

CAR-T Therapy

This leaflet explains about CAR-T therapy, including the benefits and risks and what you can expect when you come to hospital. If you have any further questions, please speak to a doctor or nurse caring for you.

Introduction

Welcome to the Haematology Department at St George's University Hospitals. This leaflet has been written to help you prepare and guide you through each stage of your Chimeric Antigen Receptor T-cell (CAR-T) therapy. Chimeric Antigen Receptor (CAR) T-cell treatments are provided for some people with blood cancers.

This leaflet provides information about what to expect during your treatment in St George's Hospital. Our aim is to do our absolute best to support you and your family during this time.

If you have further questions or would like to discuss this information in more detail, please do not hesitate to get in touch. A 'Useful Contacts' section is also included with telephone numbers you might need.

What is CAR-T therapy?

CAR-T stands for chimeric antigen receptor T-cell. This therapy is a type of immunotherapy. **T-cells are cells which naturally fight viral infections in the body and they are key players in the immune system, including attacking cancerous cells.**

It is possible to modify T-cells, so they become capable of recognising a marker on the surface of cancer cells. These modified cells will target and attack the cancer cells.

While many patients with blood cancers can be treated with chemotherapy, there are still patients who relapse and for whom the outcome with existing treatments like chemotherapy or bone marrow transplant is not effective or is poor.

Currently, CAR-T therapy is approved to treat:

- Acute lymphoblastic Leukaemia
- Some types of B-cell Lymphomas

Studies have shown that CAR-T cell therapy can be highly effective in treating such patients. The CAR-T Team will speak to you regarding the outcome of treatment on an individual basis.

Clinical trials are trying to find out if CAR-T therapy might work against other types of cancer and other diseases.

Part One: Referral to the CAR-T Cell Team at St George's Hospital

If your current doctor thinks you may benefit from CAR-T cell treatment, they will refer you to the CAR-T Cell Team at St George's Hospital. Your case will be discussed in a multidisciplinary meeting and if it is felt that CAR-T cell treatment may be suitable for you, you will be given an appointment to meet the CAR-T treatment team. Your case will be managed by different specialists including your clinical nurse specialist (CNS), supportive care experts, physiotherapist and dieticians. We also offer counselling and psychological support during this process.

We will talk with you and your carer about what CAR-T cell treatment involves and the potential side effects. You will be provided written information to help you to make an informed decision about your treatment. You will be given time to decide about the treatment.

National CAR-T panel discussion

All patients put forward for CAR-T treatment need to be approved by the national lymphoma CAR-T cell panel. The panel will review your results and other information about how fit and well you are.

This process ensures that only suitable people are treated with CAR-T cell therapy. It also ensures that the allocation of treatment is fair and unbiased.

Parent and Family support

Following the approval from the National Panel, you will have discussions with our team regarding your CAR-T journey, accommodation, identifying a suitable carer, advanced care planning, etc.

Pre-treatment tests or work-up

You will have tests to make sure you are fit enough to have this treatment. These include blood tests to find out how well your liver and kidneys are working and to check if you have any infectious diseases that might flare up during the treatment. Some of these tests might happen at your local hospital.

These might include:

Imaging – PET / CT scans / MRI to assess how your disease has responded to your treatment

Electrocardiogram (ECG) and echocardiogram to check that your heart is healthy

Creatinine clearance or glomerular filtration (GFR) scan to check your kidney function

Lung function tests, to check how your lungs are working

Bone marrow biopsy.

You may need a PICC (Peripherally Inserted Central Catheter) line which is used to deliver medications and other treatments directly to the large central veins near your heart. A PICC line can be also used for frequent blood draws and is usually temporary.

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

Leukapheresis or T-cell collection

This will take place at the Apheresis Unit in the Gordon Smith ward on the 3rd floor, Lanesborough wing. The process of collecting your T-cells is called ‘apheresis.’ Your blood will be withdrawn through a large needle or catheter into a cell separator machine / apheresis machine. The machine collects your T-cells and returns the rest of your blood into your other arm. This process takes around six hours. T-cell collections are usually completed in one day and you will need to keep your arms still during this process. Apheresis is usually well tolerated with mild side effects.

