatment, you will be provided with a post-treatment alert card. Similar to the alert card above, present this to your healthcare professional should you need to seek healthcare advice. It is important for the healthcare provider to know you have been on Immunotherapy previously.

**I AM RECEIVING OR HAVE RECEIVED IMMUNOTHERAPY**

**THE CLATTERBRIDGE CANCER CENTRE HOTLINE: 0800 169 5555**

Contact the on-call Oncology/Haematology Team and inform the Acute Oncology Team.  
Please read the information on the reverse of this card.



 The Clatterbridge Cancer Centre  
 North West Coast Strategic Clinical Network

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**Treatment Name: \_\_\_\_\_**

**ADVICE TO HEALTH CARE PROFESSIONALS**

<b>The patient is at risk of autoimmune side effects:</b> Diarrhoea and Colitis Hepatitis Skin rashes Pneumonitis Adrenaline Crisis Endocrinopathies New Type 1 DM/IDDM Neuropathies Renal toxicity	<b>Required Blood Tests:</b> Full blood count Full chemistry profile Liver function tests Random cortisol Thyroid function tests Glucose Lactate	<b>Management Guidelines:</b> <a href="https://tinyurl.com/https-cccacute-com">https://tinyurl.com/https-cccacute-com</a> Scan QR Code 
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**Steroids are frequently indicated in the management of side effects and DO NOT affect the efficacy of the immunotherapy.**  
**Review the Immuno-Oncology Guidelines to see if steroid treatment is indicated.**

**Immunotherapy Post Treatment Alert Card**

 The Clatterbridge Cancer Centre  
 and Foundation Trust

Please be aware I have received treatment with an Immune Checkpoint Inhibitor.

I completed treatment on \_\_\_\_\_ and I am at risk of immune mediated side effects for several years following completion of treatment.

For further advice, contact the Immunotherapy Team  
on [ccf-tr.io-team@nhs.net](mailto:ccf-tr.io-team@nhs.net)

**For urgent advice, call The Clatterbridge Cancer Centre Hotline: 0800 169 5555**

**Immunotherapy Post Treatment Alert Card**



 The Clatterbridge Cancer Centre  
 North West Coast Strategic Clinical Network

<b>Side effects may include:</b> Endocrinopathies Colitis Hepatitis Skin toxicity Pneumonitis Neuropathies Arthralgia Nephritis	<b>Required blood tests:</b> Full blood count Liver function tests including AST and ALT Full chemistry profile Random Cortisol Random Glucose Thyroid function tests CRP	<b>Management Guidelines:</b> 
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## What happens before every dose of Immunotherapy?

### Blood Tests

We have to monitor your bloods before every treatment, per protocol, bloods must be taken within 72 hours prior to treatment with immunotherapy.

Blood tests can be taken at your nearest cancer centre, local health centre or hospital.

You will be given a blood form from the treatment unit to show to the person taking your blood local to your home with the blood tests you need.

We will then contact them for your results prior to your treatment.

### Assessing if you're well enough to have your treatment

The day before your treatment you will be assessed by a member of the nursing team (called our on treatment review (OTR) team).

This is normally face to face for the first visit, and then will be done over the telephone to save you having to come to the cancer centre. The nurses will ask some questions to make sure that you are well enough for treatment. They will also check your blood results.

Sometimes, for your safety, it may be necessary to pause cancer treatment whilst we investigate potential Immunotherapy side

effects. Once symptoms are resolved/stable your oncology team will discuss recommencing Immunotherapy treatment when/if it is safe to do so. We will tell you about this as soon as we can and arrange another appointment for you.

Doing this the day before treatment means it can be ready for you when you arrive and limit the amount of waiting there is with each visit.

### How long will I have treatment for?

Most immunotherapy treatments are given for a maximum of 2 years as long as they are working. As well as blood tests and on treatment review, you will have regular appointments with your oncology team.

These normally happen every 8-12 weeks depending on how treatment is going. In these appointments you will see a member of your team. This may be a consultant, a registrar or a specialist nurse.

