



CAR-T Cell Therapy: Information for Carers

Ciltacabtagene autoleucel
CARVYKTI®▼

About this guide

This guide contains information and resources to help you in your role as a carer for a relative/friend going through CAR-T cell therapy. Each section will help you understand more about what to expect and highlight your role as a carer.

THIS GUIDE BELONGS TO

IF FOUND RETURN TO

This guide should not replace the advice and guidance from the healthcare team. If you have additional questions or would like more detailed information please contact the healthcare team. You can fill out the contact information of the healthcare team on Pages 26 and 27 of this guide.

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Please do not worry if you do not understand some of the language in this Table of Contents. These terms will be explained later in the guide.

Sections with a light grey background highlight information that is particularly important to carers.



An overview of the role of a carer

What is a carer?

Being a carer generally means providing emotional, practical or medical support to someone who is ill, usually a relative or friend. If you are helping to look after a relative/friend with multiple myeloma—cancer of the bone marrow—at any stage of their treatment, then you are a carer. As your relative/friend goes through CAR-T cell therapy, they will need your support.

Everybody's needs differ, and while some patients benefit from more involved support, others will be more independent. As someone who is close to your relative/friend, you are in the best position to know when to help and when to take a step back. There will be times during your relative/friend's CAR-T journey when you will need to remain close to them and be available to support them at all times. This means that you may have to make some alternative arrangements, such as for work and childcare.

You might go with your relative/friend to their hospital appointments to provide emotional and physical support. You will also play an important role in supporting and monitoring them when they leave hospital after their CAR-T cell infusion, to look out for any side effects. This guide will describe more about the many ways that you can care for your relative/friend.

When you are caring for someone else, it can be easy to overlook your own needs. It is just as important to look after your own health and wellbeing, which also means you will be able to provide better care.¹ You don't have to manage this alone. Support is available to help you along the way, and you may want to identify friends or family who can help you as well.

If for any reason you are no longer able to provide care for your relative/friend, please let the healthcare team know as soon as possible, so that an alternative carer can be arranged.

It is also important to let the healthcare team know if you develop any illness while you are caring for your relative/friend. It may be necessary to organise an alternative carer for them until you are better, for their health as well as your own.

1. Myeloma UK, Infopack for carers of myeloma patients. Available at <https://www.myeloma.org.uk>. Last accessed July 2021.

Tips for carers

Caring for someone can involve a range of support.¹ Below are some of the ways you can help your relative/friend

Your wellbeing matters

- Taking care of your own health and wellbeing
- Taking breaks every once in a while
- Accepting help and support from others
- Seeking professional help if you are feeling overwhelmed

Medical support

- Taking notes and asking questions during appointments
- Reminding them to take any medicines they have been prescribed
- Monitoring them for any side effects when they are not in hospital
- Immediately alerting the healthcare team if you notice any side effects
- Support when symptoms occur

Emotional support

- Being a good listener when they need to talk
- Encouraging them to talk about how they are feeling
- Being a calming and positive presence
- Arranging more formal support with the help of the healthcare team, such as a counsellor or psychologist, if required

Care/nursing support

- Driving them to and from appointments
- Shopping and preparing meals
- Collecting prescriptions
- Helping to organise visits from family and friends
- Making sure they are comfortable
- Keeping the house clean



1. Myeloma UK, Infopack for carers of myeloma patients. Available at <https://www.myeloma.org.uk>. Last accessed July 2021.

CAR-T cell therapy overview

What is CAR-T cell therapy?

Chimeric antigen receptor (CAR)-T cell therapy is a type of immunotherapy that helps the immune system fight cancer. CAR-T cell therapy can be used to fight multiple myeloma and other diseases. T cells—a type of white blood cell—are part of the immune system and are responsible for attacking any bacteria or foreign cells in the body. During CAR-T cell therapy, some of your relative/friend's T cells will be collected from them. Their T cells will then be reprogrammed at a manufacturing centre to become CAR-T cells. The CAR-T cells are then reintroduced into their system through an infusion. Once the cells are modified and placed back into their body, they can recognise and attack multiple myeloma cells.¹⁻³

What is ciltacabtagene autoleucel?

Ciltacabtagene autoleucel is a type of CAR-T cell therapy used to treat adult patients who have cancer of the bone marrow called multiple myeloma. It is given when your relative/friend's multiple myeloma has returned after at least three other kinds of treatment. Ciltacabtagene autoleucel may also be referred to as 'cilta-cel', 'CARVYKTI®' or 'CAR-T cells'.

1. Ali SA, et al. *Blood*. 2016;128(13):1688–700; 2. Levine BL, et al. *Mol Ther Methods Clin Dev*. 2016;4:92–101; 3. Janeway CA, et al. In: *Immunobiology: The Immune System in Health and Disease*, 5th ed; New York: Garland Science; 2001.

