

Chimeric Antigen Receptor (CAR) T- cell treatment

An introduction to your treatment at
Oxford University Hospitals NHS
Foundation Trust

Introduction

Welcome to the Advanced Cellular Therapies (ACT) service at Oxford University Hospitals NHS Foundation Trust. We provide Chimeric Antigen Receptor (CAR) T-cell treatments for some people with blood cancers.

This leaflet provides information about what to expect during your treatment in Oxford.

If you have further questions or would like to discuss this information in more detail, please do not hesitate to get in touch.

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Part One: Referral to Oxford

The Advanced Cellular Therapies (ACT) team at Oxford University Hospitals NHS Trust provides CAR T-cell treatment for adults in the Thames Valley area.

- You should be aware that not all patients referred to Oxford will be suitable for CAR T-cell treatment. We are not able to guarantee that your treatment will go ahead.
- Sometimes people who are suitable to start with will become more ill in the time it takes to make the treatment and will not be able to go ahead with it.

Referral and Multi-Disciplinary Team (MDT) discussion

Your doctor will refer your case to the Oxford team. Your case will be discussed with a group of expert doctors, nurses and other health professionals (the 'MDT'). Patients do not attend these meetings. The MDT will decide whether you should be considered for CAR T-cell treatment. They will refer you to the Advanced Cellular Therapies (ACT) team.

Meet the ACT Team

You will be invited to meet the Advanced Cellular Therapies (ACT) team. These appointments usually take place on a Tuesday afternoon in the Cancer & Haematology Outpatient Department, Ground Floor at the Churchill Hospital. You are encouraged to bring someone with you to this appointment.

- For information about finding us, please see page 23 'Sources of Further Information'.

At this first consultation, you will meet one of the ACT consultants and the ACT clinical nurse specialist (CNS). You may also meet our pharmacist too. We will talk you through what CAR T-cell treatment involves, your illness and your previous treatment. We will provide written information to help you make your decision about treatment.

The ACT team also includes physiotherapists, dietician and supportive care/palliative care experts – you may meet some of these extended members of our MDT during your treatment with us.

National Panel discussion

After you have met with the ACT team, your case will be referred to a national panel of clinical experts. CAR T-cell treatment is expensive and intensive. It is not suitable for people who are too frail or sick. The panel will look at your test results and other information about how fit and well you are. This process ensures that only suitable people are put forward for CAR T-cell therapy. It also ensures that the allocation of treatment is fair and unbiased. We need approval from this national panel before we can proceed with any other steps in the CAR-T cell treatment. The ACT CNS will contact you after the panel discussion to let you know the outcome.

Pre-treatment tests

You will have tests to make sure you are well enough to have the treatment. These include blood tests to find out how well your liver and kidneys are working and to check if you have any viruses that might flare up during the treatment. The blood tests will be done when you attend the first clinic in Oxford.

You might need a repeat of other tests such as scans and biopsies. This is to make sure we have up to date information about your illness. You will also need a heart scan (echocardiogram). For some patients we may do additional tests on your lungs (lung function test) and kidneys (nuclear medicine eGFR test). Some of these tests might happen at your local hospital.

Part Two: Cell collection, CAR T-cell preparation and 'bridging' treatments

Cell collection

The first step is to collect your T-cells, a process called 'apheresis'. We aim to collect your T-cells as soon as possible after the national panel decision.

The apheresis happens at the Therapeutic Apheresis Unit, within the NHS Blood and Transplant Service at the John Radcliffe Hospital in Oxford. It is usually done as an outpatient, in one day.

- For information about this location, please see page 23 'Sources of Further Information'

A nurse puts tubes (a cannula) into a vein in each of your arms. The tubes are quite large and rigid. They are connected to an apheresis / cell separator machine. Your blood is taken from one arm and passes through the machine. The machine collects your T-cells and returns the rest of your blood into your other arm.

This process takes a few hours. You need to keep your arms still during this process.

- For more information about apheresis, please see page 23 'Sources of Further Information'

Making your CAR T-cell treatment

After the cell collection, your T-cells are sent to a laboratory to be turned into CAR T-cell treatment.