Making your CAR-T cell treatment

Your T-cells are sent to a laboratory to be genetically modified and turned into your CAR-T cell treatment. They are then grown in the lab until there are enough for the treatment. The modified cells, CAR-T cells, will be able to find and kill your cancer cells.

Bridging Treatment

Whilst your CAR-T cells are being made, we might need to give you further treatment with steroids, radiotherapy or chemotherapy. Your CAR-T cell therapy team will discuss this with you and will co-ordinate this treatment with your primary team. CAR-T cells normally take around four weeks to be manufactured.

Your CAR-T specialist nurse will stay in touch with you and your local team throughout this period to update you.

Part Three: Hospital admission

Lymphodepletion

The week before we return the CAR-T cells into your body, you will be admitted to hospital to receive low dose chemotherapy. This will prepare your body and help the CAR-T cells to work once infused. The duration, regimen and side effects of the treatment used for lymphodepletion will be discussed with you prior to the treatment.

CAR-T infusion

You will be given medication before the CAR-T cell infusion, to prevent allergic reactions. The CAR-T cells will then be thawed and infused over approximately 15 minutes. Your nurse will monitor you closely during, after the infusion and for four hours after the infusion. The CAR-T cells are preserved in a special formula called DMSO. This can give a funny smell once infused, similar to sweetcorn. This will last approximately 24 hours.

You will remain in hospital for at least two weeks after the infusion of your CAR-T cells to be monitored for any side effects.

Side effects of CAR-T cell treatment

CAR-T is a complex treatment. Every patient reacts differently to this treatment but there are some side effects that are common after having CAR-T therapy. Your doctor will discuss risks of side effects with you before you give your consent to treatment.

The most common and potentially serious effects are discussed here:

Cytokine Release Syndrome-CRS

Cytokine release syndrome (CRS) is a common side effect of CAR-T cell treatment. It usually happens within the first 10 days of treatment. CRS is an inflammatory syndrome that causes multiple symptoms including high fevers, low blood pressure, shortness of

breath and racing heart rate. Severe cases may need to be treated in Intensive Care Unit. There are treatments to manage these symptoms and they are usually transient.

Neurotoxicity

Up to two thirds of patients can experience some neurological symptoms including confusion, difficulty with speaking or writing, loss of memory, decreased alertness or seizures.

These effects can be serious and sometimes life threatening. Severe cases may need treatment in Intensive Care. However, most people will recover. Your team will monitor for any neurological symptoms carefully. This will involve asking you to do things like write a sentence and name objects. This might feel a bit strange or frustrating but it is important you know the reasons why this is vital; detecting any changes early can help us to treat them successfully.

Increased risk of infection

The CAR-T cells target cell markers on the cancer cells as well as normal B cells which help to fight infections. Decreased numbers of normal B cells may lead to low levels of antibodies ([immunoglobulins](#)). Persistently low levels of immunoglobulins may cause an increased risk of infection. We will monitor your immunoglobulin levels. Some patients may need replacement with [intravenous immunoglobulins](#).

Low blood counts

CAR-T cell therapy can lower your blood count levels including red and white blood cells and platelets. Symptoms are bleeding, bruising, infection and shortness of breath. Your doctor will test your blood regularly to check for this and may result in you requiring transfusion support or growth factors.

Hemophagocytic lymphohistiocytosis

This is a rare complication which can occur after CAR-T treatment. Haemophagocytic lymphohistiocytosis (HLH) is a rare immune disorder where the body reacts inappropriately to a 'trigger.' Specialised white blood cells (known as T-cells and macrophages) become over-activated, causing severe inflammation and damage to tissues such as the liver, spleen and bone marrow. Your doctor will monitor you and will test your blood during your admission at the hospital to detect it early.