The CAR-T journey

There are five steps involved in your relative/friend's CAR-T cell therapy:

This map will help you follow your relative/friend's CAR-T journey and show you what your role is as their carer. Further details are provided throughout this guide.



START Start of the CAR-T journey

Your relative/friend will find out if they are eligible for CAR-T cell therapy



STEP 1 Leukapheresis

T cells are collected for use in the CAR-T cell manufacturing process



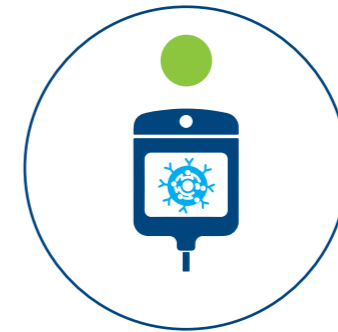
STEP 2 Bridging therapy

Therapy to stabilise cancer whilst CAR-T cells are manufactured



STEP 3 Lymphodepleting chemotherapy

Therapy to prepare the body for CAR-T cell infusion



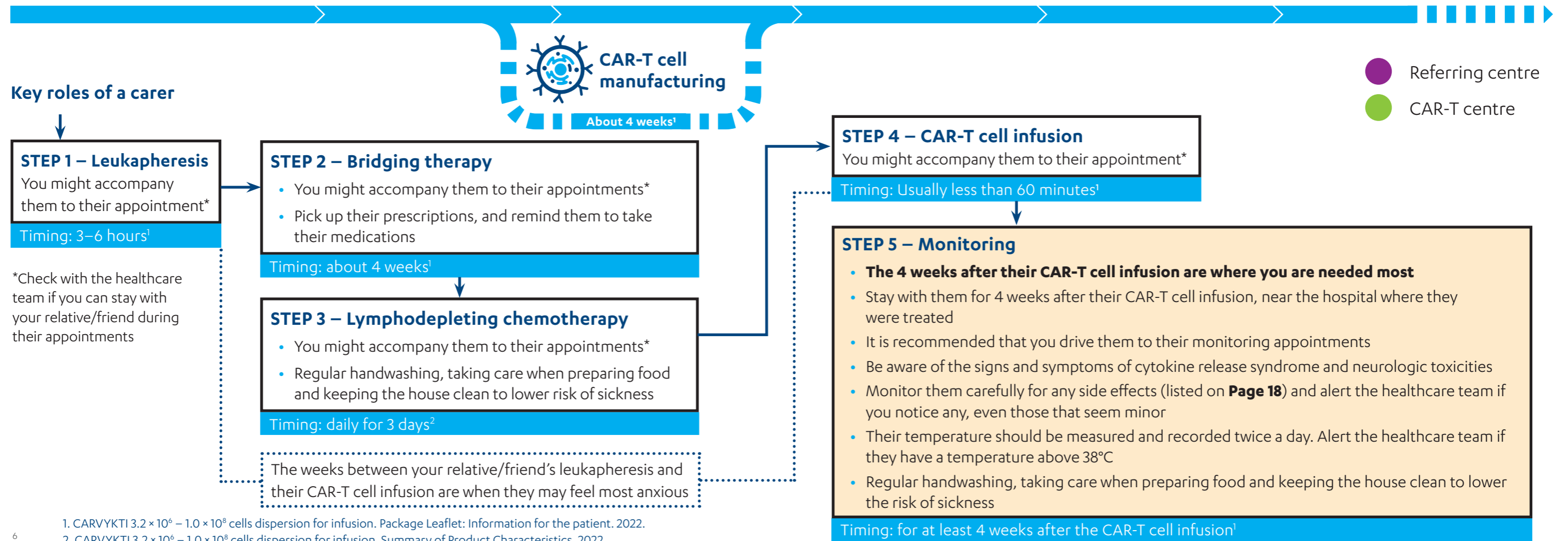
STEP 4 CAR-T cell infusion

The newly manufactured CAR-T cells are put back into the body



STEP 5 Monitoring

After infusion, your relative/friend is closely monitored for side effects



1. CARVYKTI 3.2 × 10⁶ – 1.0 × 10⁸ cells dispersion for infusion. Package Leaflet: Information for the patient. 2022.

2. CARVYKTI 3.2 × 10⁶ – 1.0 × 10⁸ cells dispersion for infusion. Summary of Product Characteristics. 2022.

Supporting your relative/ friend through their CAR-T journey



Providing emotional support

Your relative/friend's psychological wellbeing can be affected at any time during their CAR-T journey and can change over time. Stress, anxiety and fear are natural emotions that may affect them, and having someone to talk to can allow them to express their feelings. You can give emotional support by simply being a good listener when the person you are caring for needs to talk. The healthcare team will also be able to help arrange more formal support, such as a counsellor or psychologist.

