



Immunotherapy

A guide for patients and their carers



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The Christie website

For more information about The Christie and our services, please visit www.christie.nhs.uk or visit the cancer information centres at Withington, Oldham, Salford or Macclesfield.

What is immunotherapy?

The immune system is your body's natural defence and protection from infections and other diseases.

Immunotherapy is a type of cancer treatment that helps your immune system to fight cancer by improving your body's immune cells' natural ability to target cancer cells.

Immunotherapy drugs reactivate a person's immune system so it can recognise and attack the cancer cells in the body.

There are different types of immunotherapies and this treatment is sometimes called a 'targeted treatment'.

How does immunotherapy work?

The immune system recognises when a foreign organism enters the body, such as bacteria. The immune cells then attack that organism, preventing it from causing any harm. This process is called an immune response.

The immune system will attack cancer cells in the same way once it is able to recognise them. However, cancer cells often disguise themselves, so the immune system does not always recognise these cells as a threat. The body's natural immune response is not strong enough to fight off cancer cells without this treatment.

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

Depending on the type of immunotherapy treatment you are receiving, treatment will continue until it is no longer effective in fighting the cancer cells. There may be a time limit to length of treatment and this will be discussed with you by the clinical team.

How is immunotherapy treatment given?

Immunotherapy is given into your vein via a cannula (intravenously). How often you receive your treatment is dependent on which drug treatment you are prescribed and is usually given every 2, 3 or 4 weeks. Treatment can take between 30 minutes and 3 hours.

You will receive your treatment at either the Oak Road Treatment Centre (department 1) or ward 3 (department 48) or at one of our outreach sites.

The Christie offers a home treatment service for patients receiving immunotherapy as a single treatment. You will need to receive your first few treatments at The Christie, but if these occur without any issues then it may be possible for your treatment to be delivered at home or at one of our outreach sites. Please speak to your medical team for more information.

The nurses at these outreach sites are Christie nurses and you will remain under the care of your Christie consultant.

If you are having treatment with The Christie at Home service, you will still need to have your bloods and review done prior to treatment, but the immunotherapy treatment will be delivered to your home. One of The Christie at Home nurses will then attend your home to deliver treatment on your appointment day.

The Christie Hotline

You will be given a Hotline card at your first appointment in clinic. You will need to keep this with you at all times in case you become unwell when away from your home. If you feel unwell or develop any of the symptoms discussed in this leaflet, please ring this number. This is a 24 hours a day, 7 days a week helpline for patients on cancer treatment.

If you are asked by the Hotline to attend your local accident and emergency department, you will need to show them this card and inform them you are receiving immunotherapy treatment. This will assist them with your care.



What happens before my treatment?

Before you start any treatment, you must sign a consent form agreeing to accept the treatment that you are being offered. The basis of the agreement is that you have had The Christie's written description of the proposed treatment and side effects, and that you have been given an opportunity to discuss any concerns. Your consent may be withdrawn at any time before or during this treatment. Should you decide to withdraw your consent, a member of your treating team will discuss the possible consequences with you. You are entitled to request a second opinion from another doctor who specialises in treating this cancer. You can ask your own consultant or your GP to refer you.

Before your treatment date you will be seen by a member of the team for assessment, this is to ensure you are well enough for treatment. This may be done face-to-face or via telephone. You will have blood tests done in the days prior to your treatment date and these will need to be checked before treatment can go ahead. You can have your blood tests done using our Bloods Closer to Home service or you can attend The Christie.

To book your blood test using our Bloods Closer to Home service, please visit the following website:
www.christie.nhs.uk/bloodtest

If you have any questions about the blood test clinics, please contact the Bloods Closer to Home team on **0161 918 7654**.

Immunotherapy at The Christie – what actually happens?

There are a variety of different routes patients come through before treatment as detailed below. This can be confusing, so please do not hesitate to ask a member of staff if you have any questions.

■ 2-day treatments

You will have your appointments spread over 2 days. On the first day you will have your blood taken and, if needed, see the doctor. The second appointment will be for your treatment, usually within a few days of your first appointment. This is in order to significantly reduce delays as your immunotherapy will be ready for you when you arrive at the hospital.

Main outpatient clinic (department 22)

- If a blood test is required, please check in using the self check-in kiosk in central phlebotomy (department 35) or outpatients (department 22). You will be given directions to the blood room.
- You will be called for your blood test via the information screens in the outpatients waiting area.
- When you have had your blood test, please check in separately for your clinic appointment using the self check-in kiosk in outpatients. You will be called for your appointment via the same screens in the outpatients waiting area.
- Once you have seen the doctor, if you are due to be treated on a separate day you are free to leave.

