

Coming for Immunotherapy

Information for patients



This booklet contains information to help you understand more about your immunotherapy treatment.

It is a general guide and does not go into detail about every immunotherapy drug and every possible side-effect. You will be provided with specific information about your particular treatment.

Please ask any of the medical or nursing staff if you have any concerns or want more detailed information at any time.

It is advisable to keep this booklet in the pack of information as well as any consent forms that you will have been given to keep everything in one place. It is helpful to bring your pack with you when you come to the hospital or if you see your GP, other doctors, nurses or pharmacists.

At the back of this booklet is a list of medical terms and their definitions that you may hear or read about. There is also some space for you, or one of your health professionals, to write notes about your treatment and side-effects which can be useful to help you remember what has been discussed or what you want to ask at your next appointment.

This record is just for you as the hospital keeps their own set of your notes.

You will be given a contact card with telephone numbers for you to call the hospital if you are unwell. You need to keep this with you along with another card you will be provided with that has specific information about your treatment.

When to contact your hospital team?

Please contact us immediately if any of these things happen:

- diarrhoea or blood or mucus in stool – more than three episodes in a 24 hour period;
- new cough/acute shortness of breath – developed over a few days;
- extreme tiredness alongside dizziness.

Please phone for advice or make sure that you tell your doctor or nurse in clinic if you experience any of the following between treatments.

General:

- I feel more tired or confused
- I have a fever
- I feel colder than normal
- I have lost or gained weight
- I have noticed a change in my behaviour
- I have been feeling anxious or irritable.

Mouth and head:

- I feel faint or dizzy
- I have headaches that will not go away or are unusual for me
- I am more thirsty than usual
- I have a dry mouth

Throat and chest:

- I feel more short of breath
- I have chest pain
- I have developed a new or worse cough
- I have noticed a rapid heart beat
- My voice is getting deeper.

Skin and hair:

- I have developed a rash or my skin is itchy
- I am bleeding or bruising more easily than normal
- I have noticed a yellowing of my skin.

Stomach and bowels:

- I have diarrhoea or more bowel movements than usual
- My stools have blood or mucous in them or are black, tarry and sticky
- My stomach area feels sore or tender.
- I have felt sick and/or been sick (nausea and vomiting)
- I feel less hungry than usual
- I am constipated.

Muscles, joints and legs:

- My muscles ache
- I have severe or persistent muscle or joint pains, or severe muscle weakness.

Eyes:

- My eyes are sore and irritated
- My eyesight has changed or become blurred
- I have double vision
- I have noticed a yellowing of my eyes.

Urine:

- The amount and colour of my urine has changed
- My urine is dark.

You can refer to your specific immunotherapy drug information or alert card for further details. More information about side-effects is on page 11.

Clinical research trials

The Haematology and Oncology Department is involved in many large research trials.

Trials are needed so that we can develop better cancer treatments. Any new treatment must work better than the standard treatments before we can use it. This can only be done through a carefully carried out research trial.

As part of your treatment, you may be asked if you would like to be included in a research trial. This might involve using a completely new treatment or looking at a way of improving standard treatment.

You will be given lots of information by the research nurse team to enable you to make your decision about whether to take part or not.

If you do take part, you can change your mind at any time and we will offer you standard treatment. If you don't want to take part in the trial, we will offer you standard treatment.

You can get independent advice on research trials from patient groups/forums. Please ask the research team for more information about this.

What is immunotherapy?

Immunotherapy is a type of cancer treatment that is different from traditional chemotherapy drug treatment as it uses the immune system to treat cancer. The drug or drugs you are having are a particular type of immunotherapy called a Checkpoint Inhibitor.

Traditional chemotherapy and cancer cell targeted drugs directly affect the growth and multiplication of tumour cells. Immunotherapy drugs instead aim to use the body's natural defences by helping the immune system to recognise, attack and destroy the cancer cells.

The immune system

The immune system includes the lymph glands, spleen and white blood cells. It works to protect the body against infection, illness and disease. It can also protect us from the development of cancer.

Normally, it can spot and destroy faulty cells in the body, stopping cancer developing. However a cancer can sometimes develop when:

- the immune system recognises cancer cells but it is not strong enough to kill them;
- the cancer cells produce signals that stop the immune system from attacking them;
- the cancer cells hide or escape from the immune system.

