

# CAR T-cell therapy

Your guide to having CAR T-cell therapy for blood cancer



**Blood  
cancer  
UK**



**ANTHONY  
NOLAN**

Saving lives through stem cells

The content in this booklet was developed in partnership with Anthony Nolan (**[anthonymolan.org](http://anthonymolan.org)**). The booklet has been funded by Autolus Therapeutics Ltd and Beefy's Charity Foundation. They provided funding but had no further input.

## Need to talk?

Contact the Blood Cancer UK Support Service with questions or worries about your diagnosis, family, work, mental health, the future.

We're the UK's specialist blood cancer charity, supporting anyone affected by any blood cancer. Family and friends can contact us for support too.

Call free on **0808 2080 888**

Email **[support@bloodcancer.org.uk](mailto:support@bloodcancer.org.uk)**

Visit **[bloodcancer.org.uk](http://bloodcancer.org.uk)**

Talk to others **[bloodcancer.org.uk/our-forum](http://bloodcancer.org.uk/our-forum)**



For our support line opening hours, go to **[bloodcancer.org.uk/call-us](http://bloodcancer.org.uk/call-us)** or you can call anytime and leave a message.

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## Key facts about CAR T-cell therapy

- CAR T-cell therapy is a type of cancer treatment that uses your immune system to fight cancer cells. It's an option for some people with blood cancer, when other treatment has not worked.
- The treatment involves removing some of your blood cells, called T cells, and genetically modifying them in a lab. These cells (called CAR T-cells) are then put back into your bloodstream, where they attack and kill cancer cells.
- CAR T-cells can stay in the body and keep working for a long time. So, unlike many other cancer treatments, CAR T-cell therapy is designed to be a treatment you only have once.
- You will receive treatment at a specialist CAR T-cell therapy centre. You'll usually need to stay in hospital for around two to four weeks.
- Your recovery will continue for several months after you leave the hospital, and will include regular appointments with your care team.

This booklet gives a brief summary of CAR T-cell therapy. We have more information on our website at **[bloodcancer.org.uk/car-t](http://bloodcancer.org.uk/car-t)**



## Jacquie

### What would you say to other people having CAR T-cell therapy?

"If there's one piece of advice I would offer, it's this: trust the science, but also trust your body and its strength. To know that my own cells fought this battle and won is nothing short of extraordinary."

Read Jacquie's story at [bloodcancer.org.uk/jacquie](https://bloodcancer.org.uk/jacquie) or call us and we'll post it to you.

## Preparing for CAR T-cell therapy

There are some steps before starting CAR T-cell therapy.

### Referral to a CAR T-cell therapy centre

If CAR T-cell therapy is an option for you, you'll be referred to your closest CAR-T centre. Here you'll meet a specialist doctor to discuss the treatment in detail.

If you choose to go ahead, a panel of clinical experts will review your case to make sure CAR T-cell therapy is the right treatment option for you. They'll look at your medical history and general health.

### Holding therapy

You might need some treatment before your T cells are collected, to keep the blood cancer under control.

### Tests

You'll have several tests to check you are well enough for CAR T-cell therapy. These may include blood tests, scans and checks on your heart, lungs and kidneys.

### Prehabilitation

Prehabilitation (prehab) helps you prepare for treatment by keeping active, eating well, and looking after your mental health. It can make recovery smoother and help you feel more confident going into treatment.

Your hospital can give you advice and support for prehab.

# Getting ready

To find out more about preparing for CAR T-cell therapy, including things to think about and tips on what to pack for hospital, visit

**[bloodcancer.org.uk/car-t-preparation](https://bloodcancer.org.uk/car-t-preparation)**

You might go through many emotions as you prepare for CAR T-cell therapy. If you have any questions or would like to talk about how you're feeling, call our

Support Line free on **0808 2080 888** or email  
**[support@bloodcancer.org.uk](mailto:support@bloodcancer.org.uk)**

## Having CAR T-cell therapy

The therapy has three main steps:

### Step 1: Collecting your T cells

Your medical team will collect your T cells by a process called leukapheresis. You may also hear this called apheresis.