You will also be monitored with scans approximately every 12 weeks.

**You should always have the appointment of your next clinic review with your oncology team. If you haven't please mention it to the nursing team at your on treatment review assessment.**



## Treatment at home

Clatterbridge Cancer Centre offers a home treatment service for patients receiving immunotherapy as a single agent. You would need to receive the first few treatments at the treatment unit in one of the Clatterbridge hubs. If these occur without complications then it may be possible to deliver your treatment at home.

You would still need regular blood tests and on treatment review along with the follow up appointments with the Oncology team, but the actual drug treatment can be delivered at home.

Ask the nurse at your next treatment if this is something you are interested in, and further information can be provided.

## What are the side effects of Immunotherapy treatment?

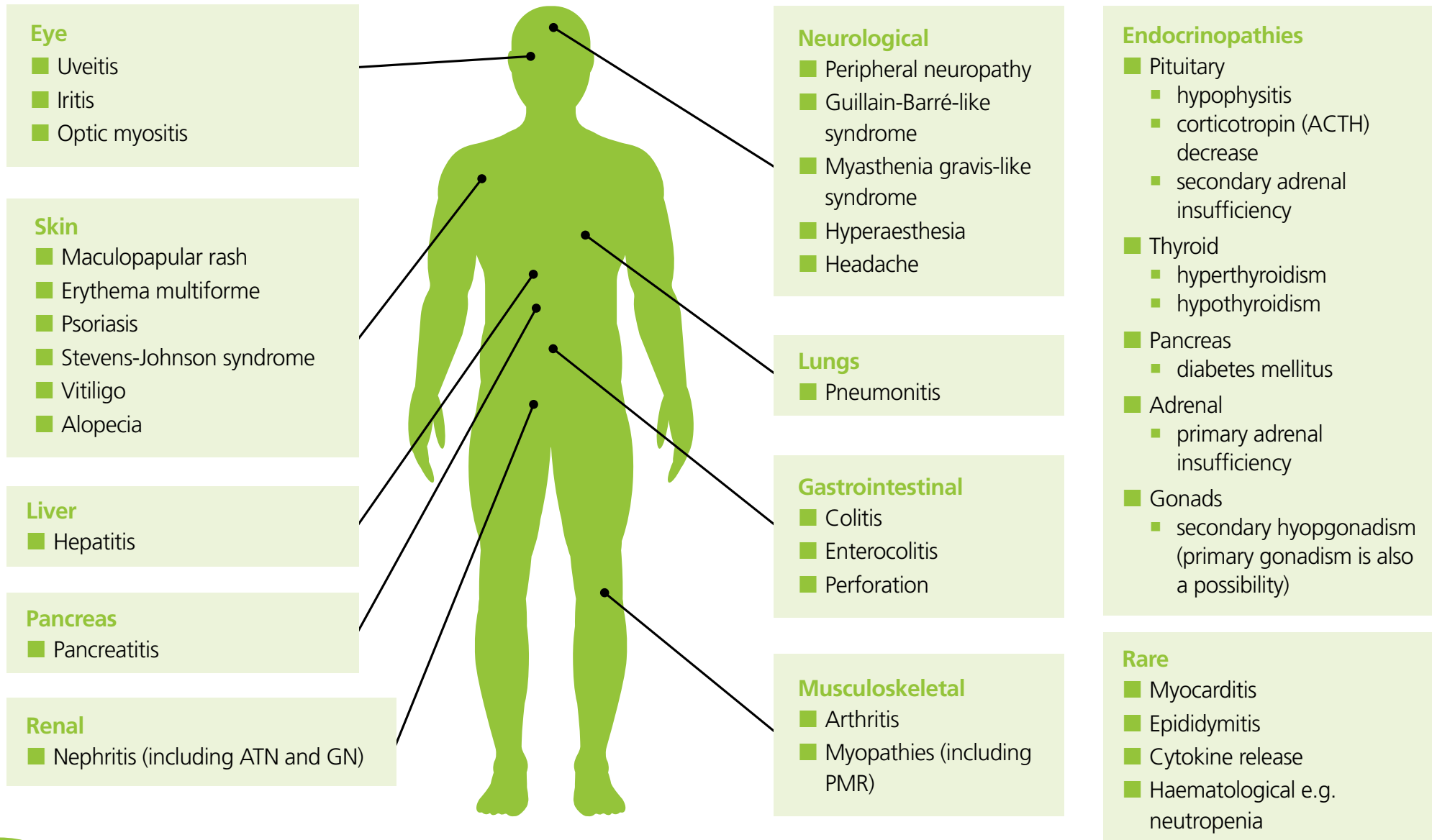
You may experience some side effects during your treatment with Immunotherapy. Immunotherapy can occasionally cause your immune system to inflame healthy tissues. These can lead to immune related side effects. When these side effects occur, it is as a result of an uncontrolled immune response. These side effects often require treatment with immunosuppressant's such as steroids. Whilst on treatment you will require blood tests to monitor for certain side effects.