The cells are genetically modified. They have something called a chimeric antigen receptor (CAR) added to them.

The modified cells – CAR T-cells – will be able to find and kill your cancer cells. They are allowed to reproduce until there are millions of them. These are collected and frozen.

Making and growing the CAR T-cells can take **3-6 weeks**.

- If you would like more detailed information on the creation of your CAR-T cells, ask the ACT team.

Bridging therapy

While your CAR-T cells are being created, you might need chemotherapy or radiotherapy to keep your illness under control. This is called 'bridging therapy'. You may have your bridging therapy at a hospital nearer home.

Repeat PET-CT scan

After your bridging therapy you will have another PET-CT scan at Oxford. This will confirm that your disease has not progressed too far and that you are still suitable for the CAR T-cell treatment.

Summary of Part One and Two

- Your care will need to be approved by the Oxford MDT and a national CAR T-cell expert panel.
- You will need to be relatively well to be suitable for CAR T-cell treatment. If your disease changes during the first few weeks, it might not be possible to continue with your CAR T-cell treatment.
- These first steps require several visits to Oxford for meetings, cell collection and scans.
- If necessary, you may have 'bridging' treatment to keep your disease under control while we wait for your CAR T-cells. This means chemotherapy or radiotherapy.
- It takes a few weeks from your first appointment with us until you are ready for your treatment.
- Call us on 07920 183239 if you have any questions or concerns.

Part Three: Hospital admission

Haematology Ward and Ambulatory Care Unit (ACU)

Many patients begin the CAR-T treatment in the Ambulatory Care Unit (ACU). The unit is found on Level 1 of the Cancer and Haematology Centre. The ACU allows you to spend the day having treatment at the hospital but return home or to local accommodation overnight. See page 22 for more info. The ACT CNS will discuss these options with you in more detail.

- You will be given a leaflet about ACU. See page 23 'Sources of Further Information' for an online copy of the leaflet and to access videos about ACU.

You will have your inpatient treatment on the Haematology Ward on Level 1 of the Cancer and Haematology Centre at the Churchill Hospital.

- You will be given a leaflet about the ward. To access a copy online, see page 23 'Sources of Further Information'.

Central line insertion

If you do not already have a PICC (peripherally inserted central catheter), we will insert one in Oxford before your chemotherapy begins. This is a tube that goes into a central vein. It stays in throughout your treatment.

Lymphodepletion chemotherapy

Before you have your CAR T-cell infusion, you will have intravenous chemotherapy to reduce the number of

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white blood cells in your body. This is called 'lymphodepletion chemotherapy'. It prepares your body for the CAR T-cells so they can multiply and work more effectively.

This is given over a period of 3 - 4 days, depending on what chemotherapy you are having. You will be given information about this treatment and the side effects. You then have 2 rest days before your CAR T-cell infusion. We describe these days as Day -6 to Day -1. Day 0 is the day of the CAR T-cell infusion.

The chemotherapy is usually given as an outpatient, in our Ambulatory Care Unit (ACU). You will then be admitted to the ward in time for the CAR T-cell infusion.

CAR T-cell treatment infusion

Once you've finished your lymphodepleting chemotherapy, you are ready to have your CAR T-cell treatment.

You will have medications before the infusion to help prevent any reactions. This is usually paracetamol and antihistamines (anti-allergy medicines).

The CAR-T cells arrive frozen and are thawed out before you have it. It is given as a drip into your PICC or a cannula. It takes around 10-30 minutes. It might smell like sweetcorn. It is very similar to any other transfusion of blood products.

You are monitored carefully in hospital during and after the treatment. You will remain in hospital for at least 10 days to allow us to keep a close eye on you.

Side effects of CAR T-cell treatment

CAR T-cell treatment is considered a high-risk treatment with many possible side effects. Some of these side effects might be serious or life threatening.

Your doctor will discuss your risks of side effects with you before you give your consent to treatment. You will be provided with information about possible effects and how many people have had these effects.

