



Family and Friends Guide to **CAR T** Cell Therapy

Treatment information and advice for family members and friends of patients undergoing treatment with CAR T Cell therapy

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A Guide to CAR T Cell Therapy

You have been given this information booklet because someone you know is undergoing CAR T cell therapy.

The aim of this booklet is to give you more information on what CAR T cell therapy is and how you can support your family member or friend and look after yourself during this time.

There are organisations and charities who can support people coping with cancer. You can find their details on [page 13](#).

CAR T Cell Therapy

The chimeric antigen receptor (CAR) T cell therapy that your friend or relative is receiving is a kind of individualised treatment that may be offered to people living with certain types of blood cancer.

CAR T therapy is a form of immunotherapy, which means it uses the individual's own immune system to remove the cancer.

Unlike other kinds of cancer treatment, it is made from the patient's own white blood cells, known as T cells.

The job of T cells is to target and remove bacteria, viruses and cancerous cells.

However, in some cases, cancerous cells have ways of hiding from T cells, which makes it difficult for the body to remove the cancer.

How it Works

CAR T cell therapy works by transforming T cells to help them find and remove cancerous cells.

T cells are collected from the patient's body, inserted with a gene that causes them to produce chimeric antigen receptors (CARs) on their surface and then infused back into their bloodstream.

These newly modified cells – known as CAR T cells – have the ability to recognise and bind to the cancerous cells in the body.

Once attached, the CAR T cells release a chemical that directly attacks the cancer and may help remove it.

Specialist Treatment Centres

Your friend or relative's CAR T therapy can only be given in specialist treatment centres.

These treatment centres are based in specialist hospitals, which have expert healthcare teams and services.

If you are accompanying your family member or friend become familiar with where you need to go, journey time, parking facilities etc. All these details can be found within the hospital website.

What May Happen Next

Your family member or friend may have several appointments before the CAR T treatment begins to undergo a series of tests and checks. These could include:

- Tests to check blood pressure and pulse
- Tests to check the function of the liver
- Tests to check the function of the kidneys
- Tests to check the function of the lungs

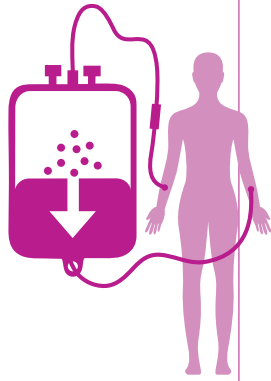
It may help if someone accompanies your family member or friend to these appointments to note key information such as key contacts, appointment dates and to understand what will happen next.

You may also want to talk through with your family member or friend any questions they or you may have. Do this before the hospital appointment so that you have the questions to hand.



Treatment Process


To help support your family member or friend it can help to understand more about this type of treatment. CAR T cell therapy involves several steps over a number of weeks. These steps are outlined in the diagram below:



1

T Cell Collection

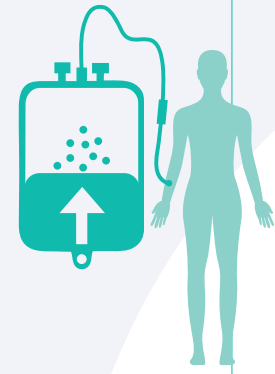
The first step is collecting white blood cells (T cells) from the body through a process called apheresis (AY-fur-EE-sis). Blood is collected and filtered through a special machine that is able to separate T cells from other blood cells. These T cells are then sent to a laboratory to be turned into CAR T cells (see page 16 for more information).



2

Preparing for Treatment


It takes several weeks for the CAR T cell to be manufactured in the laboratory. During this time, the patient can maintain their normal lifestyle, though they may receive ongoing cancer treatment, often referred to as bridging therapy. To prepare their body for cell therapy, they will also need to undergo 3 days of lymphodepleting chemotherapy. This is a low-dose treatment intended to remove other immune cells to make more room for the CAR T cells to do their job.



3

Infusion


If successfully manufactured, your family member or friend will be given a date to return to their treatment centre. At this stage the healthcare team may decide that they need to undergo further tests. If they are well enough, they will receive a single infusion of CAR T cells. These newly modified cells may now have the ability to find and remove the cancerous cells in their body.



4

Monitoring

After the infusion they will need to remain at the treatment centre where their healthcare team will monitor them for approximately 10 days, in case they have a reaction to the treatment. Once discharged they will need to remain within easy access of the centre. During this time, they will not be allowed to drive for at least 8 weeks. If you're able to, offer to drive your family member or friend to appointments.



5

Follow-up

The healthcare team will arrange any follow-up appointments or ongoing care the patient may need. As a family member or friend, your help during this time can make a big difference.