Sex, contraception, and fertility

CAR-T is a new therapy and currently there is no information on how the treatment may affect fertility. Potential effects on an unborn child are unknown and therefore we recommend that you use effective birth control during and up to a year after your treatment. It is important that you do not get pregnant or father a child during your treatment. We also recommend women should stop breast feeding as it is unknown if the medication is excreted through breast milk.

Part Four: Hospital discharge and recovery

It is difficult to say precisely how long your hospital stay will be. You will be in hospital for at least 14 days after the CAR-T infusion. Our team will work with you and your relatives and care givers to prepare you for discharge from hospital. After discharge, you will need to remain close to hospital for at least 30 days following your

treatment with CAR-T cells.

If you live more than one hour's drive away, accommodation closer to the hospital will be arranged for you for a few weeks.

You will also need to always have someone with you for the first 30 days post CAR-T cell infusion. This person will need to be able to act on your behalf and drive you to the hospital if necessary. You will be reviewed by your doctor and the team every day during the first 30 days after your CAR-T cell infusion, in the Haematology Day unit on the 2nd floor of St James Wing.

Contact us

It is particularly important that you and the people caring for you for the first 30 days should get in touch if you feel unwell or if you have symptoms that are worrying you. You or your carers should ring the CNS (on Monday to Friday 9 to 5pm) or the haematology triage 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, seizures
 - bad headache
 - reduced level of consciousness

Longer term follow-up

Your care will be transferred to your original team if you are well after day 30. You may still need regular blood tests until your blood

counts are stable. You will be given some medications to take at home to prevent infections. You may need regular transfusions of blood products. We will also offer follow-up appointments with the team every one to three months for the first year. Some of these appointments might be over the telephone or via a video call.

You will have a PET-CT scan approximately 28 days after receiving your CAR-T cells and then at three months, six months and one year to monitor your response to treatment.

Practicalities

Accommodation

If you live more than one hour away, you will be offered accommodation in the Pelican Residence and Hotel which is situated on the St George's Hospital site, from the date of your discharge from your inpatient admission to 30 days after your CAR-T infusion. If you might require accommodation this will be identified at your initial CAR-T Team clinic appointment and our CAR-T CNS will facilitate this for you.

Contact us

- Clinical Nurse Specialist: 020 8725 2442 ext. 1146
- St. George's University Hospital: 020 8672 1255
- Ruth Myles Day Unit: extension 0611
- Haematology Secretaries: extension 1172
- CAR-T bleep 6130
- "CAR-T Team" email address
ruthmyles@sgnhs.onmicrosoft.com

If you need further information or assistance, please ask your nurse specialist.

For more information leaflets on conditions, procedures, treatments and services offered at our hospitals, please visit www.stgeorges.nhs.uk

Additional services

Patient Advice and Liaison Service (PALS)

PALS can offer you advice and information when you have comments or concerns about our services or care. You can contact the PALS team on the advisory telephone line Monday, Tuesday, Thursday and Friday from 2pm to 5pm.

A Walk-in service is available:

Monday, Tuesday and Thursday between 10am and 4pm

Friday between 10am and 2pm.

Please contact PALS in advance to check if there are any changes to opening times.

The Walk-in and Advisory telephone services are closed on Wednesdays.

PALS is based within the hospital in the ground floor main corridor between Grosvenor and Lanesborough Wing.

Tel: 020 8725 2453 **Email:** pals@stgeorges.nhs.uk

NHS UK

The NHS provides online information and guidance on all aspects of health and healthcare, to help you make decisions about your health.

Web: www.nhs.uk

NHS 111

You can call 111 when you need medical help fast but it's not a 999 emergency. NHS 111 is available 24 hours a day, 365 days a year. Calls are free from landlines and mobile phones.

Tel: 111

AccessAble

You can download accessibility guides for all our services by searching 'St George's Hospital' on the AccessAble website (www.accessable.co.uk). The guides are designed to ensure everyone – including those with accessibility needs – can access our hospital and community sites with confidence.



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