



IOCN

The Immuno-Oncology Clinical Network

Immunotherapy Patient Information Leaflet (Checkpoint Inhibitors)

The Immunobuddies Podcast

Catch up with the Immunobuddies Patient Podcasts for more information on immunotherapy! Scan the QR code or type the web link into your internet browser.



1. Fundamentals of Immunotherapy - rb.gy/j2ad4g

This podcast covers the basics of immunotherapy, its differences from chemotherapy, and what to expect during treatment. It explains administration, monitoring effectiveness, the timeline for results, and the importance of regular follow-up appointments.



2. Side Effects Explained - rb.gy/59xlez

This podcast covers key immunotherapy considerations, including side effects, when to seek medical advice, and communication with healthcare providers. It also discusses the impact on sexual activity, contraception, fertility, and what to expect if treatment is stopped.



3. Advice on Family, Friends & Career - rb.gy/3ll7we

This podcast discusses support for family and friends, managing work during treatment, and self-care strategies. It also addresses lifestyle considerations, such as alcohol consumption, medications, and activities to avoid while undergoing immunotherapy.



4. During and After Immunotherapy - rb.gy/8ooazx

This podcast discusses the long-term effects of immunotherapy, including post-treatment side effects, steroid use, and their impact on efficacy. It also covers treatment frequency, potential risks, and whether breaks due to side effects affect outcomes.



5. How Will It Impact Me & My Family? - rb.gy/08wttq

This podcast explores practical aspects of immunotherapy, including family interactions, driving, herbal remedies, and managing fatigue or sleep disruption. It also highlights diet, GP cancer reviews, vaccines, alternative treatments, and reliable resources for further information.



6. Understanding Medical Jargon - rb.gy/1gvu3j

This podcast explains immunotherapy, cancer staging, grading, and adjuvant treatment. It covers why adjuvant therapy is recommended, its benefits, post-treatment steps, alternatives, potential rechallenges, and provides guidance on finding additional information.



Information about your treating centre

Name of Hospital:

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Location:

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Telephone:

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CNS Telephone Number:

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Triage Hotline number to contact in an Emergency:

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Information about your treatment

Name of Treatment:

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Other Drugs in your regimen:

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Frequency of treatment:

.....

Frequency of blood tests:

.....



What is Immunotherapy?

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Diet, Lifestyle and Exercise

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. While there are various types of immunotherapy used to treat cancer, such as CAR T-cell therapy and monoclonal antibodies, this leaflet focuses specifically on immune checkpoint inhibitors (ICIs), which work by helping the immune system recognise and attack 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 these 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 include:

Pembrolizumab

(for further information regarding this drug – visit <https://www.macmillan.org.uk/cancer-information-and-support/treatments-and-drugs/pembrolizumab>)

Nivolumab

(for further information regarding this drug – visit <https://www.macmillan.org.uk/cancer-information-and-support/treatments-and-drugs/nivolumab>)

Ipilimumab

(for further information regarding this drug – visit <https://www.macmillan.org.uk/cancer-information-and-support/treatments-and-drugs/ipilimumab>)

Atezolizumab

(for further information regarding this drug – visit <https://www.macmillan.org.uk/cancer-information-and-support/treatments-and-drugs/atezolizumab>)

Avelumab

(for further information regarding this drug – visit <https://www.macmillan.org.uk/cancer-information-and-support/treatments-and-drugs/avelumab>)

Cemiplimab

(for further information regarding this drug – visit <https://www.macmillan.org.uk/cancer-information-and-support/treatments-and-drugs/cemiplimab>)

Durvalumab

(for further information regarding this drug – visit <https://www.macmillan.org.uk/cancer-information-and-support/treatments-and-drugs/durvalumab>)

Dostarlimab

(for further information regarding this drug – visit <https://www.macmillan.org.uk/cancer-information-and-support/treatments-and-drugs/dostarlimab>)

Relatlimab

(for further information regarding this drug – visit <https://www.macmillan.org.uk/cancer-information-and-support/treatments-and-drugs/nivolumab-relatlimab>)

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. Some patients receive a combination of targeted treatment and immunotherapies where both drugs are continued long term.

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), or subcutaneously (under the skin). How often will depend on the drug you are prescribed. Intravenous treatment can take between half an hour to 3 hours to give. The subcutaneous injection takes approximately 10 minutes to give, but you will be in the centre for longer than this. Not all the treatments can be given this way and your doctor will advise if this is possible. Different centres provide immunotherapies in different ways, so you may be offered treatment at the central site, a peripheral site/satellite hub or at home.

Sometimes two immunotherapy checkpoint inhibitors are given together; commonly either ipilimumab and nivolumab or nivolumab and relatimab. These treatments are either given with a combination phase at the beginning (e.g. ipilimumab and nivolumab in melanoma & kidney cancer) or regularly throughout treatment (e.g. ipilimumab and nivolumab in mesothelioma, or nivolumab and relatimab in melanoma). Your team will talk through with you which drugs you will receive, when, and how long you will receive treatment for. After you have received your first treatment you will be given appointments for your next treatment.

What happens before every dose of Immunotherapy?

Blood Tests

Typically bloods are monitored before each dose of immunotherapy, but this can vary between protocols, and often depends on which other drugs you are also receiving. Bloods are usually needed within a week of treatment but this can be shortened to 72 hours before treatment, e.g. when you are also receiving chemotherapy, or in some cases extended if you are on immunotherapy only.

