CAR-T Therapy: Information for carers

This leaflet is for the carer(s). The aim is to briefly explain the CAR-T Therapy journey and your role during this.

As a carer for someone who has received CAR-T cell therapy, you are their most important resource and are providing the companionship that is critical at this time. The role of the carer(s) will change as the CAR-T journey progresses. Everybody has unique physical, emotional and family needs and will be affected by this journey in different ways. At the start of the CAR-T journey the role may be more emotionally supportive. However, after discharge from the ward your role will become more involved as we ask you to monitor the patient for us when they are at home.

There may be times that you feel alone and overwhelmed or the situation may be out of your control. Being a carer is daunting but be assured there is a healthcare team that is ready to assist and support you at all times.

The healthcare team is your partner in helping you care for your loved one and you can discuss your concerns with them. You may also have other family and friends that can help support you too.

This leaflet has been written for you, the carer, after your friend / family member has been confirmed to receive CAR-T Therapy.

The person you are caring for will also receive a leaflet explaining the CAR-T journey, but from a different perspective.

Understanding the CAR-T process

CAR-T cell therapy involves many steps:

Initial Assessment

Once identified for CAR-T therapy, the patient treatment plan will be discussed before a national panel for CAR-T therapy. When approved, an appointment will be made for the patient to meet the CAR-T team and be assessed. The assessment will include a physical assessment, blood tests and a discussion of the first stage of treatment, to which we will then ask them to consent and we will ask for who their nominated carer(s) are. We will also ask them to go for a chest X-ray and an ECG. The first stage of treatment is **apheresis** and you may hear it referred to as a ‘harvest’ as we will need to harvest the special cells needed for CAR-T treatment.

You are welcome to attend these appointments and ask questions.
As a carer, the main role at this point, may be to support your loved one / friend or take them to appointments.

Apheresis
Apheresis involves having a cannula inserted into both arms. The blood is removed via one of the cannulae for a short time and it will pass through a specialised machine.
The machine will remove the cells we need for the CAR-T infusion and the blood will be returned using the other cannula. This should be a painless procedure that will take a few hours. The cells taken will then be sent away where, over a period of weeks, they will be made into their personalised medicine. If there are any problems with making the medicine, we will update the patient. The apheresis team will discuss the details with the person for whom you are caring before any treatment begins.

Bridging therapy
It takes about three weeks for the cells being manufactured. During this time your loved one / friend may need chemotherapy or radiotherapy as an outpatient to treat their disease before they come in for admission. Appointments will be made to check their teeth / lungs / kidneys / heart and an appointment with our psychologist. This can be a stressful time for all as there are a lot of appointments.

At this time, there will be a date for admission and as a carer the main role at this point will be a supportive one. If you have any questions the CAR-T team will help you.

Admission
Two days before admission we will ask the patient to come in for a Covid swab as part of our routine admission screen.

The patient will be admitted to the Ruth Myles Ward six days before the infusion. They will have a PICC (Peripherally Inserted Central Catheter) line inserted on the day of their arrival and they will then receive chemotherapy for three days. Two days after that they will receive their CAR-T infusion. They will then be monitored for 14 days. If they need more treatment, they may need to stay in longer. The minimum stay in hospital will be three weeks.
During the admission the patient will be monitored by the healthcare team each day and your role as carer will remain a supportive one. All rooms are single rooms and visiting times are 1pm to 8pm. A maximum of two visitors can visit and we ask them to do a lateral flow test for Covid before visiting.

When do we leave hospital?

The planned day of discharge from the ward will be 14 days after the infusion. If the patient is not well enough to be discharged at this time, they will remain in hospital until fit for discharge. Your treatment team will inform you and the patient nearer the time. Once discharged, you and the patient will receive a discharge pack, explaining for what you will need to monitor and how to record it and the contact details of your healthcare team. You will need to do this until 28 days after the CAR-T infusion.

The person you will be caring for will be under the care of the CAR-T healthcare team for 14 days after discharge or longer if needed. They will be referred back to their original referral team.

After leaving the hospital

If you live within two hours of St. George's Hospital, you will be caring for the patient at home and monitoring for side effects there. You may also be running or helping to run the household. It will be helpful to set up regular times in which to monitor for side effects and build it into a routine. You will need to remain with them 24 hrs a day until 28 days after the CAR-T infusion.

If you are not within two hours of St. George's Hospital you will both be staying at The Pelican Hotel on site. There will be practical details to take care of whilst you are away. These can include taking time off from work, childcare, elderly care or generally running the household. Good preparation and asking friends and / or family may help you with this.

In The Pelican Centre tasks may include food preparation, cleaning and managing medications amongst other things. Once you are settled and have a schedule of your required visits, you'll be able to set up a routine. Routine can help lower the stress you may feel after the treatment and in new surroundings away from home.