You may not experience side effects straight away, these could occur at any time during your treatment. Not every person will get side effects, however, it is important to report any side effect immediately because you may need treatment to prevent the problem from becoming more serious.

Generally speaking people feel well whilst receiving immunotherapy but significant side effects occur in 15-30% of people receiving one immunotherapy drug, and approximately 55% of those receiving two immunotherapy drugs together.

**If you experience any symptoms, feel unwell or notice any changes from your norm, you should report these as soon as possible to the Clatterbridge Cancer Centre Hotline (24 hours a day 7 days a week): 0800 169 5555**





## What are the main side effects to look out for?

### General

- Feeling more tired or confused
- Difficulty sleeping
- Feeling shivery or cold
- New or persistent headaches
- Feeling dizzy or light headed
- Change in your appetite
- Changes in your mood, feeling more anxious or irritable
- A loss or gain in weight
- Eyes become red or watery
- Pins and needles; leg weakness; issues with walking

### Gastrointestinal

- Feeling nauseous and/or vomiting (Very rare)
- An increase in bowel movement and/or diarrhoea. Any change in bowl habit should be taken seriously
- Blood, watery or foul smelling stools
- Cramping pains

### Breathing

- A new or worsening cough
- Changes in your breathing
- Feeling more short of breath

### Skin

- A yellow tinge to your skin
- A skin rash or your skin is itchy
- May be confined to one area or all over your body
- Bleeding or bruising
- Sweating more than usual

### Musculoskeletal

- Muscle aches
- Severe or persistent muscle or joint pains
- Swelling to your legs
- Pain, Weakness and/or paralysis in your arms and legs

### Glands

- Some of the glands that produce hormones become inflamed e.g. Thyroid Gland
- This leads to the glands becoming underactive
- Hormone replacement therapy in the form of tablets may be required
- Glands will be checked regularly on blood test

### General symptoms of gland issues may include:

- Lack of energy or motivation (fatigue)
- Muscle weakness
- Low mood
- Loss of appetite and unintentional weight loss
- Increased thirst
- Constipation
- Loss of libido (sex drive)
- Dry and scaly skin
- Brittle hair and nails
- Pain, numbness and a tingling sensation in the hand and fingers
- Sensitivity to cold
- Weight gain





## What will happen if I get a side effect?

It is important to be aware of side effects. If you experience any of the above symptoms, or notice any general changes, you should contact the Clatterbridge Cancer Centre hotline for assessment and they will advise on the best course of action.

**Call the hotline on 0800 169 5555, which is available 24 hours a day 7 days a week.**

You may need to go for an extra blood test or come to Clatterbridge to be assessed. The hotline nurse may suggest you need to go to your nearest A&E. Please follow this advice as it is in your best interests. Remember, on arrival at another hospital please show them your immunotherapy alert card (yellow card) which will give the doctors and nurses there a lot of information about your treatment and side effects.

## How are side effects treated?

Once you have been reviewed you may need to be admitted to hospital. You may need to start treatment for your side effect. This is normally with steroids – drugs either called prednisolone or methylprednisolone.