As a carer, you may also experience a range of emotions as your relative/friend goes through their CAR-T journey. It is very important to look after your own wellbeing. Do not be afraid to ask for professional help if you are struggling.



Providing support at appointments

Your relative/friend will go through a series of tests before they start their CAR-T cell therapy. This is to check that it is the right treatment for them.

Your relative/friend will receive a lot of information at the start of their CAR-T journey, and will have a lot of important paperwork to fill in. As a carer, you might help them take care of the paperwork. Anything you sign on their behalf must be documented appropriately – the doctor will advise you about this.

You can also provide support by taking notes during appointments, so that they can focus on what is being said. Space for your own notes is provided towards the end of this guide, on Pages 29–33.

If either of you have questions about any aspect of treatment, ask a member of the healthcare team. They anticipate that you may have lots of questions, and they understand that providing answers will help you and your relative/friend on their CAR-T journey. Some patients and carers might feel nervous or anxious about speaking to doctors. It can help to prepare for appointments beforehand by making a list of questions or concerns that you want to raise. A list of common questions that you may want to ask is included on Page 24. You may also have questions that you don't want to ask in front of your relative/friend. Ask the healthcare team for the best way to get in touch with them to talk privately, though remember that they will not be able to share any confidential information.

Getting a second opinion

Some patients and carers feel that they will offend a doctor if they ask for a second opinion about treatment decisions. However, most doctors will welcome a second opinion. Patients and carers should feel comfortable about asking for this.

Key roles of a carer

- It is recommended that you accompany your relative/friend to their appointments, if permitted by the healthcare team
- If either you or your relative/friend have questions about any aspect of treatment, ask a member of the healthcare team
- Before going to appointments, make a list of questions that you and your relative/friend would like to ask the healthcare team
- Take notes during your relative/friend's appointments

Leukapheresis

Some of your relative/friend's white blood cells will be collected from them through a process called leukapheresis. This involves drawing their blood into a machine and separating out the T cells—a type of white blood cell—from the rest of the blood. To collect the T cells, a small and flexible tube called an intravenous catheter will be placed in a vein to collect blood. After the machine separates the cells from the rest of the blood, the remainder of the blood components are then returned into the vein. The collected blood cells are then sent for cell manufacturing to make the CAR-T cells.¹

As a carer, you might go with your relative/friend to their leukapheresis appointment. Before the appointment, make sure they are dressed comfortably, and that they have followed any guidelines given by the healthcare team to prepare for leukapheresis. Once they return home after leukapheresis, ensure they get plenty of rest.

After leukapheresis has taken place, your relative/friend's T cells are shipped to the manufacturing site. It then takes about 4 weeks to make their CAR-T cells.¹ Once ready, the cells are shipped to the CAR-T treatment centre and prepared for infusion. In the waiting period between their leukapheresis appointment and CAR-T cell infusion, they may receive other therapies to help stabilise their cancer. You can find more information about these therapies on the next page.

Your relative/friend may be feeling particularly anxious during this waiting period, as there is a risk that they could become too unwell to receive their CAR-T cells. They may also be worried about potential issues in the manufacturing process which might prevent them from receiving CAR-T cell therapy. They may benefit from your emotional support during this waiting period. You can also offer to arrange more formal support with the help of the healthcare team, such as a counsellor or psychologist.

Key roles of a carer

- Make sure your relative/friend is dressed comfortably and has followed any guidelines from the healthcare team to prepare for leukapheresis
- It is recommended that you accompany your relative/friend to their leukapheresis appointment, if permitted by the healthcare team
- Ask the healthcare team if you need to bring anything specific to the appointment

Timing: Leukapheresis can take 3–6 hours and may need to be repeated¹

1. CARVYKTI 3.2 × 10⁶ – 1.0 × 10⁸ cells dispersion for infusion. Package Leaflet: Information for the patient. 2022.

Bridging therapy

Once leukapheresis has taken place, your relative/friend may undergo bridging therapy so that their multiple myeloma does not get worse while waiting for their infusion.¹ Bridging therapy is intended to stabilise their cancer between leukapheresis and infusion so they may remain eligible to receive CAR-T cells. Therefore, bridging therapy essentially serves as a 'bridge' from one therapy to another. The therapy will be a type of anticancer treatment that the healthcare team will recommend. It may be important for the healthcare team and your relative/friend to plan regular visits during bridging therapy to ensure the therapy is well tolerated and stabilising their disease. Ask the healthcare team about any side effects your relative/friend may experience from bridging therapy.

As a carer, it is important that you remind them to take any treatments they have been prescribed during this time. You may also pick up prescriptions for them.