Possible Side Effects of Treatment

Like all medicines, the CAR T treatment prescribed can cause side effects, although not everybody gets them. The healthcare team will help identify and manage these side effects. But as a family member or friend it is important for you to understand what to look out for and let the team know as soon as possible should any side effects occur. For the prescribed CAR T treatment, two of the most common side effects are neurological adverse reactions and cytokine release syndrome (CRS).*

Neurologic adverse reactions

This refers to a range of side effects that affect the brain or central nervous system and are caused by the body reacting against the CAR T cells. **Signs or symptoms may include:**

- Confusion and disorientation
- Difficulty speaking
- Difficulty understanding speech
- Difficulty understanding numbers
- Memory loss
- Tremors (shaky arms or body parts)
- Agitation
- Increased sleepiness
- Dizziness
- Fits
- Loss of consciousness
- Loss of balance or coordination

*Other CAR T treatments may have different side effects

Cytokine release syndrome (CRS)

Also known as infusion reaction, this occurs when CAR T cells release large amounts of cytokines (proteins) into the bloodstream, provoking an inflammatory response. **Signs or symptoms may include:**

- Fever (e.g., temperature above 38°C)
- Light-headedness
- Dizziness
- Low blood pressure
- Shortness of breath
- Rapid heartbeat
- Chills
- Extreme tiredness
- Weakness
- Headache
- Cough

If you notice any of these symptoms in your family member or friend during their stay in hospital or when back at home, it is important to tell a member of their healthcare team immediately.

Reporting of side effects

If your family member or friend gets any side effects, they should talk to their doctor, pharmacist or nurse. This includes any possible side effects not listed in the package leaflet. Side effects can also be reported directly via the Yellow Card Scheme at www.mhra.gov.uk/yellowcard. Reporting side effects can help provide more information on the safety of medicines.



Support for family members and friends undergoing treatment

As with other treatments, CAR T cell therapy may be an exhausting experience both physically and mentally for your family member or friend receiving it. Your support, and the support of those around them, can make a difference in their quality of life and recovery after treatment.

There are a number of things that you can do to support your family member or friend undergoing treatment during this time.

Practical Support

Your family member or friend will have several appointments before, during and after their treatment. It can help if someone accompanies them to these appointments to note important information such as key contacts, appointment dates and what happens next.

You may also want to talk through and note any questions in advance so during the appointment you can, if required, ask those questions on behalf of your family member or friend.

CAR T cell therapy involves several steps over a number of weeks. During this time you can help with day-to-day tasks which they may not feel up to, or may not be allowed to do themselves such as;

- Looking after children or older relatives
- Looking after pets
- Gardening
- Preparing healthy meals
- Food shopping

Following treatment and while their immune system is recovering you can support them in maintaining their health by helping to;

- Keep their living areas clean and tidy
- Keep clothes & bedding regularly washed
- Ensure visitors remove shoes when entering the home and wash their hands
- Take note of side effects and report to the healthcare team if required

You should also make sure not to visit if you are feeling unwell.



Emotional Support

Your emotional support can also make their treatment easier to cope with. Try and listen to your family member or friend and be responsive to how they're feeling.

Remember that they may not always want to discuss their illness or how they are feeling. Distracting them with day-to-day conversation can help keep your friend or family member more positive.

Being open and honest, while respecting their privacy and trying to maintain a level of normality for them can also make a big difference.

The healthcare team can also help them access professional support, such as counseling.

Support for you

It's important to remember to look after yourself as well. Taking on the responsibility of caring for and supporting your friend or family member can be physically, mentally and emotionally tiring for you too.

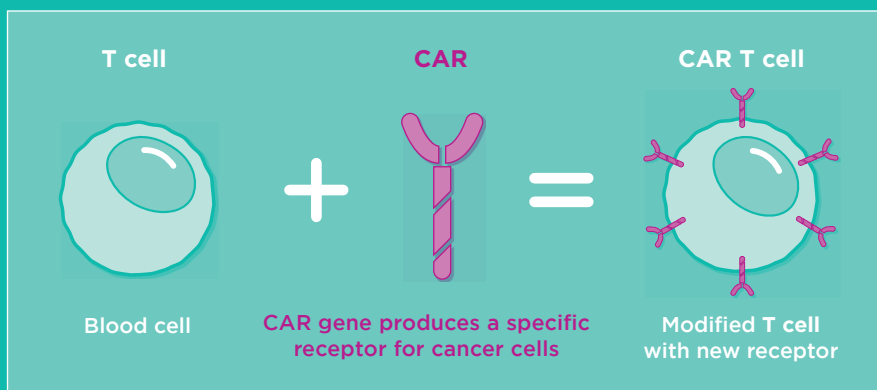
Make sure to continue eating well, exercising and getting enough sleep. If you can, share the responsibility with other family members or friends so that you can take time for yourself. Talking to others and sharing how you're feeling may also help.



How CAR T is Manufactured

Once collected through the process of apheresis, the white blood cells (T cells) are frozen and sent to a laboratory.

Here, scientists transform them into CAR T cells by inserting them with a chimeric antigen receptor (CAR) gene.



These newly modified CAR T cells are then multiplied for several days to produce the number of cells your treatment requires.

Once quality checks have been undertaken, these cells are frozen and sent back to the treatment centre, where they are ready for infusion.