During this process, a nurse will put a needle and a thin tube (called a cannula) into a vein in each arm. From one arm, blood will flow into a machine that separates your T cells from the rest of your blood. The rest of your blood will be returned to your body through the other arm.

Some people have their T cells collected through a thin tube (a central line) in their chest or groin.

Collecting your T cells usually takes a few hours, so you may want to take something to keep you busy, like a book or tablet computer.

### Step 2: Making your CAR T-cells

After collecting your T cells, the hospital will send them to a laboratory to make your treatment.

Scientists will genetically modify the DNA of your T cells to make CAR T-cells. They will then grow the cells until there are enough for your treatment. This usually takes a few weeks. Once your CAR T-cells are ready, the laboratory staff will freeze them and send them back to the hospital.



Occasionally, the laboratory isn't able to make the CAR T-cells successfully. If this happens your doctor will discuss options with you.

While you wait for your CAR T-cells, you might have treatments to keep the blood cancer under control. This is often called bridging treatment.

You will also have chemotherapy about a week before receiving your CAR T-cells. This treatment is called lymphodepletion.

### Step 3: Infusion of the CAR T-cells

On infusion day, you'll receive your CAR T-cells at the hospital. Hospital staff will thaw your frozen CAR T-cells, and a nurse will give them to you through a thin tube into a vein.

The infusion process is similar to getting a blood transfusion and should take about 15-30 minutes. Before your infusion, you will be given medicine to help prevent allergic reactions and fever.

After all the preparation, infusion day might feel quite simple, but it's an important milestone. People have told us they felt excited to receive their CAR T-cells, but also nervous.

You may have many emotions on the day, so be kind to yourself. Your hospital team are there to talk to about how you feel and answer any questions.

## Side effects of CAR T-cell therapy

After your infusion of CAR T-cells your hospital team will monitor you closely for side effects, and give you treatment to manage them. Most side effects happen in the first few days, but some can happen up to eight weeks later.

Over the next few pages, we cover common side effects your team will monitor you for. Speak to your hospital team if you have any questions or worries about side effects.

### Cytokine release syndrome (CRS)

When they enter your body, CAR T-cells can trigger other immune cells. Sometimes this can cause a full-body inflammatory response. This is called cytokine release syndrome (CRS).

Symptoms of CRS include:

- flu-like symptoms
- high fever
- low blood pressure.

If you have these symptoms it can be tricky to tell if you have an infection or CRS, so your hospital will usually give you antibiotics straight away.

In severe cases, CRS can be life-threatening and you may need treatment in intensive care.

## Neurological problems

CAR T-cells can affect the nervous system and cause neurological problems. You may hear these side effects referred to as immune effector-cell associated neurotoxicity syndrome (ICANS), or neurotoxicity.

Symptoms vary, but can include:

- confusion
- shaking (tremors)
- headaches
- problems with speech, movement or writing
- feeling dizzy.

While you're in hospital, your nurses will check you every day for any signs of neurological problems. They will ask you various questions and assess your handwriting.

If needed, your hospital can treat neurological symptoms with medicines such as steroids.

If neurological problems happen, it's usually within the first month after infusion. There's a small risk they could happen later than this, up to eight weeks after the infusion. For safety reasons, you are not allowed to drive for eight weeks.

## Tumour lysis syndrome

CAR T-cell therapy quickly breaks down cancer cells, releasing chemicals in the body. At high levels these chemicals can affect your kidneys. This is called tumour lysis syndrome.

Your hospital team will monitor you for this and provide treatment, including fluids and medicine, if needed.

## Allergic reactions

Some people may have an allergic reaction to the CAR T-cells. Your nurse will give you medicine before your infusion to prevent allergic reactions, but let them know immediately if you feel unwell during or after your infusion.

## Low B cell count

B cells are part of your immune system and help fight infections. CAR T-cell therapy aims to destroy cancerous B cells, but it also reduces your numbers of healthy B cells. This can put you at higher risk of infections.

Your hospital team will monitor your B cell count and may give you a type of treatment called intravenous immunoglobulins if needed.

## Low blood counts

As well as a low B cell count, you might have low numbers of other blood cells. Your hospital team will check your blood counts regularly, and if needed will give you treatment to increase them.