Key roles of a carer

- It is recommended that you accompany your relative/friend to their bridging therapy appointments, if permitted by the healthcare team
- Remind your relative/friend to take any treatments they have been prescribed
- You may need to pick up your relative/friend's prescriptions
- Ask the healthcare team if you need to bring anything specific to the appointment

Timing: Bridging therapy takes place in the weeks between your relative/friend's leukapheresis appointment and lymphodepleting chemotherapy. Note that some patients may not need bridging therapy

1. CARVYKTI 3.2 × 10⁶ – 1.0 × 10⁸ cells dispersion for infusion. Summary of product characteristics. 2022.

Lymphodepleting chemotherapy

Between 5 and 7 days¹ before your relative/friend's CAR-T cell infusion, they will undergo lymphodepleting chemotherapy to prepare their body for their CAR-T cells.² This treatment reduces the number of white blood cells in their blood, so the CAR-T cells can grow in number when they are returned to their body.²

Once their CAR-T cells are ready, your relative/friend will receive lymphodepleting chemotherapy infusions of cyclophosphamide and fludarabine daily for 3 days.¹ As with most forms of chemotherapy, side effects are expected and can range from mild to severe. Any side effects should be reported as soon as possible. Common side effects are listed in the table below. Speak with the healthcare team about other potential side effects.

Your relative/friend will usually be able to come home in between their lymphodepleting chemotherapy and their CAR-T cell infusion. Their immune system will be weakened after lymphodepleting chemotherapy, so it is important that you both wash your hands regularly, take care when preparing food and keep the house clean to lower the risk of sickness. You should also both avoid people who are unwell. The healthcare team will be able to give you more information about this.

Most common side effects from lymphodepleting chemotherapy^{3,4*}

- Bleeding or bruising easily[†]
- A lowering of blood cell counts[†]
- Infection[†]
- Vomiting
- Fever
- A burning feeling when passing urine or blood in urine
- Hair loss
- Cough
- Feeling tired

*Please see the Patient Information Leaflets for cyclophosphamide³ and fludarabine⁴ for more information

[†]These side effects may affect your relative/friend's CAR-T cell therapy and they will be monitored closely

Key roles of a carer

- It is recommended that you accompany your relative/friend to their lymphodepleting chemotherapy appointments, if permitted by the healthcare team
- Wash hands regularly, take care when preparing food and keep the home clean to lower risk of illness. Ask the healthcare team if you have any questions about this. We have included some common questions you may want to ask on Page 24
- Closely monitor your relative/friend carefully for any side effects, and alert a member of the healthcare team immediately if you notice any
- The healthcare team will explain what side effects to look out for after lymphodepleting chemotherapy. Do not hesitate to ask for more information if you have any questions or concerns

Timing: Lymphodepleting chemotherapy will be given daily for 3 days starting 5–7 days before the CAR-T cell infusion.¹

1. CARVYKTI 3.2 × 10⁶ – 1.0 × 10⁸ cells dispersion for infusion. Summary of Product Characteristics. 2022.

2. CARVYKTI 3.2 × 10⁶ – 1.0 × 10⁸ cells dispersion for infusion. Package Leaflet: Information for the patient. 2022.

3. Cyclophosphamide 500 mg Package Leaflet, 2019.

4. Fludarabine 50 mg Package Leaflet, 2019.

CAR-T cell infusion

A few days after your relative/friend's lymphodepleting chemotherapy ends, the healthcare team will do a final confirmation to make sure they are ready for their CAR-T cell infusion.

Thirty to sixty minutes before infusion, your relative/friend may be given other medicines. These may include:

- Antihistamine medicines for an allergic reaction such as diphenhydramine.¹
- Medicines for fever such as paracetamol.¹

The doctor or nurse will check carefully that the ciltacabtagene autoleucel treatment your relative/friend is given is from their own white blood cells.¹

Ciltacabtagene autoleucel is a one-time treatment. It will not be given again.¹

- The doctor or nurse will give your relative/friend ciltacabtagene autoleucel by a drip into their vein. This is called an intravenous infusion and is usually less than 60 minutes.¹

As a carer, it is recommended that you go with your relative/friend to their infusion appointment and stay with them during the process. You should check with the healthcare team if this will be possible.

Key roles of a carer

- Make sure your relative/friend has followed any guidelines from the healthcare team to prepare for their CAR-T cell infusion
- It is recommended that you accompany your relative/friend to their CAR-T cell infusion appointment, and stay with them during, if permitted by the healthcare team
- Ask the healthcare team if you need to bring anything specific to the appointment

Timing: The infusion will usually be completed in less than 60 minutes.¹

1. CARVYKTI 3.2 × 10⁶ – 1.0 × 10⁸ cells dispersion for infusion. Package Leaflet: Information for the patient. 2022.



Safety and monitoring after CAR-T cell infusion

The 4 weeks after your relative/friend's CAR-T cell infusion are where you, as a carer, are needed most.