The two most common and potentially serious effects are discussed here.

Cytokine Release Syndrome

Cytokine release syndrome (CRS) is a common side effect of CAR T-cell treatment. It happens when your immune cells release substances called cytokines, which can have a range of effects on the body.

Symptoms of CRS include:

- Fever
- Dizziness
- Low blood pressure
- Shortness of breath
- Racing heart rate
- Chills
- Muscle weakness and fatigue
- Headache
- Bleeding
- Nerve problems such as confusion and loss of co-ordination.

CRS usually happens about 2 days after your CAR T-cell treatment. It can range from mild to more severe CRS.

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Severe cases of CRS may need to be treated in the Intensive Care Unit. However, most people will recover completely from CRS.

Brain and Nervous System Adverse Reactions

CAR T-cell treatment can also cause short term problems with your brain and nervous system. Your clinical team calls this ICANS. They usually happen about 5 days after your treatment.

Again, there is a spectrum of mild to more severe ICANS. Unfortunately, ICANS can be serious and in very rare cases life threatening. Severe cases will need treatment in the Intensive Care Unit. However, most people will recover completely.

Symptoms of ICANS include:

- Confusion
- Difficulty/changes in speaking
- Loss of memory
- Shakiness
- Loss of co-ordination
- Reduced consciousness
- Fits
- Agitation.

Please tell us if you have any of these symptoms, even if they seem minor.

From the day of your CAR-T infusion, your team will ask you the same, specific questions (eg what year is it?) and will monitor your handwriting twice a day to check for neurological problems.

Keep us informed

Please be reassured that we will monitor you very carefully and keep a close eye on you. Many of the common side effects of CAR T-cell will get better on their own within a few days.

It is important that you tell us if you feel unwell or if you have any symptoms that are worrying you. Tell any visitors you have to let us know if they notice any change that worries them.

Part Four: Hospital discharge and recovery

Discharge

It is difficult to say precisely how long your hospital stay will be. You will be in hospital for at least 10 days.

Our team will work with you and your family to prepare you for discharge from hospital.

After discharge

You will need to remain close to Oxford for at least 28 days after the transfusion of the CAR T-cells.

If you live more than two hour's drive away, we will arrange accommodation closer to the hospital for a few weeks.

You will also need to have someone with you at all times until 28 days after your CAR T-cell infusion. This person will need to be able to act on your behalf and drive you to the Churchill hospital if necessary.

Initial appointment schedule

After discharge from the ward, you will be reviewed at the Churchill hospital at least three times per week during the first 28 days after your CAR T-cell transfusion.

These reviews will happen on the Ambulatory Care Unit (ACU).

If space in the ACU is not available, you will be seen on the Day Treatment Unit (DTU) or the Haematology Ward.

Contact us

It is very important that you and the people caring for you get in touch if feel unwell or if you have symptoms that are worrying you.

For the first 28 days, there is a small risk of cytokine release syndrome or ICANS as described on pages 13 – 14.

Your or your carers should ring the Oxford Triage Service on **01865 572192** immediately if:

- you develop a fever of 37.5 degrees C or over
- if you generally feel unwell
- you notice any nervous system problems, such as:
 - difficulty/changes in speech
 - loss of memory
 - loss or reduced coordination
 - agitation
 - bad headache
 - confusion
 - seizures
 - reduced level of consciousness

Beyond 28 days the main risk to you is the risk of infection. You should do what you usually do during chemotherapy and avoid exposure to infection while your immune system recovers. Ask us for information about this.

Longer term follow up

Your care will be transferred to your local hospital if you are well after day 28. You will need to be seen 2-3 times

each week until your blood counts are stable. You may need regular transfusions of blood products.

We will also offer follow-up appointments with the team at Oxford every 3 months for the first year. Some of these appointments might be over the telephone or via a video call. You will be followed up by Oxford at least once per year for 15 years after the CAR-T cell treatment.

