

CAR-T Therapy: Patient Discharge and going Home

This leaflet explains what will happen when you are discharged from the ward. If you have any further questions, please speak to a doctor or nurse looking after you.

Although you are well enough to be discharged and your CAR-T cell infusion has been completed, there are still precautions you will need to take and matters for you of which you should be aware.

Before you are discharged you will be seen by the healthcare team and this will give you and your nominated carer the opportunity to ask any questions which you may have and to identify any extra support you or your carer may need. You will receive a discharge pack that will include:

- Discharge summary
- Carer's leaflet
- A medication record
- A treatment alert card
- Symptom diary (This will allow us to monitor your handwriting for signs of neurotoxicity).

It is important to carry your Treatment Alert Card with you. It will inform any healthcare provider of the treatment you have had.

When can I leave hospital?

The day of discharge will be approximately 14 days after the infusion. This could be later if clinical input is still needed after day 14. Your treatment team will inform you and your carer nearer the time. You will need to be with your nominated carer as you leave hospital.

What happens after I leave hospital?

When you are discharged from the ward you will be reviewed by the CAR-T team for a further 14 days or longer if necessary. After this you will be referred back to your original healthcare team and they will continue your care with input from the CAR-T team. You will be reviewed by the CAR-T team for 28 days after your infusion, as an inpatient and as an outpatient.

During your post infusion care you need to remain a maximum of a one to two hours drive from St. George's Hospital (SGH). If you do not have a carer or live over two hours from SGH, then we will arrange for you to stay in the Pelican Hotel and residence. The hotel is on the St. George's Hospital site and is approximately a 5 to 10-minute walk to the

Haematology Day Unit Centre. You will need to remain with your nominated carer 24 hours a day during this time.

If you do not have a nominated carer then you will need to remain an inpatient for 28 days after the CAR-T infusion.

It is important to remember that you cannot drive for eight weeks after your infusion or eight weeks after any side effects affecting your nervous system have been resolved.

Transportation to hospital appointments

If you are travelling from home, we advise against using public transport as we want to reduce the possibility of you picking up infections and it can also be very tiring for you. We advise that your carer drives you to the hospital (we can issue you with a weekly parking permit) or you take a taxi if possible.

Once your 28 days have been completed, we still advise against using public transport as you will still be at a higher risk from infection.

If a period of eight weeks has passed post infusion or post nervous system side effects, you will be able to drive yourself to appointments.

Can I go outside?

Yes, you can go outside. You are at a higher risk of infection and you should stay away from crowded areas such as restaurants and only go to supermarkets when they are quiet. Precautions such as a mask and alcohol gel should be used at these times. If going for a walk, be mindful as you will get tired more quickly. This is normal and will improve over time.

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

Once you are home after the post CAR-T infusion outpatient reviews have been completed, we understand there may be events you want to attend. We advise that you continue to take extra precautions such as masks and alcohol gel, asking unwell visitors not to visit and maintaining some social distancing.

Will I have a follow-up appointment?

After discharge from the ward, you will be seen in the Haematology Day Unit twice a week for two weeks (unless a more regular review is required), usually on Mondays and Thursdays. The time of the first appointment will be made for you at your time of discharge.

During these appointments we will take blood tests and check you for signs of infection and other side effects that might be caused due to your infusion. These will include having your observations taken and checking your symptom diary. We will also review you and check how you are feeling. If you need a further review or any other clinical interventions (such as extra fluid or other infusions), extra appointments will be made for you. This may extend the length of time for which you remain in the care of the CAR-T team as an outpatient.

When you are not at the Haematology Day Care Unit, your carer can help you check for these symptoms yourself and the CAR-T Clinical Nurse Specialist and / or a member of the CAR-T team will call you every day to see how you are.

What symptoms should I look out for?

- Temperature of 37.5 deg C or higher
- New shortness of breath
- 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.

It is important that if you have a fever, feel unwell or have neurological symptoms, you should go to the Emergency Department. If you are unsure what to do, contact the CAR-T team.

After 28 days post CAR-T infusion you will not need your carer to be with you every day but if you have any of the symptoms listed, you should attend the Emergency Department and present the Treatment Alert Card. This will alert the emergency department team to your CAR-T treatment and they will be able to notify the St. George's CAR-T team or haematological service for advice.

How can I check if I have neurological symptoms?

When you are an inpatient, the nurses will monitor you for neurological symptoms twice a day using a score called the **ICE** score. When you are discharged from the ward, we will ask your nominated carer to complete this for us.

The ICE score allows us to monitor for any neurological symptoms in the same way it is done on the ward. This needs to be done daily. We will do it in your appointments with us but on days we don't see you your carer will do it. We recommend the morning when doing it at home / away, as we will call you daily to see how you are. The ICE score is a series of set questions and a handwritten sentence. The ward nurses will show you and your carer how to use the ICE score and it will also be part of the symptom diary with which you are discharged.

It is important to remember that your carer may notice symptoms before you do.

After 28 days following the CAR-T infusion you will not need to do an ICE score. However, if either you or someone who knows you has noticed any new neurological symptoms, you should go to the emergency department and present your Treatment Alert Card.

Support after treatment

Although your healthcare teams will help support you during your journey, there are ways in which you can also support yourself after discharge.

- Although important to keep active, it is normal to feel tired after CAR-T. We advise moderate exercise within your limitations (e.g., going for walks). This may need to start very slowly, if you are feeling tired, go at your own pace.
- Keeping hydrated and eating well is very important. As an inpatient you will have been advised on the neutropenic diet and we advise you to continue this after discharge whilst you still have a lowered immune system. You will be given a leaflet explaining this at discharge.
- There can be psychological and physical impacts after treatment which should not be underestimated. Please be aware recovery may feel slow, which can be frustrating. Talking to someone may help you with these feelings and give you some tools to manage the treatment and recovery process. You can let your Clinical Nurse Specialist (CNS) know if you are finding things difficult and if needed you can also access psychological support.
- Although you can have visitors after your discharge, we advise you to limit the number of visitors and make sure they are well before they do. Your immune system will still be low after CAR-T cell therapy and you are at a higher risk of infection.
- Personal finance can be difficult throughout the CAR-T journey and your CNS can help you apply for a one-off financial grant from the Anthony Nolan Charity (maximum £250). This may be affected if you have had another grant.

Long term follow up

You will be referred back to your original healthcare team 28 days after your infusion or longer if required. The team will continue any regular blood tests or medication reviews you require at this time, in communication with the CAR-T Therapy team.

You will still be monitored and you will have a PET-CT scan on day 28 post CAR-T cell infusion. The scans will continue and you will have a PET-CT scan at three, six and 12 months post infusion. Following each PET-CT you will have a clinic / telephone review with your CAR-T cell team. This allows us to monitor your progress and your response to the CAR-T therapy.

The CAR-T clinical nurse specialist or team will then monitor you annually for 15 years and this will be either face to face or by telephone.

It is important to remember any subsequent clinical interventions that are needed after day 28 will be carried out by your original healthcare team. A detailed summary of your CAR-T Cell Journey, current medications and advice on support will be provided for them.

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 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 and CAR-T team (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

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.

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.



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