After your relative/friend receives their CAR-T cell infusion, their healthcare team will monitor them to check if the treatment is working and to help if they have any side effects. You should plan to stay together near the hospital where your relative/friend was treated for at least 4 weeks after they have been given ciltacabtagene autoleucel.¹ During this time, you should remain close to them. Ask the healthcare team about a detailed plan for how they will be monitored after the infusion.

It is recommended that your relative/friend **does not drive for at least 8 weeks after their CAR-T cell infusion.**¹ As a carer, you may need to drive them to their appointments during this time.

They will need to return to the hospital every day for at least 14 days after they have been given ciltacabtagene autoleucel. If they develop serious side effects, they may need to stay in the hospital until their side effects are under control and it is safe for them to leave.¹

For the safety of your relative/friend, any side effects experienced following infusion of ciltacabtagene autoleucel, even those that seem minor, **should be reported immediately.** You are an extra set of eyes and ears for the healthcare team—you can alert them quickly if any side effects occur. Be observant and be prepared by keeping the names and phone numbers of the members of the healthcare team nearby. You can fill out the contact information of the healthcare team in the space provided towards the end of this guide, on Pages 26 and 27. Because ciltacabtagene autoleucel is a one-time treatment, the emergence of side effects will not affect your relative/friend's treatment. Please speak with the healthcare team about potential side effects.

Recognising an emergency

If you recognise any side effects related to CAR-T cell therapy in your relative/friend, it is likely an emergency requiring immediate attention.

Patients who have received CAR-T cell therapy have experienced side effects ranging from mild to serious. It is important that you are aware of these possible side effects, as your relative/friend may experience one or more of them when undergoing CAR-T cell therapy. These could be subtle changes to their mood that only someone close to them would recognise, but may point to a more serious problem that needs immediate attention.

You have an important role as a carer to monitor them closely and to alert the healthcare team immediately if you suspect any side effects. You can use the monitoring charts on Pages 36–43 of this guide to record their temperature and any other symptoms in the 4 weeks after their infusion.

Symptoms requiring urgent medical care may occur at any time after receiving CAR-T cell therapy, however, they typically occur within 1 month after CAR-T cell infusion. Do not hesitate to get in touch with your healthcare team if you have any concerns no matter what the time of day.

What are the common side effects to look out for?

Like all medicines, this medicine can cause side effects, although not everybody gets them. Ciltacabtagene autoleucel can cause side effects that may be serious or life-threatening.¹ Possible side effects to look out for are listed on the next page.

1. CARVYKTI 3.2 × 10⁶ – 1.0 × 10⁸ cells dispersion for infusion. Package Leaflet: Information for the patient. 2022.

1. CARVYKTI 3.2 × 10⁶ – 1.0 × 10⁸ cells dispersion for infusion. Package Leaflet: Information for the patient. 2022.

Cytokine release syndrome

Cytokine release syndrome (CRS) is a serious immune reaction.¹ The healthcare team may need you to monitor your relative/friend's temperature after their CAR-T cell infusion, when they are not in the treatment centre. If so, it is important for you to measure their temperature twice a day, or remind them if they are doing it themselves. **If they have a temperature above 38°C, contact the healthcare team immediately.** Similarly, if you notice any of the following symptoms, you need to **call the healthcare team immediately** and go to the CAR-T treatment centre or hospital straight away as it may be an emergency requiring medical attention:

Tell the doctor or nurse immediately if your relative/friend has any of the following:

- Chills
- Fever (38°C or higher)
- Fast heartbeat
- Difficulty breathing
- Low blood pressure which can make them feel dizzy or lightheaded

These may be signs of a serious immune reaction known as 'cytokine release syndrome' (CRS)¹

Neurologic toxicities

Immune effector cell-associated neurotoxicity syndrome (ICANS) is a serious immune reaction.¹ If you notice any of the following symptoms in your relative/friend, you need to **call the healthcare team immediately** and go to the CAR-T treatment centre or hospital straight away as it may be an emergency requiring medical attention:

Tell the doctor or nurse immediately if your relative/friend has any of the following:

- Feeling confused, less alert, disorientated, anxious or having memory loss
- Difficulty speaking or slurred speech
- Slower movements, changes in handwriting
- Loss of coordination, affecting movement and balance
- Having difficulty reading, writing and understanding words
- Personality changes which may include being less talkative, disinterest in activities and reduced facial expression

Some of these symptoms may be signs of a serious immune reaction called 'immune effector cell-associated neurotoxicity syndrome' (ICANS)¹

After CAR-T cell therapy, your relative/friend's immune system might not be working properly, so it is very important that you make sure to keep the house clean and to take extra care when preparing food to prevent them from getting sick.