Once you leave hospital you will be followed up by telephone to see how you are getting on. You may need to have regular blood tests. If you feel unwell at any time please contact the Clatterbridge hotline, even if you have a follow up appointment planned.

## Immunotherapy Toxicity Service

Here at Clatterbridge Cancer Centre we have a team of Clinical Nurse Specialists, led by a Specialist Medical Oncologist in Immunotherapy and Nurse Consultant, who are dedicated to managing patients with immunotherapy related side effects. Following confirmation of an immune related side effect you will be referred into this service. These specialist nurses will assess and help treat your side effects with regular follow ups, to manage your side effects as quickly and safely as possible.

*"Provides specialist experience over and above the usual Oncology team. a very useful service that provides help and reassurance when going through a complex set of circumstances."*

*"I have had an issue with colitis and peripheral neuropathy following my immunotherapy treatment. I feel particularly lucky to have received such wonderful professional care from all of the team."*

Patient feedback regarding the Immunotherapy toxicity service at CCC



## What happens if I have a side effect but I feel well?

Some side effects from immunotherapy have few or no symptoms. This is the reason why we do regular blood tests to make sure we identify these issues. If you are told by a doctor or nurse that you have a side effect, we need to take it seriously and often start treatment with steroids even if you have no symptoms.

If during the course of treatment you start to feel less well, even if it is just more fatigue or less appetite, it is important you contact us on the CCC hotline (0800 169 5555) to report it to us.

## What do I do when I am taking steroids?

Generally all steroids have to be gradually reduced over a period of days to weeks – you will be given a steroid diary to show you how to do this. If you stop them then side effects could return and you could become very unwell.

We sometimes have to put treatment on hold for a short period of time whilst we treat side effects. We cannot restart treatment unless you are receiving 10mg (two 5mg tablets) of prednisolone or less. Sometimes we will wait until you have stopped steroids completely before restarting treatment.

Steroids do not appear to stop immunotherapy drugs working. Sometimes you will need other treatments alongside steroids to treat the side effects. If this is necessary the immunotherapy toxicity team will discuss this with you.

## Long term replacement of hormones

If your glands are affected by the immunotherapy drug you may need to have your hormones replaced.

These drugs include:

- Thyroxine to treat an underactive thyroid gland
- Hydrocortisone to treat an underactive adrenal gland
- Testosterone (men only)

If the gland that controls all of the above hormones (pituitary) is affected then you may need to be on all three of the drugs above.

Sometimes if we have to use steroid drugs for a long period of time to settle your side effects you may need to be on hydrocortisone long term as, in a small number of cases, the steroids can make the adrenal gland less effective and a tablet supplement is needed.

Once started you will have your levels checked fairly regularly in the early days to make sure the dose is correct. In the long term your GP will help in managing this and provide your tablets.

These treatments are often for life – do not stop them unless told to by a doctor or specialist nurse.

Gland issues will not stop you from having immunotherapy treatment.

If you are receiving corticosteroid treatment there are rules you have to follow if you are unwell, known as “Sick Day Rules”.



## Sick Day Rules

Should you become in any way unwell (including a temperature of 37.5°C or more) then you must:

- Double your normal daily dose of steroid (no need to increase fludrocortisone if you are on it) and contact the Clatterbridge Cancer Centre Hotline immediately.
- If you are unable to take tablets or are vomiting you must attend A&E as you may need an injection of steroid.
- If you do vomit upon taking your steroids take a further dose of your steroids and contact the hotline for further advice/
- Steroid dose should only be reduced once you are well again and you don't have a fever.

### The Clatterbridge Cancer Centre Hotline: 0800 169 5555 (24 hours/7 days a week)

Upon starting steroids you will be provided with a Steroid Alert Card (like below). Always carry this card and show it to anybody that treats you up to one year after stopping steroids.

The image shows two patient cards side-by-side. The left card is titled 'Steroid Alert Card' and includes fields for 'Steroid Agent', 'Dose', 'Reason for Steroid Usage', and 'Start Date'. It also contains instructions on how to reduce the dose and when to stop. The right card is titled 'Steroid Sick Day Rules' and lists actions to take if a patient becomes unwell, including doubling the dose and contacting the hotline. Both cards include the Clatterbridge Cancer Centre logo and a QR code.