## Infections

You will be at higher risk of infections during and for some weeks after CAR T-cell therapy. Your hospital team will give you medicines to help prevent infections, but you should also watch out for any signs of infection.

Whether you are in hospital or at home, tell your hospital team straight away if you notice any of these things:

- feeling hot or cold (a temperature that's higher or lower than normal)
- sore throat
- cough producing green mucus
- frequent watery poos (diarrhoea)
- being sick (vomiting)
- feeling dizzy or faint
- headache or stiff neck
- skin feeling red, hot or swollen
- stinging when you wee or passing a small amount
- pain, redness or discharge (fluid) around the site of a central line
- pain, itching or unusual discharge from your penis or vagina
- new pain anywhere in your body
- generally not feeling well.

Even if your symptoms seem very mild, make sure you get medical advice.



## Grant

### What side effects did you experience?

"When I agreed to the CAR T-cell therapy they gave me a big list of all the possible side effects, but the only side effect I had was a high temperature. While I was in hospital a nurse would come and do a quiz every day to check if I had any problems with confusion or memory loss, but I was fine."

Read Grant's story at [bloodcancer.org.uk/grant](https://bloodcancer.org.uk/grant) or call us and we'll post it to you.

## Recovery at home

Your hospital team will discharge you when you are well enough to go home. For most people this will be between two and four weeks after the infusion of CAR T-cells.

After discharge, you will continue to have regular appointments with your CAR-T team and at your local hospital.

## When to contact the hospital

Before you go home, your hospital team tell you how to contact them, and will teach you to look out for any problems.

Contact the hospital straight away if you notice:

- any possible infection symptoms (see page 11)
- any signs of neurological problems (see page 9)
- any other side effects or symptoms your hospital has told you to look out for.

Keep a list of potential side effects and emergency numbers (including out-of-hours contact details) handy. If anything feels “off”, contact the hospital immediately. Don’t wait for symptoms to get worse.

Sometimes you might need to go back into hospital for assessment or treatment.

## Managing the risk of infection

When you return home after CAR T-cell therapy, you will be at more risk of getting infections. These are some things you can do to reduce the risk:

- wash your hands often
- avoid busy places, or if you can't avoid them, wear a mask
- stay away from people who are ill, and make sure family and friends understand the risk of passing on infections
- practice good food hygiene
- make sure you get your flu and COVID-19 vaccinations, and ask your medical team about any others you may need.

You can read more about infections and managing risk at **[bloodcancer.org.uk/infection](https://bloodcancer.org.uk/infection)** or call us and we'll send you the information.

## How long will recovery take?

Recovery from CAR T-cell therapy varies for each person. Typically, it can take a few months to recover. You'll continue to have follow-up visits beyond this to check on your progress.

Some side effects, such as fatigue, can take longer to fully recover from. Your hospital team are there to help during your recovery, so talk to them if you have any questions or worries.

If you work, it's usually recommended you take six months off to recover, but this will vary depending on your recovery and individual circumstances.



# More about recovery

Read more about recovering from CAR T-cell therapy, including sun safety, building up your fitness, eating well, having sex and returning to work.

Visit **[bloodcancer.org.uk/car-t-recovery](https://bloodcancer.org.uk/car-t-recovery)**

If you don't use the internet, call us on  
**0808 2080 888** and we'll send you  
what you need.

## Practical and financial support

You might need support with things like housework, childcare and pets during and after CAR T-cell therapy. It's also common to have worries about work and money.

Do talk to your hospital team about anything that's worrying you. They can help you and your family access support, and can often help you apply for any financial benefits or grants you are entitled to.

### Work

You might be worried about how your treatment will affect work. It's important to know that you are covered by disability law. This protects you, and anyone who cares for you, from discrimination at work.

Your employer must provide reasonable adjustments. This could include time off for appointments, flexible working arrangements or reduced hours. We have information about your rights at work at **[bloodcancer.org.uk/money-work](https://bloodcancer.org.uk/money-work)**

### Benefits and grants

You may qualify for benefits like Statutory Sick Pay, Personal Independence Payment, Attendance Allowance and low-income benefits. If someone is caring for you, they may be able to get Carer's Allowance and Carer's Credit.