It is important that no one with any cold, flu, or COVID-19 symptoms comes to visit when they are recovering from CAR-T cell therapy. If you develop any illness while you are caring for your relative/friend, then please let the doctor know as soon as possible, as it may be necessary to organise an alternative carer until you are better.

Key roles of carer

- **The 4 weeks after your relative/friend's CAR-T cell infusion are where you, as a carer, are needed most**
- Stay with your relative/friend for a period of 4 weeks after their CAR-T cell infusion, near the hospital where they were treated
- You may need to drive your relative/friend to their monitoring appointments. They will need to visit the hospital every day for at least 14 days after their infusion
- Be aware of the signs and symptoms of cytokine release syndrome and neurologic toxicities
- Closely monitor your relative/friend carefully for any side effects. Alert a member of the healthcare team immediately if you notice any, even those that seem minor
- Check and record your relative/friend's temperature twice a day. If you record a temperature above 38°C, contact the healthcare team immediately
- Regular handwashing, taking care when preparing food and keeping the house clean to lower risk of sickness. Ask the healthcare team for more information about this

Timing: You will need to stay with your relative/friend and monitor them for any side effects for 4 weeks after their CAR-T cell infusion¹

1. CARVYKTI 3.2 × 10⁶ – 1.0 × 10⁹ cells dispersion for infusion. Package Leaflet: Information for the patient. 2022.

1. CARVYKTI 3.2 × 10⁶ – 1.0 × 10⁹ cells dispersion for infusion. Package Leaflet: Information for the patient. 2022.

Getting back to normal

CAR-T cell therapy can be a stressful period in both a patient's and a carer's life. Other friends and family may want to visit your relative/friend after their CAR-T cell therapy. It is important that they can see people, but that they don't become overwhelmed with too many visitors. As a carer, you can help to organise these visits when they are ready. As mentioned previously, it is also important that all visitors are healthy, so they don't risk passing on any illness to you both. Phone or video calls may be a safer alternative to meeting in person.

CAR-T cell therapy is a new type of therapy for multiple myeloma. Therefore, there is a requirement to collect long-term follow-up data on patients treated with CAR-T cell therapy in order to better understand the long-term effects. Your relative/friend will be asked to enrol in a registry for at least 15 years in order to monitor their health and better understand the long-term effects of ciltacabtagene autoleucel.¹

If at any time following their CAR-T cell therapy they have any changes in health, additional questions, or any concerns, they should contact their referring physician who will be in regular communication with the CAR-T healthcare team.

1. CARVYKTI 3.2 × 10⁶ – 1.0 × 10⁸ cells dispersion for infusion. Package Leaflet: Information for the patient. 2022.

What if CAR-T cell therapy cannot take place, or does not work?

In the time between leukapheresis and their CAR-T cell infusion, your relative/friend may become too ill to receive CAR-T cell therapy. There also might be issues with the CAR-T cell manufacturing process that mean they are unable to receive CAR-T cell therapy. The healthcare team will give you advice about this if required. For some patients who receive CAR-T cell therapy, it may not work well and the cancer may still progress. For others, CAR-T cell therapy may be successful at first, but their cancer may come back later. This can be difficult and distressing. You and your relative/friend should speak to the healthcare team about other treatment options. You can help by providing emotional support (see Page 9 of this guide). The healthcare team will also be able to help arrange more formal support, such as a counsellor or psychologist.

[\[Links to local support groups or programme developed by Janssen \(TBC\)\]](#)

Caring for yourself

Understanding your emotions

Becoming a carer, especially for someone going through CAR-T cell therapy, can feel like a full-time job and can be a massive change from your normal life. It is normal to feel sad, frustrated, angry, overwhelmed and worried. If you are feeling overwhelmed or sad for more than 2 weeks, please seek professional help.

[Placeholder for countries to add links to where to get professional help]

Where to find help and support

It may be possible to have more than one carer supporting your relative/friend. All carers should make themselves known to the healthcare team, so that they can receive proper guidance on how to safely care for their relative/friend.

If other friends or family members offer to help out, please let them. They can support you and the person you are caring for with practical tasks, like picking up prescriptions or shopping. As mentioned before, it is important that all visitors are healthy so they don't risk passing on any illness to either of you.

Carer support groups can be a good way to get support and advice from other carers who understand what you're going through, as well as a way to share your own experiences. If you find it difficult to get out or if you need someone to talk to when no one else is around, then online groups can also be a great source of information and support. This could stop you from feeling alone.