Immunotherapy checkpoint inhibitors block signals from the cancer cells to the immune system so the immune system can recognise and attack the cancer. By blocking these signals the checkpoint inhibitor drugs are able to switch on and boost the immune system against the cancer cells.

Some people need more than one type of treatment to treat their cancer e.g. surgery followed by chemotherapy or radiotherapy. You may be given immunotherapy alone or alongside a combination of other treatments.

Other treatments used to treat cancer include:

- Surgery
- Radiotherapy
- Chemotherapy
- Targeted cancer drugs
- Hormone treatments.

The decision about what treatment to give you will have been made by a group of doctors using national guidelines and evidence from research. You will be given specific information about your individual regimen. Please ask your doctor or nursing team any questions you may have.

Having your immunotherapy

You will usually have immunotherapy as several doses (cycles) of treatment to aim to keep the immune system working against your cancer. Depending on your regimen, each drug is given intravenously as an infusion (drip) over 30 to 60 minutes.

You may have one or two immunotherapy drugs each visit and some patients will also have chemotherapy on the same day. The time for treatment will be longer if you have more than one drug. The intravenous line is also flushed with a saline drip before and after each drug so the time for your appointment will be longer to allow for this.

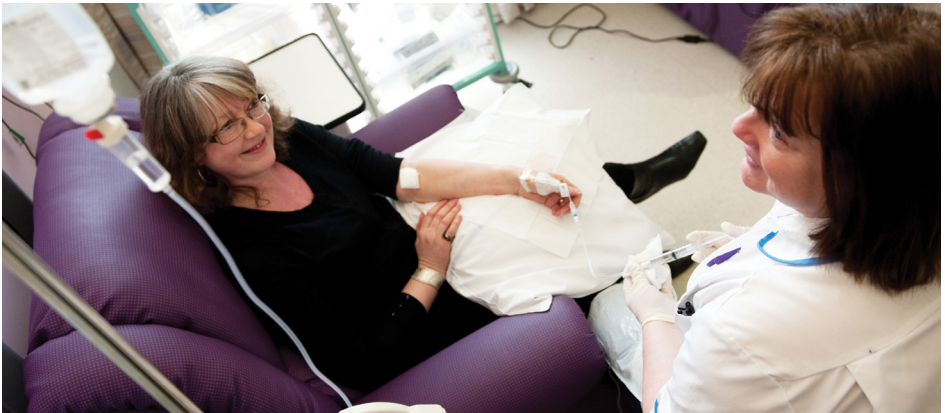
You will then have a rest period of 4-8 weeks depending on your treatment regimen. This allows your body to recover from any side-effects before the next treatment.

The number of treatments you will have depends on the type of cancer you have and how your body reacts to treatment. Your team will explain your individual treatment plan in more detail.

How you will be given your immunotherapy

The doctor or nurse will discuss this with you.

Immunotherapy checkpoint inhibitors are usually given intravenously which means they are given directly into the blood stream via a vein. The medication will usually be given through a temporary small plastic tube (cannula) into your hand or forearm. It is inserted on the day of treatment and removed once the infusion has finished. Some immunotherapy drugs may be given subcutaneously as an injection just under the skin.



Giving your immunotherapy through a cannula

You will see the nurse take many precautions to carefully give you your treatment safely. Sometimes, although this is not common, the drug can leak outside your vein into the surrounding skin and tissues.

You may need some treatment to the area to prevent any damage to the surrounding area.

Delivering your immunotherapy - how you can help

Wear clothes with short sleeves or sleeves that can be pushed up easily to keep the area from the elbow to the wrist visible. This means the site where the immunotherapy is being delivered can be seen easily by the nurse.

Before the treatment starts, place things you may need, such as tissues, drinks and the nurse call bell, near the arm that does not have the treatment infusing, so they are in easy reach for you.

If you feel unwell during the infusion you **must** contact one of the nurses on the unit. It is rare to have a reaction to the drugs however the team will be able to look after you and manage any symptoms.

Please inform the staff if you experience:

- chills or shaking,
- itching,
- rash,
- flushing,
- pain,
- nausea or
- feeling generally unwell.

You can move around the ward whilst immunotherapy is infusing but you should not leave the ward whilst treatment is in progress and movement should be limited to trips to the toilet.

If the site, or surrounding area of the cannula, where the immunotherapy is being delivered feels painful, uncomfortable, itchy, red or in any way unusual or if you knock or dislodge the tube, please let your nurse know **straight away**. Do not wait to see if the symptoms get worse.