You and the patient can have visitors, however the patient is at risk of infection, so visitors should be kept to a minimum and if the visitor is unwell, they should not visit.

Transportation

The Pelican Hotel and Residence is a five to ten-minute walk from St. George's Hospital and is on the same site.

If you are travelling from home, we advise against using public transport as we want to reduce the possibility of picking up infections and it can be tiring for the patient. The patient will not be allowed to drive, so you may need to drive the patient to their appointments. If you cannot drive then we advise taking a taxi if possible. If driving to take the patient to appointments or visiting on the ward, we can issue you with a weekly parking permit.

Can we go outside?

Yes, but the patient will be at risk of infection and we advise they should stay away from crowded areas such as restaurants and going to supermarkets. Precautions such as a mask and alcogel should be used at these times. If going for a walk, be mindful as the patient will get tired quickly.

It is important that you are not further than two hours away from St. George’s Hospital at any point during this time.

It is important to remember that the patient cannot drive for eight 8 weeks after the infusion or eight weeks after a resolved neurological occurrence.

Emotional support

Having CAR-T cell therapy can be demanding for the patient and their carer. We are aware of the negative impact stress can have on our patients and their recovery and we will check on the patient’s well-being but we recognise that you as the carer are just as likely to find the patient’s journey stressful and worrying.

Sometimes carers don’t often talk about their stress because they don’t want to draw away attention from the patient. Although you will be monitoring for signs of stress in the patient, it is important to be aware of your own emotional, mental and physical health and take care of yourself too.

We may be able to help with some practical aspects relating to the treatment but having someone for you to talk to can help you at this time. If you feel this would be helpful, please talk to the team about what is available, including our psychological support service.

What symptoms should I look out for?

When the patient is discharged after receiving their CAR-T infusion, you are an important set of eyes and ears that will help monitor for any side effects. You will need to be present at time of discharge from the ward and you will be asked to monitor and record the patient using the ICE score daily. The ICE score comprises of a series of questions and a sentence to be written by the patient and helps us to see if the patient is having any neurological side effects.

The patient will have appointments on the haematology day unit on Mondays and Thursdays and we will take blood tests and complete the ICE score. When the patient is not in clinic, you will complete the ICE score and we will contact you / the patient every day.

The patient may feel completely well at this time, in which case all you may need to do is remind them to write down the information that has been asked for and to continue to watch for symptoms.

The symptoms to watch for include:

- Temperature of 37.5deg C or higher
- Shortness of breath at rest or active
- Confusion, disorientation or hallucinations
- Difficulty speaking or understanding what you are being told
- Difficulty reading and / or changes to your writing.
- Feeling sleepy or drowsy at odd times

- New tremors (shaky arms or body parts)
- New involuntary muscle movements
- Unexplained bleeding.

If you notice any of these symptoms, please go to the Emergency Department at St. George's. Please also call us to let us know that the patient is feeling unwell and that you are on your way in.

Important: You may notice changes more easily than the patient does. You know what is normal and you may notice a change before they do or we do. Some instructions will be very clear but others may seem more difficult. Ask questions so you feel confident about what to watch for and when and whom to call.

When are the follow-up appointments?

After discharge from Ruth Myles Ward there be follow up appointments at the Haematology Day Care Unit (usually a Monday and Thursday). You will be given the time on discharge. The CAR-T Clinical Nurse Specialist (CNS) or a member of the medical team will call you every day during the post infusion period to help you monitor the progress of the patient.

Useful sources of information

www.cancerresearch.co.uk
www.bloodcancer.org.uk

Contact us

If you have any questions or concerns, please contact the CAR-T healthcare team on 020 8725 1680 (Monday to Friday, 9am to 5pm).
Out of hours, please contact 020 8672 1255 and ask for the haematology registrar on call.
You will also be given a Treatment Alert Card which will give you these numbers.
You can also contact the CAR-T Clinical Nurse Specialist at:
Hannah.Thorpe@stgeorges.nhs.uk or 07350 450 784

Other useful numbers and addresses

Haematology Day Unit Centre (Monday to Friday, 9am to 5pm)
2nd Floor, St. James's Wing
St. George's University Hospitals NHS Foundation Trust
Blackshaw Road
Tooting
SW17 0QT
Tel. 020 8725 1680

Pelican Hotel and Residence
203 Blackshaw Road
Tooting

SW17 0BZ
Tel. 020 8725 2297

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

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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.

The Walk-in and Advisory telephone services are closed on Wednesdays.
Please contact PALS in advance to check if there are any changes to opening times.

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

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.

This has been endorsed by the Patient Information Group

PInG

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