Systemic anti-cancer therapy (SACT) services (department 1)

- If you are seeing your medical team before treatment, please check in using the self check-in kiosks in either the outpatient department (department 22) or in the Oak Road waiting area (department 1).

- You will see your medical team and agree whether your treatment is going ahead. Your immunotherapy treatment will then be ordered ready for your appointment.
- When you attend for your treatment appointment, please follow the same process for booking in. Take a seat in the waiting area until you are called in for treatment.

Protocol treatment

- Not all patients need to be seen by their team on all cycles of treatment. The visits when you are not seen in clinic are called 'protocol'.
- Check in using the self check-in kiosk in department 1. If you have a mobile phone with you, please give the number to the receptionist.
- You will be called for your blood test via the information screens in the Oak Road and M&S Café waiting areas.

General points

Your treatment may have to be postponed if your blood results are not within our set ranges. We will tell you about this as soon as we can and arrange another appointment – normally a week later. We will tell you about any delays.

If you have any general queries or questions while you are waiting for treatment, please ask at reception to speak to the ground floor manager.

You may need to set aside the whole day for tests and treatment. If you have a long infusion or if there are delays for any other reason, you may not finish your treatment until well into the evening.

If there is a delay or when your treatment is ready, we might call you. Please be aware the hospital telephone number will

show up on your mobile phone as 'withheld' or 'unknown'. If you do not have a mobile phone please look for your name to appear on one of the patient information screens.

If you have any treatment at an outreach centre or at home, the logistics will be discussed with you by the treatment team.

Visitors

You will not be allowed any visitors with you whilst you receive your treatment, however they are welcome to use any of the patient and visitor areas in the hospital.

What are the side effects of immunotherapy treatment?

Immunotherapy treatment can cause the immune system to inflame healthy tissues. This can cause immune-related 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 you experience immediately to prevent the problem becoming more serious.

Sometimes it is necessary to pause your immunotherapy treatment due to side effects. Your oncology team will discuss recommencing immunotherapy treatment if/when it is safe to do so.

The side effects you get will depend on the medicine or combination of medicines you receive. Your doctor or nurse will discuss your proposed treatment with you and give you an information sheet which will describe the treatment and discuss the likely side effects.

Whilst on treatment you will require blood tests to monitor for certain side effects.

You may experience one or several of the side effects listed below. Always be on alert for new symptoms.

What are the main side effects to look out for?

General

- Feeling more tired and confused
- Difficulty sleeping
- Feeling shivery or cold
- New or persistent headaches
- Feeling dizzy or lightheaded
- Change in your appetite
- Changes in your mood
- 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
- An increase in bowel movement and/or diarrhoea
– any change in bowel habit should be taken seriously
- Blood/watery or foul-smelling stools
- Cramping pains

Breathing

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

Skin

- A yellow tinge to your skin
- A skin rash or itchy skin which may be confined to one area or all over your body

- Bleeding or bruising
- Sweating more than usual

Musculoskeletal

- Muscle aches
- Severe pain 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 in the form of tablets may be required
- Glands will be checked regularly with a blood test.

General symptoms of gland issues may include:

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

Rare side effects

- Myocarditis (inflammation of the heart muscle)
- Epididymitis (pain and swelling of the testicles)
- Cytokine release (inflammatory response)
- Haematological e.g., neutropenia

Side effects can continue for over a year after you have stopped immunotherapy treatment. It is therefore important you continue to be aware of these potential side effects.

What will happen if I get a side effect?

It is important that you are aware of the potential side effects of treatment. If you experience any of the following side effects, you should contact The Christie Hotline for assessment: diarrhoea, blood or mucus in stool (more than 3 episodes in 24 hours), a cough/acute shortness of breath developed over a few days, extreme tiredness alongside dizziness or loss of limb movement.

You will be advised about the best course of action. This may mean you need to attend your local A&E or GP. Please take your Hotline card with you as this will give the doctors and nurses all the information about your treatment and side effects. Please follow the Hotline advice.

If you experience any symptoms, feel unwell or notice any changes to your normal health, you should report these as soon as possible to The Christie Hotline (24 hours a day, 7 days a week): 0161 446 3658.

How are side effects treated?

Side effects relating to immunotherapy often need treatment with immunosuppressants such as steroids, these can usually be reduced once the side effect is stable or has gone.

Once you have been reviewed you may need to start treatment for your side effect. This is normally with steroids – drugs called prednisolone or methylprednisolone. Once you leave hospital you will be followed up by telephone to see how you are. You may also need to have regular blood tests.