Sometimes it may take more than one attempt for the nurse to insert a cannula into your vein to ensure your treatment is delivered safely. If there is any doubt about the safety of your cannula and delivery of treatment, your nurse will stop the drug and re-start it in another vein. This is for your own safety

Rarely there may be a time when it is not possible to continue delivering your immunotherapy into a vein in your hand or arm. This can be because there are no more visible veins, or your veins have become fragile causing an increased risk of the drug leaking outside your vein into the surrounding skin and tissues. To ensure the safe delivery of immunotherapy, your nurse or doctor may discuss the option of a long term catheter/tube which can be inserted into your upper arm or chest and remains in place for the whole time you are on treatment. Further information is available if this is required.

Where you will have your immunotherapy treatment?

We give most immunotherapy drugs as day case treatments in the Oncology Day Case Unit, Ambulatory Care Unit (ACU), Wharfedale Hospital or the Research Unit at St James's Hospital. Occasionally you might have immunotherapy treatment as an inpatient. Your team will let you know where you will have your treatment.

Side-effects

Unfortunately, immunotherapy can sometimes cause side-effects. We will ask you to sign a consent form before we start treatment. This is to say that we have told you about the treatment and its possible benefits and side-effects. After you have signed the form you still always have the opportunity to ask any questions you need to before, during and after your treatment.

As checkpoint inhibitor immunotherapy affects the immune system this may cause inflammation in different parts of the body which can cause side effects. These could happen during treatment, or some months after treatment has finished. In some people, these side effects could be life threatening.

Side-effects with checkpoint inhibitors can affect any organ or tissue, but most commonly affect the skin, bowels, lungs, liver and endocrine organs (such as the pituitary gland or thyroid gland) that are involved with making hormones.

Most immune-related side-effects are mild to moderate and are reversible if detected early and treated appropriately. Sometimes however, they can be serious and can take a few weeks to resolve or can be permanent though treatable. You are more likely to have worse side-effects if you have two immunotherapy drugs together.

The most important and effective way to reduce side effects is to notice them early and receive prompt treatment.

If symptoms are severe or worsening you may be assessed in the oncology assessment unit and might need admission to hospital.

Sometimes immunotherapy is stopped whilst you get better and you may get oral or intravenous steroids.

Sometimes the immunotherapy drug can be restarted after you have recovered. Some patients have lasting benefit from immunotherapy treatment even if it is not restarted again.

What are the side-effects?

Your medical team will give you separate information about your particular treatment and an alert card with details of the specific side-effects that you may get. It is important to remember that you will not get all of the possible side-effects.

You may be sent home with medications to take between treatments to manage some side effects. It is important that you take these as directed and that you contact the hospital if you feel they are not working or if you notice anything else that worries you.

When are the side-effects most likely to happen?

Immune-related side effects to checkpoint inhibitor immunotherapy typically occur quite early – mostly, within a few weeks to three months after treatment starts. However, the first onset of side-effects has been recorded as early as days after starting to as late as one year after treatment has finished

If you have any questions or concerns, or notice any worrying symptoms (or worsening of existing symptoms), you should inform your doctor or oncology team as soon as possible so they can address these promptly and give you the best possible care.

Some side-effects may occur many weeks or months after starting treatment or can occur after stopping treatment with immunotherapy checkpoint inhibitors.

You should always carry with you the contact card for the hospital and the drug specific information card that you will be provided with so you can show them to any health professionals to ensure you get the most appropriate care.

Monitoring whilst on Immunotherapy

You will be closely monitored whilst on immunotherapy. You will have an assessment to check for any side effects and ensure you are well enough for treatment before each cycle of treatment. This assessment might be in hospital or might be over the phone. You will also have blood tests a few days before each treatment. The blood tests check how your body is coping with the treatment. They may pick up early signs of side effects before you become unwell with symptoms so your medical team can treat them as quickly as possible. You may have these bloods taken in the hospital when you attend for a clinic appointment or you may have them at your closest available service, for example at your GP's surgery.

When you complete treatment you will have regular follow up checks by your hospital team and you can go to your GP for advice. You should tell health professionals that you have had immunotherapy or show them the alert card so they are aware to look for late side effects of treatment.

General advice

Fertility and immunotherapy

Women

During immunotherapy you remain fertile if you haven't already been through the menopause. It is important to prevent pregnancy whilst on immunotherapy treatment as the treatment may cause damage to a developing baby in the womb or an early miscarriage. It is safest to use barrier contraception (condoms) during intercourse to prevent pregnancy and also to reduce risk of infection.

