

T-Cell Therapy (CAR-T)

Department of Haematology
Information for Patients

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Important Dates

Date of pre-admission covid test

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Date of admission to hospital

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Date of Line insertion

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Date treatment starts

.....
Date of CAR-T infusion

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Medications to be stopped

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Introduction

Coming into hospital for your CAR-T cell therapy

On the day you come into hospital, please go to the **Cellular Therapy Suite**. When you arrive, a nurse will check your blood pressure, temperature and other observations. A member of staff will then take you to your appointment to have your line fitted if you do not have one already.

Before you go to the ward, you will meet a doctor and a nurse who will complete your admission.

Chemotherapy before CAR-T cells

Once you are admitted, you will have a few days of chemotherapy. This is called **leukodepletion**. It helps prepare your immune system by lowering the number of normal T - cells in your blood. This creates space for the new CAR - T cells to work and grow.

The type and length of chemotherapy can vary depending on your condition and the type of CAR - T cells you are receiving.

Like all chemotherapy, it can cause side effects. You will be given a separate information sheet explaining these in more detail.

CAR-T cell infusion

On the day you receive your CAR - T cells, a doctor will check that you are well enough to go ahead with treatment. When you are ready, your nurse will:

- Give you medicine through your vein to help prevent allergic reactions
- Start fluids through your vein
- Check your blood pressure, temperature, oxygen levels and pulse

Your CAR - T cells arrive frozen. On the day of your infusion, staff will thaw them, and a nurse will give them to you through your **PICC line**. The infusion is similar to having a blood transfusion and usually takes **15 - 30 minutes**. A nurse will stay with you the whole time.

The CAR - T cells contain a preservative that protects them during freezing. This preservative has a smell similar to sweetcorn. You may not notice it, but your family or visitors might smell it for up to 24 hours after the infusion.

The first 28 days following the infusion.

After you receive your CAR - T cells, you will stay in hospital for **at least 14 days**. During this time, the team will check you closely for any side effects. These may include:

- Allergic reactions
- Cytokine Release Syndrome (CRS)
- **Neurotoxicity** (effects on the brain or nerves)
- Tumour Lysis Syndrome (TLS)
- Infection

You can read more about these possible side effects at the end of this leaflet.

When you go home, you will need a **family member or friend** to stay with you. They can help with daily tasks and watch for any signs of infection or changes in your thinking, speech or behaviour.

For the first **28 days**, please keep contact with other people limited to reduce your risk of infection.

You should **not drive or use heavy machinery for at least two months** after CAR - T treatment. If you had **CRS grade 2 or higher**, you may need to avoid driving for longer.

You may need to come to hospital **2 - 3 times a week** until your blood counts improve. Some people need regular blood or platelet transfusions during this time.

Follow-Up

After the first 28 days, your healthcare team will decide how often you need follow - up appointments.

For the first year, these appointments are usually **every 1 - 3 months**. They may be in person or over the phone. These visits may include tests such as:

- PET or CT scans
- Blood tests
- Sometimes a bone marrow test

You will also be checked for any late side effects.

How to support your recovery

Please follow the advice below:

- Call the Haematology–Oncology **24/7** Emergency Number: [0808 178 2212](tel:08081782212) immediately if your temperature is **38°C or higher**, or if you feel unwell in any way.
- Drink **2–3 litres of fluid** each day unless your team has told you otherwise.
- Wash your hands often with warm water and soap, especially after using the toilet and before preparing food.
- Cook meat and eggs thoroughly.
- Wash raw fruit and vegetables carefully.
- Avoid gardening and crowded places, as both increase your risk of infection.
- Brush your teeth after every meal to help prevent infections in your mouth.
- Do not drive any vehicle for two months after your infusion.
- If you don't feel strong enough to manage on your own, it can help to have someone stay with you for a few weeks after you leave hospital. They can support you with daily tasks and watch for any signs of infection or changes in your thinking or behaviour.
- Always keep your CAR - T contact card and your irradiated blood card with you.
- Whenever you speak to any doctor, nurse or other health professional about your symptoms, make sure you tell them that you have recently received CAR - T cell therapy.

What are the potential side effects of CAR T-cell therapy?

CAR -T cell therapy can cause some serious side effects. It is important that you, your family or your carer know what to look out for and contact your hospital team straight away if any symptoms appear.

Allergic reactions

Some people have an allergic reaction when the CAR - T cells are infused. Symptoms can include:

- Fever (temperature above 38°C)
- Shivering
- Trouble breathing
- Low blood pressure
- Rash
- Feeling or being sick

Your CAR -T team will watch you closely during and after the infusion so they can treat any reaction quickly.