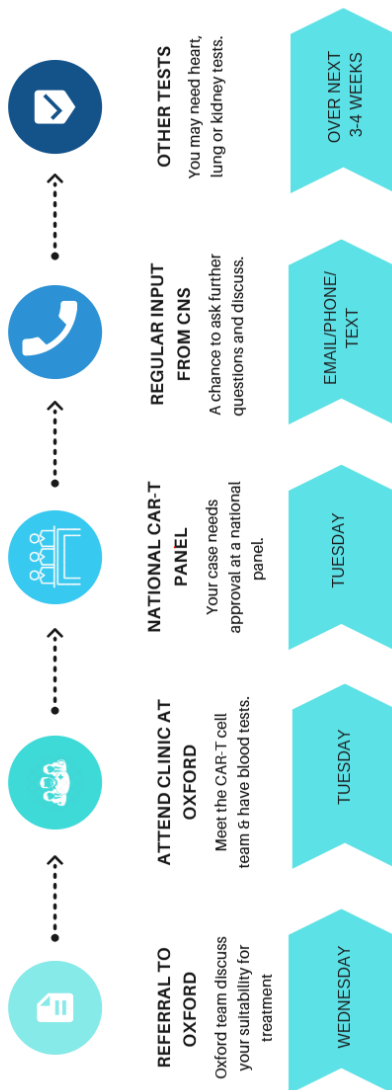
Part Three and Four Summary

- You will have lymphodepletion chemotherapy before the CAR T-Cell infusion. This is usually given in ACU.
- Your CAR-T infusion is given on 'Day 0'. It takes about 10-30 minutes.
- You will be closely monitored throughout your admission. **You must tell us if you are worried about any side effects.**
- The most common side effects can be serious. However, most people make a full recovery within a short period of time.
- You will be in hospital for at least 10 days.
- We will work with you to plan your discharge from hospital.
- You will need to stay close to Oxford for 28 days after the CAR T-Cell infusion.
- If discharged from the ward, you will need someone with you at all times until D+28.
- You will need to call triage immediately on **01865 572192** if you feel unwell after you leave hospital.

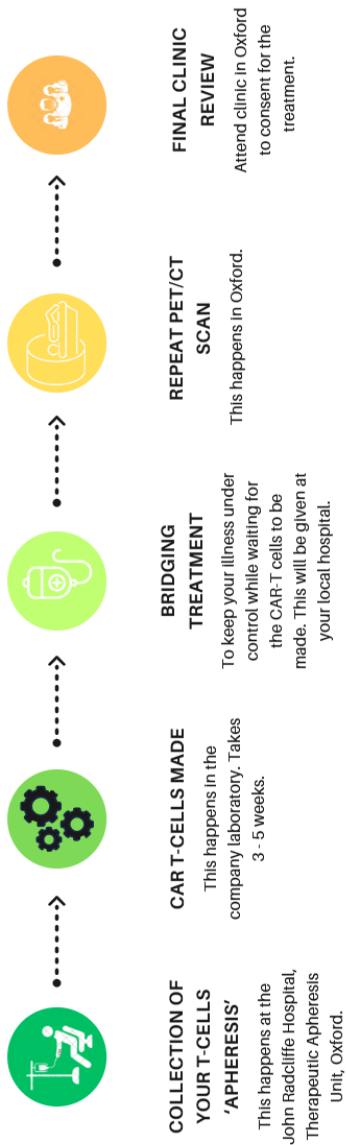
Your treatment pathway diagram

CAR T-CELL TREATMENT PATHWAY:

REFERRAL TO OXFORD, ASSESSMENT, DECISION MAKING

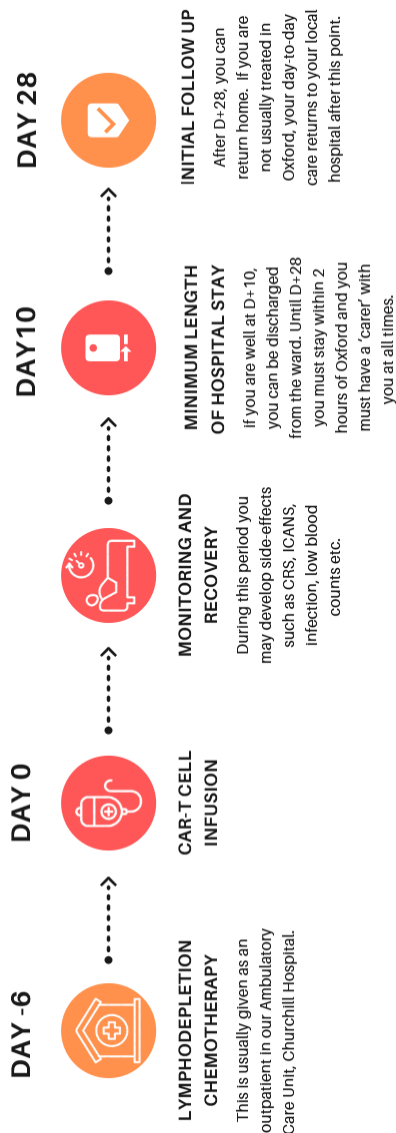


CAR T-CELL TREATMENT PATHWAY: CAR T-CELL PREPARATION AND 'BRIDGING' TREATMENT



CAR T-CELL TREATMENT PATHWAY:

CAR T-CELL TREATMENT AND RECOVERY



Practicalities

Accommodation

We are able to offer accommodation for some of your time in Oxford if you live more than one-two hours away.

There are two options:

- On-site self-catered flat located on the Churchill hospital site. You and a relative/friend can both stay in the flat. You would each have a separate, lockable room with a single-bed and ensuite. You need to provide your own bedding. You may be sharing the flat (living space and kitchen) with one other patient.
- Local hotel, paid for by us. Usually located about 10-15 minutes away from the Churchill. This option requires you to have someone with you that can drive you back and forth to the hospital. We will arrange breakfast and evening meal at the hotel, paid for by us.

Key Contact details

Haematology Ward: 01865 235048

Ambulatory Care Unit: 01865 226513

Triage: 01865 572192

Haematology Secretaries: 01865 235185

ACT/CAR-T Specialist Nurse: 07920 183239

Suggested Items to Bring into Hospital

- comfortable clothing (separate day and night clothing) + lots of layers as sometimes it can be hot or cold on the ward. We do encourage you to get up each day and get washed/dressed.
- comfortable shoes or slippers to wear when walking around the ward
- toiletries (unperfumed as your skin may be quite sensitive). Moisturiser + Vaseline is also a good idea.
- soft toothbrush + toothpaste (we will provide you with mouthwashes if needed)
- Fluffy blankets / dressing gown for comfort and warmth.
- Some patients bring in their own duvet, duvet covers and pillows for use on the ward. If you stay in the on-site self-catered flat, you will definitely need to bring your own bedding.
- Things to keep you entertained (eg iPad, laptop, books etc). Often a radio is a good idea for days when you feel too tired to concentrate on anything. There is free wifi in the hospital but it can be temperamental so it is worth downloading a few things in advance of your admission.
- Snacks (you will have a fridge in your room that you can use + cupboard space).
- Water bottle
- Eye mask and ear plugs (if you are a light sleeper)

Sources of Further information

Finding the Churchill Hospital https://www.ouh.nhs.uk/hospitals/churchill/find-us/car.aspx
Churchill Hospital Map https://www.ouh.nhs.uk/hospitals/churchill/documents/ch-hospital-sitemap.pdf
Therapeutic Apheresis Service (including map to get there) https://www.nhsbt.nhs.uk/what-we-do/diagnostic-and-therapeutic-services/therapeutic-apheresis/therapeutic-apheresis-units/
Therapeutic Apheresis Service (what to expect) https://www.nhsbt.nhs.uk/what-we-do/diagnostic-and-therapeutic-services/therapeutic-apheresis/therapeutic-apheresis-patient-information/
Clinical Haematology Ward https://www.ouh.nhs.uk/patient-guide/leaflets/files/75134Phaematology.pdf
Ambulatory Care Unit – access to ACU leaflet and video links https://www.ouh.nhs.uk/haematology/locations/acu/