## Am I allowed to take my other medications whilst on immunotherapy?

Generally it is fine to take your other medications whilst on Immunotherapy. Mention which medications you are taking to your oncology team before starting on immunotherapy. Remember to take a list of your current medications with you to your pre-assessment appointment and any follow up appointment.

## Can I have my flu and Covid-19 vaccine whilst on immunotherapy?

There is no evidence to suggest that the flu vaccine is associated with any issues when on immunotherapy, therefore, we are currently recommending that people should have their flu vaccine as normal.

If you are over 65 there is a new booster to the flu vaccine. There is no evidence about this and possible interactions with immunotherapies so having this booster therapy is not recommended.

If the Pneumococcal vaccine is recommended by your GP practice you can also receive this.

Public health experts and cancer specialists have agreed that people living with cancer should receive the COVID-19 vaccine. The coronavirus vaccines that are available can be given to people who are having cancer treatment. Vaccines save lives and reduce the need for hospital stays from coronavirus.



Vaccines can be given before, during or after cancer treatment. If you are due to start cancer treatment or have cancer surgery your medical team may recommend that you have a vaccination before treatment begins. Having a vaccination before treatment gives a better chance of protection.

**For further information visit:**  
[www.macmillan.org.uk/coronavirus/vaccine](http://www.macmillan.org.uk/coronavirus/vaccine)

## Is there anything I cannot do whilst on Immunotherapy?

There are no specific activities you have to avoid whilst receiving immunotherapies.

If you are able to/are well enough you can continue to work.

You can travel whilst on immunotherapy but discuss it with your oncology team prior to booking as you may need particular provisions for your trip and you need to ensure you have robust travel insurance to cover issues with your health during your trip.

We strongly advise you to only travel if you have travel insurance and carry your UK Global Health Insurance Card (formerly known as the European Health Insurance Card – EHIC).

## Research at Clatterbridge Cancer Centre

The Clatterbridge Cancer Centre is a hospital with an active research department that constantly strives to encourage patients to take part in research programmes so that medical advances can be made. This means that your doctor may discuss research programmes or clinical trials with you as one of your treatment options or The Clatterbridge Cancer Centre Biobank for cancer research. Listening to the information does not commit you to take part. You will never be entered into a research programme without giving your written consent. You would always be given plenty of information about the research to enable you to consider whether to take part and a contact number for the research team so that you can discuss it further if you wish.

Immunotherapy is a relatively new, yet rapidly expanding field of cancer treatment, and this research is important to helping us to develop our knowledge and understanding of immunotherapies. For example, at Clatterbridge we run studies that investigate the side effects caused by immunotherapy. At the moment we are researching the reasons people experience side effects, so the studies aim to look at the underlying mechanisms of these reactions to give insight into what is happening so we may be able to predict, manage and prevent them in the future.

If you are interested in getting involved in ongoing research at Clatterbridge Cancer Centre, please don't hesitate to ask your oncology team for more information.





## How we produce our information

All of our leaflets are produced by staff at The Clatterbridge Cancer Centre and this information is not sponsored or influenced in any way. Every effort is made to ensure that the information included in this leaflet is accurate and complete and we hope that it will add to any professional advice you have had. All our leaflets are evidence based where appropriate and they are regularly reviewed and updated. If you are concerned about your health in any way, you should consult your healthcare team.

We rely on a number of sources to gather evidence for our information. All of our information is in line with accepted national or international guidelines where possible. Where no guidelines exist, we rely on other reliable sources such as systematic reviews, published clinical trials data or a consensus review of experts. We also use medical textbooks, journals and government publications.

References for this leaflet can be obtained by telephoning 0151 556 5570.

If you need this leaflet in large print, Braille, audio or different language, please call 0151 556 5570.

**If you have a comment, concern, compliment or complaint, please call 0151 556 5203.**

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