

Preparing for your cancer immunotherapy treatment

Information for patients

This leaflet answers common questions about how to prepare and what to expect from your immunotherapy treatment. If you would like further information, or have any particular worries, please do not hesitate to ask your nurse or doctor.

In all cases, a doctor can explain the treatment to you and answer any questions you may have.

How does immunotherapy work?

Immunotherapy enables the immune system to recognise, target, and eliminate cancer cells, wherever they are in the body. Immunotherapy works differently to chemotherapy. It can sometimes take longer to see results so the cancer may appear to get worse before it gets better.

The side effects are different to traditional chemotherapy. Chemotherapy aims to kill cancer cells but also kills the body's 'good' cells. The main side effect with chemotherapy is the risk of infection due to a depleted immune system; this is not the case with immunotherapy.

What are T lymphocytes (T cells) and checkpoint inhibitors?

Our immune system protects us from disease, killing bacteria and viruses. It can also identify and kill cancer cells. One main type of immune cell that does this is called T lymphocytes or T cells. Immunotherapy activates T cells to recognise cancer cells.

Checkpoint inhibitors are a group of immunotherapy drugs which block checkpoint proteins on a type of white blood cell called a lymphocyte. Lymphocytes are an important part of the immune system. When they are active, lymphocytes can attack another cell, such as a cancer cell. But if they receive a certain signal from the other cell, they switch off (become inactive) and do not attack it.

Checkpoint inhibitors also block the signals that switch off lymphocytes. They do this by attaching to either the cancer cell or the lymphocyte. This means the lymphocyte stays active and can attack the cancer cell.

Who will administer my treatment?

Your treatment will be given by members of the of the nursing team who are trained to administer anti-cancer treatment.

How will my treatment be administered?

Your immunotherapy treatment will be given over a set period of time and administered in cycles ie once a month or fortnight. The length of time taken to administer your treatment may vary but will generally take less than two hours. During this time, immunotherapy therapy drugs are given by an intravenous infusion into a vein in your hand or forearm.

Before each treatment, you will need to have a blood test and see a doctor or nurse who will prescribe your medication.

How will I know when to attend my next treatment?

You will be given a cancer treatment record book at the start of your treatment. It includes information on treatment types, appointments and a test results log, together with space to record side effects and questions to ask the doctor or nurse at your next appointment.

What side effects can I expect?

Lots of people experience no or only very mild side effects as a result of their treatment but this may vary depending on which type of treatment you have received. They can range from minor symptoms to more serious conditions.

Side effects can be the result of inflammation of an organ in response to the body's immune system being over stimulated; similar to an autoimmune condition, such as rheumatoid arthritis which can cause inflamed joints. Side effects can occur at any stage of your treatment and can sometimes last up to six months after treatment has stopped.

Common side effects include:

- fatigue
- diarrhoea
- skin rash or itching
- change in thyroid function or hormone levels

Less common side effects can include:

- headaches
- change in liver function (itching, jaundice, abdominal pain)
- change in kidney function (urine output, colour)
- change in blood sugar levels
- breathlessness or cough

More uncommon symptoms may include joint pains, muscle aches or weakness, tingling or altered sensation, chest pain, sore eyes, hair thinning or hair loss, abdominal pain, nausea, vomiting and confusion.

Diarrhoea

One of the most common side effects from immunotherapy drugs is diarrhoea and/or stomach pain. You must contact the hospital for advice if you have diarrhoea (liquid bowel motions) or if you are opening your bowels more regularly than normal or at night.

Try to drink at least 2 litres (3.5 pints) of fluids every day. It can help if you avoid the following:

- alcohol
- caffeine
- milk products
- high-fat foods
- high-fibre foods

Rashes

Skin rashes are another very common side effect from the medication you receive during your treatment. If you experience a rash that is spread over several areas of your skin, or covers more than half of your body; you should tell your doctor immediately. You may need to be prescribed steroid creams or tablets to treat the rash.

During treatment, and for a few months afterwards, you will be more sensitive to the sun and more likely to burn even in cooler weather. You should wear a sun cream with a high sun protection factor (SPF) when you go out and cover up with clothing and a hat. Try to keep your skin well moisturised but avoid perfumed products. Aveeno cream or E45 are ideal for this.

Changes in hormone levels

Immunotherapy drugs can inflame some of the glands that make hormones. Glands that may be affected are the thyroid, pituitary and adrenal glands. If a gland is affected, it may change the levels of hormone that it produces.

You should tell your doctor or nurse straight away if you experience any of the following symptoms:

- headaches that do not go away
- extreme tiredness or sleepiness
- feeling cold
- weight gain
- feeling dizzy or faint
- changes in behaviour or mood, such as irritability or feeling confused

Fatigue or tiredness

Many of the immunotherapy side effects start with fatigue, but this can also be a general symptom from your cancer. If your tiredness becomes a lot worse after starting treatment, let your doctor or nurse know. This can be a sign of changes in your hormone levels.