This will be discussed with you when your doctor consents you for your immunotherapy and a separate patient information leaflet will be provided explaining the importance of not becoming pregnant whilst you are on treatment.

If you are considering becoming pregnant after your treatment, it is important to wait at least six months, because the effects of the immunotherapy could potentially cause problems with the developing baby or cause a miscarriage. This also allows time for your medical team to assess your response to treatment and to make sure no further treatment is needed.

It is important that you discuss these issues with your doctor or nurse specialist.

If you are having immunotherapy it is recommended that you do not breast feed during treatment or for three months after finishing treatment. It is not known if the drug passes into your breast milk.

Vaccinations/immunisations

Please consult your chemotherapy nurse or doctor for the latest advice on having vaccinations including the flu vaccine.

Don't have immunisations with live vaccines while you're having treatment and for at least six months afterwards. In the UK, live vaccines include rubella, mumps, measles, BCG, yellow fever and shingles vaccine (Zostavax).

You can:

- have non-live vaccines, but they might not give you as much protection as usual
- have the flu vaccine (as an injection)
- be in contact with other people who have had live vaccines as injections

Avoid close contact with people who have recently had live vaccines taken by mouth (oral vaccines) such as oral polio, the typhoid vaccine or the rotavirus vaccine.

You should also avoid close contact with children who have had the flu vaccine nasal spray.

Eating and drinking

You should eat a normal healthy balanced diet and drink plenty of fluid. You can drink a small amount of alcohol if you feel like it. There are no dietary restrictions or interactions with immunotherapy.

You should eat and drink as normal on the day of your immunotherapy treatment. It is good to drink plenty of fluids before coming for your appointment as it will make it easier to put the cannula into a vein.

If you feel sick as a result of your treatment, you could try some of the following tips:

- Avoid eating or preparing food when you feel sick.
- Avoid fried foods, fatty foods or foods with a strong smell
- Eat cold or slightly warm food if the smell of cooked or cooking food makes you feel sick.
- Eat several small meals and snacks each day and chew your food well.
- Drink plenty of liquid to stop you from becoming dehydrated, but avoid filling your stomach with a large amount of liquid before eating.
- Relaxation techniques help control sickness for some people
- Ginger can help – try it as crystallised stem ginger, ginger tea or ginger ale.
- Fizzy drinks help some people with nausea.

Exercise

You may feel more tired than usual and lack energy.

Various things can help you to reduce tiredness and cope with it, for example having a regular bedtime and getting up time. Some research has shown that taking gentle exercise can give you more energy. It is important to balance exercise with resting and inform your team if your tiredness is getting worse.

Avoid swimming if you have a rash because the chlorine in the water can make it worse.

Skincare and sun exposure

As a result of the treatment your skin may get dry or itchy, smoothing in unperfumed moisturising cream may help. Check with your doctor or nurse before using any creams or lotions. Wear a high factor sun block if you're going out in the sun.

Other medication

It is important that your hospital team are aware of *all* other medications, prescribed, over the counter medicines, supplements, vitamins and any recreational/non prescribed drugs that you are taking before starting immunotherapy; especially blood thinning treatments such as warfarin or aspirin and anti-inflammatory or immunosuppressant drugs. This is to prevent interactions with your immunotherapy.

You must inform your hospital team if you start taking any new prescribed or over the counter medication, vitamins or herbal supplements whilst on treatment.

Holidays and travel insurance

If you are planning a holiday, please discuss this in plenty of time with the hospital team because they may have to change your treatment. It is important to discuss any vaccinations for foreign holidays with the doctor.

You will need to tell the travel insurance company about your illness and treatments. They may ask for a letter from your doctor to say that you are well enough to travel. The Leeds Cancer Support Service can signpost you to organisations that have details on travel insurance.

Driving

Unless your doctor has told you to stop driving, you can usually carry on driving as normal, as long as you feel well enough to do so.

Appointments

It is very important to keep your appointments for treatment wherever possible. If you do need to change or cancel your next appointment date, please contact the ward/unit as soon as possible so it can be rearranged.

As your treatment is prepared especially for you and cannot be used for anyone else, we may need to phone you on the day of treatment to confirm that you are well enough to come in before the pharmacy starts to prepare your medication. Sometimes we have to actually see you on the unit before the drug preparation starts to ensure we do not waste it. This may mean that you have to wait a while for the drug to be delivered to the unit but you can leave the ward and come back later when the drug is ready.