Sometimes we will have to pause treatment until you have recovered, or your side effect is stable. Steroid treatment needs to be gradually reduced over a period of days to weeks. Please do not stop them yourself as side effects can return and you can become very unwell.

If your glands are affected by the immunotherapy drug you may need to have some hormone replacement treatment, such as thyroxine for an underactive thyroid gland.

Am I allowed to take other medications while on immunotherapy?

Please make sure that the doctor knows about any tablets or medicines you are taking for other conditions, including any that you buy from the chemist. These can usually be continued unchanged during immunotherapy – but do check. We will send your family doctor full details of the treatment prescribed in hospital.

We recommend that you continue to receive your flu vaccine as normal. We also recommend you receive your pneumococcal vaccine and COVID-19 vaccine booster if you are invited for these from your GP. Vaccines can be given before, during or after cancer treatment.

Alcohol:

As a general rule, you may continue to drink a moderate amount of alcohol, but it is probably best avoided for the first 48 hours after treatment. Certain medicines can react

badly with alcohol and if your treatment includes these, we will tell you before starting.

Herbal remedies and health supplements:

Some commonly taken supplements and herbal remedies can interfere with cancer treatments. Please tell your doctor about any supplements you may be taking, for example: vitamins, garlic capsules, cod liver oil, Echinacea and St John's Wort. Your doctor might ask you to stop taking these while you are having immunotherapy.

Is there anything I cannot do while on immunotherapy?

There are no specific activities you must avoid while receiving immunotherapy.

If you are able to/are well enough, you can continue to work. You can drive yourself to and from your appointment if you are well enough to do so. Be guided by how you feel but be sure to rest when you become tired.

You can travel while on immunotherapy, but you will need to discuss this with your oncology team before booking anything as you may need provisions for your trip.

We strongly recommend you only travel abroad if you have travel insurance to cover any issues with your health during your trip and carry your UK Global Health Insurance Card.

Macmillan Cancer Support has up-to-date information about travel insurance for people being treated for cancer. Contact Macmillan Cancer Support on: **0808 808 00 00** or call in at the cancer information centre for an information leaflet.

Further information

Feelings and emotions

Sometimes during immunotherapy, you may begin to feel anxious and on edge, or low and fed-up. This often improves as treatment progresses, but if you continue to feel like this, please let your doctor or chemotherapy nurse know as they can usually help. There are counsellors on the staff here. If you think counselling sessions at The Christie would help you, ask your doctor or nurse to refer you. You can also contact a social worker. Local cancer centres often offer counselling. You can find the address and telephone number of a centre near you in The Christie booklet 'Where to get help', or visit the cancer information centre.

Clinical trials

Research into new ways of treating all types of cancer is going on all the time. As no current cancer treatment is completely effective, cancer doctors are continually looking for new ways to treat the disease. These are called clinical trials and are the only reliable way of testing a new treatment. Often several hospitals in the country take part in these trials.

Before any trial is allowed to take place it must have been approved by an ethics committee. Your doctor must have your written informed consent before entering you into any clinical trial. Informed consent means that you know what the trial is about, you understand why it is being conducted, and you appreciate exactly how you will be involved. In a randomised controlled clinical trial, some patients will receive the currently available treatment while others receive the new treatment, which may or may not prove to be better.

Even after agreeing to take part in a trial, you can still withdraw at any stage if you change your mind. Your decision

will not affect your doctor's attitude towards you in any way. If you choose not to take part or if you withdraw from a trial, you will then receive the currently available treatment rather than a new one.

(We acknowledge the help of Macmillan Cancer Support for this information on clinical trials).

Outpatient prescriptions

Prescriptions from The Christie Pharmacy are free for NHS patients. You will need an exemption certificate to get free prescriptions from a community pharmacy.

Exemption certificates are available from the pharmacy and benefits advisers at The Christie and your GP.

Appointments

Your immunotherapy treatment is often made in advance of your arrival, and this helps to reduce your waiting time. If you let us know of any appointment changes, we can prevent unnecessary wastage of medicines. Your co-operation and patience during busy periods is very much appreciated. It is very important to keep your appointment for treatment wherever possible. If you do need to change or cancel your next appointment date, please contact your scheduler – the name and telephone number is on your appointment card.

If you are unable to contact your scheduler, please phone **0161 918 7606, 7608 or 7610**.

If you change your address or change your family doctor, please tell the receptionist where you are having chemotherapy or contact the hospital on **0161 446 3346 or 3347**.