To help cope with the side effects of your treatment, you should:

- Know that you may have good days and bad days.
- Use your treatment record to identify patterns of side effects so you can plan an active life around them.
- Continue to undertake any light exercise you have been doing.
- Ask for, and accept, help from family and friends.

Will immunotherapy impact my fertility or sex life?

It is not thought that immunotherapy itself affects fertility although some hormonal side-effects of immunotherapy can do. Your doctor or nurse can talk to you about possible measures to preserve your fertility before starting treatment if this is relevant to you.

Immunotherapy can impact both sexual function and desire due to effects of your treatment, such as fatigue, changes in body image perception, and changes in hormonal function.

If you do find yourself affected by any of these issues, please speak to your clinical nurse specialist (CNS) or day unit nurse, who can offer you advice and support.

As the effects of immunotherapy on a developing foetus are not known, we strongly advise that you use contraception during sex to avoid becoming pregnant or fathering a child. You should continue to do this whilst you are receiving active treatment and for six months after your treatment has ended.

What should I do if I normally take other medications?

You should ensure that the doctor in charge of your treatment is aware of any medications or supplements that you are currently taking. This includes any herbal remedies, vitamins or probiotics. You should inform your treatment team if you are taking any of the following in particular:

- warfarin
- steroids such prednisolone or dexamethasone
- insulin
- aspirin, ibuprofen or naproxen
- medication for gout such as allopurinol

Will I be able to work to during my treatment?

If you would like to work during your treatment, you should first discuss this with your doctor, but generally if you feel well enough to there is no reason not to. Each person is different and you may feel different from day-to-day, so it is important to pace yourself.

Will I need to pay for my prescriptions?

Patients receiving treatment for cancer do not have to pay prescription charges if they have a valid exemption certificate or card. Your GP or treating doctor can give you an application form for this. Exemption certificates and cards are valid for five years.

Should I have the flu vaccination?

We recommend that you and those close to you are vaccinated against the flu. You should ideally have a flu vaccination two weeks before the start of your immunotherapy treatment. This can be done at any time although we advise that you avoid having a flu vaccine in the days just before and after your treatment.

You should also not have any 'live' vaccines while you are receiving treatment, such as the shingles vaccine. If you are offered a vaccine and are unsure whether to have it, please ask your nurse or doctor for advice.

Should I have the COVID-19 vaccination?

We recommend that you have the COVID-19 vaccine when it is offered to you; however, this should not be given on the same day as your immunotherapy infusion.

What should I do if I feel unwell?

There is a team available for you to speak to 24 hours a day if you are suffering with any side effects from your treatment.

From Monday to Friday this telephone line will be answered by a member of the acute oncology nursing service. Outside of these hours you will speak to an oncology nurse on the ward who has been trained to answer your call.

Please remember that:

- This service is not for checking appointment times or administrative enquiries.
- If you are unable to reach the team, please try again as staff may be busy.
- If you have a temperature greater than 38°C (98°F), or experience new and severe chest pain or breathlessness, you should go straight to your nearest A&E or call 999 if you are unable to travel there safely.

You should contact the hospital if you have new symptoms which are worrying you, or you want advice about ongoing symptoms.

You may be advised to attend your local emergency department for blood tests and assessment. Please take your alert card and cancer treatment record book with you.

You will also be given an alert card when you start by the nurses delivering your treatment.



What can I do to help myself during my treatment?

To ensure that you stay well during your treatment, you should:

- Drink plenty of fluids.
- Maintain a balanced diet and try to eat little and often.
- Continue to maintain as normal a lifestyle as possible, including light exercise.
- Maintain good mouth hygiene.
- Avoid sunbathing and exposure to the sun.

- Call the number on your alert card if you feel unwell, or have urgent questions or concerns.
- Don't go it alone – talk to family, friends and your medical team.

At each of our hospitals we have a cancer information support centre available to patients:

- Barnet Hospital Macmillan Information Centre: 020 8216 4142
- Chase Farm Hospital Macmillan Information Centre: 020 8375 2247
- Royal Free Hospital Macmillan Information Centre: 020 7794 0500 ext 31337

Macmillan Cancer Support
Telephone: 0808 808 0000
www.macmillan.org.uk

All of our information centres have a Macmillan welfare benefits service, where you seek help and advice on welfare benefits, including help making applications and claims for hospital travel.

For more information about the Macmillan cancer information and support centre, visit our website: www.royalfree.nhs.uk/patients-visitors/advice-and-support/macmillan-cancer-information-and-support-centre

More information on how immunotherapy works can be found on the Macmillan website: www.macmillan.org.uk/cancer-information-and-support/treatments-and-drugs/immunotherapy

More information

For more information about the cancer service at the Royal Free London, please visit our website: www.royalfree.nhs.uk/services/services-a-z/cancer-services/

Your feedback

If you have any feedback on this leaflet or for a list of references for it, please email: rf.communications@nhs.net

Alternative formats

This leaflet is also available in large print. If you need this leaflet in another format – for example Braille, a language other than English or audio – please speak to a member of staff.

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Service: Cancer
Version number: 1
Approval date: April 2021
Review date: April 2023
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