Bloods tests can be taken at your nearest cancer centre and in some areas, your local health centre or hospital. In these cases you will be given a blood from the treatment unit, to show to the person taking your blood locally with the bloods tests you need. The treating unit will then contact them for your results prior to your treatment. If you need to have your blood tests at your treatment centre your medical team will advise you of this.

Assessing if you're well enough to have your treatment

The day before your treatment, or on the day, you will be assessed by a member of the nursing team, or the person administering your treatment.

This is normally face to face for the first visit, and then sometimes 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. They will tell you about this as soon as they can and arrange another appointment for you.

How long will I have treatment for?

Most immunotherapy treatments are given for a maximum of 2 years as long as they are working. Your clinical team will discuss this with you. As well as blood tests and on treatment review, you will have regular appointments with your oncology team. You will be seen at various intervals by your oncology team between every treatment (cycle) and every three treatments (cycles). The clinical team will confirm the frequency of review with you.

You will also be monitored with scans approximately every 3 - 6 months.

If you are having treatment before or around your surgery, then the length of treatment varies and your clinical team will inform you of the intended length of treatment.

If you are having treatment to try and reduce the risk of your cancer returning (adjuvant treatment), treatment is often given for up to a year.

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.

What are the side effects of Immunotherapy treatment?

You may experience some side effects during your treatment with immunotherapy. Immunotherapy can 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 immunosuppressants 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 emergency triage hotline

Sometimes signs of side effects are picked up on your blood tests whilst you feel completely well. In some cases, it is then necessary to repeat your blood test in a few days. Also, it may be necessary to treat the side effects with medication and pause your treatment even if you continue to feel well and have no symptoms.

What will happen if I get a side effect?

Immune-related side effects can affect any organ in the body, not just the commonly impacted systems like the skin, gastrointestinal tract, or endocrine glands.



It is crucial to remain vigilant, as symptoms can develop in many different ways. If you have any concerns or notice unusual symptoms, no matter how unrelated they may seem, please do not hesitate to contact your emergency triage hotline number.

Early communication is key to identifying and managing potential side effects effectively. Promptly reporting side effects increases the likelihood that they can be managed effectively, allowing you to continue with your immunotherapy treatment.

A list of the most common side effects can be seen on the following pages.

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
- Bloody, watery or foul smelling stools
- Cramping pains

Breathing

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

Musculoskeletal

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

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

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

Before starting your treatment, you will receive detailed written information about your specific treatment drug(s). It is essential to read this thoroughly, as the list provided above is a general overview and not exhaustive.

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 cancer hotline for assessment and they will advise on the best course of action.

You may need to go for an extra blood test or come in to be assessed. The hotline nurse may suggest you need to go to your nearest A&E, or you may be booked into your local oncology/medical review unit the next day. Please follow this advice as it is in your best interests. Remember, on arrival at another hospital please show them your immunotherapy alert 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 it is important you know how you are being followed up. This may be by a telephone call or an appointment in clinic. You may need to have regular blood tests. If you feel unwell at any time please contact the cancer hotline, even if you have a follow up appointment planned.

Sometimes other medications are given alongside or instead of steroids and these can either be tablets or infusion treatments. Your clinical team will go through what they are and how they are given. Some of these medications require special blood tests early in treatment to ensure the dose you have is personal to your needs.

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 your emergency triage hotline to report it.

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 suddenly 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 your clinical 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 in the long term.

These drugs include:

- Thyroxine to treat an underactive thyroid gland
- Hydrocortisone/Fludrocortisone to treat an underactive adrenal/pituitary gland
- Testosterone (men only)
- Insulin

If the gland that controls all of the above hormones (pituitary) is affected then you may need to be on the first 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, specialist nurse or specialist pharmacist.

Gland issues will not stop you from having immunotherapy treatment.

If you are receiving corticosteroid (replacement steroid) 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 emergency triage 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 emergency triage hotline for further advice
- Steroid dose should only be reduced once you are well again and you don't have a fever.

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

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.

Your clinical team may suggest stopping certain medications. You should avoid over the counter proton pump inhibitors (PPIs e.g. omeprazole, esomeprazole) whilst on immunotherapy. However, if a PPI is deemed necessary in your case, this will be discussed with your clinical team, and a decision will be made to either continue taking it, stop it, or substitute it with an alternative medicine. If you develop a side effect having recently started any new medications/herbal remedies you should let the clinical team know about this.

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.

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.

On occasion your doctor may recommend specific timing of your covid vaccine. For further information visit <https://www.macmillan.org.uk/coronavirus/vaccine>

Other Vaccines

People receiving immunotherapy are advised to avoid live vaccines. If you are offered the pneumococcal (pneumonia) vaccine then you can proceed with this vaccine whilst on immunotherapy. There are new versions of the shingles vaccine, one of which is live and the other non-live. You can receive the non-live vaccine whilst on immunotherapy.

There is a new respiratory syncytial virus (RSV vaccine). If you are offered this you can receive this on immunotherapy.

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)

Diet, Lifestyle and Exercise

It is recommended that you maintain a balanced diet whilst on immunotherapy. If you have an interest in foodstuffs that support the gut microbiome then these include a broad array of fruit and vegetables, a diet high in fibre and the intake of fermented foods such as (but not limited to) kimchi, kefir, sourdough bread and kombutcha. If you are able to remain active during treatment this is advised. Your clinical team will discuss contraception, fertility etc with you but please do ask if you have any questions. Cannabis oil and associated products are often considered. These are not licenced products, but preliminary data/studies suggest that they may have immunosuppressive activity and may make immunotherapies less effective.



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