Macmillan Cancer Support

This is a national charity which runs a cancer information service. If you have questions about cancer or need support, you can use the Freephone number: **0808 808 00 00** (Monday to Friday, 9am–8pm). Textphone **0808 808 2121**. Specially trained cancer nurses can give you information on all aspects of cancer and its treatment. They publish booklets which are free to patients, their families and carers. You can get a copy by ringing the freephone number. The information is on their website: **www.macmillan.org.uk**

Macmillan Cancer Support booklets include:

- Specific cancers, for example, breast, bone, ovary and colon & rectum.
- Cancer treatments such as 'Understanding chemotherapy' and 'Understanding radiotherapy'
- Booklets on living with cancer – some are listed below:
 - Talking about your cancer
 - Coping with fatigue
 - Talking to children when an adult has cancer
 - Coping with hair loss
 - Cancer and complementary therapies.
 - Bone health

The cancer information centres also have a full range of Macmillan booklets.

Christie information

The Christie produces a range of patient information booklets. Some of these are listed below. The booklets are free to patients attending The Christie. If you would like a copy of a booklet, please ask the ward staff. If you

are an outpatient please ask your clinic nurse, doctor or chemotherapy nurse.

■ The Christie Hotline card and leaflet

Explains when and how to make contact with The Christie if you feel unwell or have any concerns about side effects.

■ Eating – help yourself

A booklet which gives advice on coping with eating problems when you don't feel well, and when you are receiving treatment.

■ Where to get help: services for people with cancer

Lists sources of help for financial, social and emotional problems. Also lists the main cancer support groups.

■ Care of your central venous catheter, Care of your Peripherally Inserted Central Catheter, TIVADs

Guides on how to use and care for infusors or pumps, central venous catheters, TIVADs and peripherally inserted central catheters.

■ Be Active, Stay Active: a guide for exercising during and after treatment for cancer

A booklet with a simple exercise programme you can follow. There is also more information about coping with fatigue and the benefits of exercise.

Benefits and finance

You may have had to stop work and had a reduction in your income. You may be able to get benefits or other financial help.

Personal Independence Payment (PIP) is a social security benefit and has replaced Disability Living Allowance (DLA)

for new claimants. It's for people who need help either because of their disability or their illness. You can apply if you are aged 16 or over and have not reached State Pension age. You can apply for DLA if you are under 16.

If you are State pension age or older and need help with personal care or supervision, you could be entitled to Attendance Allowance.

Your carer could get Carer's Allowance if you have substantial caring needs.

Find out more today:

- To get a claim pack for Attendance Allowance, call **0800 731 0122** and for PIP call **0800 917 2222**.
- Carer's Allowance: call **0800 731 0297**.
- For benefits advice, contact Maggie's centre on **0161 641 4848** or email **manchester@maggies.org**
- The Christie at Oldham has a benefits advice session on Thursday afternoons, call **0161 918 7745**.
- Contact your local social services department for help with equipment and adaptations, or for an assessment of care needs. Visit **www.gov.uk** for further information.
- Macmillan Cancer Support can give advice on helping with the cost of cancer on **0808 808 00 00** or **www.macmillan.org.uk**

Student training

The Christie is a training hospital for postgraduate and undergraduate trainees so you may meet students in all areas of the hospital. We train doctors, nurses, radiographers and other therapists in the treatment and care of cancer patients. Placements at The Christie are

an important part of student training, so by allowing them to assist in your care, you will be making a valuable contribution to student education.

Students are always supervised by fully qualified staff. However, you have the right to decide if students can take part in your care. If you prefer them not to, please tell the doctor, nurse, radiographer or other therapist in charge as soon as possible. You have a right to do this, and your treatment will not be affected in any way. We also try to respect the concerns of patients in relation to the gender of their doctor and other health professionals.

If you need information in a different format, such as easy read, large print, BSL, braille, email, SMS text or other communication support, please tell your ward or clinic nurse.

The Christie is committed to producing high quality, evidence based information for patients. Our patient information adheres to the principles and quality statements of the Information Standard.

If you would like to have details about the sources used please contact the-christie.patient.information@nhs.net

Contact The Christie Hotline for
urgent support and specialist advice

The Christie Hotline: 0161 446 3658

Open 24 hours a day, 7 days a week

Visit the Cancer Information Centre

The Christie at Withington **0161 446 8100**

The Christie at Oldham **0161 918 7745**

The Christie at Salford **0161 918 7804**

The Christie at Macclesfield **0161 956 1704**

Open Monday to Friday, 10am – 4pm.

Opening times can vary, please ring to check
before making a special journey.

The Christie NHS Foundation Trust

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0161 446 3000

www.christie.nhs.uk



The Christie Patient Information Service
January 2024 – Review January 2027

CHR/IMM/1563/06.09.2023 Version 1