[Placeholder for countries to add links to relevant carer associations]

Looking after your own health¹

Caring for someone going through CAR-T cell therapy can be complex and demanding, both physically and emotionally, and it can be easy to forget about your own needs. It is important that you take time for yourself and look after your own health.



Take a break

Taking a break every once in a while is important. Ask those around you if they can take over from you for a regular time each week, and plan things to look forward to.



Diet

Try to make sure that both you and your relative/friend are eating a healthy, balanced diet, and drinking plenty of water and other fluids.



Physical activity

Physical activity is beneficial in lots of ways and can help give you the stamina and strength to be the best carer you can be. It is also proven to help lift your mood and alleviate stress and anxiety. Try to do some physical activity every day, such as a regular class at your local gym, or even a short walk outdoors.



Get some rest

There are many reasons why looking after someone can make it difficult to get enough sleep. Worrying about things may keep you awake, or your relative/friend may need help at night-time. To help you relax and to clear your head, you could try to incorporate some time for yourself into your day, whether it's reading a book or having a warm bath – whatever helps you to relax.



Don't be afraid to ask for help

Caring for someone is a huge task. Strong and confusing emotions are common, and they are not a sign of weakness. If you have worries or concerns, or feelings of guilt, don't keep them to yourself.

Questions for the healthcare team

Common questions to consider asking the healthcare team:

- Who should I direct my questions to throughout the process?
- What should I do if I am no longer able to be a carer, for example due to work or illness?
- Who should I speak to about help with travel/accommodation?
- If there are times when I am not available, can we use support from other relatives or friends?
- How close should we stay to the treatment centre?
- Who should I contact in case of an emergency?
- What support services are available to me?

Questions to ask on behalf of your relative/friend

- How should they prepare for their appointments?
- Which appointments will I be able to attend with them?
- What should I bring to the appointments for them?
- How long will this procedure/treatment take?
- Will they require bridging therapy?
- What happens after their CAR-T cell infusion?
- How will I take their temperature?
- What are the common side effects of cytokine release syndrome and neurologic toxicities to look out for?
- How long will their side effects last?
- Will there be any restrictions on their abilities after treatment?
- Are there any diet restrictions after treatment?
- Are they allowed to be physically active?
- Is it appropriate to have pets in the house?
- Are we allowed to share facilities in the house (e.g. bathrooms)?

Healthcare team information

Healthcare team contact information

It is important to know who is on the healthcare team and how to get in contact with them. Please use the space below to write down their contact information and function/title (e.g. CAR-T Nurse, CAR-T Coordinator, CAR-T Physician)

(Note to Countries: Please adapt the function/titles above based on your roles.)

Contact details of the CAR-T site

24/7 EMERGENCY PHONE NUMBER:

PRIMARY CAR-T HEALTHCARE PROFESSIONAL:

ADDRESS:

NAME:

PHONE NUMBER:

FUNCTION/TITLE:

BEST TIME TO REACH:

EMAIL:

NAME:

PHONE NUMBER:

FUNCTION/TITLE:

BEST TIME TO REACH:

EMAIL:

NAME:

PHONE NUMBER:

FUNCTION/TITLE:

BEST TIME TO REACH:

EMAIL:

CAR-T journey

You can use the space provided to enter the dates of your relative/friend's appointments



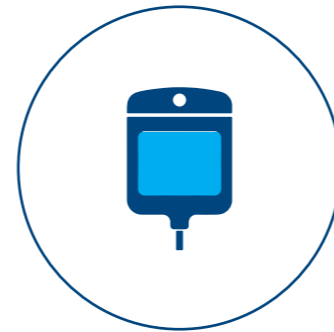
START
Start of the CAR-T journey



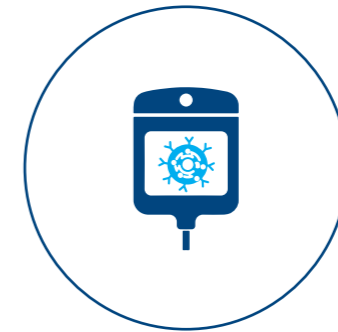
STEP 1
Leukapheresis



STEP 2
Bridging therapy



STEP 3
Lymphodepleting chemotherapy



STEP 4
CAR-T cell infusion



STEP 5
Monitoring



Date of leukapheresis:

Start date of bridging therapy:

First infusion of lymphodepleting chemotherapy:

Date of CAR-T cell infusion:

End date of bridging therapy:

Second infusion of lymphodepleting chemotherapy:

Third infusion of lymphodepleting chemotherapy:

Monitoring during the 4 weeks after CAR-T cell infusion

Date of CAR-T cell infusion: _____

Week 1 (date): _____



Alert the healthcare team immediately if you notice any side effects
 Check and record your relative/friend's **temperature twice a day**, or kindly remind them if they are doing it themselves. **If they have a temperature above 38°C, alert the healthcare team immediately**