You can have visitors to keep you company whilst you have your treatment.

If you feel unwell on the day you are due your treatment or pre-assessment appointments please contact the ward/unit before turning away transport or deciding not to come as you may need to be reviewed by a doctor.

Important

If you have a **rash** or **spots** of any kind or any signs of an infection when you visit any of the wards, outpatient departments or chemotherapy units, **PLEASE** inform the nursing or reception staff **before** sitting in any of the waiting areas or entering the ward as you could be an infection risk to other patients.

Parking at the hospital

You are eligible for free parking in the multi storey car park at St James's hospital when you attend the hospital for treatment. Show your treatment appointment letter to the attendant by the barrier at the exit of the car park when you leave.

Support for you

It may help to talk about your cancer and treatment and for you to get support from other people outside your family and friends.

This may be:

- Nurses on your chemo ward or a specialist nurse.
- The Leeds Cancer Support Service
- Maggie's Centre
- Psychologists and counsellors - your hospital team will be able to give you more information, and refer you if needed.
- Support groups and cancer specific helplines the Leeds cancer support Service can provide details of what is available

Support services

Leeds Cancer Support

Leeds Cancer Support complements care provided by your clinical team. They offer access to information and a wide range of support, in a welcoming environment for you, your family and friends.

They can be found in the information lounges in Bexley Wing and also in the purpose built Sir Robert Ogden Macmillan Centre.

There is a separate information leaflet describing the Leeds Cancer Support service, where they are located and opening hours.

Website

There is a Leeds Teaching Hospitals, Leeds Cancer Centre website with lots of information you may find useful:

www.leedsth.nhs.uk/a-z-of-services/leeds-cancer-centre/

Chaplaincy

The Chaplains (from different denominations and faiths) help provide spiritual, religious and pastoral care to everyone in the hospital; patients, relatives and staff. The Faith Centre is based on Level 1, Bexley Wing and is open 24 hours a day.

Tel: (0113) 206 4365

Macmillan Cancer Support

89 Albert Embankment, London, SE1 7UQ

Opening hours: 9am - 8pm Monday to Friday.

Tel: 0808 808 0000 (free) This line also offers an interpretation service. When you call, just state in English, the language you wish to use.

Text phone service: (hard of hearing) **10800 0808 808 0121**

Website: www.macmillan.org.uk

There are lots of other places to get support including helplines, support groups and other websites. Please ask your nurse or the Leeds Cancer Support team what is appropriate and accessible locally for you.

Specialist words

Cancer - a term for a number of diseases that can occur throughout the body where abnormal cells divide uncontrollably. Cancer cells can invade nearby tissues and may spread to other parts of the body.

Chemotherapy - treatment with chemicals that kill cells.

Clinical trials - studies to find ways to prevent, detect or treat cancer more effectively by testing new treatments and comparing with current treatments.

Grade of cancer - how aggressive a cancer is.

Immune system - the body's defence mechanism that fights off bacteria, viruses, parasites and foreign cells including cancer cells.

Invasive cancer - cancer that has spread beyond the tissue where it developed.

Lymphatic system - a network of glands throughout the body – particularly in the armpits, neck and groin. They transport and drain away fluid, waste products and damaged cells.

Lymphoedema - a condition where too much fluid collects in the tissues and causes them to swell. It may happen in an arm or leg after lymph nodes in the underarm or groin are removed or if there is a blockage in the lymphatic system.

Metastatic - when cancer has spread from its original site to another part of the body.

Palliative - when treatment is not going to cure the cancer but is aiming to reduce symptoms, extend survival and improve quality of life.

Prognosis - the expected outcome of the disease process.

Radiotherapy - treatment with high energy rays to kill cancer cells.

Relapse - when symptoms of the disease return after a period of improvement.

Remission - when the symptoms of cancer disappear. Remission can be temporary or permanent.

Side-effects/toxicities - problems that happen when treatment affects healthy cells/systems.

Stage of cancer - how far the cancer has spread, whether it is contained in one place or has become more widespread around the body.

Targeted treatment - includes a variety of treatments with drugs that target specific markers or proteins on/in cancer cells to kill or interfere with the ability of the cancer cell to grow, divide, repair and/or communicate with other cells.



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Your views matter



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