Cytokine Release Syndrome (CRS)

CAR -T cells can cause your body to release large amounts of chemicals called cytokines. This can lead to a reaction known as Cytokine Release Syndrome (CRS).

Symptoms of CRS may include:

- Fever
- Feeling very tired or weak
- Shortness of breath
- Passing less urine than usual
- Feeling or being sick
- Diarrhoea
- Irregular heartbeat
- Headache

CRS can be serious and, in some cases, life - threatening. Some people may need care in the Intensive Care Unit. Your CAR - T team will monitor you closely and can give treatments, including antibody medicines, to help control CRS if it develops.

Neurotoxicity

CAR -T cell therapy can sometimes affect how the brain works. This is called ICANS (Immune Effector Cell - Associated Neurotoxicity Syndrome).

Symptoms can range from mild to serious:

- Mild symptoms: confusion, difficulty concentrating, drowsiness
- More serious symptoms: seizures, trouble speaking, or becoming less responsive

If symptoms are severe, some patients may need care in the Intensive Care Unit (ICU). Treatment may include steroids to help reduce inflammation in the brain.

To spot any problems early, your team will check your brain function every day while you are in hospital. Some patients will also be given medicine to help prevent seizures from the time they are admitted. Your CAR - T team will let you know if this applies to you.

Tumour lysis syndrome (TLS)

CAR - T cells can destroy cancer cells very quickly. When this happens, the cancer cells release substances into the blood. If too many are released at once, it can put pressure on the kidneys, making it harder for them to work properly. This is called Tumour Lysis Syndrome (TLS).

TLS can sometimes be serious or life-threatening.

To keep you safe:

- Your blood will be checked once or twice a day while you are in hospital.
- If TLS is found, you may receive fluids through a drip and medicines to help remove the toxins.
- In rare cases, dialysis may be needed to support the kidneys.

Higher risk of infection

If you have B - cell leukaemia or B - cell lymphoma, you may be more likely to get infections after CAR - T therapy.

This is because CAR - T cells destroy both:

- the cancerous B - cells, and
- the healthy B – cells

Healthy B - cells are important because they help your body make antibodies, which protect you from infections. When you have fewer healthy B - cells, you are more likely to become unwell.

To help protect you:

- Your team will check your immunoglobulin (antibody) levels with blood tests.
- If your levels are low, you may be given replacement antibodies through an IV.

Risk of second cancer

CAR - T cell therapy works by adding a new gene to your own T - cells. In theory, this could cause T - cells to grow in an uncontrolled way, similar to what happens in some blood cancers.

So far, this has **not been seen** in the many thousands of people worldwide who have received CAR-T therapy, but it is still something we monitor for.

You will be followed up long-term so the team can check for any signs of a second cancer. It is also important to follow the same advice given to anyone who has had chemotherapy or radiotherapy, such as:

- Avoid smoking
- Limit time in the sun and use sun protection

Risk to the unborn child

We do not yet know how CAR - T cell therapy might affect an unborn baby. Because of this, anyone who could become pregnant must:

- Have a negative pregnancy test before leukapheresis and before starting chemotherapy
- Use two forms of contraception from the time you agree to treatment and for 12 months after your CAR - T infusion
- Examples of two - method contraception include:
 - The contraceptive pill and condoms
 - An intrauterine device (IUD) and condoms

This applies to all patients, regardless of gender, to prevent pregnancy during the period when CAR - T cells are active in the body

Useful Contacts

If you are unwell and need urgent medical advice, please call:

Telephone: 07483134374

24 hours, 7 days a week

For non-urgent issues between call the Cellular Therapy Suite:

Telephone: 0116 258 5124 9am and 5pm Monday to Friday,

Bone Marrow Transplant unit:

Telephone: 0116 258 5698 24 hours, 7 days a week

In an emergency:

call 999 for an ambulance or go to your local hospital.

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Health information and support is available at www.nhs.uk or call 111 for non-emergency medical advice

Visit www.uhleicester.nhs.uk for maps and information about visiting Leicester's Hospitals.

To give feedback about this information sheet, contact uhl-tr.informationforpatientsmailbox@nhs.net

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If you would like this information in another language or format such as EasyRead or Braille, please telephone 0116 250 2959 or email uhl-tr.equalitymailbox@nhs.net

We are a research hospital and you may be asked to take part in research

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