	TEMPERATURE CHECK 1	TEMPERATURE CHECK 2	BLOOD PRESSURE	SYMPTOMS/SIDE EFFECTS	OTHER CHANGES THAT YOU OR YOUR RELATIVE/FRIEND FEEL SHOULD BE CAPTURED (PAIN, FATIGUE, MOOD, APPETITE, ETC.): 1.	OTHER CHANGES THAT YOU OR YOUR RELATIVE/FRIEND FEEL SHOULD BE CAPTURED (PAIN, FATIGUE, MOOD, APPETITE, ETC.): 2.	OTHER CHANGES THAT YOU OR YOUR RELATIVE/FRIEND FEEL SHOULD BE CAPTURED (PAIN, FATIGUE, MOOD, APPETITE, ETC.): 3.
DAY 1							
DAY 2							
DAY 3							
DAY 4							
DAY 5							
DAY 6							
DAY 7							

Monitoring during the 4 weeks after CAR-T cell infusion

Date of CAR-T cell infusion: _____

Week 2 (date): _____



Alert the healthcare team immediately if you notice any side effects
 Check and record your relative/friend's **temperature twice a day**, or kindly remind them if they are doing it themselves. **If they have a temperature above 38°C, alert the healthcare team immediately**

	TEMPERATURE CHECK 1	TEMPERATURE CHECK 2	BLOOD PRESSURE	SYMPTOMS/SIDE EFFECTS	OTHER CHANGES THAT YOU OR YOUR RELATIVE/FRIEND FEEL SHOULD BE CAPTURED (PAIN, FATIGUE, MOOD, APPETITE, ETC.): 1.	OTHER CHANGES THAT YOU OR YOUR RELATIVE/FRIEND FEEL SHOULD BE CAPTURED (PAIN, FATIGUE, MOOD, APPETITE, ETC.): 2.	OTHER CHANGES THAT YOU OR YOUR RELATIVE/FRIEND FEEL SHOULD BE CAPTURED (PAIN, FATIGUE, MOOD, APPETITE, ETC.): 3.
DAY 1							
DAY 2							
DAY 3							
DAY 4							
DAY 5							
DAY 6							
DAY 7							

Monitoring during the 4 weeks after CAR-T cell infusion

Date of CAR-T cell infusion: _____

Week 3 (date): _____



Alert the healthcare team immediately if you notice any side effects. Check and record your relative/friend's **temperature twice a day**, or kindly remind them if they are doing it themselves. **If they have a temperature above 38°C, alert the healthcare team immediately**

	TEMPERATURE CHECK 1	TEMPERATURE CHECK 2	BLOOD PRESSURE	SYMPTOMS/SIDE EFFECTS	OTHER CHANGES THAT YOU OR YOUR RELATIVE/FRIEND FEEL SHOULD BE CAPTURED (PAIN, FATIGUE, MOOD, APPETITE, ETC.): 1.	OTHER CHANGES THAT YOU OR YOUR RELATIVE/FRIEND FEEL SHOULD BE CAPTURED (PAIN, FATIGUE, MOOD, APPETITE, ETC.): 2.	OTHER CHANGES THAT YOU OR YOUR RELATIVE/FRIEND FEEL SHOULD BE CAPTURED (PAIN, FATIGUE, MOOD, APPETITE, ETC.): 3.
DAY 1							
DAY 2							
DAY 3							
DAY 4							
DAY 5							
DAY 6							
DAY 7							

Monitoring during the 4 weeks after CAR-T cell infusion

Date of CAR-T cell infusion: _____

Week 4 (date): _____



Alert the healthcare team immediately if you notice any side effects
 Check and record your relative/friend's **temperature twice a day**, or kindly remind them if they are doing it themselves. **If they have a temperature above 38°C, alert the healthcare team immediately**

	TEMPERATURE CHECK 1	TEMPERATURE CHECK 2	BLOOD PRESSURE	SYMPTOMS/SIDE EFFECTS	OTHER CHANGES THAT YOU OR YOUR RELATIVE/FRIEND FEEL SHOULD BE CAPTURED (PAIN, FATIGUE, MOOD, APPETITE, ETC.): 1.	OTHER CHANGES THAT YOU OR YOUR RELATIVE/FRIEND FEEL SHOULD BE CAPTURED (PAIN, FATIGUE, MOOD, APPETITE, ETC.): 2.	OTHER CHANGES THAT YOU OR YOUR RELATIVE/FRIEND FEEL SHOULD BE CAPTURED (PAIN, FATIGUE, MOOD, APPETITE, ETC.): 3.
DAY 1							
DAY 2							
DAY 3							
DAY 4							
DAY 5							
DAY 6							
DAY 7							