Some charities offer grants for people with cancer. Contact us on **0808 2080 888** and we'll help you find what's available.

## Help with paying bills

Talk to your suppliers about energy bills, council tax and mortgage payments. There is usually support available for people with cancer. For help with managing money, visit **[moneyhelper.org.uk](https://moneyhelper.org.uk)**

## Ways to save money on health costs

- **Parking** – At all hospitals in Wales and most hospitals in Scotland parking is free. In England and Northern Ireland, some hospitals offer free parking to people with cancer – check with your hospital. If you have limited mobility, you may qualify for a Blue Badge, which allows you to park for free in many places.
- **Travel to hospital** – If you have a low income, or get certain benefits, you may be able to get refunds for your travel to hospital. Speak to your doctor or nurse to find out more.
- **Accommodation** – Some hospitals and charities offer help with the cost of accommodation, if you or family members need to stay near the hospital. Ask your hospital team what's available.

For more information about practical and financial support for people having CAR T-cell therapy, visit **[bloodcancer.org.uk/car-t-support](https://bloodcancer.org.uk/car-t-support)** or call us and we'll help you find the support you need.

## Caring for someone having CAR T-cell therapy

Looking after a loved one having CAR T-cell therapy can feel like a big responsibility. That's why we've developed information and resources to help.

If you're caring for someone having CAR T-cell therapy, visit our website at **[bloodcancer.org.uk/car-t-carers](https://bloodcancer.org.uk/car-t-carers)** for:

- Sources of practical and emotional support for you and your family.
- A checklist of things you can do to help your loved one through treatment.
- Tips from other carers, of things that helped them.
- Information about how to support your loved one when they come home, including looking out for side effects, managing infection risk, and helping them to eat well.
- Advice on how to look after yourself.

If you don't use the internet, call us on **0808 2080 888** and we'll send you what you need. We're also here for you if you have any questions about caring for your loved one, or if you just want to talk.

# If your child is having CAR-T

If your child is having CAR T-cell therapy, you may have lots of questions about what to expect and how to support them.

For information, resources and sources of support for you, your child and the rest of the family, visit **[bloodcancer.org.uk/car-t-child](https://bloodcancer.org.uk/car-t-child)**

# Because we face it together

Having blood cancer can have a big impact on your life. But we hope it helps to know that there's a community of people out here ready to support you.

Everyone needs help at one time or another. And the most important thing to take away from this booklet is that you can get help from us when you need it, and in a way that suits you.



**[bloodcancer.org.uk](https://bloodcancer.org.uk)**



**0808 2080 888** (calls are free and confidential)



**[support@bloodcancer.org.uk](mailto:support@bloodcancer.org.uk)**



**[bloodcancer.org.uk/our-forum](https://bloodcancer.org.uk/our-forum)**



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**Blood Cancer UK**

# Thank you to our blood cancer community

Blood Cancer UK is the UK's specialist blood cancer charity. But we're much more than that – we're a community of people with blood cancer, friends, family, medical professionals, researchers and everyone who works for the charity.

Many thanks to everyone involved in making this booklet. To the people with blood cancer and their family members who gave us insight into what it's like to have CAR T-cell therapy and gave us feedback. To clinical nurse specialists, Charina Ocampo and Emily John, for their input and for checking the medical content. And to Anthony Nolan for helping us develop our information about CAR T-cell therapy.

A list of references used in this booklet is available on request. Please email [\*\*information@bloodcancer.org.uk\*\*](mailto:information@bloodcancer.org.uk)

## **Disclaimer**

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# Who are Blood Cancer UK?

We're the UK's specialist blood cancer charity, working to beat blood cancer within a generation.

Since 1960, we've invested over £500 million in research, improving treatments for leukaemia, lymphoma, myeloma, MDS and MPNs. Thanks to generous donations from our supporters, we:

- fund ground-breaking research to improve survival and quality of life
- campaign for better access to treatments and services for people with blood cancer
- provide information and support for anyone affected by any blood cancer.

Find out more at **[bloodcancer.org.uk](https://bloodcancer.org.uk)**

Or call us free on **0808 2080 888**



The information in this booklet was correct at the time it was printed (April 2025). Date of next full review: April 2028.  
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